Vile Bodies:

Understanding the neglect of personal hygiene in a sterile society

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Preface

Why do some citizens in the affluent West neglect their personal cleanliness and how can relatives, friends and care professionals provide effective support?

In its mildest form, self-neglect forms a topic of arguments between mothers and their teenage children, but at its most severe it kills people. Television audience figures reveal that the topic is fascinating, while it remains under-researched and poorly understood.

Self-neglect is of interest to neighbours and relatives, the media and legal specialists as well as health and social care agencies[2], housing and environmental health, psychologists and community development workers. As Robert Francis QC commented[3], hygiene is a concern for everyone, whether in hospital or in the wider community:

> *"Cleanliness is also the responsibility of every member of staff. Everyone from the chairman and chief executive down[a] is capable of picking up and disposing of waste and of alerting staff to spillages and they need to be seen doing so. Patients and visitors should be encouraged to point out any need for cleaning that has been left unattended."*

It is difficult to define what counts as self-neglect, hard to identify who is at risk and tricky to decide whether to intervene. While all behaviour is perhaps a form of communication, self-neglect raises challenging issues of legal and moral freedoms and responsibilities. This book explores these themes, considers what might be happening, and indicates how effective support can be offered.

Who is this book written for?

No systematic literature review, formal sampling or distinct methodology directed the work, but rather a networking process by which one contact or journal article naturally prompted an email inquiry, dialogue and more reading. As an unfunded spare time occupation, this was written for myself, to tidy up the accumulated hoard and clutter in my head.

I sincerely hope it will be useful to anyone who is in touch with a relative or friend who neglects their hygiene, appearance or home, as well as helping people who work in caring services and are trying to understand what makes another human being behave in these ways. I hardly dare wonder if it will be of any use to someone who is trying to understand their own self-neglecting behaviour.

[a] Elsewhere in his report, Francis includes Consultants in this list.

I hope that as you browse these pages with that person in mind, something will resonate and shed fresh light on the situation you both find yourselves in, so that you recognise more of yourself in them, feel more potential for change in both of you, and know more compassion for the dirty jewels of humanity that we all see when we look out of a window or into a mirror.

> *Love has pitched his mansion in the place of excrement;*
> *For nothing can be sole or whole that has not been rent.*
>
> W.B Yeats

How is this book arranged?

This book is extensively referenced in endnotes (shown in superscript numbers), so that previous authors are fully credited for their work and current readers can explore sources for the assertions made here. Occasional footnotes (shown as superscript letters) add extra detail. Case studies are fully anonymised accounts from real life that were shared with me by practitioners I met during the writing of this work. Each chapter ends with a box of questions for further reflection, addressed to people and helpers alike, to help us all reflect on our attitudes and actions.

It is published online so that corrections and improvements can be added from time to time, so you may wish to check the date on the cover and use the most recent version. In addition, you may have expertise and knowledge that would improve this book – please contact me so that it can be added, along with an acknowledgement of your contribution.

A note on language

All labels are political, and there is no sterile way to refer to the people who are the subject of this book. The title, 'Vile Bodies' is borrowed from Evelyn Waugh's 1930 satire on the emptiness of wealth and fame, in order to emphasise the emotional response that is evoked by our topic and the underlying questions about what constitutes a 'well-lived life'.

In the remainder of the book, an attempt is made to avoid stigmatising labels by referring to the self-neglecting person simply as 'the person' and attaching labels to neighbours, friends, work colleagues, relatives or professional care staff as needed. This can be too clumsy to use all the time, but the point of the book is to seek a respectful understanding of the person, rather than resorting to stereotypes and critical assumptions.

Acknowledgements

I am grateful to the many people who have shared their experience with me, engaged in discussion and allowed me to test my ideas on them over the past three

years. In particular, Virginia Smith's ground-breaking work has been an inspiration, along with her commitment to move this topic forward in the context of mental health services. Alex Ruck Keene guided me through the legal issues and Jeremy Patton helped with discussions of mental capacity. Linda Offord and Steve Stickley helped with stories, while Desmond Graham and Dorothy Grace helped with overall editing. Much of the work was done during the time I was on the payroll of the National Development Team for Inclusion and I gratefully acknowledge their encouragement and support.

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1. Introduction

Case Study One

"These newspapers are combustible, Mr Dearnley," said Amanda as she stepped over yet another large stack of Daily Mirrors and freebies, "that means they're a fire hazard. They can burn. You understand? We wouldn't like to lose you that way would we? Eh?"

"Are you from the ambulance?" Fred's agitation had kicked in again but he was calming down now as he clung on tightly to his filthy cardigan wrapped tightly around him. It was obvious that Fred had some serious mental health issues.

"No, Mr Dearnley. I'm a Fire Prevention Officer."

"What's your name?"

"I'm Amanda. Can I call you Fred?"

"Not the ambulance then …"

"No, not the ambulance, Fred, Fire Prevention."

"Fire Prevention."

"That's the one. Now then, let's have look at this cooker shall we? It's pretty grimy. See? We've got to get this cleaned up, Fred. If the grease on here catches fire goodness knows what'll happen, the whole place would go up and that would be very bad news for you and all the other tenants in this block, wouldn't it?"

"Nice uniform. Stop the fires. Yes … Very good very good …" Fred stared at his new visitor.

"That's it Fred, the best sort of fires are those that don't start in the first place."

Three weeks later, with the help of a cleaner, Fred's flat was much safer and the newspapers gone. A routine visit, as well as an impressive uniform, had done the trick with Fred whereas his regular support worker found it hard to help him see reason.

Why does self-neglect matter?

Most children complete their 'toilet' training soon after starting school and thus begin a lifetime of daily ritual involving toothbrush, comb, flannel and cosmetics. These personal hygiene practices are supplemented by what zoologists called 'allo-grooming' - help from our parents, close family or friends, and paid staff such as hairdressers. Such help involves touch and promotes bonding between people, whether in combing nits out of hair, getting ready for a night out or dressing for a wedding, and embed bodily hygiene into the social order.

Being clean, as Schnall[4] attested, is a 'fundamental human desire', but, despite this, some adults routinely have dirty skin, severe body odour, unwashed, untrimmed hair

and nails, body lice, and wear stained, torn and filthy clothing. This is important for five main reasons:

- It can occur alongside and be a signal of more serious problems, such as abuse or dangerous domestic squalor[5]
- On its own, it is not regarded as a serious matter that would entitle people to care and is sometimes considered to be a lifestyle choice made by the person themselves, but a proportion of people using health and social care services live this way
- It is highly corrosive to social relationships, damaging the person's standing with their family, neighbours, employer and anyone else who meets the person, leading to social exclusion, as well as being hazardous to health[a]
- It is difficult to discuss, and raising the matter can spoil a friendship or lead the person to withdraw from essential health or social care supports
- Policy changes that promote self-determination, independent living and self-directed supports, combined with shrinking investment in community care create the social conditions where self-neglect may become more prevalent.

Self-neglect may be just one more expression of the human condition, driven variously by ignorance, denial, anxiety, immediate gratification, depression or self-harm - as much a kind of 'slow suicide' as smoking or eating too much. As such, it deserves our attention.

Is there a standard definition?

There is no government definition or guidance on self-neglect, and the sheer variety of available terms show that we are dealing with an untidy concept - ablutophobia, acopia, coprophilia, Diogenes Syndrome, disposophobia, gross domestic squalor, self-care, senile squalor syndrome, severe domestic squalor, social breakdown syndrome, social breakdown squalor syndrome and syllogomania.

The reference to Diogenes, an ancient Greek philosopher (412-323 BC) who flouted social convention by making a virtue of poverty and homelessness, highlights the social context within which self-neglect occurs. Gibbons (2006) reinforces this point when he suggested that self-neglect is:

> *'The inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious*

[a] It might be possible to test whether malodorous patients have shorter sessions with the general practitioner, increasing the risk of under-diagnosis or misdiagnosis. At least one doctor has asked patients to wash before their appointment (see http://blogs.livewellnebraska.com/2012/05/14/dress-up-for-your-next-doctors-appointment/ for an example.)

consequences to the health and well-being of the self-neglecters and perhaps even to their community[6].

Keeping house and unreasonable refusal of help are further elements, and the problems become more severe when they constitute a nuisance to others, as William Buchan noted, in 1769:

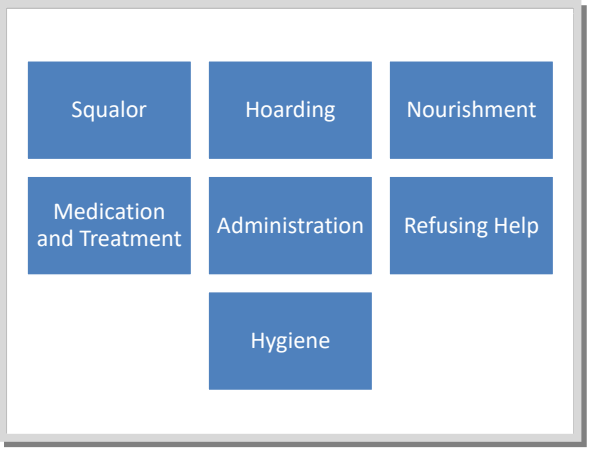
'It is not sufficient that I be clean myself, while the want of it in my neighbour affects my health as well as his. If dirty people cannot be removed as a common nuisance, they ought at least to be avoided as infections. All who regard their health should keep a distance even from their habitations."[7]

Other writers extend the definition of self-care, including within it the taking up of medical and social care services and the managing of one's financial affairs:

'the result of an adult's inability, due to physical and/or mental impairments or diminished capacity, to perform essential self-care tasks including: providing essential food, clothing, shelter, and medical care; obtaining goods and services necessary to maintain physical health, mental health, emotional well-being and general safety; and/or managing financial affairs.'[8]

Seven components of self-neglect

The following indicators may suggest dangerous self-neglect, although any of these items may be caused by a lack of opportunity or may be a lifestyle choice.



Squalor. Living in very unclean or verminous circumstances and neglecting household maintenance, including living without running water, heating, gas, electricity or sewerage – a highly hazardous situation for both the person and neighbours. Sinks, baths, cookers and other household appliances may be unused.

Hoarding. This includes eccentric behaviours or lifestyle, such as obsessive hoarding of belongings or pets. Excessive hoarding has been estimated as affecting between one and two percent of the UK population[9] and is considered problematic when living spaces cannot be used in the way that they were intended and the person's functioning is impaired because of it[10]. For the first time, the 2013 edition of the Diagnostic and Statistical Manual includes 'hoarding disorder' among its catalogue of psychiatric disorders[11]. However, Protocol 1, Article 1 of the Human Rights Act 1998 provides the right to peaceful enjoyment of their property and this can only be restricted in very specific circumstances.

Malnourishment. Poor diet and nutrition, perhaps evidenced by disused kitchen equipment, little food in the fridge, poor personal hygiene, sores and poor healing, dehydration and weight loss. Some nurses like to weigh people to obtain data about this, while a court concluded[12] that, in one case, a person with anorexia nervosa could not have the mental capacity to make the choice to die through refusing food, and so the court required that person to be fed against their will. On another occasion[13], choosing not to eat was seen as unwise rather than evidence of a lack of mental capacity.

Refusing Treatment. Declining or not using prescribed medication or other healthcare. However, almost everyone declines treatment from time to time - the general population only consult medical expertise in 10% of potential situations (falling as low as 1 in 74 occurrences of depression)[a], while only a half of the people invited to attend health check appointments actually do so[14]. If prescribed medicine, an increasing number of prescriptions are not collected[15], only one in five courses of medication are taken properly[16] and people start the habit of non-adherence in childhood[17]. While article 8 of the Human Rights Act 1998 has been judged to include the right to refuse medical treatment, failing to take medication properly is wasteful in a country where there are 21 million visits a month to the general practitioner and community pharmacists dispense 2.3 million prescription items per day. Denial is also common in patients with life-changing illnesses[18], addictions and stroke[b], and may be part of the adaptive process[19] to help the person gradually face up to an unpleasant situation. The UK Self Care Forum[20] promotes self-management of health and wellbeing.

In passing we note that on some occasions, persons who are in a persistent vegetative state or minimally conscious state are kept alive through the provision of Clinically Assisted Nutrition and Hydration. When the time comes to withdraw that intervention, the machines are switched off and the person slowly dies through dehydration and starvation[21].

Ignoring Administration. Failing to open post, manage finances or pay bills, answer phone calls or meet appointments. This is different from the next component as it is a simple disregard for these administrative tasks, rather than an active choice to refuse help that is offered. One local older person's mental health service has a specialist team member who helps people with these tasks[c].

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[a] "Professional medical help is normally only sought for roughly one in ten medical episodes – or even less (for depression 1 in 74; for headache 1 in 60; backache 1 in 38; sleeplessness 1 in 31; muscle and joint aches 1 in 18; cold or flu 1 in 12; a sore throat 1 in 9)." Smith V (2007) op cit. p334.

[b] Some stroke patients with a distinct loss of function report no deficit whatsoever, even when their inability to perform motor tasks is pointed out to them. This only affects people with a lesion in the right hemisphere of the brain and is called anosognosia in the medical literature.

[c] In early 2011, the older person's mental health team in Barnet had a specialist support worker who concentrated on working through client's piles of unopened post where permission was given and relatives were not available to take on Lasting Power of Attorney or deal with mail.

Refusing Help. Refusing to allow access to staff who can help with personal hygiene and care or to other organisations such as gas and electricity suppliers. This includes unwillingness to attend external appointments such as with housing agencies. We note that people find it easier to refuse unwanted help in settings where they have more power, such as at home rather than in hospital[22], while rejection of social norms may be one way that people express their feelings of powerlessness[a]. People who refuse services occasionally rather than uniformly refusing everything are more complex to support, as are people who accept some services (or some individual staff) but reject others.

Poor Hygiene. Neglect of personal hygiene and grooming by failing to take care of the body surface – skin, hair, nails – and failure to wash and change clothing.

Each of these seven components is distinct and the presence of one issue does not guarantee the presence of others. For example, while environmental neglect is easy to hide - Quentin Crisp, Howard Hughes, Francis Bacon and Iris Murdoch all achieved success and maintained high standards of personal hygiene while living in domestic squalor - neglect of person hygiene is much harder to conceal. Like Thomas Paine and Ludwig van Beethoven[23], some modern celebrities appear to neglect their personal hygiene, despite the public's focus on their appearance[24].

Research studies have found varying levels of co-occurrence of the problems of hygiene and squalor. In one study, 10% of people living in severe domestic squalor were rated as maintaining 'good' levels of self-care[25], in another, 23% of respondents had trouble with both issues[26], and in a third study, 36% of elderly hoarders were judged to be clean[27].

The focus of this book is personal hygiene, but it will inevitably include some discussion of the other six components of neglect[28]. 'Neglect and Omission' has become the commonest reason for a safeguarding referral in England since monitoring began in 2015[29].

[a] After visiting a locked psychiatric ward, Chris Muirhead wrote, "My recommendation would be to not wash if you want to, leave everything lying around, spill your coffee on the work surface, it can't be helped anyway with the side effect of shaking, and do your utmost to rebel in whatever way suits you." http://chrysmassociates.blogspot.co.uk/2013/01/created-by-service-users-for-service.html?spref=tw

Reflection time – Chapter One

- What hygiene routines did you learn as a child?
- How do you feel about other people touching your body?
- Are your hygiene habits causing any problems to you or other people?
- Does your local safeguarding team or other organisation have a written or generally understood definition of self-neglect?
- Do you consider all seven aspects of self-neglect when you use the term, make an assessment and plan your intervention?
- If you find one of these aspects, do you assume that the others are present also?

2. Hygiene in context

Case Study Two

The day centre staff knew George of old. Little by little, bit by bit, they had gently encouraged him to clean himself. It hadn't happened overnight and the staff knew to work at his pace. Irene and Precious had known George the longest, serving him hot meals and drinks for what had seemed like an age.

"Living on the streets is not for the faint-hearted," Precious told younger staff, "and George has been doing it for thirty years." She and Irene had started putting out some clothes for him and, after a few years, he took to changing in the toilets. Gradually, George was persuaded to take a shower and finally came the big day when he agreed to let the two women buy him a new set of clothes. His pride was palpable. The new clothes were his very own and were treasured among his very few possessions.

Some time later George found himself on a psychiatric ward. Bemused and anxious, his personal space was invaded, his belongings spoilt and the new clothes were stuffed like rags into a bag.

"That's better George," said the worker who had accompanied him into the shower room, "now you're very smart … you'll have the ladies after you now, you know." Offended and insulted as a result of this encounter, George withdrew all co-operation.

The history of personal hygiene

A brief history of hygiene habits may help us make sense of the contemporary situation and generate useful questions and insights.

Hygiene practices, as Virginia Smith[30] points out, are hard-wired into our survival as a social group. All primates, including ourselves, clean our own and others' skin by removing dirt and vermin such as lice and nits; and our in-built psychology of disgust (of which more later) is a powerful response that helps us avoid places of threat, contamination and infection.

Particular care has always been taken with grooming and hygiene at the vulnerable times in the human life-cycle - birth, puberty, pregnancy and special social occasions. Even in death, people are washed, groomed and dressed carefully to create the best possible appearance. Girls are commonly socialised to spend time on grooming and dressing-up games and are more sensitive to disgust at vulnerable times – especially at puberty[31], and in pregnancy, although this quickly disappears after childbirth. Teenagers and young men use more deodorants than older adults[32]

and both men and women pay more attention to hygiene when they are seeking a mate[33].

The link between personal hygiene, health and beauty was understood in ancient times. More than 20,000 years ago, hair was being braided[34], and by the Bronze Age, people in Europe were using metal grooming tools and wearing washable clothes, enjoying public fountains and utilising public rubbish dumps, while their royalty were sleeping in bedrooms with en-suite washing areas.

Medieval books of manners[35] outlawed 'abominations' such as farting, sweating, spitting, slurping or burping, while their recipe books contain large numbers of skin and beauty preparations and the 'regimen of health' included a daily morning grooming routine. Warm communal baths and langorous bathing were popularised by the Romans. It continued in cities throughout Europe until the shortage of firewood and an epidemic of syphilis in the 1490s[a] linked bathing with illness in the popular imagination and closed many of the public bath-houses[b]. In an interesting echo of these medieval events, recent public health analysis in the USA found that illnesses such as Legionella were most likely to arise through use of hotel swimming pools and hot tubs[36].

The idea that warm baths could be harmful was not new, and it had motivated the Visigoths to demolish the public bath houses when they conquered Spain in the fifth century. Some people believed the skin was permeable and would lose essential substances or be invaded during a bath if the body's defences were low, and so some people rarely bathed. Dirt was removed from the body and the environment for aesthetic rather than health reasons[37] and so Queen Elizabeth ! took a bath one a month "whether she needs it or no'. .

From the beginning of the eighteenth century[38], sea swimming and cold baths were being encouraged by doctors, educators and sanitary reformers as a way to build up the body's hardiness - an idea that was popular in many British public schools until well into the twentieth century[c] and enjoyed a resurgence in the twenty-first[39]. For example, Robert Baden-Powell, creator of the Scout movement, advocated cold showers and slept outdoors in all weathers for the last twenty years of his life.

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[a] 'The bubonic plague killed at least one out of every three Europeans within a four-year period in the mid-fourteenth century.' Ashenburg p91. Prostitutes were banned from bathhouses and the area surrounding them (Bryson, 2010 op cit, p492)

[b] Smith V (2007) dates the German bathhouse closure to the 1490s, while Ashenburg (p112) blames it on the Thirty Years war at the beginning of the seventeenth century, and the dwindling supply of firewood for heating the water.

[c] "Sir John Floyer wrote in 1697 that people should, 'leave off the imprudent use of hot baths, and regain their ancient natural vigour, strength, and hardiness by a frequent use of cold bathing.' ..."In Some Thoughts Concerning Education (1693) John Locke recommended that boys should mostly play in the open air, and 'as little as may be by the fire...thus the body may be brought to bear almost anything.'...Locke's Roman hardiness, his Greek athleticism, and his Protestant naturalism clearly appealed to large numbers of the English upper classes." Smith V (2007) p219-222.

This demand for hardiness has perhaps especially persisted into the modern era in the standard of school and public toilets, which remain dirty, frightening and threatening places for many children and adults[40], although we must be cautious of assuming that we know what these spaces symbolise for others[41]. Some people respond by refusing to use them which leads to constipation, urinary tract infections, distress and a restricted social life[42]. The physical inaccessibility of many public toilets is perhaps experienced most significantly by people who need Changing Places provision, while transgender people are perhaps most likely to endure discrimination and hatred in this setting. This has led to a call for gender inclusive toilets, otherwise known as gender neutral toilets[43] or toilets for all. South Gloucestershire has created a Can't Wait scheme to allow cardholders to use staff toilets in shops that are within the scheme[44].

Victorian reformers divided toilets by gender[45] and promoted hygiene within a broader context of morality and political activism; including David Urquhart, who introduced Turkish baths to the United Kingdom[46], and the Salvation Army, whose founding motto was 'soup, soap and salvation'. These links are still relevant to us, as we continue to describe a person about whom we have doubts as 'fishy' and urge a person who uses offensive language to 'wash your mouth out'. People who wish to distance themselves from a decision they disapprove of are said to 'wash their hands of it.'[47]

In the modern period, the medical profession gradually discovered the health benefits of cleanliness through medical pioneers such as Antonie van Leeuwenhoek who invented the microscope in the seventeenth century, John Pringle who developed early ideas on antiseptic practice in the eighteenth, and Florence Nightingale (evidence-based nursing), Joseph Lister (sterilisation) and Louis Pasteur (germ theory and vaccination) in the nineteenth[48]. Sanitary reformers such as Edwin Chadwick were intent on removing squalor, drunkenness and sloth from the rapidly expanding cities, but had to go to Paris to study, as no attention was paid to hygiene in UK medical schools when he began his career in the 1820s[49]. Repeal of the Soap Tax in 1853 along with new urban housing legislation led to a variety of changes, including the revival of public baths and washhouses.

The popularisation of germ theory and development of domestic science at the start of the twentieth century introduced white porcelain and tiling, gave directions for food storage, transferred hygienic cleansing regimes from the hospital to the home, especially bathrooms and kitchens, and created a mass market for disinfectants. Rationing of soap in the UK from 1942 to 1950 during and after the Second World War created something of a setback, and some older people may still be influenced by the memory of those days of austerity.

Rising affluence, the communications revolution and global culture has encouraged the widespread adoption of hygienic habits, reinforced by new threats, such as

MRSA[a]. Nowadays, the domestic bathroom is idealised in Western society as the place where hygiene is combined with erotic hedonism, narcissism and luxury[50]. This preoccupation has not gone unnoticed, as Huxley satirised cleanliness in his 1932 classic *Brave New World* and Horace Miner spoofed the American culture of hygiene in 1956[b].Cultural references continue in music, poetry and literature[51].

Equipping the modern home

Whilst the main focus of this book is on bodycare, there of course can be a close link with care of the home, as our bodies are constantly shedding skin, evacuating urine and stools, emitting gases and perspiring. Around 2500 BC, the city of Mehenjo-Daro in the Indus valley had rubbish chutes, trash bins, a drainage system and a scavenging service, while the Babylonians had cesspools, drains and a sewage system[52], but Europe took many years to catch up. In 1184, Philip II ordered the streets of Paris to be paved to reduce the stench[53]. The ruling classes have indeed made many attempts to clean up the people – Rosie George[54] describes the legal challenge made by Mr Tinkler in 1857 when his local council insisted on installing an unwanted flush toilet in his cottage.

Our waste products and discarded items need regularly cleaning up and washing away – practices that were boosted by popularisation[55] of the flushing toilet in the 1880s[c], the invention of the portable, motorised vacuum cleaner in 1901[56] and the domestic washing machine in 1914[57]. The proliferation of domestic appliances in the last hundred years may have outstripped our ability to use them[d], and so many modern Westerners surround themselves with technology that bewilders them. It has been suggested that between 75 and 80% of vacuum cleaner dirt consists of human

[a] "In the UK, MRSA-related deaths rose from 13 in 1992 to over 1600 in 2004; and cross-infection is only controlled through strict and old-fashioned hygienic measures: thorough hospital ward cleaning, hand-washing, asepsis, and quarantine." Smith V (2007) p349.

[b] Horace Miner (1956) Body ritual among the Nacirema *American Anthropologist* 58, 503-507. The name Nacirema is a reversal of the word American, and Ashenburg says that 'Miner's classic spoof is still taught in universities as a satire aimed at anthropological method and Western condescension towards the "others" they study.' Ashenburg p263.

[c] The flushing toilet was invented by Sir John Harington (1561-1612), not Thomas Crapper (1836-1910) as is popularly believed. Forsyth M (2011) *The Etymologicon* London: Icon Books Ltd, page 55. A toilet was built in in Clifford's Tower, York for Henry III (1207-1272) that was flushed with rainwater collected on the palace roof.

[d] There appears to be research on the public's ability to use the newest technology, especially amongst specific communities, such as older people or people with autistic spectrum disorders, but it is harder to find studies that have looked at the general population's ability to use commonplace domestic appliances.In responding to correspondence, neither Professor Mark Blythe at the University of Northumbria nor the Centre for Usable Home Technology were able to point to any research on this issue.

skin cells[a]. Domestic appliances have not eliminated housework, however, and a study by Ann Oakley in 1974 found women spending an average of 77 hours a week on it[58].

The ancient Greeks revealed their understanding of the link between housework and health by linking the word kosmos (to order) with kosmetikos (to beautify), and the sibling goddesses Hygieia (from where we obtain the word hygiene) and Panacea ('Cure-all)[59]. In medieval Germany, employers regularly paid the bath house fees as a salary perk[60], a forerunner of the gym and spa memberships funded by some contemporary employers[b].

Bedding was a valuable commodity[c], rarely replaced, which quickly becomes smelly and so in the eighteenth century, beds were transferred from a curtained corner into the middle of the room next to an open window, and this did much to disperse stale air[d]. Standards of behaviour were different to those of today, and so Louis XIII of France had a commode in his throne so he could defecate in public, but he ate in private, and in the palace of Versailles, aristocrats urinated in corridors and defecated in the gardens[61]. It was during the French Revolution that the idea circulated that every man deserved his own bed[62], while the modern continental habit of airing duvets every day helps even more. The theory that disease was caused by miasma in foul air was popular in the 18th and 19th centuries and this further encouraged the airing of rooms[63]. A clean and tidy house was also linked to assumptions about morality, and so the front room was kept clean and tidy to impress guests, and the front step was coloured and washed daily as a demonstration of respectability[64].

The scientific discoveries of the late nineteenth century highlighted the health risks carried by mosquitoes and flies, and this changed habits in the bathroom by increasing personal hygiene[e]; in the kitchen by encouraging people to cover food; and in the street by encouraging the removal of dung. Street hygiene received a second phase of attention from the 1990s as the 'poop scoop' phenomenon

[a] Smith V (2007) op cit, p11 – although this must vary according to the climate, location and a host of other factors.

[b] The UK tax system discounts the cost of sporting facilities provided by employers – see http://www.hmrc.gov.uk/paye/exb/a-z/s/sports.htm

[c] My own 5 x great grandmother Mary Messenger inherited from her father Richard 'my best bed and the bedding thereto belonging'. The fact that it is named in his will (written in 1756) alongside 10 acres of land and £100 indicates its value.

[d] Smith V (2007) op cit, p218-20. Window Tax (1696 to 1851) and Glass Tax (1746-1845) had produced unventilated bedrooms, so abolition improved the flow of fresh air through houses.

[e] Improved understanding of vermin living on the body reduced tolerance. In 1910, perhaps one in three schoolchildren were verminous (Ashenburg p233).

dramatically cleaned many streets of dog faeces[a] after the advertising campaign of 2002[b], providing another example of the malleability of the disgust response.

In countries[65] that lack a well-established sanitation system and where many people defecate in the open air, human excrement carries considerable health risks. While ingesting one's own excrement is not necessarily harmful to health and is sometimes used medicinally[c], the risk from other people's faeces is considerable[d].

Changes in gender roles in the latter part of the 20th century have influenced some men to take an equal share of domestic chores and childcare duties, but in general, women still carry out most of the housework, and the men who do assist prefer to do shopping and childcare rather than dealing with dirt. Victorian routines of the annual spring clean and the weekly wash have given way to on-demand cleaning driven by anxiety that we have never done enough. Despite all these changes, wealth continues to make a difference even in modern times, as Ashenberg recently commented: 'the working classes are dirtier than more prosperous people, because their work is more physical, their workplaces are often unclean, and they lack the plumbing that makes cleanliness easy.' [66].

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[a] Local English byelaws have been enthusiastically adopted in many places so that it is now commonplace for dog owners to carry away their pet's faeces from public streets and parks, even though they are unobserved. The disgust response has clearly been suppressed in the public interest. More recently, Councils have taken to using community disgust and public shame as levers in the campaign – for an example, see the rogues gallery at http://www.rctcbc.gov.uk/EN/GetInvolved/Campaigns/WhoDoneIt/Whodoneit.aspx?RogueGallery_List_GoToPage=1

[b] Seven million dogs in the UK generate 1000 tonnes of faeces per day. When dog faeces disintegrate, eggs are released into the surrounding soil, becoming a source of toxocariasis infection, which can lead to fever, hepatosplenomegaly, respiratory problems and skin lesions; there may occasionally be convulsions, heart problems and ocular lesions, such as loss of visual acuity with people in lower socioeconomic groups at greater risk – see https://academic.oup.com/cid/article-abstract/66/2/206/4103318?redirectedFrom=fulltext. A systematic literature review found no good quality academic studies of the effect of specific interventions to prevent dog fouling - see Atenstaedt RL & Jones S (2011) Interventions to prevent dog fouling: a systematic review of the evidence *Public Health* Volume 125, Issue 2, February 2011, pages 90-92. However, the June 2002 campaign that was run by Keep Britain Tidy reported a 40% reduction in dog fouling. See http://www.keepbritaintidy.org/Campaigns/pastcampaigns/dogfouling/Default.aspx accessed 11 March 2011.

[c] Intractable diarrhoea caused by Clostridium difficile depopulates the normal intestinal bacteria. It can be treated by fecal bacteriotherapy in which a healthy stool from a close relative or spouse is administered by nasogastric tube, enema or capsule. The practice is increasingly popular – see the study published in May 2018 at http://click.email.taylorandfrancis.com/?qs=bb1003a6b612ca485bfc5ad544a3ce409204492111cf97bb5ec23b2755e954b03129aac056da6560d0b0315aa89ab5587bae8f70e0aba11b87a7bbc3e6d613f6

[d] The risks include botulism, cholera, campylobacter, cryptosporidiosis, dengue, dysentery, giardia, hepatitis A, hookworm, leptospirosis, meningitis, roundworm, salmonella, scabies, schistosomiasis, tapeworm, typhoid, and many more. Feachem RG, Bradley DJ, Garelick H & Mara DD (1983) *Sanitation and disease: Health aspects of excreta and wastewater management* Chichester: John Wiley & Sons for the World Bank.

Building the private bathroom

Standards of privacy have changed over the centuries. For example, when the Longhouse was built in London in the twelfth century, it contained 64 toilet seats, but no partitions between them[67].

The ancient Babylonians and Egyptians were using soap by 2000 BC but it was the seventeenth century before it was in regular British household use[a] as an aid to washing clothes. People combined materials such as sand, milk, urine, vinegar, turpentine and borax in their own individual recipes[68] to make cleaning products up until the last quarter of the nineteenth century, when in 1878 Proctor and Gamble launched the first commercially available toilet soap that was gentle enough to use regularly on the skin[69].

Domestic bathrooms did not appear until the nineteenth century[b] and countries varied in the speed at which they were built into homes[c]; until then, most people used a washbasin and a jug of water in their bedroom[70]. Porcelain enamel was invented around 1910 which made baths durable and attractive, but advisers still considered it necessary to encourage a daily bath with warm water and soap in the 1920s[d]. Journalists working for the British *Women's Own magazine* in the 1950s were forbidden to do features on bathrooms because not enough houses had one[71]. By the end of the twentieth century, many people staying in a hotel[72] or a private hospital expected to have a private bathroom not shared by others[73], while the larger new homes were built with two or three bathrooms[74]. Despite this, the old 'once a week' lifestyle may still persist amongst older people or remain as an enduring tradition within families - many middle aged and older people can remember bathing only once a week and changing their shirt every two or three days or even less frequently.

Disposable sanitary goods appeared in the 1920s, including paper tissues that were originally developed for tuberculosis patients, paper toilet rolls[75], and commercially made sanitary pads[76].

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[a] "Soap was used to wash clothing but rarely bodies in fifteenth-century England." (Ashenburg p89). Also, "By 1643 English soap production and consumption had risen so steadily that soap was designated one of the eight staple 'necessities' (namely; soap, beer, spirits, cloth, salt, glass, leather, and candles) that were to be taxed under a new Commonwealth Excise." Smith V (2007) p193.

[b] Ashenburg (p166) "Around 1812 the master of a Cambridge college... when it was suggested that baths be built for the students: there was no need, he responded, since "these young men are with us only for eight weeks at a time."

[c] The percentage of houses and apartments with a bath or shower is now very high in Western Europe: 100% in the Netherlands, Sweden and Malta and percentages in the high 90s in most other western European countries (the anomaly is Portugal, with only 65% in 2001). In some of the countries in the former Soviet bloc, full bathrooms are still relatively rare, with Lithuania, Latvia and Estonia all reporting percentages in the 60s in the early years of this century." (Ashenburg p265.)

[d] William M Handy published a detailed and practical guide in 1923. (Ashenberg p247)

Showers were introduced from the Indian Raj[a] but taking a shower in England was rare until the habit was recognised as quick and so became popular as part of the adoption of American culture in the 1950s[b]. Some UK homes lacked piped water[77], electricity, inside toilets, baths or showers[c] until well into the twentieth century, making it hard for people to take up the most effective daily hygiene routines. In some places in the world, water is becoming scarce as aquafers are exhausted and pipework neglected[78]. Nowadays, one survey found that almost everyone (91%) takes a shower or bath each day[79], but another found only 59% of men and a 67% of women doing so[80], and these statistics may vary by country[d]. In 2014, a survey of 181 inmates of HMP Nottingham found only 29% could shower each day[81].

Despite this potent social norm, some local Councils in the United Kingdom, through their needs assessment guidelines, consider that a strip wash is a satisfactory way to keep clean and so feel under no obligation to ensure that people have access to a bath or a shower. Similarly, some people living in residential care or nursing homes have no more than a weekly bath or shower due to the limited availability of staff[82]. This can be a significant barrier to maintaining routines of good personal hygiene[83], as well as being deeply distressing to people who have grown up with a routine of daily showering.

These historical changes in social norms may be modulated on a cyclical basis, as during a clean period more people neglect their personal hygiene and community sanctions are abandoned, gradually leading to an increase in dirt and disease, which eventually reinvigorates the personal and communal regulation of hygiene practices.

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[a] "European colonialists had rapidly discovered that perfect bodily cleanliness was expected of them in accordance with the caste system, and was essential to the authority of their rule. Among other things they were fascinated by the deft and rapid daily Indian strip wash, the expert Indian champu, or 'shampoo' massage, and the ease of the Indian shower-bath, all of which became widely adopted in Indian colonial circles – habits which they later brought back home." Smith V (2007, p235).

[b] "Public shower houses in America.... built around the year 1900. Once an American patron picked up his two-inch bar of soap and towel, he had twenty minutes for undressing, showering and dressing, in contrast to the European standard of half an hour." Ashenburg op cit p219.

[c] "In some parts of rural Ireland in the 1950s and 1960s there were no toilets at all... and only on Sundays would children 'wash our face and neck, our hands up to our elbows, and our feet up to our knees' ...In Shoreditch in London in 1938, only 14% of the population had baths. ...In many tenements or small apartments lack of space meant that the coal really did go in the bath. ...Large numbers of isolated rural cottages and farms in Britain did not get piped water or electricity until well into the second half of the twentieth century." Smith V (2007) op cit. p311-5.

[d] Smith V (2007) op cit. p338. See also Ashenburg (p221) who finds Harriet Beecher Stowe in 1869 advising her American readers to wash their entire body every day, change their clothes frequently, and avoid sleeping in the garment that had been next to the body during the day. Ashenburg (p275) also reports that "More recently, a number of polls and studies reported that 51% of French women and 55% of French men do not shower or bathe every day and that half of the men and 30% of the women don't use deodorant. As for putting on fresh underwear every day, 40% of French men and one in four French women don't."

A similar cycle has been observed in relation to safe-sex practices and sexually transmitted disease[84].

Beliefs have always affected hygiene

By the fifth century BC, Greek literature shows that the term 'cosmetic' had already been adopted as a synonym for trivia and superficiality, a view which was taken up by later religious ascetics and continues to reinforce the restrictive role assigned to women by its association with narcissism and triviality[85].

Both personal hygiene and the lack of it can be either an unconscious routine or a deliberate statement that expresses a chosen lifestyle or belief. In both cases it represents an inner psychology or state of mind. Language links hygiene with dirt: with morality and sex through the notion of the 'dirty mind', 'dirty' sports fouls and 'clean' living, and with wealth and status through the 'filthy rich'.

The symbolism of dirt and purity appears in religious initiation rites[a] and several ancient religions and beliefs, which use specific 'dirty' items as charms or symbols of spiritual and social power, including blood, dung, funeral dust, and parts of a carcass, such as a rabbit's foot or antlers, thus revealing our strangely ambivalent relationship with cleanliness[86]. Islam includes detailed instructions to wash after defecation and before leaving the house[87], and other instructions that link daily washing and prayer in a devotional duty[b].

The launch of Christianity included an instruction from Jesus to 'wash one another's feet'[88] and advice on treating poor and unwashed people with respect[89]. In the Old Testament, Job had sat on a dungheap after the trauma of losing his family; and in the New Testament, the Apostle Paul used a vulgar metaphor[c] when he contrasted the ultimate worthlessness of his past academic and social achievements with the future hope promised by his newfound faith.

Some early Christian ascetics, such as Agnes, St Mary of Egypt, Godric[90], Olympias and Radegund, focused upon their inner, spiritual world and did not take time to wash, rejecting the physically comfortable, self-absorbed life in favour of spirituality, the self-mortification of 'alousia' (abstention from washing) and compassion[91]. This

[a] 'One of the most widespread rites of passage involves bathing the dead, an action that serves no practical purpose but meets deep, symbolic ones.' Ashenburg op cit p9.

[b] "Islamic washing practices were no light undertaking... five times daily before each of the five prayer sessions.... [and many other practices were prescribed, including] the use of the toothpick, cleansing the nose and gargling the mouth with water, clipping the ends of the moustaches, clipping fingernails, cleaning the finger joints, depilation of the armpits, shaving of the pubic hair, cleaning with water or dry earth or a piece of stone after evacuation and urination, washing hands before and after meals, and circumcision." Smith V (2007) op cit. p140. In contrast, the monks of Cluny, living around 1075, 'bathed twice a year, before Christmas and before Easter.' Ashenburg op cit p67.

[c] In Philippians 3:8, Paul used a vulgar expletive that is usually translated as dung or garbage.

was sometimes taken to great extremes[a], as when Francis of Assisi, and, in our own day, Mother Teresa, embraced lepers and washed puss from their wounds. Some medieval divines such as St. Margaret Marie Alacoque, Mme Guyon, Blessed Angela of Foligno and St John of the Cross[92] describe ecstatic experiences that are linked with nursing the sick which are expressed in ways that would commonly be deemed disgusting these days.

Care is needed with some of these accounts for at least five reasons. First, medieval art and literature contains a great deal of bizarre and fantastic imagery, including many scatological scenes[93]. Second, its portraiture is full of symbolism[94] and the presence of animals, jewellery, colours and perhaps even hygiene symbols may not have been intended to be taken literally. Third, while some commentators suggest that the saints experienced simple (although perhaps aberrant) pleasure in disgusting acts, others[95] suggest that more complex processes were at work. For example, St Catherine of Sienna felt the need to overcome her own disgust response in order to care for sick patients, and so deliberately imposed upon herself an intense experience of disgust – using the familiar psychological process of flooding[96] to overcome negative emotions. Fourth, medieval spirituality links disgust in general and faeces in particular with sin, Satan and hell[97]. Fifth, as in our own day, competing subcultures within the medieval world co-existed to form a complex interplay of differences of view[98].

So it is not surprising that the medieval church took up the ancient practice of using incense to mask the stench of unwashed pilgrims[b]. In our own day, Richard Beck[99] has suggested a link between the psychology of disgust and the church's response

[a] Ashenburg op cit p111 explains that, "In Spain, Moors who converted to Christianity were not allowed to take baths, and a damning piece of evidence at the Inquisition, levelled against both Moors and Jews, was that the accused 'was known to bathe'. Spanish confessors were urged to question their female penitents minutely about private washing and not to absolve those who washed regularly." Ashenburg also tells us (p72) that '... the odour of sanctity.... was a euphemism for 'foul smell', but it came to represent Christian godliness, and many of the saints are pictured [in early art] sitting in their own excrement.' However, other scholars dispute this. Martha Bayless (author of *Sin and Filth in Medieval Culture*) disputes this. She wrote in a personal communication on 22 March 2014 that 'the common image is of Job sitting on the dungheap (Job 2:8), which was interpreted as man recognizing his own sinfulness and the sinfulness of the earthly world. A dungheap would be a much more common thing to encounter [and is] typically indicated by a large dark mound with bits of straw in it. The number of holy people who accepted their own personal filth was vanishingly small.... Generally people who lived in filth of their own making were identified as sinners -- that was the common interpretation attached to it. There are innumerable stories in which sinners are afflicted by their own filth.'

[b] Whilst it has been suggested that inhabitants of the Medieval world simply did not notice the pungent smells of their neighbours, a variety of activities were taken up to help people cope with the unpleasant smell. For example, 'St Thomas Aquinas approved of incense in church because it masked the prevailing body odour, which, he admitted, "can provoke disgust". Ashenburg op cit p77. Similarly, Ashenburg op cit (p99) tells us that, "At the French court... aristocrats perfumed themselves so as not to smell their neighbours."

to hospitality, sexual conduct and death, while the abject artist Andres Serrano provoked controversy by submerging a crucifix in urine[a]. It seems clear that there is a complex interplay between beliefs, emotions and hygiene practices.

The behaviour of medieval ascetics may seem far away from our modern life and be difficult to understand. A more recent example of the link between hygiene and belief is found in the 'dirty protest' in Northern Ireland. Between 1976 and 1981, men held in the Maze prison and women in Armagh prison sustained a five year long protest in an attempt to block the downgrading of their status from political prisoners to criminals.

They smashed the furniture in their cells, wore only blankets or went naked, and refused to wash and 'slop out', instead smearing faeces on the cell walls. In an attempt to manage the situation, prison staff broke cell windows and sprayed disinfectant into the cells, leaving prisoners without heat. By the summer of 1978, between 250 and 300 prisoners had joined the protest declaring that they were willing to die for their political beliefs, with morale remaining high despite the living conditions. By late 1979, 90% of newly arriving prisoners were joining the protest. In June 1980 the European Commission of Human Rights ruled that the conditions were self-inflicted and "designed to enlist sympathy for the [prisoners'] political aims."

Back in the Age of Enlightenment, Protestant reformers encouraged personal hygiene as part of the search for heaven or utopia. For example, the eighteenth century founder of Methodism, John Wesley, told his congregation that 'Cleanliness is next to Godliness'[100] and advised them to 'avoid all nastiness, dirt, slovenliness, both in your person, clothes, house, and all about you - do not stink'.

Age and disability sometimes bring physical pain that inhibits hygiene practices[101], and it has been suggested that some people transcend the disappointments of the deteriorating physical body by focusing upon a sense of identity and purpose that is beyond the physicality of chronic illness and discomfort[102]. Meanwhile, dirt acts as an unsettling reminder that all our bodies will decay – a topic that we prefer to avoid.

Many of these issues come together in narrative accounts from older people who are facing the challenge of managing personal hygiene. So, for example, when investigating self neglect, Kutame[103] heard from many research respondents who had developed coping mechanisms informed by religious faith and prayer, and Gibbons[104] similarly found many interviewees who wished to explore their personal philosophy of life and death, including personal control, protecting the self and managing fears.

[a] Serrano's 1987 photograph of a crucifix submerged in his own urine was named *Immersion (Piss Christ).* It sparked vigorous and sometimes violent protests in the United States, Australia and France, with opponents feeling that it demeaned a precious icon. Serrano claimed it represented the way contemporary society has treated Christ, and others have suggested that it provides a contemporary metaphor for the incarnation – God sending his holy Son into the least attractive and most despised parts of our world.

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Contemporary culture

Personal identity has been emphasised in postmodern culture, where it has been viewed as a plural, malleable feature through which people constantly reinvent and promote themselves[105]. Indeed, many people feel considerable aesthetic pleasure in wearing clothes they have carefully selected[106], and taking 'time to prepare a face to meet the faces that you meet'[107].

Contemporary society presses home the powerful message that if we look good we will feel good and so in times of economic boom people respond to this message with a noticeable increase in the demand for cosmetic and health products. Economic recessions accelerate government efforts to renegotiate the social contract between individuals and the state, re-emphasising the duty on each citizen to make the most of themselves via diet, exercise, appearance and preventative healthcare and thus rely less upon public funds.

In addition to the ever-growing fashion and cosmetics industry[a], the 1980s saw the launch of a global and still expanding market in wellbeing through organic products, vitamins and minerals, spas, beauty salons, gymnastic products and surgery[b], along with the resurgence of multicultural approaches to wholeness as diverse as Reiki, massage, and colonic irrigation. While data seems inconsistent, one 2006 survey supposedly found that the average woman in the UK spends more than £8 per day on cosmetics[c], and women spend more time and money on clothes, more time shopping for them and read more about fashion than their male counterparts[108]. Cosmetic use often influences self esteem and can also affect task performance[109].

Despite (or perhaps because of) narcissistic[d] advertising and considerable expenditure, many women feel bad about their bodies[110]. As Ashenburg[111] says,

> *There seems to be no resting place, no point at which we can feel comfortable in our own skins for more than a few hours after our last shower. "Clean" keeps receding into the distance. ... In some ways, we are as repulsed by our*

[a] "All the advertising gambits – testimonials, premiums, prizes, catchy slogans and jingles, continuing characters – that were later refined and adapted in ad campaigns for a variety of products made their first appearance in advertisements for soap." Ashenburg op cit p243.

[b] 2.5 million cosmetic surgery procedures were carried out in Britain in 2002, according to James O (2007) *Affluenza* London: Vermilion p52)

[c] A 2006 survey found an average of £8.20 a day was spent on cosmetics and hair products. See http://www.cosmeticsdesign-europe.com/Financial/UK-women-spend-big-to-look-better accessed 7 Feb 2011. The 2007 worldwide retail value of all cosmetics and toiletries was more than $290 billion (source: ©Euromonitor International, quoted in Russell, R (2003) Why cosmetics work **in** Adams, Ambady, Nakayama, & Shimojo (Eds.) *The Science of Social Vision*, Oxford University Press).

[d] The Greek male god Narssicus was absorbed by self worship of his own physical perfections.

real bodies as were the medieval saints, although without their religious motivation.

This means that asking women to focus on their personal appearance can make them feel worse, not better[a]. Indeed, body image has consequences for goal striving, wellbeing[b] and self-esteem[112]. Such patterns begin early, as research has shown that girls who spend a lot of time identifying with the *Disney princess* culture are less confident in maths and science and dislike getting dirty[113].

There is much less evidence to hand about men's views, although a similarly conflicted situation has been reported with men simultaneously claiming to be disinterested in their appearance while spending perhaps $200 million globally on male cosmetics[114], a figure that appears to be rising[c]. Meanwhile, one team of researchers found that poor hygiene to be almost a badge of membership for a motorcycle gang[115].

The academic and political arenas show similar ambivalence. The last decade has seen the widespread emergence of academic studies in positive psychology and the introduction of wellbeing into national policy[116] as a public health complement to treatments for mental illness, but both wellbeing academics and policy makers have largely ignored personal hygiene[117].

The culture of the 'performing self' puts pressure on us all to be constantly on display and judged[118], by promoting external, measurable aspects of our selves rather than the inner life of character traits, values and resilience[119]. Many strategies for self-help including measuring our weight[d], calorie intake, and even our daily footsteps, are, for some, almost an obsession, whilst the broader acceptance of individualistic clothing and hairstyle preferences simply increases the opportunity to make an overt grooming display. Since 2018, an increasing number of US states have felt it necessary to formally prohibit employers, schools and housing providers from discriminating against people on the basis of hair or hairstyle[120].

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[a] "Indeed, Clarke and Miller (2002) argue that postmodern fluidity and optionality produce anxiety as much as pleasure and agency, with the wish to choose the right clothes and fear of choosing the wrong dominating many women's shopping choices." Twigg J (2009) Clothing, identity and the embodiment of age in Powell J & Gilbert T (eds) (2009) *Aging and Identity: A postmodern* dialogue New York: Nova Science Publishers.

[b] Life goals that are challenging but realistic improve wellbeing. Some life goals (an extreme example would be gaining employment as a model) depend heavily on appearance. Problems with processing information about appearance (such as eating disorder) make all this more difficult. See http://about.elsevier.com/bodyimage/Vol3Iss2/BI-3-2-0008/index.html

[c] The UK sales of male cosmetics increased by 800% in the seven years to 2006 according to the *Independent* newspaper - see http://www.independent.co.uk/news/uk/this-britain/male-grooming-suits-you-sir-466360.html Accessed 10 March 2011.

[d] "Sanctorius Sanctorius (1561-1636) set off a popular craze for weighing and measuring one's own body – forerunner to the 'weight-watching' regimes of the modern slimming diet." Smith V (2007) op cit, p202-4).

But we should also note that the act of grooming can carry a symbolic meaning for the individual that goes beyond mere performance. Levi describes[121] the morning routine in the concentration camp in Auschwitz as follows:

> *"I suddenly see Steinlauf, my friend aged almost fifty, with nude chest, scrub his neck and shoulders with little success (he has no soap). [He] sees me and asks me severely why I do not wash. Why should I wash? Would I be better off than I am? Would I please someone more? Would I live a day longer?…. Does Steinlauf not know that after half an hour with the coal sacks every difference between him and me will have disappeared?….*
>
> *[Steinlauf says]"…even in this place one can survive, and therefore one must want to survive, to tell the story, to bear witness; and that to survive we must force ourselves to save at least the skeleton, the scaffolding, the form of civilisation.*
>
> *"We are slaves, deprived of every right, exposed to every insult, condemned to certain death, but… … we must certainly wash our faces without soap in dirty water and dry ourselves on our jackets.... ...for dignity... We must walk erect, without dragging our feet... ...to remain alive, not to begin to die."*

Similarly, Lieutenant Colonel Gonin[122] describes the liberation of the Belsen concentration camp directly after the end of the Second World War, where women survivors received and enthusiastically used a consignment of bright red lipstick to mark their enduring humanity.

These shocking accounts provide extreme examples of a general process that, in more usual times, continues to exert a quiet influence on all our lives. In particular, Clarke has studied the range of ways in which women are influenced throughout their lives by the ideals of beauty and femininity they learn from their mothers, by media representations, and by sometimes resisting current norms of attractiveness. For example, applying make-up has been shown to enhance achievement in cognitive tests, probably mediated through the intermediary impact of self-esteem[123], which in turn suggests that people with poor hygiene and grooming levels may have reduced cognitive function as a result.

Ageing affects these expectations and norms of appearance, and many older women believe that they should refrain from wearing bright colours or revealing styles and should cover up bodily signs of ageing[124]. Other older women and men adopt playful, bright, loose resort and leisure wear that accommodates their changing body shape and appearance[125], but is also redolent of a second childhood and of care settings where easy-on and wipe-clean fabrics are prevalent[126].

As well as dressing up, we also dress down to feel good. Taking a leisurely bath and spending time on grooming is relaxing and pleasurable, as is its opposite - taking a day off from the discipline of shaving, applying make-up and wearing smart clothes to create a public face for the world. Some women have chosen to wear men's

clothing as it is more comfortable[127]. A more extreme example of dressing down may be the enthusiasm that young adults have for mud play at rock music festivals.

In the Western world since the mid-1980s, there has been a marked shift away from formal and perhaps uncomfortable clothing to leisure wear across all age groups[128], but some employers continue to enforce a dress code[a]. The tolerance of eccentricity that is thought to be a key feature of English culture may contribute to our ambivalence towards those who neglect their appearance and hygiene[129].

Challenging the cult of hygiene

> *'"There's one thing you have to be careful of, you know...". "What's that?" "The hygiene! It can be most awfully dangerous. The purity! The terrible determination not to adulterate anything! You will be very careful of it, won't you?'*
>
> Horace Rumpole[130]

While physical attractiveness and health promoting behaviour are highly valued norms, some people adopt an alternative stance, rejecting the usual imperative to stay healthy and conventionally beautiful[131], such as members of the Punk movement in the 1980s and contemporary young people who choose artfully torn jeans, confrontational fashion (such as Pigeon-chiq-wear[b]) and carefully worked 'just out of bed' hairstyles. As Norman observes, 'Even the rebellious have to change continually, carefully noticing what is in fashion so as not to be following it, carefully creating their own fashion of counterfashion."[132] Other people reject the use of cosmetics, deodorants or fashionable clothes for a wide variety of other reasons, including rejection of sexism that reduces women to objects of a sexualised gaze[133].

The modern 'hygiene hypothesis' suggests that the human immune system has been weakened in affluent, clean communities and the downside to all this cleaning may have caused the increase in allergies seen in more sterile populations. It suggests that the immune system is weakened by lack of exposure to threats, leading to a rise in hay fever, asthma and allergies, so perhaps we do need our 'peck of dirt' after all[c].

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[a] For example, the dress code at Alpha Hospitals (October 2014) includes the following advice: "tie long hair back, keep nails short and well manicured and do not wear hooded jumpers or sweatshirts; T-shirts and sweatshirts with advertising or inappropriate or offensive language or pictures; visible tattoos; low cut necklines with excessive cleavage on view; denim; athletic wear; fashion scarves and accessories; short skirts or dresses or with extreme splits; high heels or stilettos; jewellery (except stud earrings and wedding bands), or facial body piercings (including tongue studs)."

[b] This 2014 fashion addresses the rise of 'unpleasant design', in which urban architecture and street furniture is shaped to exclude marginalised people, unprofitable leisure activities and wildlife – see http://unpleasant.pravi.me/.

[c] "In 1989, a British epidemiologist, D. P. Strachan, published a groundbreaking article in the BMJ called *Hay fever, hygiene and household size*. In it, he suggested that unhygienic contact and infections, both of which are facilitated by large families, might prevent the development of allergies. The so-called Hygiene Hypothesis, first voiced by Strachan, is that our immune system needs a certain amount of bacteria on which to flex its muscles.... The list of diseases possibly contracted in

While the hygiene hypothesis has been largely dismissed[134], people who continue to hold to it as a basis for not washing need to consider how to create 'safe threats' that strengthen the immune system, without killing themselves or harming their social standing.

It might be argued that people with an obsession with hygiene are driven by too strong a disgust response, while self-neglect is caused by too little. In the past, many people had an opposite fear or phobia, which was about water touching the skin. They believed that the skin was like leather, and that washing off the dirt would fatally weaken the body. They had to feel 'strong' if they were to have a bath; this fear of water may persist in people with poor balance or muscular weakness who have an understandable fear of slipping or falling during entry or exit from a bath. Alternatively, such individuals may prefer the sedative comfort a bath gives, rather than the stimulating high-pressure shower, and so end up doing neither.

Some people respond to all this social pressure by feeling totally unable to control their circumstances or improve their performance; and this leads to fatalism and resignation in which they give up taking care of their own health, grooming and appearance[135].

this way came to include rheumatoid arthritis, diabetes, Crohn's disease, multiple sclerosis and even heart disease." (Ashenburg op cit p290-2). 'An asthma study of East German and West German families by Erika von Mutius found that the children in the dirtier and less hygienic East had significantly fewer cases of asthma than children from the cleaner and more modern West.' Smith V (2007) *Op cit*, p349. For a discussion of the correlation between microbiome diversity and obesity, see Blaser M (2014) *Missing microbes* New York: Henry Holt.

Reflection time – Chapter Two

- Describe your personal hygiene rituals in response to a special occasion – do you buy new clothes for a wedding or take an extra shower before going out to a party?
- What 'folklore beliefs' did you learn as a child about taking a bath?
- Do you like spending time in the bathroom?
- Do you own tools and equipment to help keep yourself and your home clean? Do they work and do you know how to use them?
- Is it worth spending time on cleaning?
- Is it women's work?
- Do you have the use of a bathroom and is it comfortable, warm and private, with everything working properly and all the products you need?
- What is your preference - a bath or a shower? Can you use it without pain or fear?
- What helps to give your life meaning and direction and boosts your self-respect?
- What impact does your faith or core value system have on your hygiene routines?
- 'Looking after yourself' is a big thing in today's society. How do you feel about this?
- What are you communicating to others through your choice of clothing, hairstyle and appearance? 'Looking after yourself' is a big thing in today's society. How do you feel about this?
- What are you communicating to others through your choice of clothing, hairstyle and appearance?

3. Who is at risk?

Case Study Three

"You doing okay here Charlie? Not bad is it? It's Jerry, remember me?" Jerry had been his support worker from two years ago. Charlie had eventually refused to answer his door to anyone - including him. Jerry remembered visiting him previously and how Charlie always used to open the windows to try to eliminate the unpleasant odour in his rooms. Living on his own and eating only sandwiches and no hot meals, Charlie had given up attending any social events. His fear of chemicals in shampoo and soap meant that he was very reluctant to wash himself or his clothes. By that stage, Jerry had referred him for a fresh assessment.

"Oh … hi Jerry. Long time no see …"

"You look well Charlie," it was obvious to Jerry just how much progress had been made recently, "I heard you'd been in hospital. You'd lost weight hadn't you?"

"Much better now Jerry! Like my clothes? Look, new trainers." Charlie was smiling broadly.

"That's great. Lovely. Only I heard you'd been very confused and worried hadn't you? I was sorry to hear that." Charlie nodded at him and lifted up his trainers again so Jerry could get a better look. Charlie's mental state had deteriorated drastically and he had been detained in hospital under the Mental Health Act. Six months later and in supported accommodation, Charlie had turned a corner.

"They're Adidas Jerry," Charlie smiled, "better than yours." Jerry was forced to agree with him … and the two men laughed.

Self-neglect is a widespread phenomenon, not confined to any particular group[136,137], but the meagre research evidence that is available suggests that there are a number of groups of people who may be at particular risk of self-neglect. These include older people, those with mental health issues or visual impairments, homeless people and adolescents leaving care. Other groups, such as people with learning disabilities who live alone and indeed anyone living on a small budget may face challenges too but have not come to the attention of researchers. As the available data relates to the broader topic of self-neglect, we know even less about the specific issue of poor hygiene.

Self-neglect is a common feature of serious case reviews in the UK, while in the United States it is the commonest reason[a] for reporting to the £500 million[138] adult

[a] "In a population-based study of Texas adult protective services division of the state protective services program, 62.5% of the clients were referred for self-neglect." Dyer, C.B., Goodwin, J.S., Pickens-Pace, S., Burnett, J. and Kelly, P.A. (2007) 'Self neglect among the elderly: a model based

protection services[139]. Neglect of personal hygiene is often a signal that there are other problems - in one study[140] of 81 people who used a special cleaning service, 85% had one or more chronic physical health problems, 70% had mental disorders, and 32% were misusing substances.

An estimated 3% of people (equating to 1.53 million people in England) sweat excessively[141], and in general, men sweat more than women, so may have more difficulty managing body odour.

Older people

The estimated incidence of self-neglect in the UK is 0.5 per 1,000 in the population aged over 60[142], occurring equally in men and women[143], which is higher than the rate amongst younger people[144]. In a population-based study in Texas, 90% of the self-neglect cases were aged 65 years or older[145].

Demographic changes, including the increase in dementia, reduction in the value of pensions and the frequency in which people outlive their support systems, may increase this rate. In addition, frailty, functional decline, cognitive impairment, or psychiatric illness may increase vulnerability[146].

Sometimes dementia affects the person's daily routine so that they omit meals and medication, disrupt sleep patterns and neglect to wash, so restoring a healthy time structure can help to re-establish self-care routines. Relatives, neighbours, staff or telecare schemes can sometimes help with this[147] and advice is available[148].

Ageism comes into play when people consider self-neglect as a natural consequence of ageing or when a complaint from the general public[149] is not taken as seriously by services as it would be if a child was involved[150].

Some hints have been offered[151] to those seeking to support people with dementia stay clean, including the following:

- Simplify routines, perhaps by going for a shorter haircut
- Invest in multiples, so people can enjoy their comfortable clothes and stay clean
- Change the offer, so people find it easy to comply
- Consider what might be upsetting
- Try distraction, such as music in the bathroom.

on more than 500 patients seen by a geriatric medicine team', *American Journal of Public Health*, vol 97, no 9, pp 1671–6.

People with mental health issues

Tearing one's clothes and putting on sackcloth and ashes is an ancient symbol of grief and desolation[152]. Self-neglect is sometimes associated with an underlying mental disorder, such as depression[153], perhaps as a response to bereavement, although researchers have not always found a statistically significant correlation[154]. Certainly the combination of mental illness, social isolation, and poor self-care increases death rates[155]. Indeed, a study of over 9000 people who had been risk assessed as part of their mental health treatment found that clinician-assessed self neglect was a predictor of mortality, while there was no such association with risk of violence or suicide[156].

Obsessive compulsive disorder has also been linked with self-neglect, as it diverts attention away from other activities on to the focus of the compulsion, and this may mean people neglect their personal hygiene routines or refuse help from one or all services[157]. This is sometimes portrayed in the stereotypical character of the absent-minded professor who is so busy with his thoughts and in such a state of flow[158] that he forgets to eat or wash. People with agoraphobia have been shown to have heightened disgust sensitivity[159].

In the sample of self-neglecters studied by Graeme Halliday and his colleagues, between 50% and 70% had a psychiatric disorder or condition that could reasonably explain their behaviour[160]. Some people diagnosed with borderline personality disorder neglect their personal hygiene. Prompt assessment (under the Mental Health Act if necessary) and treating the psychiatric difficulty or substance misuse may avoid deterioration and lead to improvements in self-care.

One research team[161] found that self-neglecting people who were diagnosed with a psychiatric condition were more likely to be offered access to social work and other help, while those without such a condition received very little help and were more likely to be subject to enforcement actions by environmental health and housing services.

Mental health services have had a long history of using hygiene as therapy, illustrated by the Victorian use of enforced bathing, haircutting and re-clothing as treatments, and by the locations chosen by their asylum builders – always on high ground in the countryside so that fresh, clean air could blow away people's distress.

Indeed, baths were used in many ways including: cold baths to calm down 'excitable' patients; warm baths to invigorate the passive and depressed; the 'bath of surprise', in which a floor unexpectedly gave way and plunged the patient into water that was designed to shock people back into sanity; and long baths that could last for hours aimed to calm the violent[162]. We notice that the preoccupation with hygiene was generally a public affair, and some hospital, hostel and care home settings continue to lack opportunities for privacy[163].

By the turn of the twentieth century, bathing as therapy was set aside in favour of viewing the asylum as a clinically hygienic hospital. Despite this theory, from an

international perspective, many psychiatric services remain underfunded, housed in dilapidated buildings that provide poor amenities and hygiene standards[164]. Even in the UK, provision in hospitals has not always been of an acceptable standard[165].

In our own day, Jeannette Pols[166] suggests that the preoccupation with hygiene as in its turn been replaced by the modern psychiatric values of empowerment and recovery through which many staff have shunned the 'old school' traditional approaches of insisting on a clean environment and bathing passive patients. However, UK mental health services have been required to assess and respond to chronic self-neglect since 1995[167] or earlier, and supporting learning disabled people with personal hygiene is a core competency required of all health and social care staff[168].

Qualification thresholds for nursing have also risen in recent years so that it now almost entirely a graduate profession, moving the focus away from simple care functions so that nurses are accused of being 'too posh to wash' their patients[169], while others[170] disagree and assert that touching and tending the patient's body surface is part of 'real' nursing. In some places, the principles of empowerment and recovery may be superseded by a preoccupation with hospital borne infection – of which more later.

Overlying all this is the carapace of demand pressure, which is changing practice across all kinds of healthcare and prevents nurses from doing all the things they might want to do, as one paediatrician illustrated[171]:

> *'On day eight of my admission, a lovely nurse made the time to wash my hair, cunningly using a flattened bucket with a drain attached. This was not just a vanity exercise. As she rinsed away the blood and road debris from my hair, I started to feel human again. Now I reflect that I have I never asked a patient about support with personal hygiene while on the ward.'*

A study by Hope and colleagues[172] found that some hospital patients responded to 'distracted' or 'dismissive' staff by suppressing their own needs and requests for assistance with washing until the next shift, only asking 'engaged' staff for this kind of help.

People with sensory differences

A range of causes, including increasing age, can lead to reduced vision and an impaired sense of smell[173], which may reduce standards of environmental and personal hygiene[174]. Sometimes impairments occur in combination, such as where people with learning disabilities are ten times more likely than others to have a visual impairment[175]. Other impairments can also affect the person's ability to take care of

their grooming[a], as when the person cannot lift their arms to head height to comb their hair, a staircase is too much effort to climb to get to the toilet, or skin complaints make bathing painful. People with a visual impairment may be unable to see that their clothes are dirty, and, if they use a wheelchair, this may also end up bearing rotting food scraps or other spillages that create a neglected look or an odour. Occupational Therapists may be able to provide a lift or handrail to help the person get into the bath or provide other equipment or adaptations.

As well as impaired sensory functions[176], sensory processing or sensory integration[177] disorders can affect hygiene routines including handwashing[178]. For example, autistic children have been found to experience sensory sensitivity which negatively impacts their oral hygiene through difficulties with toothbrushing[179] and using the toilet[180]. Tactile defensiveness[181] and other aversive responses sometimes cause avoidance behaviour to evade experiences that are perceived as extreme, whether that is the loud noise of shower water landing in the tray, the sensation of water hitting the skin like needles or the overwhelming smell of shampoo[182]. Baths may be no better, as the process has been described as being submerged in 'human soup'[183].

Some people may find that their vestibular system is hyper-reactive, especially in detecting head position and movement which can make the person fearful of the movements involved in self-care, such as sitting down on the toilet, stepping into the bath or tipping the head back for washing. This so-called 'gravitational insecurity' can interfere with hygiene practices. Other people can be hyper-reactive to interoceptive sensation, such as that of needing to use the toilet and find this dominating their day.

In contrast, some individuals are under-reactive to sensory stimuli. This can result in them not responding to the need to use the toilet, to the bath water being too hot, to their own odour, or to the appearance or 'feel' of mess which can mean that they do not initiate hygiene activities. Under-reactivity can also result in a person seeking the sensation they are under-reactive to, such that it impacts on the progression of the hygiene activity e.g. becoming so obsessed with splashing or smelling toiletries that they don't actually wash.

Poor ability to discriminate sensations can have an impact on hygiene practices, such as through the proprioceptive system. Proprioceptors are located within muscles and joints and they normally send information about muscle work and about how body parts are moving and where they are located. Poor proprioception can make bottom wiping an extreme challenge, for example.

Poor proprioception discrimination can combine with poor vestibular discrimination to make maintaining the posture and balance required for hygiene activities a challenge

[a] Xinqi Dong has established a link between physical impairment and self-neglect in older adults. http://jah.sagepub.com/content/21/4/596.abstract accessed 7 February 2011.

(postural insecurity) whilst various combinations of discrimination dysfunction in the tactile, proprioceptive, vestibular and visual systems can result in a difficulty with praxis. Praxis relates to forming the idea and motor plan for action and then executing this in a co-ordinated way. This can have a severe impact on the initiation and / or execution of the physical actions required to perform hygiene activities. Poor ideation may make the person seem very disorganised. With poor motor planning and execution, the person may seem to have the mental and physical capability to do a task, but, due to poor information from their senses, cannot then send good messages from their brain back to their body to bring about efficient, co-ordinated actions to perform the task well. They may end up avoiding tasks altogether.

Homeless people

There are many reasons for people becoming homeless or vulnerably housed and these change over time and in response to the wider societal and political context. For example, over half of rough sleepers in London are now reported to be non-UK nationals[184].

For homeless people the battle of daily survival can overtake all else and it may be necessary to spend all their money[a] on what is absolutely necessary for daily survival, leaving nothing for clothing, laundry, cosmetics and grooming[185]. One study found 19% of homeless people had skin problems[b]. An American project gives out Just Add Water kits to homeless people, comprising soap, shampoo, a toothbrush, paste, washcloth, comb, razor, bandages and antibiotic ointment[c].

Local councils in England were required to provide public toilets for the first time after the 1848 Public Health Act[186], and almost one million people had the opportunity to 'spend a penny' and use a flushing toilet while visiting London's Great Exhibition of 1851. In contrast at this time, up to 30,000 visitors a day to the British Museum shared the use of just four outside toilets[187]. The need for public toilets continues, as demonstrated in Paris in 2006, where charges were removed and usage jumped from 2.4 million to 8 million visits[188]. More recently however, provision has declined, partly because of worries that the toilets were being used for illegal drug-taking or

[a] As an aside, we note that dishonesty with money can be a factor in self-neglect for some individuals (but this is not, of course, to imply a general link between dishonesty and neglect). For example, in Liverpool, 95 year old Olive Maddock died of natural causes in early 2010 and her daughter and granddaughter simply closed the bedroom door on her dead body and continued to collect her pension for six months until neighbours raised the alarm. The house was filthy and vermin-infested. *Metro* 14 June 2011.

[b] Lawless M, & Corr C. (2005). *Drug use among the homeless population in Ireland: A report for the national advisory committee on drugs*. Dublin: National Advisory Committee on Drugs. In this study, homeless people included both street dwellers and 'sofa surfers'.

[c] http://www.dentistryiq.com/index/display/article-display/373083/articles/rdh/volume-30/issue-2/feature/the-5ndashw-process.html

sex. Indeed, engaging in sex in a public toilet, even in a cubicle, remains an offence under Clause 71 of the Sexual Offences Act 2003. There is also a problem with finding these public toilets[189].

As a result of these concerns, some 40% of public toilets in England closed between 2000 and 2008[190], and the decline has continued[191], prompting the Chancellor to provide 100% mandatory business rates relief for all lavatories made available for public use from autumn 2018. Despite this, shops and restaurants provide most of the service (sometimes through a Community Toilet Scheme[192]), which excludes some citizens, such as people with mobility issues and people with dementia[193], despite the availability of funding[194] and excellent advice on the design of 'Changing Places' accessible toilets[195] and dementia-friendly toilets[196]. Such provision not only assists people who are homeless and surviving on a small income, but also supports women during menstruation[197]. People who have a home may nevertheless lack some basic amenities, such as a bath or shower, private and lockable space for personal care and a safe place to keep cosmetics or clean clothes, and the money to afford them, while those who rely on shelters may find that the bathroom is dirty or unsafe. All of these issues can be replicated in specific settings too, such as the UK school which closed most if its toilets in response to vandalism, resulting in pupils choosing to spend their lunchtime queuing rather than eating[198].

The picture is worse in low income countries around the world, where at least one billion people have no access to toilets and so must defecate in the open, while another three billion use toilets that lack sewage treatment, and so raw waste is dumped and seeps into water courses[199]. While large-scale programmes are building toilets, they are often basic pit latrines and smell so foul that people continue to defecate in the open. In response, the Bill and Melinda Gates Foundation is supporting the development of fragrances that block the operation of specific receptors in the nose, effectively cancelling the message sent to the brain by the unpleasant smell[200].

The practical difficulty of finding a safe place to get undressed and put down one's belongings perhaps obscures a core emotion that both homeless and securely housed people share in response to personal hygiene practices – vulnerability. Whether standing at a urinal, sitting on a toilet seat that someone else has used or removing one's clothes to wash, people feel exposed and vulnerable, and sometimes this feeling is sufficiently potent to curtail the behaviour itself.

This feeling of vulnerability has been harnessed at the Glastonbury music festival, where in 2015, WaterAid highlighted the plight of the 2.5 billion people in the world who lack access to a safe and private toilet by creating a cubicle with a door formed of a one-way mirror, so that people sitting inside could see out, but those in the queue could not see in[201].

Indeed, there is some justification for the feeling of vulnerability, as Rosie George points out[202] that both Henri III of France and James I of Scotland were murdered in

their toilets. A more mundane driver for feelings of vulnerability is ‘bladder leash’ that prevents disabled people going out through the fear of being unable to find a toilet when they need one – although a smartphone app called Satlav may help to locate the nearest one - and paruresis or ‘shy bladder syndrome’ which prevents people from urinating in public places[203].

Children and Adolescents

Guidance[204] on child protection has defined a number of categories of neglect, including physical neglect, which is described as:

> “At its worst this is the physical environment characterised by dirt, unwashed clothes, rotting food, untrained animals, broken or damaged furniture, soiled mattresses with little or inappropriate – sometimes wet - bedding, with little space free from clutter, detritus or even excrement. ... they may present as unwashed, sometimes smelling of body odour or urine, in dirty or ill-fitting clothes, sometimes going to school in the clothes that they slept in. Consequently, such children may experience name-calling and bullying, and can fluctuate between a resigned acceptance and embarrassment. These children may become socially excluded within their peer groups...”

Children may be at serious risk when their carers neglect hygiene in the home. In Bradford, England in 2011, four year old Hamzah Khan died of starvation after a lifetime of neglect. His mother lived in severe domestic squalor[a] and left the dead boy’s body in his cot for almost two years until it was found by Police.

More recently, limits to the resources available have raised the threshold at which children become eligible for social work intervention, increasing the risk of child neglect and death, as in the case of Abigail[205]. However, guidance is available on recognising and responding to neglect[206].

In the context of care proceedings, the courts have emphasised that society must be willing to tolerate “very diverse standards of parenting, including the eccentric, the barely adequate and the inconsistent[207]. Further, the courts have emphasised that “*the test for severing the relationship between parent and child is very strict: only in exceptional circumstances and where motivated by overriding requirements pertaining to the child's welfare, in short, where nothing else will do.*"[208]

These understandable limitations upon the ability of the state to intervene by removing children can sometimes leave the child at serious risk where their carers neglect their own hygiene and that of their children.

These distressing stories may divert attention away from the much more frequent occurrences of neglect. Interviews with over 3,000 eight to twelve year old children in

[a] Photos can be seen at http://www.bbc.co.uk/news/uk-england-24401112

2010 found “almost 61% had seen suspected signs of neglect; children as young as eight are seeing signs of neglect in their peer groups; 25% had seen a child who was wearing ill-fitting or smelly clothing; 19% had seen a child who looked unwashed or dirty; 7% had seen a child who may not be receiving meals at home and 34% had seen children who did not appear to have any friends at home or at school.”[209] The problem seems to be getting more common[210].

Care leavers may have difficulty in social interaction, leading to limited engagement through relationships, friendships and support networks[211]. These and other adolescents who experience a dysfunctional early family life[212] may struggle to form healthy relationships built on trust and this will impair their ability to benefit from any subsequent help which is offered to them. As a result, their life after care is often difficult. One study found 40% experiencing homelessness in the first six months after leaving care[213], and another calculated that care leavers are more than twenty times more likely than the average to spend time in prison[214]. These personal circumstances increase the likelihood that hygiene will be neglected and reduce the chance that the topic will be raised by trusted friends.

Sick, injured and disabled people

A forty-year cleanliness campaign in Singapore has made it perhaps the cleanest country in the world, resulting in the world’s lowest infant mortality rate[215]. Poor body surface hygiene increases the risk of staphylococcal, streptococcal and tetanus infections, especially through fluid transfer from and to skin lesions and from inanimate objects that can carry infection, known to scientists as fomites[216]. Wounds, whether from surgery or by accident, are more likely to become infected if the patient fails to observe strict hygiene practices.

Some wounds such as leg ulcers become malodorous (referred to by medical staff as a fungating or malignant lesion or wound) and are caused by the infiltration and proliferation of malignant cells through the epidermis of the skin. The mechanism has not been identified by which the wound becomes malodorous. As well as the challenges of managing the ulcer, associated psychological problems include: body image alteration, denial, depression, embarrassment, fear, guilt, lack of self-respect and self-esteem, problems with sexual expression, revulsion or disgust and shame[217]. Supportive evidence comes from a study of patients with malodorous wounds that found people anxious that others could smell their wound and a consequent reluctance to socialise with others or be intimate with their partner[218].

People with poor physical health are more likely than others to appear in the group of self-neglecters[219], with neglect sometimes the cause and at other times the effect. Even common conditions may affect hygiene-related behaviour. For example, constipation is sometimes relieved by squatting to defecate, as this opens the colon[220]. The embarrassment felt by many people leads to a taboo about discussing bodily functions and health issues, such as chronic constipation, which might

sometimes result in poor hygiene habits. People with learning disabilities are at an increased risk of constipation and this can be serious[221]. For 33 year old Richard Handley, a man with Down's syndrome living in a care home, complications arising from severe constipation resulted in his death[222]. In an attempt to raise awareness of these risks, Dimensions have made a short video[223] and Books Beyond Words have produced 'The Trouble with Poo'[224].

People living with physical or sensory disabilities may find that the functional impairment, the cost of aids and adaptations[225], or the pain associated with hygiene practices inhibit hygiene routines. Research by Naik and colleagues[226] has shown a correlation between functional impairment (restrictions in the ability to perform activities of daily living), self-neglect and damage to the frontal lobe of the brain, such as that caused by dementia, depression, diabetes mellitus and cerebrovascular accident. In particular:

- "When damage or disease affects the mesiofrontal region, apathy, distractibility, and failure to keep targeted goals results.
- When the orbitofrontal region is involved, persons display irritability, mood lability, and resistance to care—especially if they perceive the care as threatening.
- Lesions in the dorsofrontal region affect planning, hypothesis testing, judgment, and insight."[227]

A key aspect of home, as Twigg[228] has shown, is the freedom to choose who enters, with the bathroom marking the most private and autonomous space. Being bathed by another person strips the disabled individual of all protection, identity and autonomy, and for some is an intrusion that is simply too hard to bear. For others, particularly those who live alone and have no-one to support their efforts to prevent trespass, being bathed by a stranger represents the final indignity of disability. This shows some of the possible motivations of the person labelled as a 'service refuser'.

Before leaving this section, it is worth spending a further moment reflecting on the nature of 'service refusal'. It was mentioned above that this behaviour may be enacted by people who feel powerless and unable to make themselves heard by conventional means. Many other explanations are possible, and it is unwise to make too many assumptions. Some interesting parallels were suggested during a conversation with a researcher[229] who is investigating why some people are frequent attenders at their doctor's surgery, as a number of the factors that drive frequent attendance may equally drive the opposite behaviour – so-called service refusal.

- People who feel that their needs are being neglected may return for a further attempt, while others in the same situation turn their back on help-seeking behaviours.

- Those who have numerous interlocking needs may visit often, each time with genuine but diverse symptoms, while others abandon hope of improvement and turn away from would-be helpers.
- Doctors, along with other professionals, may find it equally difficult to discuss over-use and under-use of their service with the person concerned.

Both groups evoke feelings of helplessness in health and care professionals, trigger stereotypes, and provoke worry. Both groups of patients may feel embarrassed or ashamed. Perhaps the treatment seeker can teach us something about the service refuser, just as the fastidious person can teach us about the self-neglecter.

Reflection time – Chapter Three

- What data is available from your local Public Health department on the numbers of people in your community who have difficulties with self-neglect?
- How often is it a concern amongst the helping agencies – fire and housing, health and social care, environmental health and voluntary organisations?
- Are local organisations that provide support giving their attention to this issue?
- Are efforts being made to combat ageism and support people to re-establish positive hygiene routines?
- Do you have access to Occupational Therapy skills to help you assess your ability to carry out tasks related to personal hygiene?
- Do you know about relevant aids or adaptations?
- Where can local people get access to a bathroom and laundry facilities if they do not have a home or lack amenities?
- How do people find out about local help if they are not good at asking?
- Do local programmes designed to support care leavers address issues of personal hygiene and care for the home?
- Do you have untreated wounds or broken skin that could lead to infection?
- Does disability, illness or pain restrict your ability to recognise, organise and carry out hygiene routines?

4. The Consequences of Self-Neglect

Case Study Four

"Hi. My name's Adam and I'm a support worker. Sometimes patience really does pay off. Take Bill, a middle-aged man living alone whose idea of getting out of the house was to the corner shop and back. Bill, not his real name obviously, lived off a diet of sandwiches, pies and sixty ciggies a day. Sometimes I'd catch him on his way to or from the shop, but most of the time our conversations took place on his doorstep or - a couple of times - through his letterbox.

"Bear in mind it took me over a year to get him comfortable with me entering his flat. It was worse than I'd expected and I've seen a lot of examples, I can tell you. Filthy … disorganised of course … stuff strewn about, unused medication all over the place. Bill wore just one set of clothes at a time until they practically rotted on him, then he'd throw them away. His physical and mental health were very poor and our team took the decision to get him into residential care. It's a real shame he's lost his independence but at least now he looks much better and is taking his medication … and, of course, is being cared for. His quality of life has improved and his family … a sister and her son … at least they visit him now."

A heavy price can be paid by people who present themselves in public with poor personal hygiene or body odour. They can experience shame[a] and embarrassment, fail to establish or maintain relationships[230], avoid contact with people who comment on their condition, and become obsessive about their negative presentation. The damage can extend to schooling, personal life, career and relationships, resulting in social isolation, exclusion and low self-esteem.

In addition to these self-inflicted psychological wounds, other people stigmatise, shun and discriminate against people who do not look good. Ants, fish, bullfrogs, mice, lobsters and chimps, as well as humans shun those who show signs of disease[231]. A systematic review of the literature[232] found no UK research on public attitudes towards those who self-neglect[233].

In addition to appearance, smell has been shown to matter too, in a study where the researcher asked subjects to judge photographs in the presence or absence of fragrances. As Kate Fox writes, “If a person is clearly outstandingly beautiful, or extremely ugly, fragrance does not affect our judgement. But if the person is just ‘average’, a pleasant fragrance will tip the balance of our evaluation in his or her favour… Beauty is in the nose of the beholder”[234].

[a] Erin Engle has researched body shame and how people respond – particularly with avoidance of settings where these negative feelings may be exacerbated, and with camouflage, so others do not see that part of their body. See http://about.elsevier.com/bodyimage/Vol6Iss1/BI-6-1-0015/index.html

Disgust

The anthropologist Mary Douglas defines dirt as 'matter out of place' and suggested that each individual has his or her own threshold of 'pollution fear'[235]. The disgust response is helpful in avoiding risks, but may also protect in other ways too – as Leon Kass remarked, 'Shallow are the souls that have forgotten how to shudder.'[236] Curtis and her colleagues explain that disgust appears to be a universal response to 'bodily wastes, body contents, sick, deformed, dead or unhygienic people, some sexual behaviour, dirty environments, certain foods – especially if spoiled or unfamiliar – and certain animals'[237]. Other stimuli evoke varying responses – how do you feel about kissing a heavy smoker, or working with Amoret Whitaker[238], a forensic entomologist at London's Natural History Museum who studies how blowfly maggots consume a rotting carcass? In contrast, tears, unlike other bodily fluids, do not generally evoke disgust, and the intimacy of a loving relationship can displace disgust of the other.

A more detailed model comes from Tybur and colleagues[239], who have developed the Three Domain Disgust Scale (TDDS) and empirical support for their analysis, comprising:

- Pathogen disgust, which motivates the avoidance of infectious micro-organisms. The TDDS has seven questions on this, of which 'Standing close to a person who has body odour' is the most closely aligned to the overall factor of pathogen disgust.
- sexual disgust, which motivates the avoidance of sexual partners and behaviours that would jeopardize one's long-term reproductive success
- moral disgust, which motivates the avoidance of social norm violators.

A variety of sensory stimuli including 'the smell of rotting flesh, the taste of faeces and the sight of deformity'[240] act as potent disgust flags.

The disgust response generates:

- a characteristic facial expression that is recognisable across cultures, wrinkling the nose and flaring the nostrils,
- behaviour patterns that include turning away, withdrawal, distancing, stopping or dropping the object of disgust and shuddering, sweating and spitting (our unconscious use of language highlights this as we do not calmly 'put away' rubbish, but instead energetically 'throw away' our discarded items.[241])
- physiological changes including going pale, lowered blood pressure and galvanic skin response, recruitment of serotonin pathways, increased immune strength, and
- reports of negative affect including nausea, stomach convulsions and vomiting.'[242]

There may also be a biological drive to remember the threat and issue a 'warning cry' to others, which might explain both our fascination with disgusting, filthy and grotesque stimuli and our need to alert others by talking about it, film-making, and

even humour. Thus, in addition to violent aversion, we see signs of a positive enjoyment of disgust through toilet humour[a] and, for some, a love of films showing blood and gore[b]. Novels[243], TV shows[c] and exhibitions demonstrate a continuing interest in self-neglect and dirt[d].

Care workers may spend time with people who are distressed and experiencing a variety of intense emotions, but there seems to be something very distinctive and almost primal about the power of the disgust response. Similarly, disgust differs from fear, as it is usually proximal and immediate, while fear can be more distant or deferred and therefore less potent as a stimulus for behaviour change. This is not always the case, as fear of accidents can reduce speeding, while fear of disease is too remote, especially for the young, to make much difference[e].

Statistical analysis of responses from 38,845 people found that disgust responses vary by geographical region[244]. Communities that have endured high levels of pathogen threat become more inward looking as a way of staving off further threats from contaminated outsiders[245] who may harbour unfamiliar diseases, adopt unfamiliar hygiene regimes or disrupt the social order and so constitute a threat to the survival of the community.

These variations apply to individuals too, as those who show high levels of disgust sensitivity have more negative attitudes towards foreigners[246]. Women consistently demonstrate more disgust sensitivity than men yet often take on the most challenging tasks while the men hold back from cleaning up vomit or assisting people to use the toilet. Women are particularly sensitive to sexual disgust[247], which may be because they pay a higher price when faced with sexual threat. As Curtis remarks, 'women need to be disgusted enough for two people if they are to keep their dependent children free of disease'[248].

Although disgust is a universal response, it is also plastic, and can be shaped. One experiment had parents give their 14 month old babies a new toy, along with a 15 second verbal and visual display of disgust towards the toy. The babies avoided the object for at least the next hour[249]. Parents often evoke disgust responses in their children by using the characteristic facial expression and telling them the object or activity is dirty. Feelings of fear and disgust are commonly associated with snakes (that kill almost no-one in the UK), while cars commonly evoke feelings of pleasure rather than fear, disgust and withdrawal, despite being a major cause of death and injury[250], reinforcing the message that the disgust response is indeed malleable. It

[a] The annual World Cow Chip Throwing Contest is held in Oklahoma USA, in which entrants compete by throwing cow dung as far as they can.

[b] Just seven horror films have together grossed over a billion dollars at the box office (www.boxofficemojo.com/genres accessed 10 March 2011. An analysis of the appeal of horror cinema can be found at http://web.calstatela.edu/faculty/sfischo/horrormoviesRev2.htm.

[c] 4.98 million people in the UK watched the show 'Grimefighters' in August 2009. Data from http://www.imagedissectors.com/article/22

[d] A major exhibition in 2011 at the Wellcome Collection in London was called 'Dirt'. See http://www.wellcomecollection.org/whats-on/exhibitions/dirt.aspx

[e] Albarracin examined the methodologies and results obtained by 354 AIDS-prevention programs. Threats and fear never worked to increase condom usage. Albarracin D et al (2005) A test of major assumptions about behaviour change: a comprehensive look at the effects of passive and active HIV-Prevention interventions since the beginning of the epidemic *Psychological Bulletin* 131:856-97.

works for individuals too, as shown in a small study of women who successfully gave up smoking and found that their perception of smoking shifted from comfort to disgust[251].

Elias's commanding sociological work[252] on 'The Civilising Process' in Europe from the Middle Ages to the present describes a growing threshold of shame and repugnance for bodily functions, along with a growing demand for privacy. This changing threshold can be seen in the school playground, as the crowd scapegoat a lonely or unwelcome child by calling him 'smelly' or 'disgusting'[253]. Political movements, too, have manipulated the disgust response, such as the Nazi propaganda that represented Jews as dirty rats[a]. There are, of course, many complex issues at work in creating the conditions under which such efforts coalesce into a popular movement that ostracises the target group, and that is well beyond the scope of this book. We simply note that the community's disgust response is malleable and subject to changing fashions, as perhaps illustrated by the hardening of modern Western attitudes towards obesity and the growing market for 'Turkey teeth'[254].

Exclusion

We should not assume that people who self-neglect are always socially isolated - in a study of 209 people known to the Environmental Health Department because of excessive hoarding, 21% of the people concerned were receiving help from family and friends[255]. But many are.

Social isolation creates a downward spiral in which the traditional courtesies of welcoming guests – cleaning the home, inviting the newcomer to wash, and exchanging personal news and perhaps confidences – are lost, reducing the opportunity for mutually accountable relationships in which people sometimes encourage one another to change their behaviour or seek help. This is exacerbated by geographical mobility, the changing demographic profile of the population and social changes such as the rise of divorce, which all sunder relationships. Many of us clean for love and stop bothering when there is no one to clean up for. In addition to hospitality, house-cleaning can also be a way of asserting social status[256], and by extension, abandonment of house-cleaning routines may be a rejection of the pressure to maintain social standing in this way.

As a result, isolated people seek medical and other help less often, suffer more illness and other difficulties and report lower levels of subjective wellbeing. Diminished social networks have been found[257] in the backgrounds of those who self-neglect, and the relationship between isolation and self-neglect has been found to operate in both directions[258]. However, there appears to be a link between feeling excluded and subsequent harmful behaviour. Baumeister and colleagues created feelings of exclusion by giving bogus feedback to research subjects that they would

[a] Such as the 1940 film *The Eternal* Jew. See http://en.wikipedia.org/wiki/The_Eternal_Jew_(1940_film)

end up without a partner or friends, or by telling the person that nobody in the group wanted to work with them. Subjects were then asked to drink a health drink that tasted bad, resist sweet biscuits and complete tasks that required sustained concentration. Across all six linked experiments, the results were the same, and showed that social rejection depleted people's ability to regulate their own behaviour and exercise self-discipline[259].

Disease and death

There can be direct health consequences to poor hygiene too. Combined with incontinence[a], failure to wash adequately becomes a health hazard. Dirty, broken skin can provide an entry point for bacteria and infections, such as hepatitis A. There is a possibility that dirty skin leads to higher incidence of amputation[b]. The parents of sixteen year old Kaylea Titford were charged with gross negligence manslaughter, causing or allowing her death by failing to ensure her needs were met, including her need for a healthy diet, sufficient exercise, personal hygiene, a safe and hygienic environment, maintenance of her physical health and access to reasonable medical help[260].

Severe domestic squalor is a dangerous lifestyle, linked to an increased risk of death and institutionalisation[261]. The mortality rate of self-neglecters admitted to hospital may be as high as 50%[262,263] and only a few people sustain any improvements that they make. This may be partly because people prefer a sense of control over their own environment and resent changes imposed by others[264]. Because of the health risk both to individuals and whole communities, there are a range of legislative instruments that seek to control behaviour.

[a] Elaine McDonald lost her case at the Supreme Court in July 2011, where she had asked the Royal Borough of Kensington and Chelsea to fund a night time care worker so she could go to the toilet, as she has restricted mobility due to a stroke. The Court upheld the Council's decision to refuse to provide a care worker and instead advised her to wear incontinence pads at night. Her appeal to the European Court of Human Rights partly succeeded in May 2014, but not on this central point.

[b] Dr Jonathan Bodansky hjbodansky@hotmail.com emailed the following remarks: *'The patients in our Limb Salvage clinic are often particularly dirty and we wish to test the hypothesis that this is the case. The bacterial culture in their foot ulcers are often faecal and some patients probably have human or pet faecal contamination of their wounds. It is surprising that the deodorant and soap manufacturers do not seem to have such a tool for market research purposes. I'd like to include questions like, "How often do you wash/shower per week? How often do you change your socks? How often do you have clean trousers/skirt? How often do you wash your hair?'*

Reflection time – Chapter Four

- Have you noticed members of the public responding to people who are dirty or smelly? What happens?
- What triggers your personal disgust response?
- How do you give a ‘warning cry’ to keep others safe?
- Has your disgust response changed over time?
- Do you discuss these feelings with anyone else (such as a professional supervisor or a mentor) as a way to ‘get over them’?
- Do you have positive social roles, visitors and social contacts that provide helpful obligations to clean your body and home?
- Have you suffered experiences of being rejected or excluded that make you want to give up on your personal disciplines of keeping clean?

5: The legal context of neglect and squalor

Where neglect and squalor become serious and the safety of the person or others is put in jeopardy, then proportionate legal action may become necessary. The following table sets out some of the possible considerations and legal options. It is important to consider how these different rights and duties interact with one another and legal advice should be obtained prior to taking formal action.

It can be helpful to workers, relatives and friends to have an understanding of the point at which legislators consider that a person's right to self-determination gives way to the community's right to environmental safety.

Question	Possible legal action if this is the case
Is the person protected under equalities legislation?	Ensure that any actions taken are not considered as discriminatory[a] under the Equalities Act 2010. The law covers impairments that have a substantial and long-term impact on the person's capacity to wash, amongst other activities of daily living[b].

[a] Disability (such as a mental health problem) must not be the sole reason for actions against nuisance or hazard, but rather the behaviour that causes the nuisance or hazard This point was established in the House of Lords (LB Lewisham vs Malcolm (2008) UKHL43).

[b] The Equalities Act 2010 defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. Long term means that the effect of the impairment has lasted or is likely to last for at least 12 months (there are extra rules covering recurring or fluctuating conditions).

Question	Possible legal action if this is the case
Does the local authority have a duty towards the person?	Section 9 of the Care Act 2014 requires local authorities in England to carry out an assessment of an adult who appears to have needs for care and support, and under section 18 to provide those assessed needs which meet the eligibility criteria (subject to certain other criteria). The equivalent duties in Wales are found in sections 19 and 35 of the Social Services and Well-being (Wales) Act 2014. Section 29 of the National Assistance Act 1948 places a duty on the local authority to promote the welfare of people with disabilities. Section 45 of the Health Services and Public Health Act 1968 places a duty on the local authority to promote the welfare of old people. The Chronically Sick and Disabled Persons Act 1970 covers the provision of practical assistance in the home, works of adaptation of the home and the provision of meals. A local authority in England is under a duty under Section 42 of the Care Act 2014 to make inquiries where they have reasonable cause to suspect that an adult in its area (a) has needs for care and support; (b) is experiencing, or is at risk of, abuse and neglect, and (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it. A local authority in Wales is under the same duty under Section 126 of the Social Services and Well-being (Wales) Act 2014. Section 13(1) of the Mental Health Act 1983 places a duty on the local authority to make arrangements for an Approved Mental Health Professional to consider the case if they have reason to think that an application for admission to hospital or guardianship may be required.

Question	Possible legal action if this is the case
Is the person protected under adult safeguarding procedures from immediate risk to their health or safety?	Self-neglect is included in the definition of 'abuse and neglect' accompanying the Care Act 2014[265], triggering the duty to inquire under Section 42. It is described as covering "a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding."[266] Neither the Social Services and Well-Being (Wales) Act 2014 nor the accompanying statutory guidance expressly provide for self-neglect, and there is at present no case-law as to whether it is capable of triggering the duty of inquiry.[a]
Are children likely to be at risk of significant harm?	Section 44 of the Children Act 1989 provides for an Emergency Protection Order to remove a child or young person from immediate danger[267].
How should the person's human rights be upheld?	Article 2 of the European Convention on Human Rights (which forms a direct part of English law by virtue of the Human Rights Act 1998) protects the right to life, Article 3 the right not to be subject to torture or inhuman or degrading treatment, Article 5 the right to liberty and Article 8 the right to respect to private and family life. Each of these rights has a 'negative' aspect – i.e. to protect the individual against actions by the State – and a 'positive' aspect – i.e. to require the State to protect the rights enjoyed by the person (for instance, to take steps to ensure that a person is not subject to inhuman or degrading treatment).
Is the home unfit for habitation, filthy, verminous or a health hazard to others?	Environmental Health officers can take action[b] to enforce improvements or cleanse and repair property under the Public Health Acts of 1936 and 1984 or demolish under the Housing Act 2004[a]. The destruction of vermin may be at the authority's expense, but other costs will be charged to the person (this might be by putting a charge on the property which would be recouped when the property was sold). A tenant may be in breach of their tenancy contract, subject to eviction and consequently deemed to be intentionally homeless under the Homeless Persons Act 1977.

[a] It is suggested that it is entirely possible to construe the duty of inquiry to encompass self-neglect, and that such a construction may be necessary to satisfy the state's positive obligations under Articles 2, 3 and 8 of the European Convention on Human Rights: see further below.

[b] Sections 83 to 85 of the Public Health Act 1936 requires Environmental Health officers to intervene (and, if necessary to override the person's refusal to cooperate) if a dwelling is 'filthy, unwholesome and verminous', with evidence of filth, usually faecal matter, and rodent or insect infestation. They can

Question	Possible legal action if this is the case
Is the welfare of animals at risk?	A number of people who neglect their self-care and environment also keep a large number of pets that may be protected by the Animal Welfare Act 2006 and the RSPCA and the Police can act to protect animals[268].
Is the garden or open land causing a hazard?	The Prevention of Damage by Pests Act 1949 requires steps to be taken to keep land clear of rats and mice. Section 92A of the Environmental Protection Act 1990 allows the local authority to serve a Litter Clearing Notice if land which is open to the air is defaced by litter or refuse and is detrimental to the amenity of the locality.
Are there signs of a mental health problem?	Consider whether to move to a place of safety under Section 135 of the Mental Health Act 1983. Under section 135, the local authority can seek a warrant authorising a police officer to enter the premises and remove someone to a place of safety for the purpose of assessment if it is believed that the person is suffering from a mental disorder, is being ill-treated or neglected, or, being unable to care for himself, is living alone. Refer to an Approved Mental Health Professional for potential compulsory admission under Sections 2 or 3 Mental Health Act 1983 (for assessment or treatment respectively) or application for guardianship.

obtain a warrant to gain admission to assess, impose enforcement notices, cleanse or destroy property in the house or on open land.

[a] Section 83 of the Public Health Act 1936 allows the use of gas to destroy vermin, section 84 requires cleaning or destruction of filthy or verminous clothing and furnishings, and section 85 to compulsorily cleanse verminous persons. As most or all cleansing stations have now closed, the task usually now falls to a reluctant NHS. The Housing Act 2004 allows the local authority to demolish a house that is a severe hazard.

Question	Possible legal action if this is the case
Does the person appear to lack mental capacity?	Follow the provisions of the Mental Capacity Act 2005, including the duty to consult any attorney under a Lasting Power of Attorney for Health & Welfare and relatives if they are available and decide on where the best interests of the person lie[a]. The Mental Capacity Act Code of Practice recommends that a professional mental capacity assessment is undertaken in relation to persons who self-neglect. If the steps proposed go beyond delivery of routine care and treatment (and in particular if removal of the person from their home is considered to be in their best interests, and bringing about that removal is likely in any way to be resisted by the person), it is likely that an order will be required from the Court of Protection[269].
Is the person refusing informal access to allow the condition of the home to be assessed?	Housing officers may apply to the civil courts (usually the county court for the place where the property is located) for an access injunction in the case of tenant's properties with or without formal notification to the tenant. Entry may be forced where there is an emergency situation, such as a flood or gas leak. Environmental Health staff have right of entry to owner occupied, privately rented and registered social landlord properties. Section 17 of the Police and Criminal Evidence Act 1984 allows a constable to enter and search any premises for the purpose of saving life or limb or preventing serious damage to property.

[a] Much relevant legal material is summarised at http://www.39essex.com/resources-and-training/mental-capacity-law/

Question	Possible legal action if this is the case
Does the person need to be forcibly removed from their home?	Under s.45G of the Public Health (Control of Disease) Act 1984, a magistrate can (amongst other things) order the removal to and detention of a person at hospital or other suitable establishment of a person who is or may be infected or contaminated, if the infection or contamination is one which presents or could present significant harm to human health, there is a risk that P might infect or contaminate others, and it is necessary to make the order in order to remove or reduce that risk. Under the Housing Act 1998 the court may evict a tenant if they are causing a nuisance to others. Consideration needs to be given to the person's rights under the Homelessness Act 2002. Forcible removal can also be done under some of the other provisions set out in this table (for instance, the Court of Protection can in an appropriate case order that it is in the best interests of an individual lacking capacity to decide as to their residence and care arrangements to be moved from their own home into a care facility). Section 21 of the National Assistance Act 1948 places a duty on the local authority to provide residential accommodation to people aged over 18 years who are in need of care and attention which is not otherwise available to them.
Is the person homeless or begging?	The Vagrancy Act 1824 remains in force and is used by around one third of local authorities to punish people for being homeless. The act includes no duty to provide help or support.
Is the person causing a nuisance to others?	Consider prosecution under the Antisocial Behaviour Act 2003 or the Clean Neighbourhoods and Environment Act 2005[a]. Both antisocial behaviour orders and antisocial behaviour injunctions create sanctions for non-compliance, including possible loss of tenancy.
Is the worker safe?	The Health and Safety at Work Act 1974 and employer's lone worker policies set limits on the conditions that staff should tolerate in gaining access and working with the person concerned, and what to do if safe access is not achieved.

[a] The Antisocial Behaviour Act 2003 and the Clean Neighbourhoods and Environment Act 2005 allow a wide range of annoying and antisocial behaviours to be treated as offences.

Question	Possible legal action if this is the case
Is there a duty to investigate after serious harm or death due to self-neglect?	The Care Act 2014 requires Local Adult Safeguarding Boards to conduct a Serious Case Review where neglect has contributed to the death or serious harm of an individual, and where there is reasonable cause for concern about how professionals and agencies have worked together.

Reflection time – Chapter Five

- What are the relevant legal rights of all the stakeholders in this situation and are they being upheld?
- Are you in touch with the relevant agencies who can help you understand in more detail how these legal duties are enforced?
- What further deterioration would need to occur to trigger further action?
- Where can you obtain an independent opinion to check that local authorities and individuals are fulfilling their legal obligations rather than neglecting them?
- How do you keep informed about changes in caselaw and legislation?

6. Can I help? Some factors that influence first impressions

Case Study Five

Despite his smart appearance, everyone knew Bob was present by his smell – and Samir was determined to get him to wash, somehow. The two men had met one day when Bob had watched a bowls match in the park where Samir and his team had thrashed the visitors. That summer, Samir bumped into Bob a few times as he returned to watch practices and home matches. Despite being labelled 'loopy' by locals, Samir realised that Bob was okay … just very smelly. Later Samir discovered that Bob had lived in institutions for most of his adult life and had very few friends or contacts. He also lived on his own. One day Samir suggested that they both visited some elderly residents at a nearby care home who were in need of company.

Bob took Samir's advice, shaved, and put on some fresh clothes. The visit was a success and any aroma that Bob possibly emanated was not noticeable in the care home. Bob carried on with the visits. Next, Samir suggested that he might like to come along on an away match with the bowls team, but he would need to have a shower beforehand because of sitting next to people on the minibus. The trip was a great success and Samir discovered something new about Bob – that he had a fear of water, and that this was the reason why he hadn't been washing.

Beauty

Those who do not fit the current stereotype of youthful beauty have particular challenges in maintaining a positive sense of their identity[270], especially people living with facial disfigurement[271]. This is because Western society generally favours attractive people[a] and employs their aesthetic labour in places where part of the job is to look good[272]. Appearance affects social interaction so that people who have an attractive appearance gain many advantages over others[273]. The face is particularly important, with physical characteristics such as symmetry playing a key role. Large eyes and prominent cheekbones are important for women while a wide lower face and pronounced brow improve attractiveness ratings for men[274]. The appearance of skin plays a part too, and skin that is judged unhealthy reduces attractiveness ratings[b].

[a] Gordon Patzer has studied 'lookism', (see for example, Patzer G (2008) *Looks: why they matter more than you ever imagined* New York: Amacom) showing how attractive people get a clear advantage in the workplace and elsewhere. He has looked at fixed aspects of attractiveness, such as height and bone structure, but not at elements that can be manipulated, such as grooming (personal communication, 13 August 2010).

[b] Jones BC, Little AC, D Burt M, Perrett DI (2004) When facial attractiveness is only skin deep *Perception*, 2004, volume 33, pages 569 – 576. Digital images of small patches of skin were rated by

Human faces made up to look sick evoke higher disgust ratings than healthy counterparts[275]. Individuals who are perceived to have disabilities activate similar responses to those with contagious diseases, even when the observer is explicitly aware that they are neither sick nor contagious[276]. The disgust system's preference of erring on the 'safe side' may also affect epilepsy, mental illness, learning disability, obesity[277], skin conditions such as psoriasis, cancer and HIV[278]. In passing, we might question whether the 2012 Paralympics affected these responses in the wider population.

There is some evidence to say that as people age they become more contented with their body image. This may be because self-acceptance gradually overcomes competitiveness[279], and older women in particular are freed from the particularly heavy pressure to conform that they are subject to in their younger adult lives[280], although that pressure may be replaced by another - to avoid the stereotype that Professor Twigg graphically describes as 'the monstrous, grotesque crone'[281].

We note that several research studies in this field are presented from within the worldview of evolutionary biology, which suggests that these processes are universal, primitive and inevitable. Opponents of this viewpoint would have to concede that liberal care professionals are not free of the tendency to devalue and shun the very people they claim to support, and so we must be vigilant and self reflective.

Facial expressions and the feelings they convey

Relatives, friends and care workers who are concerned about the person can experience considerable stress. Senses are assaulted by an unpleasant appearance and odour, advice and encouragement is often ignored, making the would-be helper feel powerless, and worry about the person's health and one's own all combine into a dangerous mixture that can lead to abuse or withdrawal. Relatives struggle with the dilemma of whether to intervene or 'allow' the person to live as they choose[282], and sometimes end up neglecting their own needs through preoccupation in caring for their relative[283].

As it is so hard to discuss the topic of self-neglect, some relatives, friends or care staff resort to using facial expressions in an attempt to subtly convey their feelings. However, it may not work. A few individuals have prosopagnosia[284] or face blindness, which means that they do not recognise faces at all, while others are 'super-recognisers' who never forget a face[285]. In addition to this variation in the

one group for health. The original images were digitally blended to form a new typical 'healthy' and 'unhealthy' image of skin that was then overlaid on images of faces. Each pair of faces was rated by a second group to show that apparent skin health affects attractiveness ratings independently of facial shape.

general ability to recognise faces, there seems to be variation in the extent to which we are sensitive to emotions expressed through facial expression[286]. In particular, researchers[287] have found that people with a diagnosis of schizophrenia were less likely to detect facial expressions of disgust, so it may be necessary to speak rather than merely grimace[a]. Computer-based facial recognition software will eventually provide more evidence of the link between skin appearance, expression and response[b].

Perhaps more importantly, there is a link between facial expression and the intensity of negative feelings. Judith Grob[288] found that sucking the end of a pencil prevents the person twisting their mouth into the characteristic snarling expression associated with disgust, and people doing so while being shown disgusting images reported lower levels of disgust than those who were allowed to give full rein to their reactions[289]. This fits in with the Facial Feedback Hypothesis[290] that has also been found in relation to smiling[291], frowning[292] and nodding[293], in which facial expression triggers or modulates the intensity of emotions[c], and underlines the need for caution in the use of facial expression as a way of communicating disapproval.

However, Grob also found that those who suppressed their facial expression were more likely to interpret the word gr*ss as 'gross' rather than 'grass', suggesting that negative emotions need to be dealt with rather than ignored, and what is suppressed in the interview may reappear later in the notes.

Physical environment

Our environment affects our behaviour. The personal hygiene standards of the worker may fall in a dirty or untidy environment, in a lesser version of the process that may prompt people to commit crime in scruffy neighbourhoods[d].

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[a] We should avoid stereotypes that too readily link a diagnosis with an assumed ability to read faces. For example, it might be assumed that someone with ADHD might miss facial expressions through inattention, but Kohls (2009) found that positive facial expressions were a more powerful reward than money in shaping behaviour.

[b] Michel.Valstar@nottingham.ac.uk is developing automatic measurement of tics in people with Tourette's syndrome.

[c] The Facial Feedback Hypothesis has been explored recently in relation to the use of Botox, which paralyses facial muscles and so reduces the person's ability to communicate emotion through facial expression. The Hypothesis remains a contested concept.

[d] "Researchers have concluded that if there is litter on the ground or graffiti on the wall, people will not only litter and draw graffiti, they will begin to commit crimes. People adjust their behaviour to fit the message sent by their physical surroundings about what a neighbourhood finds acceptable." (Rosenberg T (2011) *Join the Club* New York: Norton, page 34, quoting Zimbardo P (1969) The human choice: individuation, reason and order versus deindividuation, impulse and chaos *Nebraska Symposium on Motivation* 17:237-307). It must be noted that this 'broken windows theory' has been subject to challenge as people have questioned both the evidence and its theoretical basis. The most

The décor of a room also affects how we feel about the person we meet there. Maslow and Mintz[294] showed the same portrait photographs to research subjects in different settings. The respondents in the ugly room found less energy and wellbeing in the faces they saw there compared to respondents looking at the same photographs in a beautiful room. Others[295] have found that a barren environment reduces self-disclosure and a physically cold room reduces feelings of interpersonal attraction[296], selflessness and generosity[297] and emotional closeness[298], while holding a hot drink[a] evokes feelings of trust and emotional warmth[299] towards other people.

A smelly room is likely to affect behaviour, even when we are not aware of the process. Bad smells in a sales room signal a pathogen threat and this changes the behaviour of both buyer and seller, as both try to distance themselves from the item that the smell implies might be disgusting. It lessens the chance that the potential buyer will take the product at all and reduces the amount of money they will pay, while it makes the seller willing to offer a knockdown price[300]. Similarly, the presence of a disgusting smell strengthens people's resolve to use a condom in future sexual activities[301], while a clean smell increases the amount of prosocial behaviour[302].

People who are induced to feel disgust, perhaps through seeing a pile of rotting food in the sink or visiting a dirty toilet, transfer their negative feelings from the environment to the person and make more severe moral judgements about the person[303]. Using handwash, mouthwash or other prompts relating to cleanliness can soften these judgements[304, 305], as people take up the opportunity to 'wash away their criticisms' by undertaking a definite cleansing ritual after visiting the person.

All these responses may be exacerbated in circumstances where expectations are high. For example, when insect larvae were found just inside the back door of Dale Surgery, in an area that is not used by patients, public outrage driven by an intensified disgust response generated newspaper headlines referring to the 'shock and horror of filthy maggots'[306].

Does helping involve touch?

Part of our difficulty may be to do with our complicated feelings about being touched and touching ourselves. Grooming requires gentle touching by ourselves or someone else, and touch evokes powerful responses. Men are more likely than

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unsettling challenge to this theory comes from Diederik A Stapel & Siegwart Lindenberg (2011) Coping with chaos: How disordered contexts promote stereotyping and discrimination *Science* 332, no 6026 (8 April 2011) pp251-3. DOI: 10:1126/science.1201068. The paper showed how people who were forced to spend time in a messy environment compensated by tidying people up into neat stereotypes. But it turned out that, despite being published in a prestigious journal, the experiment had never been carried out and the evidence was faked.

[a] Many care workers report intense emotions when offered a hot drink in a dirty cup. There is also a wealth of conflicting issues at work here – the positive welcome of a hot drink, the social expectation to accept it and the heightened threat of ingesting contaminated food.

women to interpret touch in a sexualised way and resent unwelcome touch as an expression of dominance[307]. In contrast, a caress stimulates the body's production of opiate endorphins that reduce heart rate and produce mildly narcotic effects, as lovers and people who like massage will confirm[308]. Many of those who rely on physical care provided by others can discern the difference between a peremptory and functional service, a gentle and respectful touch, an exploitative intrusion and a loving caress. The touch involved in all types of personal care, including washing, can also be a way of establishing personal connection and communicating care without words getting in the way.

For some people, being touched in any way, such as by a hairdresser, generates acute self-consciousness and discomfort. The sense of privacy or modesty is so acute in some people that they prefer to lock the bathroom door before washing their hands. The modern Westerner has perhaps more access to private space than at any other time or place in history, and this has amplified feelings of control, but also awkwardness[a] when it is violated, such as when disability renders us dependent on others for our personal hygiene[309].

Such feelings can be reinforced within specific families or subcultures, particularly religious sub-cultures: for example the Rule of St Benedict forbids nudity, even when alone, and the Benedictine monk's body has to be concealed whilst being washed[310]. This seems strange to modern Western eyes, where naked flesh seems to be on show everywhere. The gender of the carer can also be stipulated by the religious rule or personal feelings regarding intimacy, privacy and shame.

Touch is intimate, embarrassing and potentially sexualised, so simply talking about washing the body can be a shameful violation of privacy. People respond by either ignoring the topic or generating an emotional 'energy burst' to overcome the shame, which can take them into bullying or dominating behaviour or attitudes. These responses might apply in an even more marked way to discussions about incontinence[b].

An antipathy towards being touched is also present in some people with an obsessive compulsive disorder related to hygiene, but for completely different reasons - they fear the contamination of germs, and spend much of their time washing and cleaning[c]. By way of comparison, zoologists have found that primates

[a] This awkwardness may be most vividly illustrated by behaviour in communal changing areas, where we feel self-conscious, but avoid the freely available and convenient booths, which offer privacy and simultaneously draw attention to their users.

[b] A colleague of Jeannette Pols is studying the shame associated with discussions about incontinence.

[c] "In one memorable experiment, Tolin and colleagues created a chain of contagion where a pencil was touched to a toilet bowl and then wiped on another pencil, and that one onto another in sequence. 'Normal' participants, and those with chronic anxiety, reported diminishing contamination that had largely disappeared by the fourth pencil. However, the OCD patients reported appreciable contamination even beyond the tenth pencil. They described a world of spreading, looming

spend up to 20% of their time grooming[311] and humans are constantly touching their face[312].

Coping with our own negative feelings

The human disgust response is so powerful that it is contagious, so objects, memories or people that are associated with the disgusting item or person are then identified as disgusting themselves[313]. It has been suggested[314] that this is the cause of the low status accorded to those whose work includes the bodily care of disabled people, although surgeons have high status despite their association with wounds and body contents.

On a positive note, manipulating disgust responses has been proposed as a way to drive health promotion programmes[315] and social marketing may harness disgust to shape cultural attitudes, as where young people now consider racism and homophobia disgusting[316].

The disgust response can be dissipated through washing contaminated items, through the passage of time and through social learning. Children commonly experience a disgust response towards a wide variety of foods, but this can be dissipated if they see adults eating the foods without any negative emotion[317], while others maintain their dislike of healthy food throughout life. After spending months dissecting bodies, medical students have been shown to become desensitised to disgust related to surgery[318].

People with lower disgust sensitivity are known to suffer from more infectious disease[319], so it may be that care staff who have adapted in the face of disgusting stimuli will have higher levels of sickness absence. However, the idea that care workers can adapt may be limited – established nurses have reported[320] continuing to feel nauseous in response to malodorous wounds.

Healthy people who are preoccupied with avoiding illness are likely to have negative attitudes towards others. In particular, they are less likely to have friends who are disabled[321], will have an above average dislike for obese individuals[322] and will display implicit ageism[323].

Inaccessible services

Health and social care services vary in the message they are sending out regarding personal hygiene. In the UK, traditional paternalistic approaches in residential care

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vulnerability where they cannot control the threat of contagion" Tolin, D. F., Worhunsky, P. & Maltby, N. 2004 Sympathetic magic in contamination-related OCD. J. Behav. Ther. Exp. Psychiatry 35, 193–205. (doi:10. 1016/j.jbtep.2004.04.009) Quoted in Curtis, V (2011) Why disgust matters. *Philosophical Transactions of the Royal Society Bulletin* (2011) 366, 3478–3490. doi:10.1098/rstb.2011.0165, page 3482).

settings until the 1980s imposed a hygiene regimen on the people they cared for. This was replaced by an emphasis in some services (particularly in social care and by the third sector, compared to health settings) on promoting choice and freedom of expression, by which some staff abdicated almost all responsibility in respect of personal or domestic care routines on the basis that it was the person's choice to be dirty or live in squalor. The recent emphasis on personalisation will further shift the focus in favour of freedom of expression, while recent concerns about MRSA and other infections have pushed in the opposite direction with a renewed focus on imposed hygiene[a]. This return to a more controlling stance may be reinforced if the UK government implement its proposals to create a criminal offence of wilful neglect towards others[324].

This may lead people to use their neglect of personal hygiene as a bargaining counter in reclaiming some power in a setting that they perceive as overpoweringly in control of their lives, while others may find that the increased freedom in other areas, such as self-directed support arrangements, will reduce their need to adopt a combative approach in areas such as hygiene.

These challenges become more intense when health and social care agencies are perceived to, or actually fail to offer approachability, respect[325], empathy, trust, or listening[326], leaving people with no access to acceptable help – a problem that might be summarised as service inaccessibility rather than service refusal. Similar issues arise when a person refuses all services because they fear being forcibly moved into a hospital or workhouse-style institution.

Services are perceived as inaccessible when:

- professionals employ language (such as referring to Diogenes Syndrome) or values that are unfamiliar to the person[327]
- The helping agency acts or is perceived to be acting as a 'soft police force', enforcing compliance with behavioural norms, or is seen to be trying to 'nudge' people into choosing a way of living that is acceptable to the majority[b]
- The person has a lifetime habit of independence in which they persistently fail to ask for help from family or services, or they have tried it and had a poor experience, feel unworthy of assistance, or fear intrusion.
- The person finds that the only way to express their preference is to say yes and then be unavailable, find fault with the service that is offered, or

[a] Managers in one psychiatric setting insist that care staff wear alcohol gel on their belts as the environment is designated as a hospital. This may be good for hygiene, but not very homelike.
[b] The UK Coalition government of 2010 embraced the 'nudge' approach of libertarian paternalism as described by Thaler R & Sunstein C (2008) *Nudge: Improving decisions about health, wealth and happiness* Penguin.

agree with the idea of help, but not at this time or from this person or agency[a]

- One of the few ways that the person has to exercise any kind of control in their life is to say 'no' and refuse this help.

Access to social care support from the state is regulated (in England) under the Care and Support (Eligibility Criteria) Regulations 2015[328]. The local authority must first be satisfied that the adult's needs arise from or are related to a physical or mental impairment or illness. The local authority must then be satisfied that, as a result of the adult's needs, the adult is unable to achieve two or more specified outcomes. One of these includes maintaining personal hygiene. A similar approach applies in Wales under the Care and Support (Eligibility)(Wales) Regulations 2015[329].

Should we intervene?

Some local policymakers suggest that intervention is unnecessary if the self-neglecter is not 'causing any harm to themselves or others'[330], although it is very hard to see how severe self-neglect could avoid causing harm. Finding out what is happening and building a therapeutic relationship may be hard, as the person may be aloof, suspicious, unfriendly or hostile[331], and this is likely to get worse if enforcement action is taken[332]. Despite evidence that some people rapidly return to their previous lifestyle[333] or even deteriorate in response to the intervention, intervention can make the situation worse, prompt action has been recommended[334].

As poor hygiene is insufficient grounds for entitlement to social care, workers are often reluctant to risk the therapeutic relationship by opening a discussion about cleanliness, as this may lead to withdrawal from what are seen as more important services.

Tenants or hostel residents who live in squalid conditions are usually in breach of their tenancy agreement[b] and may be evicted as a last resort[c], but there are fewer controls over homeowners, so the policy shift to supported living and self-directed support may exacerbate problems for some people. Sometimes the problem lies with a landlord who refuses to maintain the property to a decent standard. In this case, there is anecdotal evidence that landlords often evict any tenants who complain to their Environmental Health department[335]. The legal framework set out in chapter 5 shows how the person's autonomy is balanced against community safety and where action needs to be taken.

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[a] These ideas were presented by Hilary Brown through a conference presentation on 15 Oct 2010.

[b] We need to enquire if the tenancy agreement is clear about the tenant's duty to maintain their property and themselves in a hygienic state, whether the agreement is presented in an accessible format, and whether support has been made available to the tenant to enable them to understand its implications.

[c] They may then be deemed intentionally homeless within the terms of the Homeless Person's Act 1977.

Care and support may be available to assist with maintaining the home. Compulsory removal merely to ensure cleanliness and conformity is discouraged[336], as "simply going into the individual's residence and cleaning does not improve the situation"[337] and can make things worse[338], although in a few situations, people express relief and appreciation when forcible action is taken[339]. Others may compare the experience of compulsory cleansing[340] with being burgled, with its associated distress and sense of violation[341]. Despite these cautions, poor hygiene and grooming continue to exacerbate social exclusion.

Why is it so hard to talk about?

Whilst complimenting someone for their pleasant appearance is commonplace, most people shy away from discussing poor hygiene with another person. We seem to respond with both aversion and fascination. Hygiene is often the first thing that we mention in describing someone who displays these characteristics, but many people have real difficulties in opening a conversation with the person themselves about their personal hygiene.

One possible explanation[a] is that this is an extension of the biological urge to remove ourselves from the social group when we constitute a pathogen threat (so, for example, we prefer to defecate and vomit in private), and this process reinforces the private, rather than social management of self-neglect.

An alternative view is what Goffman[342] called 'civil inattention' – a coping mechanism that helps us take note of the presence of other people and then behave as if they were not there. It allows people to apply their make-up whilst on a crowded train, wash their bodies in a campsite shower block or brush their teeth in the airport restroom while studiously ignoring their fellow travellers. We tend to notice moments when this civil inattention is under threat, as when we see evidence that someone else has used a public toilet before us, or even when we sit down and discover that the seat has been warmed by another naked bottom[343]. While this inattention is helpful in many situations, it may also prevent us from having a real conversation about hygiene.

It is easy for relatives or staff to feel disgusted, frustrated, helpless and useless in response to the person who neglects their personal hygiene and grooming, particularly when faced with noisome sights and smells. Frustration increases yet further when the person denies that any improvement has taken place and clearly prefers their previous, dirty lifestyle. Self-neglect causes management difficulties, ethical challenges, anxiety and worry[344]. Many different responses are possible.

[a] Joshua Tybur offered this hypothesis in a personal communication 31 Jan 2012.

Firstly, the helper may mirror the behaviour of the self-neglecting person, becoming chaotic, feeling powerless, denying there is a problem, ignoring risk and withdrawing[345]. The problem of withdrawal is not confined to the affluent West, for, as Curtis et al[346] comment: 'failure to address the need to sanction non-co-operators is one of the key reasons why village level water supply systems so often fail in developing countries.'

Secondly, the personal hygiene standards of the helper may be affected, either falling in a mild version of the mirroring just mentioned or becoming excessively fastidious. Thirdly, the helper may unconsciously adopt a negative attitude towards the person, as we saw above in the discussions of the human disgust response and the influence of the environment. These may combine into attempts to control the person through a forced wash when the helper decides that dirty has become too dirty, as illustrated by the following example of an assault:

> *"Nurse William says he could not stand the way Bill looked any longer, all dirty and with scabs on his face (he had a skin problem). They had tried "personal responsibility" and gentle insistence, even a prohibition to enter the common room in this dirty state, long enough, with no result. William ordered Bill out of bed, dragged him under the shower and scrubbed off all the scabs."*[347]

A less violent, but similarly harmful response is when people respond by creating a 'high expressed emotion' environment. Research on expressed emotion has shown that the risk of relapse is increased by three to five times for people with a broad range of psychiatric diagnoses if they are surrounded by overly controlling, critical, hostile, or emotionally over-involved people. Staff[a] or relatives might adopt these damaging practices in the mistaken belief that the self-neglecting person needs guidance, encouragement or prompts delivered in this form.

[a] 'Professional caregivers express the same amount of criticism and hostility as do family members, but they make fewer positive remarks… they are significantly less emotionally over-involved than family members.' Van Humbeeck, G., Van Audenhove, Ch. (2003). Expressed emotion of professionals towards mental health patients. *Epidemiologia e Psichiatria Sociale* 12, 4, 232-237.

Reflection time – Chapter Six

- How do you feel about your physical appearance?
- How do you feel about the persistent self-neglect of another person?
- Are you relying on facial expression rather than talking to the person?
- When meeting someone in an unattractive environment, how do you compensate for all the pressures that encourage you to adopt a negative attitude towards the person?
- Are you an expressive person who is comfortable with touch or do you prefer to keep your distance from others?
- How do you respond at the hairdressers or in other settings where your body is touched?
- Have you adapted over time so that your negative feelings have reduced in intensity?
- Do you take time off work because of ill health, and what causes this?
- How do current users describe local services? Are they trustworthy, helpful and respectful?
- Does the least powerful person have maximum choice and control over their own life?
- Do you have a clear understanding of the harm that is caused by self-neglect?
- How do you feel when someone comments negatively on your personal hygiene or appearance?
- How do you start a conversation on this topic with someone else?

7. Making an assessment

Sometimes the simplest approaches are most effective. Genuine interest and curiosity, combined with clear questions, such as ‘Can you tell me why you are doing these things that could eventually cause your death?’ may draw out the explanation[348].

Listen to the person’s own story

Case Study Six

In our locked residential rehabilitation unit, one resident did not wash. The multidisciplinary team were persistent in trying to understand his behaviour and eventually developed a hypothesis. They suspected that he was afraid to use the shower as he could not see clearly through the steamy cubicle screen to check that the bathroom was unoccupied.

As he was unable to put his anxieties into words, the team decided to make a practical trial. They obtained his agreement, and then refurbished the bathroom to make it a wet-room, so that the shower head was no longer enclosed. The gentleman began to wash and shave every few days, which significantly improved his social relationships.

It is the responsibility of the worker and others who care about the individual to try and learn the history of how this person has lived and their values, in order to develop an appropriate intervention, unique to that person and that particular situation. It is particularly important to find out if the problem with personal hygiene is a recent change or whether they have had a longstanding issue with hygiene or personal disorganisation. Of course, it may be necessary to ‘listen’ to the person’s behaviour as well as their vocal communication.

There is a need for improved research into causes and effective interventions[349], specifically paying attention to the views of people themselves[350]. For example, while observers described one person’s hoard as ‘clutter’ or rubbish’, the person themselves called their excess items ‘treasures’[351]. Support groups for hoarders have been established in Coventry, London and Edinburgh[352]. There is evidence that researchers and/or research funders may find poor hygiene a repulsive rather than an attractive topic[a], and Fox comments that smell is the most undervalued and therefore under-researched of the senses in modern Western society[353].

[a] “Disgust studies, however, face the same problem of repulsion that they confront. Olatunji searched the published literature and found 10–20 times more papers per year on anger and fear than on

Local services should be guided, co-produced and evaluated by people with lived experience of these issues.

We look in more detail at the person's own perception in chapter 8.

The person's situation matters

Hygiene routines are more important for people working in the food industry and living in close proximity to others, in intimate relationships[a], sharing a home or receiving personal care. People seeking employment, intimacy or social acceptance in a specific ethnic[b], cultural or social group will need higher standards of conformity to the expectations of others[c]. Some people need to learn about these norms, sometimes as part of the task obligations (such as clean nails in food preparation areas) and sometimes as the social aspect of participation (to be accepted by work colleagues[354]). The requirements of a specific location may vary over time – for example, when smoking was banned in public houses in England in 2007, body odour became more apparent - it had previously been masked by the smell of cigarettes. If the person shares a home with other vulnerable people or animals, then

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disgust, perhaps owing to its lack of attractiveness when compared with other emotions. A similar problem afflicts public health. Though diarrhoeal diseases are the number two killer of children in the world today, they still attract only a fraction of the research funds that go to malaria or HIV, for example. Lack of sanitation and hygiene are among the biggest culprits, yet it is hard to attract students to carry out studies of the faecal–oral transmission of infection, or on how to meet 40 per cent of the planet's urgent need for sanitation. A recent review found that menstrual hygiene had been comprehensively ignored in health research. Our group is devoting efforts to finding ways of making sanitation sexy, setting-up events such as the 'Golden Poo Awards' for example. Artistic exploration of the disgusting such as the Wellcome Trust's season on 'Dirt' and the 'Grossology' exhibitions that tour the world, help to attract interest and expose disgust to the light of day. Such efforts are beginning to pay off in terms of increased research funding." Curtis, V (2011) Why disgust matters. *Philosophical Transactions of the Royal Society Bulletin* (2011) 366, 3478–3490. doi:10.1098/rstb.2011.0165. Page 3486.

[a] "In 1931, halitosis was cited as grounds for divorce." Ashenburg op cit p240. Forty percent of singles in a recent Australian survey considered poor hygiene the most important deal breaker when deciding whether to proceed beyond a first date – see http://www.rsvp.com.au/cms-media/54104.pdf.

[b] Some American researchers have explored the relationship between ethnicity and self-neglect. Dyer, C.B., Goodwin, J.S., Pickens-Pace, S., Burnett, J. and Kelly, P.A. (2007) 'Self neglect among the elderly: a model based on more than 500 patients seen by a geriatric medicine team', *American Journal of Public Health*, vol 97, no 9, pp 1671–6. Also Dong, X., Simon, M., Fulmer, T., de Leon, C.M., Rajan, M. and Evans, D. (2010a) 'Physical function decline and the risk of elder self-neglect in a community-dwelling population', *Gerontologist*, vol 50, no 3, pp 316–26. Also Dong, X., Simon, M., Beck, T. and Evans, D. (2010b) 'A cross-sectional population based study of elder self-neglect and psychological, health, and social factors in a biracial community', *Aging and Mental Health*, vol 14, no 1, pp 74–84.

[c] "Although African Americans make up 12% of the US population, they account for 25% of the total spend on cosmetics and toiletries. Smith V (2007) *Op cit*, p340.

their safety or welfare may be compromised by the person's self-neglect[a]. For this reason, health and social care workers need some knowledge of environmental health and animal welfare legislation.

One team of researchers[355] investigated the risk assessment practice of 46 mental health workers, and found that, when it came to self-neglect (compared to the other scenarios that were studied), workers tended to ignore relevant history of the person and their family as well as giving little consideration to their motives and intentions. In other aspects of life, taking risks is often associated with pleasure and fulfilment, so it is important here too, to explore what motivates risky behaviour.

Self-neglect in context - dimensions of a holistic assessment

There is a need to ensure 'whole-person' assessments that are inter-disciplinary and inter-dependent[356]. Staff will need to consider the following themes as they undertake an assessment: safeguarding, mental capacity, dignity, diversity, race and culture, gender, sexual orientation, age, religious and spiritual needs and personal strengths.

The specific self-care assessment will include the person's ability and willingness to undertake or be supported to undertake self-care in terms of: opportunities to learn new skills, support networks, ways in which the environment might be improved by means of specialist equipment or assistive technology, information needs, communication needs (that may include material in community languages, braille, photos or simplified language), ability to identify risks for oneself, ability to find solutions, least restrictive options, social isolation, inclusion, exclusion, quality of life outcomes and the risk to independence of 'doing nothing'[357]. In contrast to this broad range of issues, the EQ-5D measure is frequently used in health research as a basis for the development of QALYs – the notion of Quality Adjusted Life Years that is often used in health economics. EQ-5D assesses quality of life across five dimensions of which number two is self-care. The 5L version offers the following options for response

EQ-5D-5L Quality of Life measure[358] – the Self-Care dimension

I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

In the UK, difficulty in attending to one's own physical cleanliness or need for adequate food were part of the criteria indicating whether a person is eligible for

[a] The potential association between poverty, self-neglect and animals has been recognised since ancient times – see Luke 16:21. In Stuttgart, Germany, a public bathhouse opened in the 1880s which included a bath for dogs. Ashenburg op cit p179.

Disability Living Allowance, and continued to be supported when Disability Living Allowance was replaced by Personal Independence Payments,[a] as has taken place on a rolling basis for adults since 2013.

Safeguarding

In England and Wales, the Mental Capacity Act 2005 states that wilful neglect and ill treatment of those without capacity by their carers[359] is a criminal offence, but in practice self-neglect will not usually lead to the initiation of adult protection procedures unless the situation involves a significant act of commission or omission of someone else with established responsibility for the person's care[360].

It may be that this situation will change with the introduction of new offences in the Criminal Justice and Courts Act 2015. With respect to incidents occurring on or after 13 April 2015, the provisions of the Courts and Criminal Justice Act 2015 have made it an offence[361] for an individual who has the care of another individual by virtue of being a care worker to ill-treat or wilfully to neglect that individual.

A 'care worker' is an individual who, as paid work, provides health care for an adult or a child (with certain exceptions), or social care for an adult. Significantly, a care worker also includes those with managerial responsibility and directors (of equivalents) of organisations providing such care. There is also a separate offence[362] relating to care providers. A care provider will commit this offence where:

(1) an individual who has the care of another individual by virtue of being part of the care provider's arrangements ill-treats or wilfully neglects that individual;

(2) the care provider's activities are managed or organised in a way which amounts to a gross breach of a relevant duty of care owed by the care provider to the individual who is ill-treated or neglected; and

(3) in the absence of the breach, the ill-treatment or wilful neglect would not have occurred or would have been less likely to occur. It should perhaps be noted in relation that neither of these offences are relevant to service users who are receiving direct payments.

Prioritising those abused by others is perhaps justified by the findings of an American longitudinal study[363], where, on a 13 year follow up, 40% of the group that had no contact with Adult Protection services were still alive, compared with 17% of those who were assessed as self-neglecting and only 9% of those who had been abused by others. However, it must be noted that preventing premature death is not the only factor that should be considered in the allocation of resources. In contrast,

[a] Accessed 20 December 2011: http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10018702 Accessed 24 December 2011: http://www.dwp.gov.uk/policy/disability/personal-independence-payment/#second The overall budget for PIP is planned to be 20% lower than the projected cost of DLA – see Disability Alliance (2011) When the PIP squeezes *New Bulletin* October/November page 12.

most jurisdictions in the United States include self-neglect within the responsibilities of the adult protection services.

Despite the lack of a clear perpetrator, a small number of local authorities have included self-neglect in their safeguarding procedures rather than leave the matter beyond formal oversight[364]. Others[365] have established a parallel process to the safeguarding procedures called the VARMS – the Vulnerable Adult Risk Management Strategy – that is interagency, external to adult social care and not restricted to those people deemed eligible to Fair Access to Care Services restrictions. A similar initiative, called the Harm Reduction and Vulnerable Victims Forum started in Coventry in 2011 and in Solihull in 2012, largely in response to the deaths of Fiona Pilkington[366] and Steven Hoskin[367], and these Forums expect to include severe self-neglect in their orbit.[368]

A person who has capacity to decide as to their living arrangements has a clear right to disagree with the views of the local authority or other agency. It does not preclude the local authority or other agency entering into a discussion with the person and exploring the basis for the contrary view[369]. This includes positive risk taking, as risk is part of everyday life, inherent in everything that we do, and it is often through taking risks that we develop and learn[370].

Taken together, these things mean that individuals may need to explore for themselves and then take an adult and responsible decision about how they will live, rather than comply with the opinions of care staff. Workers will then have met their duty of care where they can demonstrate that they have clearly communicated and recorded the advice to the person and carers in accordance with the guidance[371].

The tension between ensuring protection and promoting autonomy which lies at the heart of the Mental Capacity Act 2005 remains much easier to identify in the abstract than it does to carry out in practice. This was a particular theme of the post-legislative scrutiny of the Mental Capacity Act 2005 carried out by a Select Committee of the House of Lords which reported in March 2014. [372]

If there is the prospect of a formal dispute on what constitutes the best interests of the person, then application may be made to the Court of Protection. The Court has shown itself astute to ask searching questions as to assertions of the risk of self-neglect in the assessment of where the best interests of the person lies, and also to accept a degree of risk on behalf of the individual which professionals may – understandably – feel uncomfortable with[a].

Anyone who assists someone else with washing, eating, drinking, toileting, bathing, dressing, oral care, care of the skin, hair or nails or teaches someone to do one of these tasks or teaches them to wash occupies a position of trust. The Disclosure and

[a] Perhaps the clearest example of this to date is the case of *Westminster City Council v Manuela Sykes* [2014] EWHC B9 (COP); for a summary and comment on the case, see here.

Barring Service (DBS) does not involve itself in these things where they are carried out by a close family member or where there is a personal, non-commercial arrangement, but otherwise describes these as Regulated Activity, requiring the greatest level of protection[373].

The same is true of a worker or volunteer who offers assistance with a person's cash, bills or shopping because of their age, illness or disability and those who convey adults for reasons of age, illness or disability to, from or between places where they receive healthcare, personal care or social work (but this excludes friends, family or taxi drivers). It is a criminal offence for organisations to recruit a volunteer who appears on either of the DBS barred lists in Regulated Activity with the group from which they are barred from working. Likewise, it is a criminal offence for a person to seek work, or work in, activities from which they are barred.

Cruel, inhuman and degrading treatment

These safeguarding arrangements should reduce, but sadly not eliminate, the number of occasions when workers abuse those in their care. It is noteworthy that physical torture is often accompanied by cruel, degrading or inhuman treatment and its widespread[374] and shameful history includes occasions where people have been deprived of privacy and the opportunity to wash, urinate or defecate[375]; where the disgust response has been put to work as a tool to break down the person's will and sense of self, such as through forced contact with excreta[376, 377]. This has happened in severe ways, such as forcing adults to wear diapers during standing sleep deprivation, and through smaller abuses, such as public nudity and shaving a prisoner's hair and beard[378]. It has happened in a variety of settings, including a seclusion room in a psychiatric facility[379].

The International Criminal Court have made clear that such actions are criminal, whether or not the victim is personally aware of the humiliation, and this therefore protects unconscious and severely learning disabled or mentally ill persons[380]. However, the threshold for protection under Article 3 of the European Convention on Human Rights seems to vary with the context, as follows:

- In prisons and psychiatric wards, where there is deprivation of liberty, poor conditions of hygiene will easily cross the threshold of severity and be considered degrading treatment[381]. Denying a prisoner the chance to use the toilet in privacy and keep clean on a daily basis has been judged to meet the definition of 'cruel, inhuman and degrading treatment', which will have

  > *'diminished the applicant's human dignity and aroused in him feelings of anguish and inferiority capable of humiliating and debasing him and possibly breaking his physical or moral resistance'.*[382]

  A 2014 report[383] on conditions at Nottingham prison found; "showers and toilets were poorly screened and dirty. Prisoners had insufficient access to

clean bedding and clothes." Prisoners in the USA in 2022 had to work for 14 hours to earn enough money to buy a tube of toothpaste[384].

- But in care homes, bad hygiene conditions need to occur alongside other factors to contribute to a finding of degrading treatment[385]
- Healthcare settings have been identified as a specific location where such abuses may occur and protection should be afforded to patients[386], but
- In community settings, lack of access to hygiene has not been considered to be a breach of Article 3[387].

We may consider whether the court sets its threshold for legal protection in response to a standard that most ordinary citizens would count as 'cruel, inhuman and degrading', or whether political or financial factors have influenced the position of the threshold for protection.

More generally, the UK government has made a clear declaration that 'restrictive interventions should never be used to punish or for the sole intention of inflicting pain, suffering or humiliation.'[388]

The imposition of cruel and inhuman treatment has been shown to leave a serious psychological legacy comparable to that left by physical torture[389] through triggering shame that encompasses the whole sense of self, rather than merely a response to specific events and actions. That such things happen in services which are supposed to keep people safe and promote their wellbeing should disturb us all.

Making the connection between neglect of personal hygiene and the hygiene violations which are employed in torture prompts a further consideration. Jerry Piven[390] writes about the motives and emotions of the torturer, suggesting that arousal, joy and conquest are used to avoid facing the reality about ourselves. Is it possible that some of the people who choose to neglect their personal hygiene are driven by the same powerful forces, turned inward?

Case Study Seven

"The inquiry heard that children were beaten for bedwetting and had soiled sheets placed on their heads to humiliate them. Young people were known by numbers rather than their names, and many were allegedly subjected to humiliation, threats and physical abuse, said Christine Smith QC, senior counsel for the inquiry...

She told the inquiry that as well as making children eat vomit when they were ill, nuns used sticks, straps and kettle flexes to beat their young charges. The nuns removed Christmas presents from some children as punishments...

Witnesses also accused the nuns of locking them in cupboards and threatening to transfer them to an adult mental hospital if they did not conform. Rather than sending the children to school, the Sisters of Nazareth sent them out to work on farms or in the home's laundry, Smith said. She said allegations also included sexual abuse by

older children, visiting priests, employees and in one instance a nun." [391]

Mental Capacity[a]

Mental Capacity is a critical issue in cases of self-neglect. After all, if somebody has mental capacity and is choosing not to wash, the approach may have little in common with somebody who is unable to decide issues about personal hygiene and who, it might be argued, is not self-neglecting at all, but suffering neglect.

Legislation in the UK includes the Mental Capacity Act 2005[392], which is supported by a Code of Practice[393]. Together, these documents provide guiding principles for all interactions with people who may lack capacity, as well as a test for use in assessments[b].

In order to lack mental capacity, a person must have an impairment of the mind or brain, which could be temporary or permanent, such as mental illness, learning disability, intoxication, confusional states due to infection or poison, damage to the brain or any other mental disorder.

Capacity is always considered to apply to one specific decision and at the time that decision needs to be taken. Tests that address general cognitive impairment, such as the Mini Mental State Examination (see the next section on Assessment Tools), are not tests of mental capacity, as capacity applies to a specific decision. Similarly, a lack of mental capacity today is not relevant to a decision which needs to be taken in the future, as capacity is assessed at a particular time.

The test itself is in four parts. In order to have capacity to take a decision, a person must satisfy each part. The inability to do just one will demonstrate a lack of capacity.

To have mental capacity, a person must be able to:

1. Understand the information relevant to the specific decision for which they are being tested;
2. Retain that information long enough to make the decision;
3. Weigh up or process the relevant information in order to make the decision; and

[a] I am grateful to Jeremy Patton for assistance with this section.

[b] A practical guide to carrying out capacity assessments has been prepared by members of the 38 Essex Chambers Street Court of Protection team, and can be found at http://www.39essex.com/mental-capacity-law-guidance-note-brief-guide-carrying-capacity-assessments/ (accessed 21 July 2015).

4. Communicate the decision.

The Code of Practice gives more detailed advice about each component of the test.

All activity relating to mental capacity is governed by the five Principles of the Mental Capacity Act. The Mental Capacity Act does not give powers to anyone, but rather protects people in relation to the acts for which they are considered to have capacity.

These five principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The first principle is often remembered in the short form, "assume capacity". This has led to many people assuming capacity in vulnerable people rather than doing a proper assessment in the mistaken belief that letting someone who does not have mental capacity make their own decisions somehow protects their human rights, rather than being a form of neglect in itself.

The Mental Capacity Act is not about giving powers to professionals, but rather it is about giving people the right to make their own decisions. Everyone has the right to make their own decisions if they are able. Only after a proper assessment of capacity can that right be taken away from someone (which is what the first principle really means) and even if they do not have capacity for one decision, they still have the right to make other decisions (which is part of what the fifth principle means).

When considering self-neglect, most professionals will think of the third principle. This is often shortened to "The right to make unwise decisions". Choosing not to wash may indeed be simply an eccentric decision and it certainly does not by it itself tell us anything about a person's mental capacity. This can only be determined by a proper assessment.

Organisations whose staff work with people who may lack capacity, need to ensure that staff have been properly trained in how to assess capacity in line with the Mental Capacity Act and its Code of Practice. The Court of Protection[394] has shown itself to be rightly intolerant of poor assessments which include assessments which may be satisfactory but are poorly recorded.

The foundation to a good assessment is establishing what mental capacity is needed for. If mental capacity is decision-specific, it is vital that someone assessing capacity is sure what that decision is and competent professionals are often misled.

The following case study illustrates this:

Case Study Eight

Mr Selby, who has dementia, was seen crossing a busy road in a dangerous manner. As a result, his family and carers asked the social work department to arrange a move to residential care.

The social worker was sent out to assess his capacity and returned with the verdict that the man was indeed lacking mental capacity to cross the road safely.

However, the decision to be made was whether the man should remain in his own flat or be moved to residential care. The decision for which his mental capacity had to be tested was, "Does Mr Selby have mental capacity to decide where he should live and what care he should receive?"

Crossing the road was actually part of the relevant information which Mr Selby needed to be able to understand, retain and weigh up in making this decision, not the decision itself.

In cases of poor personal hygiene, many people will assess for "the ability to make a decision about how often they wash, change clothes and so on." Washing or not is actually part of the context for making a different decision (which will vary according to the circumstances). It is important to spend some time thinking about what the actual decision is and usually discussing this with others. The decision for which a person will need to be assessed will often be related to a course of action to address the self-neglect: "Does the person have capacity to agree to a visit by a carer?"

Of course, as stated in the principles, just because someone is assessed as lacking capacity on a particular issue, whatever action is taken should be the less restrictive option. Workers and family need to remember that a person without capacity still has rights and even within the area for which they lack capacity, actions must be in their best interests and sometimes the proposed solution may be more harmful than the problem.

The second part of the planning process for an assessment is some consideration of the questions that may be used to elicit the information about what the person can understand, how well they can retain that information and the extent to which they can weigh up the information.

Assessing capacity is almost never easy and sometimes it can be very difficult indeed. As people sometimes feel pride, shame or other complex feelings in relation

to self-care, the person may develop sophisticated techniques for hiding the extent of their self-neglect. Assessing capacity in cases of self-neglect can therefore be even more difficult than in other circumstances.

If a worker is afterwards called to the Court of Protection and asked about their assessment of capacity, they will be asked about the specific questions they asked and what the responses were which led them to their conclusions. This indicates that crafting the questions in advance is time well spent and in controversial cases workers should keep detailed records of the assessment, including both the questions and the answers elicited.

In addition, the following considerations[395] need to be taken into account:

- As well as the *decisional* capacity, described above, does the person have *executive* capacity to carry out the decision that they have made? In one example[396] a woman could clearly choose who to admit to her home, and so was assumed to have mental capacity, also experienced such pain in physical movement that it prevented her from attending to her hygiene needs, and so she lacked executive capacity.
- Some practitioners[a] ask the person to articulate and demonstrate. This helpfully looks for evidence of executive capacity – such as writing a cheque rather than merely saying it is in the post – and highlights the danger of reducing decisional capacity to the ability to communicate the decision process rather than undertake it.
- Has the assessment generalised from simple decisions to complex ones, or from one aspect of life to another - and is this generalisation reasonable?
- Does the person understand both the simple consequences of today's actions and their cumulative impact over time?
- How does the person's capacity to make decisions vary over time[397]?

Workers consider the person's decision-making abilities alongside legal and ethical issues such 'best interests' intervention, supporting the person's rights, community safety and self-determination. Finding the right balance is hard, and the law does not always help[b]. Decision support tools[398], support from peers and supervision will help

[a] Sherman F.T. (2008) 'Geriatric self-neglect – the bill-paying performance test', Geriatrics, vol 63, no 2, pp 9–12. Shillerstrom and colleagues found that executive measures are rarely used during capacity assessments. See Schillerstrom, J.E., Salazar, R., Regwan, H., Bonugli, R.J. and Royall, D.R. (2009) 'Executive function in self-neglecting adult protective services referrals compared with elder psychiatric outpatients', *American Journal of Geriatric Psychiatry*, vol 17, no 10, pp 907–10.

[b] The tension is captured in the case of the death of a 59 year old man in Wandsworth in 2009 – see http://www.wandsworthguardian.co.uk/news/4634815.Review_of_vulnerable_patients_after_man_dies_in_squalor/ Speaking in court, Dr Ruth Allen, director of social work at Tooting's Springfield Hospital, said the law allowed for patients living in squalor to be removed temporarily but this had to be balanced with the patient's right to choice. She said: "What we have to bear in mind is that this is

ensure good practice[399]. For example, West Sussex[400] uses the FACE Mental Capacity Assessment Tool alongside a risk assessment, such as the FACE Risk Assessment Tool[401].

Even where capacity is lacking, the worker still has an obligation to align their intervention to the values of the person and apply the least restrictive practice[402]. The concept of 'least restrictive practice' applies both in terms of the general freedom to live independently, free from surveillance and interference, but also in the particular area of applying the least restrictive hold to someone, even for therapeutic purposes of administering treatment or attending to the person's hygiene. Guidance on restrictive practices has been drafted by the UK Department of Health[403] and the Royal College of Nursing[404] and an assessment tool is available[405] to help staff consider and record their response in these circumstances.

Concluding that the person lacks capacity does not give permission to set aside all their preferences, ignore their agency or dismiss their strengths[406]. Rather we may wish to review the use of the term *self*-neglect, as it implies a deliberate decision by the person, and this may therefore be an inappropriate term when the person is entirely unable to attend to their own hygiene, ask others to do so on their behalf, or comply with efforts made by caregivers.

Case Study Nine[407]

"Jane is a woman with learning disabilities [who]... lives in a residential care home.. Sometimes, Jane is reluctant to go to the bathroom to have her pad changed, including when she has been doubly incontinent... workers were lifting Jane and carrying her to the bathroom where she could have her pad changed in privacy. Jane... would often struggle when being carried... Under the Mental Capacity Act (2005) Jane was deemed not to have the mental capacity to decide whether and where to have her incontinence pad changed.

The multi-disciplinary team [tried] ... to understand the reasons why Jane was reluctant to have her pad changed.. a health screening (from a community nurse), a sensory assessment (from an occupational therapist) and a communication assessment (from a speech and language therapist). The physiotherapist in the team also advised that Jane should only be lifted in 'emergency' situations.

This information led to a new care plan that took much greater account of the reasons why Jane may have been reluctant to have her pad changed. This led to:

not the only piece of legislation in terms of people's rights that the care team have to balance." Dr Paul Knapman, the coroner, said: "The pendulum may have swung too far."" See also http://www.communitycare.co.uk/Articles/2011/03/17/116453/self-neglect-cases-how-should-social-workers-intervene.htm

- prevention strategies that meant that Jane was generally happy to accompany workers to the bathroom to have her pad changed.
- improved communication strategies so that Jane could understand what workers were asking and what would be involved.
- a change in the décor of the bathroom, so that it was much more calming to Jane from a sensory perspective.
- more clarity about the circumstances in which they would have to step in and change Jane's incontinence pad, even if she was refusing to go to the bathroom (based on a clear risk assessment). In this (now considerably less likely event), workers would find a way to screen Jane from others' view in whatever room she was in and change her pad there."

Assessment Tools

Some tools may help in understanding the wide range of issues that may affect self-neglect. The following have been suggested:

- WASH is a measure of access to Water, Sanitation and Hygiene[408] that has been used in low-income countries and may be relevant for people who are homeless, living in poorly equipped and maintained homes or who are deprived of access due to disability or other reasons.
- Mental state: the Mini-Mental State Examination[409] is a screen for cognitive function in dementia
- Depression: Geriatric Depression Scale[410]
- Executive function: Wolf-Klein Clock Drawing Test[411]
- Daily living: Kohlman Evaluation of Living Skills[412] contains 17 items that cover the following five areas: self-care, safety and health, money management, transportation and telephone, and work and leisure. The measure is a combination of self-report items (i.e. hygiene, cooking, social engagements, transportation, monthly income) and performance based items (i.e. writing a cheque and balancing a cheque book, purchasing items and receiving correct change, reading a phone bill, identifying hazards in pictures, dialling a telephone, balancing a budget, finding a number in a phonebook). It is a good predictor of the ability to live safely and independently in the community[413].
- Self-care is one of the four major aspects of the Personal and Social Performance Scale[414].

- Coding systems for assessing entitlement to the Personal Independence Payment analyse the person's ability to independently prepare food, take nutrition and manage washing and bathing (see below) as well as managing toilet needs[415], dressing and undressing[416] and make budgeting decisions[417].
- Dressing – the Nottingham Stroke Dressing Assessment[418] has been developed to explore impairment in independent dressing following stroke, but some of the items in the assessment may have broader application.
- Alcohol: FAST Alcohol Screening Test[419]
- Nutrition: Malnutrition Universal Screening Tool[420], and a classification system is available to describe the person's ability to independently prepare food[421] and take nutrition[422].
- Social Support: Duke Social Support Index[423],
- Sense of Smell: A simple and cheap test for anosmia has been developed and validated that can be administered in just four minutes[424].

Scales that examine personal hygiene may well be found within general self-neglect scales such as the:

- Environmental Cleanliness and Clutter Scale (ECCS)[425]
- Self-Neglect Severity Scale[426]. Testing indicated that further work was needed to improve the scale's sensitivity.
- Impact of Squalor Checklist[427]
- Work by Naik and colleagues, that includes personal appearance and hygiene amongst other themes[428]

The Recovery Star[429] is widely used in UK mental health services and includes one axis called Physical Health and Self Care that refers to hygiene as follows:

Recovery Star – Physical Health and Self Care	
7	**I'm learning what makes me feel good.** You are getting a sense of which things work in terms of your self-care – sleeping and eating patterns, activities and exercise and presentation. You are starting to feel better because your self-care is better.
6	**I'm doing things differently because I want to feel better.** You are making lifestyle changes (such as to diet and sleep habits), and doing things to care for your physical health. You are trying new things, such as meditation, walks in the countryside, art classes, tennis and relaxation exercises. You may be trying out new clothes, image and presentation. Personal hygiene is unlikely to be an issue
5	**I want to take responsibility for looking after myself well.** You are resolving to make changes for the better and have a sense that you can do it. You are open to exploring what gives you a feeling of well-being and what disrupts your well-being and how and why your sleeping, eating and exercise patterns become disrupted. You are addressing personal hygiene and presentation (if they were issues of concern).

4	**I'm working with someone to feel better.** You are taking action on key areas of need (e.g. diet, sleep, exercise, personal hygiene, presentation), but the initiative comes from workers or professionals. You are very dependent on others to create and maintain healthy living patterns. You have no inner sense of what creates your own feeling of physical well-being.
3	**I didn't used to feel so bad – I want help.** You will discuss your well-being and/or self-care and accept help with physical health problems. You recognise you may need to change your sleep patterns or eating habits or routines for washing and dressing but you are not able to sort it out without help.
2	**I don't look after myself but occasionally I realise I don't feel well.** As in 1 below, but you are occasionally aware that you don't like how things are. These moments of awareness are brief and you still don't want help with self-care.
1	**I don't look after myself.** You are not looking after yourself at all and you are out of touch with your physical well-being. If you are unsupported, your sleep and eating patterns may be irregular, your diet poor, you may have no healthy exercise pattern and you may not be keeping clean or dressing appropriately. You may neglect yourself to the point of self-harm. You won't discuss health issues and you refuse help. You won't seek treatment for physical health problems.

There is more detail regarding hygiene behaviours in the following coding system[430] that is used to judge eligibility for a Personal Independence Payment in the UK.

Washing and Bathing: this activity considers a claimant's ability to wash and bathe, including washing their whole body and getting in and out of an un-adapted bath or shower	
1	Can wash and bathe unaided
2	Needs to use an aid or appliance to be able to wash or bathe - suitable aids could include a long-handled sponge, shower seat or bath rail
3	Needs supervision or prompting to be able to wash or bathe - may apply to people who lack motivation or need to be reminded to wash or require supervision for safety
4	Needs assistance to be able to wash either their hair or their body below the waist - may apply to claimants who are unable to make use of aids and who cannot reach their lower limbs or hair
5	Needs assistance to be able to get in or out of a bath or shower
6	Needs assistance to be able to wash their body between the shoulders and waist
7	Cannot wash and bathe at all and needs another person to wash their entire body

One project[431] works on the basis that if 75% of the floor space in your home is covered, then you are a hoarder. MacMillan and Shaw[432] introduced a rating scale that has been incorporated into a wider measure used to assess for severe domestic squalor in New South Wales[433]. The hygiene part of the scale is shown below:

	0	1	2	3
SKIN	Neat and clean	Mildly or slightly dirty	Moderately dirty, flaking or greasy skin	Filthy, peeling skin, old dry flaking skin, exposed sores, infestation

HAIR	Neat and clean	Mildly dirty: untidy, uncut uncombed	Moderately dirty: greasy, overgrown, uncombed	Filthy: overgrown, extremely dirty, matted, infested
FINGER NAILS	Neat and clean	Mildly dirty, ragged	Moderately dirty: nails poorly kept, long, dirty, nicotine stained	Filthy: grossly overgrown, ground in dirt, very nicotine stained
CLOTHING	Neat and clean	Mildly dirty or untidy: unironed and dirty	Moderately dirty: some stains, mildly malodorous	Filthy: many stains and badly needing washing, may have cigarette burns, excrement, very malodorous

A draft version[434] of the Self-Neglect Severity Scale shows photographs as well as text and includes the following aspect

	0	1	2	3	4
INSECT INFESTATION	No apparent infestation	Fleas	Lice or scabies	Maggots	Multiple infestations

In passing, this raises the question of whether care workers or family members would recognise infestation by nits, fleas, body lice, cockroaches, bedbugs or worms, which sometimes take up residence alongside the other flora and fauna in our bodies that make up the ninety percent of cells in the human body that are non-human[435]. Resources are available to assist learning disabled people to understand about general hygiene[436] and oral health[437] and to guide services.[438]

The Oral Health Assessment Tool[439] includes the following item to be coded by a care worker, rather than a dental professional:

Category	0 = healthy	1 = changes	2 – unhealthy
Oral cleanliness	Clean and no food particles or tartar in mouth or dentures	Food particles/tartar/plaque in 1-2 areas of the mouth or on small area of dentures or halitosis (bad breath)	Food particles/tartar/plaque in most areas of the mouth or on most of dentures or severe halitosis (bad breath)

An alternative 8-question assessment for oral health has been devised for use by non-dental staff or for self-assessment[440]. The eight themes are set out below.

1. Does the client have natural teeth?
2. Does the client have dentures? Are they more than five years old?
3. Does the client have any problems, such as pain, difficulty eating, decayed teeth, denture problems, dry mouth, ulcers, halitosis?
4. Does the client smoke?
5. Is the client on medication with oral side effects?

6. Does the client need urgent dental treatment?
7. When did the client last see a dentist?
8. Is the client registered with a dentist?

We notice that this does not ask the person if they own a toothbrush or what they understand to be a healthy regime of oral care.

The TELER indicators[441] help nurses to assess the severity of leg ulcers and other wounds which generate an unpleasant odour. There are several dimensions of this measure, as shown below. Although nurses will have different thresholds at which they detect the odour, this does provide a framework that might be adapted for use in relation to body odour. A particularly helpful element is that this approach examines both severity of the odour and its impact on the person's life.

Code	Odour is detected…	Code	Which of the following does the patient experience?
1	No odour	A	Aware of the odour
2	On removal of the dressing	B	Concerned that other people will notice the odour
3	On exposure of the dressing	C	Reluctant to socialise
4	At arm's length from patient	D	Affects appetite
5	On entering the room	E	Nauseated by odour
6	On entering the house, ward or clinic		

A more widely used approach for the assessment of skin health by nurses involves understanding the technical language of tissue viability and using the Waterlow assessment[442].

Reflection time – Chapter Seven

- What is the person's own explanation of their circumstances?
- What is the person saying through their behaviour, choices and non-verbal messages, rather than through their words?
- What is important to the person in terms of ambitions, goals and preferences, and how clean do they need to be to achieve these things?
- Are people who live with self-neglect involved in the governance of local services?
- What arrangements are in place in your local area to keep people safe? Do they include people who self-neglect?
- How do you track changes in self-care?
- How does the person demonstrate mental capacity to make decisions and execute them?
- Do you have a shared language for talking to other people about the severity of self-neglect and assessing its impact?
- Do you use assessment tools to help you be accurate and precise?

8. What is the person's own explanation?

Case Study Ten

Pat had knocked on Sue's door month after month. Sue had only ever opened it a few inches but it was enough for Pat to recognise the need. Greasy, straggled and uncombed, Sue's hair and her poor complexion gave clues as to what might lie beyond the threshold. Realising that she needed to offer reassurance and build trust, Pat patiently engaged her in conversation without ever asking to gain entry.

"Hi Sue, just wondering if you're okay? Did you sleep alright, what with all the fireworks last night?"

"Hello Sue, how are you doing? It's only me. You've got old bin bags out here, is it okay if I pop them in your wheelie bin for you?"

Sue's eyes often shown suspicion and fear but as the months rolled on Pat's regular friendly visits built a little more confidence. At first, she knew Sue would not ask her in, so she waited until the timing seemed right. Eventually Pat's concern for Sue's wellbeing prompted her to ask. It had become clear that she had been losing weight and was sometimes confused or sleepy as she had stood in the doorway ... Sue finally felt able to let Pat inside.

Sue had been abusing drugs, her heating didn't work, her gas had been cut off and her living conditions were squalid. Added to that, her medication made her feel unwell and so diet and hygiene were far from satisfactory. Having established the good relationship, Pat persuaded Sue to move out of her flat temporarily and arranged with housing colleagues for it to be cleaned. The combination of improved living conditions and support with medication meant that Sue subsequently made good progress.

Problems with vision and attention

It is necessary to 'see' or 'perceive' dirt before it can be removed. Older people with poor vision may be unable to see crumbs, grime, or (because of distance) problems with their feet. People experiencing acute psychosis, obsessional thoughts, depression or elation may be so absorbed with their thoughts and feelings that they are broadly unaware of their environment or personal care issues, losing that sense of internal, bodily feelings and responses that some people call interoception. It can help to gently prompt the person to pay attention to the warmth of the room, the clothing that they are wearing and the other messages from their senses in order to help them restore connection with their environment.

The sense of smell

> *"Smell is a potent wizard that transports us across thousands of miles and all the years that we have lived. The odours of fruits waft me to my southern home, to my childhood frolics in the peach orchard. Other odours*

instantaneous and fleeting cause my heart to dilate joyously or contract with remembered grief. Even as I think of smells, my nose if full of sents that start to awake sweet memories of summers gone and ripening fields far away."[443]

We often notice a smell when entering a room and quickly acclimatise so we can no longer detect it, but this process has limits. One study paid research subjects good money to endure a full-face blast of skatole, the most powerful ingredient in the smell of animal excrement, but nobody was able to endure it for more than five minutes[444]. In medieval times, the idea of hell included its foul stench[445]. It has been suggested that some autistic people do not habituate and so the awareness of a smell does not fade from their awareness[446]. Some care workers prepare for visiting particularly noxious houses by smearing peppermint essential oil on their upper lip[447].

Smelling salts, traditionally used to revive people who had fainted, show how powerful the sense of smell can be[448], while daily use of pleasant-smelling colognes significantly improves the mood of middle-aged men and women[449]. Powerful emotions, memories and physical responses can be evoked by a particular smell, which raises questions both about the tolerance of the person who lives in squalid conditions and the coping strategies of the worker who visits them.

Our smelling ability is at its best at about the age of eight, peaks in the moist days of Spring[450], declines in old age, is affected by our state of mental and physical health[451] and can be trained[452], hinting at the prospect that people can learn to detect unpleasant body odour. As we have seen, neglect seems to affect as many men as women, despite the finding that women consistently outperform men on all tests of smelling ability and are more likely to feel ill from the smell of common environmental chemicals, such as paint and perfume[453]. Humans can detect up to a trillion smells[454] and may be especially sensitive to body odour[a].

Some people with negative symptoms of schizophrenia have, according to research undertaken by Brewer et al[455], almost no sense of smell at all - and this was not attributable to smoking, antipsychotic or anticholinergic medication. Indeed, while smoking is widely believed to reduce sensitivity to smell, it does not always do so on smell tests[456]. However, some prescribed and some recreational drugs can alter and diminish sensitivity to smells[457].

[a] Fox illustrates this point in three ways (1) newborn babies sought the unwashed breast rather than the washed breast in one test; (2) childless women held someone else's baby in their arms for an hour and could then identify 'their' baby by smell alone; (3) women and men could distinguish T-shirts worn by their marriage partners from among dozens of others, by scent alone. Fox K (1995) *The Smell Report* Social Issues Research Centre. Pages 9-11. For more on point (2), see Case, T. I., Repacholi, B. M., & Stevenson, R. J. (2006). My baby doesn't smell as bad as yours: The plasticity of disgust. *Evolution and Human Behavior*, 27, 357-365. Point (3) has been taken up by dating agencies who invite singles to bring their used t-shirt to a 'pheromone party' – see http://www.theguardian.com/lifeandstyle/shortcuts/2014/mar/30/pheromone-parties-sniff-new-lover-dating

The term ‘anosmia’ is sometimes used for those who have lost the ability to detect smells while hyposmia is the term for reduced sensitivity to smell. Recent studies[458] have found 5% of the population aged over 45 to be anosmic and another 15% to be hyposmic, with only a few of these people showing a clear cause for the condition, such as head trauma, viral infections of the upper respiratory tract, or sinu-nasal disease. However, people with a diagnosis of psychopathy have been found to have statistically lower sensitivity to smell[459].

Anosmia has been cited as the cause of a number of other difficulties, such as food poisoning, late detection of fires and gas explosions[460]. Fifty percent of patients with anosmia were found to be depressed[461], while others feel cut off from the world around them, lose interest in food and experience emotional blunting, sometimes leading to malnutrition and weight loss[462]. Reporting on a survey of 267 anosmics, Van Toller[463] remarks, ‘it is common to find anosmics obsessed with bodily hygiene’, but we note the possibility of the opposite response in which anosmia drives neglect and such individuals do not come to the attention of researchers. The UK’s first anosmia treatment centre opened in 2011[464], working alongside the anosmia self-help group[465]. Sometimes simple treatment such as nasal douching, the use of an antihistamine or a steroid nasal inhaler or removal of nasal polyps can restore the sense of smell.

Temperature regulation and body consciousness

It has been suggested that some people with learning disabilities have low awareness of their body temperature and so sometimes overdress and sweat excessively. Encouraging such people to notice the signals from their own body or pay attention to what other people are wearing may help.

This is one aspect of what some researchers have called interoception and others[466] ‘Private Body Consciousness’ (PBC). Those with high PBC are very sensitive to feeling heat or cold, feeling tense inside, hunger or a dry throat, while those with low PBC may be unaware that they have not eaten recently or are dressed adequately for the weather.

But we do not yet know whether people who neglect their personal hygiene are unusually insensitive or have become desensitised, perhaps as a result of chemical changes involved in depression that ‘switch off’ the disgust response, while obsessive hand-washing may be the result of other changes in the insula, that part of the brain where the disgust response appears to be seated.

As we have already seen, variations also occur over the life-course and indeed whole communities have changed their responses over time; wealthy, modern communities are less tolerant of strong smells and sounds. Individuals train themselves to detect the subtlety in a highly spiced curry, a classical symphony, an expensive perfume or a famous painting. All our inbuilt sense-receptors are highly adaptive and, as Ashenburg says, ‘the nose is adaptable, and teachable’[467].

Some people who are labelled as self-neglecters consider their own behaviour to be within the normal range, or are secretly aware of their difficulties, but shame, embarrassment or a desire for privacy leads to public denial and refusal to discuss or address the issue. Where specific behaviours are driven by compulsions or delusional beliefs[a], arguing the case for changes is unlikely to be successful, but skilled intervention, such as cognitive behavioural therapy may help[468].

Personal preference

Individuals vary in their demand for hygiene. Smith sums it up: "we all know people who seem to have been born clean and tidy, those who acquire cleanness and tidiness, and those who definitely have it thrust upon them."[469] We have many words for describing what we see and hear, but few (outside of the perfume and wine industries) for the nuances of smell and many of us react with a crude binary response of either delight or disgust[470]. Researchers have asked people about their favourite smells and "some respondents name odours that are generally regarded as unpleasant, such as petrol and body perspiration, while other scents usually perceived as pleasant (such as flowers) were violently disliked by certain respondents."[471]

Over a quarter of the 81 people who received the services of a special cleaning service[472] because of domestic squalor considered that their home was 'clean' or 'very clean' and this raises questions about whether people are in denial about their problem, think their behaviour is in the normal range, or are simply unaware of the way their behaviour is perceived by others. Pavlou and colleagues found that people who neglect themselves often minimise their behaviours[473].

[a] "Mrs Andersen says, "I have to be dirty or terrible things will happen to me. If I take a shower and wash, my skin will fall off. …And her hair is not supposed to be washed either, it has to be just fatty, otherwise she thinks it will all fall out." Pols J (2006) Accounting and washing: Good care in long-term psychiatry *Science, Technology & Human Values* Vol 31, No 4, pp409-430.

Reflection time – Chapter Eight

- How sensitive are you to smell and has this changed over the course of your life?
- Do particular smells trigger memories or emotions?
- Do you sometimes become so absorbed that you forget to eat or notice that the room is cold?
- Which senses give you particular pleasure and which are less significant?
- When you miss out on washing and cleaning, does it give you pleasure or generate other feelings? What are these?

9. What causes the problem?

Genetics

Research shows that two-thirds of people with hyperhidrosis, or excessive sweating, have a close family member who also has the condition[474]. There is also a much rarer, genetic disorder called Trimethylaminuria or TMAU that causes the sweat and breath to smell like rotten fish and this is impossible to control with personal hygiene measures[a]. Whilst rare, it may be significant for some. A study[475] undertaken by the Monell Chemical Sciences Center in Philadelphia examined 353 people with unexplained malodour production by using a standard choline challenge and biochemical analysis. They found approximately one third of them tested positive for TMAU[b].

> *"Most of the nurses are nice. One I really did not like told me one night that I stank of fish and needed a shower. I complained about her."*[476]

Body changes and illness

Puberty, pregnancy and menopause affects the body's internal temperature regulator, causing excess sweating from time to time. Menopause can also cause temporary loss of the sense of smell. Medical conditions such as diabetes, thyroid disease[c] and carcinoid syndrome heart disease, respiratory failure, gout, and overactive thyroid gland (hyperthyroidism), tuberculosis, HIV and malaria, some types of cancer (such as Hodgkin's disease) and neurological disorders (such as Parkinson's disease) can cause excessive sweating.

There may also be a link between brain function and living conditions. Halliday and Snowden[477] note that, 'there is limited but growing evidence that frontal lobe dysfunction is a major factor accounting for deterioration of living conditions and various associated features', and Saxena[478] found different patterns of cerebral glucose metabolism in the brain scans of hoarders.

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[a] Because of mutations on the FMO3 gene, people with TMAU cannot metabolise choline and the other precursors of trimethylamine. TMAU is inherited in an autosomal recessive fashion. It is still considered a rare disorder but is thought to be under diagnosed and perhaps up to 1% of the population carry the mutations that produce the disorder.

[b] Personal communication from Dr George Preti (2 June 2012) of Monell Chemical Science Centre who has studied the nature and genesis of human odour for 40 years. He says that the people they see are meticulous in their personal hygiene habits and neither he nor any of his colleagues are studying neglect of personal hygiene.

[c] An overactive thyroid will speed up metabolic rate and so heat up the body and induce sweating.

Diet and exercise

Some studies of people who were self-neglecting found a high level of vitamin deficiency[479] and other suggestions of nutritional deficits have been put forward as a cause[480], although it may also be a consequence of self-neglect. One study[481] found a statistically significant connection between vitamin D deficiency and poor scores on an Activities of Daily Living test, as well as a significant connection between self-neglect and high levels of reported pain.

Once diet and hydration are neglected, it becomes harder to re-establish a varied and sufficient intake of food, as under-nourishment makes the person feel tired, vulnerable to infection, dizzy and of low mood, as well as slowing wound healing. Being unable to afford to eat protein regularly is one of the markers of 'severe material deprivation', and comparisons show that people residing in the United Kingdom are better fed than some of their European counterparts[a]. Despite this, malnutrition affects over 3 million people in the UK, of whom two thirds are under the age of 65[482], and the cost to the NHS of around £13 billion annually[483] has triggered the development of improvement campaigns in the UK[484] and worldwide[485]. The problem seems to be getting worse[486]. Local advice may be available from a qualified nutritionist or a professional dietician[b].

Sometimes people want to eat and drink but are unable to do so. This was particularly observed at Mid Staffordshire NHS Foundation Trust between 2005 and 2009[c], but this problem appears to be more than one isolated example. The 2011 hospital inpatient survey found one in five patients who needed help with eating did

[a] People are counted as experiencing 'severe material deprivation' if they cannot afford four or more of the following items: To pay their rent, mortgage, utility bills or loan repayments; to keep their home adequately warm; to face unexpected financial expenses; to eat meat or protein regularly; to go on holiday for a week once a year; a television set, a washing machine, a car, or a telephone. 5.1% of people in the UK were considered to be experiencing severe material deprivation, compared with an EU average of 8.8%. The UK's severe material deprivation rate is broadly unchanged since 2005 when comparable figures were first produced. ONS (2013) *Poverty and social exclusion in the UK and EU, 2005-2011*. Available at: http://www.ons.gov.uk/ons/dcp171776_295020.pdf

[b] The title 'dietician' may only be used by people recognised as such by the Health and Care Professions Council: see http://www.hcpc-uk.org/.

[c] "Some families felt obliged or were left to take soiled sheets home to wash or to change beds when this should have been undertaken by the hospital and its staff….The Inquiry heard of many cases in which relatives had to spend extended periods attending to their relatives' hygiene needs. This included having to get the patient to and from the bathroom, washing, and attending to other personal care needs… The evidence included complaints about the poor hygiene practice of staff when they did attend to the washing of patients. Bad practice observed included using a razor on more than one patient, and the use of a shared bowl for washing. The Inquiry heard several accounts of poor mouth care in which mouthwash was not provided for patients with mouth ulcers, and neglect of basics such as cleaning teeth and rinsing out of dried mouths. A particular concern for a number of elderly female patients was the failure, in some cases, to wash and brush patients' hair." The Mid Staffordshire NHS Foundation Trust Inquiry chaired by Robert Francis QC (24 February 2010) *Independent Inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 – March 2009, Volume I*. paras 20, 26, 27.

not receive it[487]. An Office of National Statistics report found 43 people who starved to death in hospital, 287 people were malnourished when they died in hospital, and in 558 cases doctors recorded that a hospital inpatient had died in a state of severe dehydration[488].

This pattern has continued over time, as dehydration was named as either the underlying cause of death or a contributory factor for a total of 1,158 care home residents between 2003 and 2012, according to analysis of death certificates by the Office of National Statistics. Over the same period, 318 care home residents were found to have died from starvation or when severely malnourished[489]. Staff may be unaware that adults need to drink 1.5 litres of fluid per day to reduce the risk of urinary tract infections[490], or that rapid restoration of a goo d diet after a prolonged period of malnutrition can itself trigger Refeeding Syndrome' which can be fatal[491].

The same issues can arise in community living too: in February 2013, Gloria Foster suffered terminal dehydration after her care provider was summarily closed down and the four visits a day that kept her alive in her own home were discontinued[492].

We do note that some illnesses make it difficult to eat or drink, so these figures cannot be entirely attributed to poor care. However, a comparative study of 21,610 people admitted to hospital between 2011 and 2013 found that people admitted from care homes were ten times more likely to be dehydrated in comparison with people admitted from their own homes[493].

The eccrine sweat that occurs all over the body is normally odourless but can start to smell if the person has eaten curry, garlic or strong spices. Alcohol and substance misuse can also increase sweating. People who eat a lot of red meat sweat more, as do people who are overweight[a]. The majority of psychotropic medications cause weight gain[494].

Exercise will make people sweat, but helps to keep obesity at bay, especially strenuous cardiovascular stimulation, but even passive movement, such as riding on moving vehicles, may stimulate muscle activity and ward off the many consequences of 'sitting disease' – obesity, coronary heart disease and death[495]. There is no evidence to indicate whether people who neglect their personal hygiene are particularly sedentary and inactive.

[a] "Older people, particularly post-menopausal women, tend to gain weight." Twigg J (2009) Clothing, identity and the embodiment of age in Powell J & Gilbert T (eds) (2009) *Ageing and Identity: A postmodern dialogue* New York: Nova Science Publishers. "The percentage of adults who are obese has roughly doubled since the mid-1980s." http://www.annecollins.com/obesity/uk-obesity-statistics.htm accessed 11 May 2011.

Stress

Stress can increase the amount of sweat the body produces, and excessive sweating can make people feel self-conscious and anxious about how they will be perceived by others. However, research has shown[496] that people with hyperhidrosis are no more susceptible to feelings of anxiety or stress than anyone else. Any negative feelings they have tend to be the result of excessive sweating rather than the cause.

Continence

Some people may have difficulties with interoception and so be unable to interpret the early warning signs that it is time to urinate or defecate. Others may be acutely aware of the sensation and find the act of urinating or defaecating pleasurable, even if its products are unpleasant for the person or for others. To illustrate this point to staff who are bewildered about why a learning-disabled adult who wears an incontinence pad may deliberately wet themselves, a continence nurse encourages them to try the experiment at home and experience the warm and comforting sensations before passing judgement on others.

Of course, the pleasure may not be just sensory, and other gains may be involved. For example, one man with autism urinated in public places, so the care team provided a large wet space and toys where he gradually learnt to enjoy the sensations of water play in an appropriate way, while another man, who had learning disabilities, loved the fuss that people made when he urinated in public, so the team learned to ignore this behaviour.

It is worth noting that cultural differences in relation to privacy and bodily functions may also affect how people respond. Medieval toilets sat people side by side and nineteenth century dining rooms often had a chamber pot ready for use in the sideboard, so modern Western sensibilities may not be uniform or immutable.

Incontinence of urine[497] or faeces[498] may be a temporary problem linked with a particular illness or disorder, such as prostate cancer, a response to a specific phase of life, such as childbirth or the menopause, or a lifelong difficulty. Urinary tract infections, sexually transmitted diseases, and menstruation[499] can increase body odour or reduce control, while use of other medications, such as antibiotics, can cause diarrhoea or vomiting. Incontinence can lead to very serious problems with odour and increase the risk of infection, General practitioners or specialist continence management nurses will be able to offer advice on treatment and management.

Medication

Some medicines can increase sweating or give the eccrine sweat that occurs all over the body a smell. The following is not a complete list, and advice from a doctor or

pharmacist should be sought before drawing significant conclusions[a]. However, increased sweating has been noted from the following medicines:

- Clomipramine hydrochloride (Anafranil)
- Duloxetine hydrochloride (Cymbalta)
- Escitalopram oxalate (Cipralex)
- Fluoxetine hydrochloride (Prozac)
- Paroxetine hydrochloride (Seroxat)
- Sertraline hydrochloride (Lustral)
- Venlafaxine hydrochloride (Effexor)

Body odour has also been reported with

- Bupropion hydrochloride (Zyban) – usually used to aid smoking cessation
- Omega-3-acid ethyl esters (Omacor), a medicine used to reduce a specific type of fat in the blood
- Leuprorelin acetate in Europe (Prostap), which is used to shut down the production of certain hormones for cancer treatment
- Topiramate (Topamax) to treat seizures and epilepsy.
- Anticholinesterases such as Donezepil (Aricept) which are used in the treatment of Alzheimer's disease

Some people take supplements such as garlic, which may also cause body odour and bad breath.

Sweat

The human body contains 3-4 million sweat glands. There are three types of gland: eccrine glands that are spread across the skin and regulate the body's temperature by cooling the skin with sweat that is normally odourless, apocrine glands that are concentrated in the armpits, genital area and breasts and sebaceous glands that are spread over much of the body surface and secrete lipids and fatty acids.

Apocrine glands develop during puberty and release scented pheromones which act as a sexual attractant[a] and have a high level of protein that bacteria find easy to

[a] In addition, there are anecdotal reports about valsartan (Diovan), pericyazine (Neulactil) and simvastatin (Zocor). 'There is little formal evidence on this issue at http://www.ncbi.nlm.nih.gov/pubmed/ or https://www.medicinescomplete.com/mc/martindale/current/login.htm?uri=http%3A%2F%2Fwww.medicinescomplete.com%2Fmc%2Fmartindale%2Fcurrent%2F' personal communication, Dr Ivan Stockley 12 April 2011.

break down. In particular, the male pheromone androstenol is sexually attractive to both men and women but can only be detected at a distance of about 18 inches and oxidises into the repellent androstenone within 20 minutes in contact with the air[500]. Indeed, one company claims that bills that have been scented with androstenone are perceived as threatening, and those who receive them are 17% more likely to pay up than those receiving unscented bills[501] - a finding that may go some way to explaining those occasions when care workers feel threatened by unwashed clients.

In the first quarter of the twentieth century, various commentators suggested that members of specific ethnic groups had characteristic body odours. Whilst there may be some regional differences in diet, sweat gland activity and distribution on the body, and use of scented products on the skin, most statements on this issue are not supported by satisfactory evidence and may be motivated by racist assumptions[b].

The data on age differences seems to be clearer. A recent study[502] has found support for the commonly held view that there is a 'smell of old age' (the Japanese call it kareishu[503]) although the details challenge many of those assumptions. Research subjects washed with odourless soap and then wore a pad at the armpits for five nights. A second group of subjects then rated the smells. Subjects correctly identified men and women in the young (20-30 years old) group and the middle age group (45-55 years old) but there was no significant difference between men and women in the third, older group (aged 75-95 years). Further, subjects correctly assigned the odours to the age bands. Smells were rated for unpleasantness and intensity and those from middle aged males were most intense and most unpleasant, with those from older persons judged to be least intense and neutral rather than unpleasant. When the smells were manipulated to remove the intensity differences, they could still be assigned to the correct age band. The authors contemplate the possibility that ageism unconsciously loads the neutral smell with negative connotations to generate the popular idea of the 'smell of old age'.

Some people, such as the comedian Lee Evans, have hyperhidrosis[c], a poorly understood condition in which the sweat and oil producing glands are highly active, meaning that the person may need to shower and change their clothes several times a day. Sometimes it is only particular parts of the body that sweat a lot, such as the armpits, hands, feet, groin or face. Hyperhidrosis is usually diagnosed where the

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[a] Unlike some other animals, we don't spray mark with urine to establish personal territory or exude poisons or poisonous smells. The nearest we get to establishing personal odour-space is probably perfume, which is very personal and which reacts differently on different people, according to their body-chemistry.

[b] An example of the kind of assertions made from time to time is Ashenburg op cit p11 "Asians have few or no apocrine glands and so can find even clean Westerner very smelly." But See Sharon Lynn's summary of the research at www.zebra.sc.edu/smell/ann/myth6.html accessed 23 March 2011.

[c] Doctors also use the terms, apocrine bromhidrosis, body sweat, bromhidrosis, bromidrosis, fetid sweat, malodorous sweating, osmidrosis or ozochrotia.

person has at least one episode of excessive sweating a week, only parts of the body, rather than the whole, are affected, both of the affected body parts (such as both armpits or both hands) are excessively sweaty, and there are no night sweats.

Although the condition is generally under-researched[504], several medical treatments are available including antibacterial bodywash[505] that is available without prescription from a pharmacist, and assessment by a dermatologist who may be able to offer iontophoresis[506], Botox[507] or surgery[508].

Bad Breath

People in antiquity had a persistent problem with oral hygiene[a] and so teeth were often painful, broken and stained, and everyone at the court of Louis XIV in seventeenth century France knew about the Sun King's halitosis[509]. In 1787 the artist Elizabeth Louise Vigee Le Brun broke with formal tradition and painted the first romantic open smile, with gleaming white teeth, that had ever been seen in European art. After that, new soft toothbrushes and better pastes gradually replaced the damaging sticks and grits that had been used, leading to gradual improvements in dental care and appearance[510]. In recent years, tooth whitening has become a major industry[b].

Despite these improvements, halitosis, or persistent bad breath affects some 25% of the population in varying degree. Vigorous advertising for Listerine mouthwash in the 1920s emphasised that people often do not know that their breath smells and encouraged people to take firm action against this undetected threat to employment, marriages and friendship, harnessing 'presentation anxiety' to boost sales[c].

Poor oral health (gingivitis, periodontal disease, bleeding gums) can lead to halitosis. People on low incomes[511], people with mental health issues[d] and people with learning disabilities[512] have poorer oral health than the general population and people with serious mental health issues are less likely to seek medical advice[e]. In a

[a] In the *Art of Love*, Ovid instructed, ""Keep your nails pared, and dirt-free; don't let those long hairs sprout in your nostrils; make sure your breath is never offensive, avoid the rank male stench that wrinkles noses."

[b] Ashenburg op cit p269: "tooth whitening dates from 2002. ... by 2005, whitening strips had become a $500 million industry.

[c] Ashenburg op cit p244-6. This was also the first major advertising campaign that used technical, medical sounding jargon.

[d] "People with severe mental illness had 3.4 times the odds of having lost all their teeth than the general community. They also had significantly higher scores for the mean number of 'decayed, missing and filled' teeth or surfaces." Kisely S, Quek LH, Pais J, Lalloo R, Johnson NW and Lawrence D (2011) Advanced dental disease in people with severe mental illness: systematic review and meta-analysis *British Journal of Psychiatry*, 199:187-193. Quote from page 187.

[e] Khokhar WA, Clifton A, Jones H, Tosh G (2011). *Oral health advice for people with serious mental illness.* Cochrane Database of Systematic Reviews Issue 11, page 2. Page 3 says, "Oral health problems are not well recognised by mental health professionals and people with serious mental

2023 study, four in five teachers had given schoolchildren toothbrushes and toothpaste[513] and another study found that dental decay amongst young children was leading to hospital admissions costing the NHS £50 million per year[514].

There are several other medical conditions that may cause foul breath, but these are extremely infrequent in the general population and tend to be accompanied by other symptoms. They include:

- chronic liver failure, leading to fetor hepaticus
- lower respiratory tract infections (bronchial and lung infections)
- renal infections and renal failure
- carcinoma
- trimethylaminuria, as mentioned above
- diabetes mellitus
- metabolic dysfunction

In addition, people with sensory processing disorder may have real difficulty in tolerating the process of brushing their teeth[515].

Some mental health medications (antipsychotics, antidepressants and mood stabilisers[516]) can decrease the flow of saliva in the mouth (xerostomia) and this can lead to halitosis, as well as difficulty swallowing, mouth infections, discomfort and reluctance to use a toothbrush. Such problems can affect diet as well as social confidence and health[a].

A survey[517] found that the vast majority of psychiatric patients had never been asked about any dental problems by their hospital or community staff, and so use of a checklist by non-dental staff or the person themselves has been recommended.

Another survey of an inpatient psychiatric unit found that only half of the respondents cleaned their teeth at least once a day, ten percent did not own a toothbrush and fifteen percent said that they would visit a dentist if someone told them to[518]. The staff response was to offer a training session[519] on dental care, toothbrush

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illnesses can experience barriers to treatment including low tolerance to their lack of compliance with oral hygiene, and a lack of understanding of mental health problems from dental professionals."

[a] Bhambal A, Jain M, Saxena S and Kothari S (2011) Oral health preventive protocol for mentally disabled subjects – A review *J. Adv Dental Research.* 2(1):21-26. Also "reduced salivary flow is caused by conventional and atypical antipsychotics, all classes of antidepressants, and mood stabilisers." Kisely S, Quek LH, Pais J, Lalloo R, Johnson NW and Lawrence D (2011) Advanced dental disease in people with severe mental illness: systematic review and meta-analysis *British Journal of Psychiatry*, 199:187-193. Quote from page 191. Also "Selective serotonin reuptake inhibitors, tricyclic antidepressants, lithium carbonate, butyrophenones, phenothiazines, and sedatives (including benzodiazepines) used in depression and bulimia, cause xerostomia or dry mouth, which itself shifts the plaque index scores." Matevosyan NR (2010) Oral Health of Adults with Serious Mental Illnesses: A Review *Journal of Community Mental Health* 46:553–562. Quote from page 554.

exchange, a list of available NHS dentists, referral to a dentist and support with filling in claim forms to obtain exemption from dental charges – leading to an audited improvement in personal dental care for inpatients[520].

Another project developed the Oral Health Assessment Tool[521] and Care Plan that requires residential care staff who are not dental professionals to screen for oral health problems and directs them to refer the person to a dentist if they score more than zero on any category, as well as assist people who can't swallow properly, struggle to rinse and spit, or constantly grind their teeth. There are eight questions in the assessment tool, none of which include access to a toothbrush or the person reporting dental pain.

The UK General Dental Council has created a 'special care dentistry list' to register those dentists who have additional training and experience in providing a service to people with specific problems[a], as well as providing specialist advice[522]. Despite these attempts to provide suitable care, some people with learning disabilities and perhaps others are finding that the care system neglects personal hygiene. This is illustrated by the story of Rachel Johnstone, who lived in a care home but was found to have such severe tooth decay that a hospital dentist decided to remove all her teeth at one go. A day after the surgery she was readmitted to hospital, where she died a fortnight later, in November 2018[523].

[a] There were only 170 such dentists in 2010, averaging about one per county. Khokhar WA, Williams KC, Odeyemi O, Clarke T, Tarrant CJ & Clifton A (2011) Open wide: a dental health and toothbrush exchange project at an inpatient recovery and rehabilitation unit *Mental Health Review Journal* March, Volume 16 Issue 1 pp 36-41. Details of the curriculum is at https://www.gdc-uk.org/professionals/specialist-lists and the list can be searched by going to SearchRegisters (gdc-uk.org), selecting 'Specialist List' and then scrolling down to 'Specialty' where 'select by specialty type' offers an option of 'Special Care Dentistry'. In December 2023, this returned a message indicating that there are more than 250 records.

Reflection time – Chapter Nine

- In the story of your life, how did major body changes affect your health and hygiene – puberty, pregnancy, menopause?
- Which aspects of your diet and exercise will affect your bodily hygiene?
- Does you have a health condition that is causing problems with hygiene?
- How are your teeth and gums?
- Can a visit to the doctor be arranged to carry out a health check?
- When medication is prescribed, do you discuss its possible impact on obesity, sweat production and body odour?

10. Hygiene routines in more detail

The UK government's Department of Health has made it quite clear that hospital and other care environments need to pay attention to personal hygiene and ensure people have adequate support to remain in charge of their own hygiene routines wherever possible. A detailed description of the standards one can expect are set out in *Essence of Care 2010*[524]. However, delivering this is not always as straightforward as it may at first appear.

Bathing

Advisers to previous generations suggested that bathing was hazardous to health[a] or character[b], so should not be attempted after eating[c] and people should stay indoors after their bath, perhaps in recognition of cold and damp living conditions. Nevertheless, there were exceptions, such as Beau Brummel, who took a daily hot bath in his Mayfair home in the early nineteenth century.

Recent researchers[525] have found that lonely people take more frequent, longer and hotter baths and showers, and report less loneliness afterwards, as if the physical warmth could substitute for the lack of social warmth. This confirmed the opinion of the poet Sylvia Plath, who declared[526], "There must be quite a few things that a hot bath won't cure, but I don't know many of them." Perhaps the Victorian psychiatrists with their warm bath therapy were right after all!

Handwashing

In those parts of the world that have easy access to a toilet and sewerage system, clean water and soap, one might hope that hands were reasonably clean. Unfortunately, as Rosie George explains in her book *The Big Necessity*[527], many people in the world lack these things, and even where they are available, local

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[a] "Even when the plague was not imminent, the fear of water that dated from the late Middle Ages became more and more generalised. Doctors believed that baths threatened the body in various, bewildering ways." (Ashenburg op cit p100). Also "In 1610... the doctor pronounced that the man would be vulnerable for several days after his bath." (Ashenburg op cit p115). The French Ministry of Public Education in 1884 found that, "France's large peasant population feared washing and glorified dirt. Proverbs underscored the belief that dirt was protective:... "If you want to reach old age, don't take the oil off your skin." (Ashenburg op cit p194.

[b] "In 1860, the Countess Drohojowsha advised: 'Never take more than one bath a month. There is in the taste for sitting down in a bathtub a certain indolence and softness that ill suits a woman.' Ashenburg op cit p188.

[c] A writer in 1860 said that a bath was "a perilous venture even a day after eating a heavy meal" Ashenburg op cit p168. Baroness Staffe in 1893 advised her readers to "Wait three to four hours after a full meal before bathing, and don't bathe in someone else's water, no matter how healthy that person." (Ashenburg p191).

customs sometimes form a barrier to good hygiene[528]. She points out that in the West, our preference for using paper rather than water to clean up after defecation is highly inefficient[529], while the male habit of standing to urinate increases air pollution. In addition, a survey showed some ninety-five percent of British people admit to urinating, defecating or vomiting in a public place[530].

Despite considerable social pressure, handwashing routines remain patchy[a]. Recent research by Professor Cutler[531] found faecal bacteria present on 26% of hands in the UK, 14% of banknotes[532] and 10% of credit cards. These findings suggest 11% of our hands are so "grossly contaminated" they are carrying as many germs as a dirty toilet bowl. Incidentally, we note one study[533] which found that dominant hands (i.e. the right hand in a right-handed person) carry a very different array of bacteria than the left or subordinate hand.

One insurance company reported that about half the claims for water damage to mobiles are caused by people dropping their phones into the toilet[534], showing that many people use their phones whilst using the bathroom, and this unpleasant fact is confirmed by Professor Cutler's finding that faecal matter can be found on one in six mobile phones, as it can be found on MacDonald's touchscreens[535]. Smartphones carried by doctors are a source of hospital infections[536].

Scientifically robust advice is available on how to wash hands effectively[537] but the British seem particularly unresponsive to hygiene messages[b].

As Curtis reports,

> *"Indeed, handwashing with soap, were it practised globally, could save over a million lives a year, mainly from the infectious enteric diseases. Direct observation showed that only 3 per cent of mothers in Ghana, 4 per cent in Madagascar, 12–14% in China, Tanzania and Uganda and 18 per cent in Kyrgyzstan were washing their hands with soap after using the toilet[538]. In the UK, a survey found that only 43 per cent of mothers washed their hands with soap after changing a dirty nappy[539]. Electronic sensors showed that only 32 per cent of men and 64 per cent of women washed their hands with soap after using a public toilet... In our public toilet study using unobtrusive sensors, we found that rates of handwashing decreased when there were few people in the facility, and the message that had the biggest positive effect was: 'Is the person next to you washing their hands with soap?'[540]"*

[a] "When asked, people in US movie theatres swear they washed their hands in the restroom, but Gerba and his gimlet-eyed researchers say only 65% do, only half of those who do wash with soap, and only half of the ones who use soap wash long enough." Ashenburg op cit p286.

[b] SteelFisher GK, Blendon RJ, Ward JRM, Rapoport R, Kahn EB & Kohl KS (2012) Public response to the 2009 influenza A H1N1 pandemic: a polling study in five countries *The Lancet Infectious Diseases*, Early Online Publication, 5 October 2012 doi:10.1016/S1473-3099(12)70206-2Cite. This study study examined whether handwashing routines changed in response to a new health threat – the H1N1 virus. The British were the worst of the five countries studied.

In addition to placing electronic sensors in the public toilets of motorway service stations[a], the researchers asked people if they washed their hands and found that 99% of respondents claimed to do so[541], a figure which is inflated by social desirability bias[542].

Concerns about hospital-borne infections have led to a recent increase in sales of antibacterial gels[b] and some changes in the hospital itself. One in 16 patients pick up an infection whilst in hospital and so UK[543] and international guidance has pressed hospital staff to decontaminate their hands between patients.

In the 2011 survey of 72,000 hospital inpatients, only 79% said that doctors 'always' washed their hands between touching patients and only 80% of nurses were reported to do so[544]. In a UK survey[545], student nurses also noticed these lapses in the handwashing routines of their qualified colleagues, with 75% reporting that they have witnessed staff failing to wash their hands between patients.

Whilst such occasional lapses may be attributable to busyness, other actions, such as wearing nail extensions (60% of students reported seeing them being worn while caring for patients), are clear decisions to prioritise fashion over hygiene. The reference to fashion implies a relationship with practices that might be seen as trivial, but deeply held beliefs are at work here too. This is illustrated by a news report[546] that circulated in 2014, suggesting that some Muslim nurses had been given permission to avoid handwashing out of respect for their desire for modesty. This story spread quickly and provoked outrage but was later found out to be untrue[547] and an unsupported rumour[548] - the Muslim faith in fact highlights the need for cleanliness. This incident neatly illustrates how the discussion of lack of hygiene, especially in the healthcare setting, can spark fear among the population.

In the UK, local people join visiting inspectors to carry out Patient Led Assessment of the Care Environment (PLACE) assessments to assess how the hospitals support patients' privacy and dignity, food, cleanliness and general building maintenance[549]. The World Health Organisation has set 5 May as Global Hand Washing Day[550] and explains how patients can politely prompt hospital staff to wash their hands[551].

Hospital regimens of handwashing become ever more controlling[552] while, paradoxically, patients' own wish to wash is neglected so often that NICE has been obliged to issue guidelines[c] insisting that nursing staff heed these requests, as some

[a] Rosie George notes that some English pubs have introduced CCTV cameras into their toilet areas (George R (2008) *The big necessity: adventures in the world of human waste* London: Portobello Books. Page 148).

[b] http://www.bizjournals.com/columbus/stories/2010/01/18/story5.html reports that one American outlet has seen sales double in a year.

[c] National Institute of Clinical Excellence (February 2012) *CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: Improving the experience of care for people using adult NHS services.* Paragraph 1.2.9. sets out the following quality standard: "Ensure that the patient's personal needs (for example, relating to continence,

hospital patients have remained unwashed for weeks[a]. One campaign group[553] has suggested that a solution to staffing shortages in the hospitals would be to oblige relatives to help with feeding and washing by making it as compulsory as jury service.

Work with young people with learning disabilities suggests that people can be trained to take up good handwashing regimes[554] and imaginative approaches to training staff are available, such as the Poopology Game[555].

Hair care, shaving and deodorants

The word shampoo entered the English language in 1796 but referred to body massage until the 1860s when it began to be used for washing the hair. Both men and women wore wigs or fancy hairstyles in the eighteenth century and, for women, these could be so carefully constructed that they would leave them untouched for months on end, inviting infestation.

By the start of the twentieth century, American women were encouraged to wash their hair as often as once a fortnight[556]. Hairdressers have the potential to communicate care and value to their customers, as illustrated in the following quotation from a thankyou letter:

> *My wife was suffering from dementia, and you treated her as if you'd been working with dementia patients all your life. You let us sit next to each other, and when it came time for her cut you turned her chair towards me so that I could watch her expression as you cut her hair. That haircut was one of the last, best moments of her life. She felt so pretty. She visited the mirror in her bathroom several times during the day and would come out beaming. To see her so happy was priceless. Looking back, it was likely one of dozens of haircuts you gave that day. But one which revitalised a woman's sense of self and her own singular beauty."*[557]

The first razor for women was marketed by Gillette in 1915, prompting significant shifts in attitude to body hair[558]. The Second World War gave the fashion and cosmetics industry a further boost as propaganda encouraged women to link beauty

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personal hygiene and comfort) are regularly reviewed and addressed. Regularly ask patients who are unable to manage their personal needs what help they need. Address their needs at the time of asking and ensure maximum privacy."

[a] Patricia Bridle was not washed for 11 weeks, and Laurence Hodges had his dentures removed and was deprived of food and drink. See http://www.telegraph.co.uk/health/heal-our-hospitals/9763018/Victims-of-neglect-at-the-Alexandra-Hospital.html. Others say they suffered dehydration because nurses left drinks out of reach and allege that they were left in dirty sheets and claim nurses told them to soil their beds because they were too busy to take them to a toilet. See http://www.mirror.co.uk/news/uk-news/ten-hospitals-may-face-legal-action-1571719. Evidence shows that junior doctors are too busy to go to the toilet themselves and this is severe enough to damage their health – see Solomon AW, Kirwan CJ, Alexander NDE, Nimako K, Jurukov A, Forth RJ et al. (2010) Urine output on an intensive care unit: case-control study *BMJ*; 341 :c6761.

and duty[559] but British women were only washing their hair once a week or even less frequently by the 1940s[a].

Now we know that washing with soap and water[560] removes bacteria from the skin that otherwise thrive on stale sweat and cause the smell. Hair, especially in the armpits and groin, provides a greater surface area for sweat to adhere to and gives bacteria a fertile breeding ground. Shaving helps sweat to evaporate more quickly, giving the bacteria less time to break it down and generate odour.

The first commercial underarm deodorant was patented in 1888 in the United States and by the 1920s talk about 'BO' (body odour) had become a routine marketing ploy. They were imported to the UK the 1950s and spread through a large advertising campaign - combined with the persistence of women who bought toiletries for their husbands and male relatives until the habit was adopted[561], although substantial gender differences remain in attitudes towards sweating. Men also found that increasing competition in the workplace pressed them to make the most of themselves. By 1965 over half the female population were using underarm deodorant daily[562] rising to 90% of American men by the end of the millenium[563], with British men lagging behind[b].

Anecdotes have suggested that some people mistakenly view deodorants as an alternative rather than an adjunct to washing. Deodorants work by masking the smell of sweat with fragrance, while antiperspirants reduce the amount of sweat the body produces[c]. Roll-ons tend to be more effective for heavy sweating, but, as different deodorants and antiperspirants have varying active ingredients, some will work better than others.

Clothing and laundry

Since the repeal in 1604 of the medieval sumptuary laws which prohibited the use of certain types of clothing by the lower classes, clothing has been a matter of economics, culture and choice. Clothes are chosen for a variety of reasons, including the fight against invisibility and the opposite need to blend into the crowd[d], attracting or retaining a romantic partner, approval from others or employment. Like hairstyle,

[a] "In 1949 British women apparently did a hair-wash 'on average between once a week and once a fortnight.'" Smith V (2007) *Op cit*, p338.

[b] Only 66% of men used deodorant daily in 2005. http://www.cosmeticsdesign-europe.com/Market-Trends/Less-is-more-for-British-mens-grooming-routine

[c] In medieval times, blocking the pores was seen as a way to seal off the body from infection, but this was accomplished by keeping the body dirty and avoiding washing, rather than use of antiperspirants. Ashenburg op cit p100.

[d] "Wearing the right clothes, the appropriate dress for the occasion, fitting in rather than standing out, are the dominant concerns of most people." Twigg J (2009) Clothing, identity and the embodiment of age in Powell J & Gilbert T (eds) (2009) *Aging and Identity: A postmodern* dialogue New York: Nova Science Publishers.

clothing and grooming can also be a badge of membership of a particular group, or a mark of rejection of that group[a], and so people may use their appearance as a way to endorse or erase a particular role or aspect of their identity[b]. As well as communicating to others, clothes help people to take up a particular role – researchers found people performed better at a concentration task when wearing a scientist's lab coat compared to those who wore an identical white coat that they had been told belonged to a painter[564].

Those who rely on others to dress them can find the caregiver writing these messages on their body, such as some adults with learning disabilities who are dressed to look like children[565]. Dirt can become an artistic medium for artistic expression too, as revealed in the mud-smeared faces of the rugby player and commando[566]. It also carries symbolic value by association, as shown in the following account from the spring of 2016.

Case Study Eleven

As part of his Christian faith, a frequent visitor to Nairobi has befriended dozens of the children who live on the rubbish dump at the edge of the city. Because of his relentless campaigning to improve their life opportunities, he has been honoured with a tribal name which means 'The Man who Walks with the Dirty People'.

Indeed, we might wonder what signals some senior academics are choosing to send out by their appearance, as shown by Einstein's dishevelled clothes, uncombed hair and refusal to wear socks, or the 'prof or hobo?' quiz created at the University of Toronto[c].

Whilst the message conveyed by dress and appearance is often contextual, fluid and ambiguous, it has been used to communicate social class, age, ethnicity and sexual orientation, and the ease by which we read these signals in old portrait photographs or choose an age-appropriate clothes shop demonstrates the power of the norms and the effectiveness of this visual language[567]. Wolfensberger[568] highlights some of the ways in which physical appearance can reinforce devalued imagery and so help to create social deviance, while Russell[569] distinguishes the two overlapping functions of cosmetics use, as 'beautification' and 'signification'. Beautification

[a] Might body odour be a kind of scent marking, to establish personal territory and keep others away?
[b] Twigg, J (2007) Clothing, age and the body: a critical review *Ageing & Society* 27, pp285-305. In addition, anthropologists have developed Costly Signalling Theory that analyses rites of passage and other dangerous and risky ways to signal status to the social group. In contrast, Taleb suggests that wearing unconventional clothes is a kind of 'cheap signalling' (Taleb NN (2007, 2nd edition 2010) *The black swan: The impact of the highly improbable* London: Penguin. Page 6.
[c] http://individual.utoronto.ca/somody/quiz.html accessed 12 Nov 2013.

makes the wearer more attractive but leaves her place in society unchanged, while signification places the person in society in terms of identity, social status or rebellion against social norms. Signalling theory suggests that neglecting one's personal appearance – an action that would routinely be seen as socially risky and costly – may be perceived as a deliberate, conspicuous challenge to social norms that confer high status and competence, an action the researchers call the 'red sneakers effect'[570].

The multiple, competing intentions and effects of manipulating one's appearance are perhaps illustrated by the long history of cosmetics. For centuries, they were intended to enhance beauty but also poisoned or injured the user – belladonna eye drops to dilate the pupil, white lead foundation to cover blemishes, dilute arsenic drink to improve the complexion, crushing corsets to narrow the waist and stiletto heels to enhance height, to name but a few. It seems unfair to criticise those who neglect their personal hygiene when the mainstream beauty industry has been so disinterested in welfare.

Loose fitting clothes from warmer climates allow odour to disperse, whilst the medieval development of close-fitting undergarments are suitable for a cold winter but increase the need for frequent washing[571]. A daily change of shirt became normal for men in French court circles by the late sixteenth century[572] and it was believed that linen absorbed the body's dirt, and so there was only a need to wash the parts of the body 'that showed' – hands, face, neck and ears[573]. It took another two hundred years to establish a weekly wash day in most urban households in England[574]. The first combined wash house and bathhouse in England was opened in Frederick Street, Liverpool in 1842[575].

Nowadays, more than 80% of the population change their underwear every day[576] with slightly higher figures for unemployed and manual workers compared with the middle class[577]. However, some people are less fastidious with other hygiene habits, such as washing bedsheets, where a UK survey in 2013 found that men aged 18-25 changed their sheets on average every three months, while women aged 35-50 changed their bed sheets every 18 days on average[578]. Pillows have been found to be loaded with unwelcome contents[579]. Meanwhile, barristers may not wash their gowns and wigs at all![580] The standard for English prisons is a weekly change of bedding, but this is not always adhered to[581].

Washing clothes and bedding will only effective if it is done correctly, and the recent increase in the numbers of lice has been attributed partly to their growing resistance to pesticides and partly to the trend to wash in cool water rather than hot, which cleans rather than kills the lice[582].

Before the days of bright electric lighting, patterned fabrics were sometimes discouraged as they could hide the presence of dirt[a] and the domestic scientists of the early twentieth century opposed long dresses, as they brushed dirt in from the street to the home[583].

Early academic studies suggested that 'power dressing' was a universal language and Elliot and Niesta[584] found that while the colour red acts as a definite stimulus, boosting physical and sexual attractiveness without either the signaller nor the person signalled to being aware of its impact.

In general, this approach has given way to a more dynamic view in which the meaning of clothes is recognised to vary from one context to another, and so clothes are selected to convey a message to a particular audience at a particular time[585]. Twigg[586] suggests that clothing has been theorised as a kind of semiotic code, a means by which people send out messages about themselves, although she suggests that it may be more of an aesthetic rather than a linguistic code, deliberately designed to communicate a measure of ambiguity and complexity rather than simple, straightforward messages.

We might usefully consider how these ideas could improve our understanding of the meaning of poor hygiene and self-neglect, both considering the impact of dirt in reducing the brilliance and contrast of coloured garments and viewing the person's overall appearance as complex communication.

First impressions of a stranger will be strongly influenced by appearance, including clothing, grooming and jewellery, but the importance of these factors diminishes as people get to know one another and personality factors take over[587]. We also remember that personal grooming affects not just the impressions formed by others, but the person's own self-image.

Some further education colleges have run courses to help people learn how to buy cheap, sometimes second-hand clothes that are practical and fashionable[588]. The choice of clothing can affect sweating, and this can be minimised if the person wears natural-made fibres, such as wool, silk or cotton (rather than man-made fibres such as nylon) as they allow the skin to breathe and sweat to evaporate more quickly. Wearing white or black clothing can help minimise the signs of sweating. Armpit shields are available that absorb excessive sweat and protect clothing.

Problems with body odour are minimised if fresh clothes are worn every day, washed frequently and then dried as quickly as possible, as bacteria can survive in damp clothing. The health risk associated with laundry practices has been scientifically reviewed[589], and high-risk items should be should be washed at 60°C or more using an oxygen bleach-based laundry product and following manufacturer's instructions.

[a] "Plainer and purer Protestant sectarians [around the 1630s] had real moral objections to [clothing with] colour and pattern... 'hiding that which is not clean by colouring our garments seems contrary to the sweetness of sincerity.'" Smith (2007) op cit, p208.

Does the person have access to working laundry equipment and do they know how to use it? Have they established a routine for washing all of their body, clothes and towels?[590] One learning disabled person was meticulous in washing his own body and his mother regularly did his laundry, but the employer complained about his body odour. Investigation finally revealed that the clothes were being returned to him in a damp condition and then piled up rather than being aired.

Footcare, socks and shoes

Sweat that lies on the surface of the feet or is absorbed by shoes and socks, lies under dirty and long nails or inhabits patches of dead skin will encourage the growth of bacteria and fungi which can lead to odour and athlete's foot. These problems can be managed by the following hygiene regimen:

- Keep toenails short and clean. Remove hard, dead skin with a foot file.
- Wash the feet regularly, dry them thoroughly and dust with antifungal foot powder if necessary. Some people enjoy using a foot spa.
- Avoid closed shoes that increase sweating, such as trainers and shoes made of synthetic materials, and instead wear shoes made of leather, canvas or mesh. Do not wear the same pair of shoes two days in a row, but rather let them dry out. Remove insoles to help the drying process.
- Keep feet bare in open sandals as often as possible. Wear socks that will absorb the moisture, such as thick, soft socks made of natural fibres such as cotton, or sports socks specially designed to absorb moisture.

Many further education colleges train beauticians, nailcare workers and foot health practitioners while universities train podiatrists (chiropodists) and so may seek people who are willing to give their trainees an opportunity to practice their skills. Meanwhile, care workers occasionally claim that providing nail care is not their responsibility or should only be done by a qualified podiatrist[a], but this has been clearly established as within their range of duties after support and training from podiatrists in at least one NHS Trust[b].

[a] Choice Forum 20 March 2012. "My son lives in his own flat with 24/7 support delivered by a small group of PA's. He has complex needs and in relation to his personal hygiene he relies on someone cutting his fingernails and I'd like to know who is responsible for cutting them. He is regularly visited by a chiropodist but they only cut his toe nails. A few years ago some of his PA's had 'training' at a local college on a 'beautician' course who had 'manicures' as part of the course. My son isn't keen on having his hands touched but will tolerate his nails being cut with nail clippers providing the PA is someone he knows well. Is there any guidance on cutting fingernails and if so where can I find it?"

[b] "Some staff in our NHS Trust believed that cutting nails could only be carried out by qualified chiropodists or podiatrists. We checked with our local nurse leads, the Regional Care Quality Commission/equivalent at that time, the Royal College of Nursing and the national Nursing and Midwifery Council and found no legal or policy restrictions - subject to additional medical

Oral care

The ancients paid attention to smell as part of medical diagnosis, with traditional Chinese doctors smelling the patient's breath, Hippocrates smelling body odour and Avicenna smelling urine as part of the diagnostic process[591]. In the 21st century, there are some suggestions that that poor appearance of the mouth and teeth may generate oral health stigma[592] and even adversely affect outcomes of a job interview[593]. While some put their hope in the noses of medical alert dogs[594] or specific humans[595], others are developing electronic nose technology to detect a variety of diseases, such as Crohn's disease[596], cancer, tuberculosis, asthma and urinary tract infections.

The following strategies may help those with poor oral health:

- Maintain oral hygiene with daily tongue cleaning, brushing teeth, flossing, and periodic visits to the dentist and hygienist. Flossing helps to remove rotting food debris and bacterial plaque from between the teeth, especially at the gumline. A 2005 survey found that more than 90% of British men cleaned their teeth daily[597], but worldwide, it has been claimed that there are more mobile phones in the world than toothbrushes[598]. Staff have been issued with required standards to meet in care homes[599] and in the community[600], and can help the person use 'disclosure tablets' which discolour plaque as a way to alert the person to the need for effective toothbrushing.
- Dentures should be properly cleaned and soaked overnight in antibacterial solution, unless otherwise advised by a dentist.
- Chew gum: 'Chewing-gum' is a neglected tool for dental hygiene, although it has been used for oral hygiene from ancient times. Since a dry mouth can increase bacterial build-up[601] and cause or worsen bad breath, chewing sugarless gum can help with the production of saliva, which washes away oral bacteria, has antibacterial properties and promotes mechanical activity which helps cleanse the mouth. Some chewing gums contain anti-odour ingredients. Chewing on fennel seeds, cinnamon sticks, or fresh parsley are common folk remedies.
- Eating a healthy breakfast with rough foods will help clean the very back of the tongue.

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requirements, for example diabetes. This guidance confirmed our determination to include guidance on nail cutting within the Basic Care MOT which subsequently became a guide for staff as part of the work on Health Action Plans. Local podiatrists provided advice and training to raise the confidence of support staff and the local pharmaceutical manufacturer donated clipper and nail kits." (Sam Wellington, personal communication, March 2012) See Carr, D & Wellington S (2008) *Basic Personal Care MOT* Nottinghamshire Healthcare NHS Trust. Available from http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=119

- Mouthwash has been recommended, but the claim remains unproven[602]. Where medication or some other issue has slowed saliva production, saliva substitutes such as Xerostom and Saliva Othana are commercially available.

Housework

Possessions that look like rubbish or hoarding to an observer can carry sentimental, symbolic or artistic value to the person. For example, Marcel Duchamp signed a urinal and exhibited it as art in 1917, Piero Manzoni canned his faeces in 1961 (tin number 018 changed hands at Sotheby's in 2007 for 120,000 euros, suggesting considerable demand for this artform[603]), Helen Chadwick created 'Piss Flowers' in 1992[604] and Tracy Emin exhibited her dirty, unmade bed in 1998. While these and other creators of abject art may be intending to shock[a], Julia Kristeva[605] offers a psychoanalytic interpretation of abjection which may help to explain why such objects and actions retain their appeal. Indeed, Le Corbusier[606] described the toilet as 'one of the most beautiful objects industry has ever invented'. For public health, rather than psychoanalytic reasons, the modern world celebrates World Toilet Day each November 19. Hoarding is banned in high secure psychiatric hospitals[607], as it inhibits the regular room searches that are undertaken to find illicit weapons and drugs, but this restriction is removed for medium secure services[608], restoring the right to peaceful enjoyment of one's possessions under the Human Rights Act 1998.

Three types of behaviour that lead to clutter have been identified, with some people called accumulators, who do not throw things away (either through ignoring the issue or chronic indecisiveness), hoarders who keep things because they might need them someday[b], and collectors, who target specific possessions. Advice is available on de-cluttering[609] and some services offer practical help[c].

Establishing a plan for responding to filthy, verminous or poorly maintained property is often a significant challenge. The legal framework set out in chapter five offers some short-term solutions, but the environmental health literature[610] is generally pessimistic about the long-term benefit of single actions to clean up. Where a long-

[a] In 1964, Gunter Brus co-founded Viennese Actionism. His performance art was designed to shock his audience. In his 1968 show, he urinated into a glass, covered his body in his own excrement, sang the National Anthem while masturbating, drank his own urine and vomited. He was arrested and imprisoned.

[b] Roland Simmons summarised this as the view that 'I know it is good for nothing, but I'm keeping it until it is good for something.' (Solihull conference, 24 September 2012). Similarly, Edmund Trebus filled his house with things the rest of the world had decided were rubbish, convinced that in time a use would be found for them. His name has been adopted by the Trebus Project that collects and assembles life-story narrative from people with dementia – see http://www.trebusprojects.org/.

[c] The older person's mental health team in Barnet have a Mobile Squad to help people de-clutter their homes and call in Environmental Health when the home is deemed filthy or verminous and a public health hazard.

term plan can be put in place to support the person who wishes to change their behaviour, it may be possible to give the person a clean start and make the mess manageable. Commercial enterprises sometimes offer a de-cluttering service for a fee, but this can be quite expensive. The current wave of austerity in the public sector means that domiciliary care staff are highly unlikely to offer practical help with cleaning up, and some fear that a shortage of workers from the European community post Brexit will make it harder for social services to 'wash, dress and feed people'[611]..

People whose home is too large for them to maintain in a tidy fashion may be helped by moving to a smaller property. Welfare benefit changes (such as the so-called 'bedroom tax') may encourage people to move out of houses that are deemed too large for them[612].

Warmth and property maintenance

Not much recent data is available to show the temperature to which people prefer to heat their homes when their spending is not constrained[613], and that which is available suggests that the previous advice to adopt a minimum of 21ºC is too high[614] and the UK government now recommends 18^{0}C[615]. However, it is clear that excess cold doubles vulnerability to mental ill health difficulties[a] as well as cardiovascular and respiratory diseases[616], which in turn can lead to death[617].

Fuel poverty is defined as "households with income below the poverty line (taking into account energy costs); and where energy costs are higher than is typical for their household type'[618]. One in three people in the United Kingdom could not afford to adequately heat their homes over the 2012/13 winter and 29% had to turn the heating down or off or only heat part of their homes[619]. The number of people in fuel poverty is rising[620] with up to 200,000 more households expected to enter fuel poverty by 2016[621] and this will have the most impact upon the elderly, infants, disabled people and those with long term sickness[b]. Help[622] is sometimes available for people in fuel poverty in an attempt to reduce the death toll of some 20-30,000

[a] "Residents with bedroom temperatures at 21°C are 50% less likely to suffer depression and anxiety than those with temperatures of 15°C." Green G and Gilbertson J (2008) *Warm front: better health: Health impact evaluation of the warm front scheme.* Sheffield: Sheffield Hallam University, Centre for Regional Social and Economic Research.

[b] "The three main groups of people likely to experience particularly negative health impacts of fuel poverty are the elderly, infants, disabled people and those living with long term sickness. 34 per cent of fuel poor households contain someone with a disability or long-term illness, 20 per cent have a child aged 5 or under, and 10 per cent a person aged 75 or over." Hills J (2012) *Getting the measure of fuel poverty: Final Report of the Fuel Poverty Review* CASE report 72. ISSN 1465-3001. London: The London School of Economics and Political Science, Centre for Analysis of Social Exclusion, page 15. Also, "Of the 2.7 million households identified as 'Low Income High Cost' in 2009, 54 per cent have one or other of these characteristics." Hills J (2012) *Getting the measure of fuel poverty: Final Report of the Fuel Poverty Review* CASE report 72. ISSN 1465-3001. London: The London School of Economics and Political Science, Centre for Analysis of Social Exclusion, page 92.

people who die each year through excess cold[623] and research is underway to see if winter fuel payments achieve their goal[624] and more broadly how to recognise hart to heat homes and what to do to help[625]. Indeed, one healthcare provider[626] has been experimenting with offering new central heating boilers 'on prescription' to people who meet certain criteria and the government will expand its 'warmth on prescription' programme[627].

Utility companies have restricted rights to disconnect gas and electricity supplies to the home, particularly for vulnerable people[a] and can no longer disconnect the water supply from domestic premises. Additional supports are offered to people who are on any of the Priority Services Register[628] held by any of the utility companies. A common response to customers who have difficulty paying for their utilities has been to insist on the installation of prepayment meters, and there are now 3.7million households in the UK that have an electricity prepayment meter and 2.5 million households have a gas prepayment meter. Unit costs are higher than for other customers, and so and additional £333 million is paid for electricity and £350 million for gas by the poorest people in our society. Those using prepayment meters are twice as likely to report that that they cannot afford to wash themselves or their clothes[629].

The ban on disconnection may have led some people to prioritise paying for heat or other essentials over water. Some people respond to the introduction of a water meter by flushing the toilet less often and cutting down on washing, leading to an increase in infectious diseases[b]. Water poverty is generally defined as occurring when households spend 3% or more of their income on water bills, a situation that is getting worse and was affecting four million households by 2011[630]. Some people with water meters adopt unhygienic practices, such as washing soiled bedding by hand in an effort to conserve water[631].

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[a] The licence agreement allowing the utility companies to operate places obligations upon them in respect of vulnerable customers. See CPAG (2011) *The Fuel Rights Handbook* London: Child Poverty Action Group. Also http://www.energy-retail.org.uk/documents/Disconnection_AW2.pdf Accessed 14 April 2011. The licence amendment for gas and electricity suppliers was amended in September 2010 (see http://www.ofgem.gov.uk/Pages/MoreInformation.aspx?docid=170&refer=Sustainability/SocAction/Publications) to prevent disconnection of people of pensionable age and require that utility companies take 'all reasonable steps' to prevent disconnection for disabled people.

[b] In 1993, the introduction of domestic water metering in some areas led to an increase in disconnections and a rise in cases of dysentery, scabies and head lice, according to a Barnardo's report called Liquid Gold. http://www.independent.co.uk/news/uk/dysentery-linked-to-water-metering-1502855.html. In 1989, the water industry in England and Wales was privatised. In 1990, there were 2,756 cases of dysentery and 7,273 households were disconnected from their water supply. In 1991 there were 9,935 cases of dysentery and 21,586 disconnections. See http://www.independent.co.uk/news/uk/water-sale-blamed-for-increase-in-dysentery-1474940.html. These findings led to the prohibition of residential water disconnection through Section 7 of the Water Industry Act 1999.

Other standards for a decent home are set out in the Housing Act 2004, including a list of the 29 hazards that must be minimised[632]. One Housing Association[633] has established a very clear 'bargain' with their tenants, who must meet their responsibilities by looking after their home, paying rent and behaving well in the community. Only those who meet these responsibilities will be entitled to non-essential repairs. They also run a mutual 'fine' system through which the tenant is fined £20 if they book a visit but are then unavailable and can fine the Housing Association the same amount if staff do not turn up when they have agreed to do so.

International experts on self-neglect amongst elders have asserted that while

> *'It is wrong to impose medical or social remedies on eccentric elders who have capacity, but health care professionals should not allow cognitively impaired elders to live in extreme squalor without either electricity or running water[634].*

Reflection time – Chapter Ten

- What are your personal habits in respect of bathing, handwashing, and haircare?
- Do you own a toothbrush? How often do you use it? Do your teeth or gums hurt? When did you last see a dentist?
- How do you get clothes washed and dried? What about towels and bedding?
- Do you have smelly feet? How do you manage this?
- Some people have a rigid daily routine while others live in a less structured way. How do you manage this, and how does it work for you?
- Do things have a particular place in your home?
- How much of the floor space is covered up by furniture or other belongings?
- Is your home warm and safe?

11. Theories underpinning interventions

Case Study Twelve

"I'm a support worker, my name's Jamie and I would like to tell you a bit about Ash. Right, so, I took over Ash from a colleague who hadn't really made inroads with this young person suffering depression and a social isolate. I decided that a chirpy, almost relentlessly positive approach might work. To cut a long story short, it did. It took a whole year to gain Ash's confidence but once I had, that was the breakthrough. I helped Ash to see that maybe it was the poor personal hygiene that was the reason for a total lack of friends.

"Now, it just so happened that I knew of another service user of a similar age who was also quite lonely so, making sure everyone consented, I arranged for them to meet for coffee. Bingo. It was brilliant. Ash realised the need to clean up and have a haircut. The meeting was a great success, which benefitted both of them, and more social contact has followed on. Ash even has regular haircuts now."

There are a number of conceptual models put forward in the literature that attempt to explain why people neglect their personal care and suggest remedies. As the formal evidence on interventions is so weak, none of these theories have been properly tested. Nevertheless, the various approaches have much to commend them as value-based, ethical interventions. Whatever the theory, the task is not simple, as Cavendish remarks:

> *'Helping an elderly person to eat and swallow, bathing someone with dignity and without hurting them, communicating with someone with early onset dementia; doing these things with intelligent kindness, dignity, care and respect requires skill. Doing so alone in the home of a stranger, when the district nurse has left no notes, and you are only being paid to be there for 30 minutes, requires considerable maturity and resilience.'*[635]

Jeannette Pols[636] offers a framework for understanding the link between theories of citizenship and washing practices in a long-stay psychiatric hospital environment. Pols recognises that the real world is a blend of the following four options:

- Making decisions about washing is a private activity that assists in the formation of the authentic individual and should not be intruded upon
- Washing is a trainable skill that is a prerequisite for independent functioning
- Washing is an incidental necessity that must be accomplished in order to achieve the main goal of the person's life project. This usually means doing it oneself, but it could be delegated to others in order to focus on the main goals[637].

- Washing is an aspect of relationships with both staff and others and is therefore negotiable and changeable, mediated both by words and by behaviour.

Listening and respect

Listening and respect are simple and profound qualities that are crucial pre-conditions for more task-focused work[638]. Authoritarian professionals who attempt to convey information in a harsh or hurried manner will not be effective[639] and staff must recognise when an individual is not engaging so that they can avoid collusion or avoidance[640].

Instead, workers need to demonstrate that they take the person seriously, including paying respectful attention to their own perception of themselves and their understanding of their situation[641], along with their ability to construct a preferred version of themselves and their circumstances. This includes checking out the person's belief system which drives consistent patterns of experience and action and may contribute to the development of broader personality traits[642], their sense of self and their self-care.

The recommended approach for care workers has been set out by *Skills for Care* in the following principles[643].

Principles that support self-care

1. Ensure individuals are able to make informed choices to manage their self-care needs
2. Communicate effectively to enable individuals to assess their own needs, and to develop and gain confidence to self-care
3. Support and enable individuals to access appropriate information to manage their self-care needs
4. Support and enable individuals to develop skills in self-care
5. Support and enable individuals to use technology to support self-care
6. Advise individuals how to access support networks and participate in the planning, development and evaluation of services
7. Support and enable risk management and risk taking to maximise independence and choice.

Motivation and Self-Efficacy

A sense of personal power – the eagerness that arises from a belief that it is possible to shape the world we occupy – is a powerful antidote to the fatalism that sometimes results from undue pressure on the 'performing self'.

> "Unless people believe they can produce desired effects by their actions, they have little incentive to act. Efficacy belief is, therefore, the foundation of human agency."[644]

If self-neglecting behaviours are to change, the person needs to set themselves a challenging target, direct effort toward it, and believe that there is some chance of success, as it is the combination of these three elements that forms motivation[645]. These elements thrive when surrounded by others who share that belief and convey hope to the person – but some staff have become entirely pessimistic that self-neglecters will ever change.

Unlike smoking, where considerable public resources are expended to capture the slightest flicker of willingness to change, few services seek and nurture this motivation in the self-neglecting people they encounter. It has been suggested[646] that while this belief ebbs and flows through life, only some people have a 'growth theory' of their personality and the resulting resilience with which to learn, grow and develop through life; others see their personality as fixed and are less likely to believe that change is possible. The 'Stages of Change' model[a] may help to structure the process of behaviour change.

The person may be motivated to change their hygiene regimen for the following reasons, amongst others:

- To address loneliness through feeling more confident about meeting with and speaking to other people.
- To improve health, as poor hygiene may lead to stomach upsets, skin complaints and other more serious issues
- To break a bad habit. Some people will know that their hygiene is poor and is negatively affecting their quality of life. The offer of help can be presented as an opportunity to break a bad habit and take up a more positive lifestyle.
- To avoid complaints from others. Sometimes people will agree to make some changes just to avoid being criticised by others.

Making a change not only requires a belief that it is possible, but also the skills and knowledge that will lead to better self-care. The person may not understand the consequences of their actions or know how to act differently, and so care workers

[a] DiClemente, Prochaska and others have described six stages of behaviour change as (1) pre-contemplative, (2) contemplative, (3) planning (4) action, (5) consolidation, and (6) relapse. For those individuals in stage 1, simply hearing that others in similar circumstances have changed may help to begin the process of contemplating personal change. See Prochaska JO, Redding C & Evers K, (1997) The transtheoretical model of behaviour change. In Flanz K, Lewis FM & Rimer BK (Eds) *Health behaviour and health education: Theory, research and practice (2nd Edition)* Jossey-Bass Publications, Inc.

may have a role in providing training and education[a] – taking care to ensure that they are teaching culturally appropriate practices. The person may have difficulties understanding the information or direction that they are given due to learning disabilities, hearing difficulties or other information processing impairments.

Self determination

For individuals who are depressed, who have developed 'learned helplessness' or who cannot envisage acceptable alternatives, it can be hard to take control[647]. The small amount of research on self-neglect that has been carried out[648] into the experiences of people themselves has found "pride in self-sufficiency, connectedness to place and possessions and behaviour that attempts to preserve continuity of identity and control.

However, the person is likely to make progress when they set their own goals rather than having them imposed by others[649]. As always, this is a bounded freedom:

> "self-determination does not necessarily mean total client autonomy but may be viewed within a framework that ensures client involvement based on levels of safety, risks, capacity, and family and community good"[650].

This is illustrated in the following example.

> 'A woman lives in a hostel for people with learning disabilities and works occasionally as a prostitute. She does not wash herself adequately, has developed leg ulcers and does not want to go to the doctors. Her support worker noted, "Other women make these kinds of choices"'.
>
> Preventing substantial harm and premature death should take precedence over promoting health 'choices'... Staff who support individuals often underestimate how much assistance individuals need.'[651]

There may be lessons to be learnt from the Expert Patients Programme[652] within healthcare, through which a variety of strategies are used to assist the person in moving from a 'victim' mentality to taking responsibility for their actions and their consequences. Such an approach is being tried with hoarders in Coventry[b] and could work with people who have challenges with their personal hygiene.

[a] In America in the 1920s the Cleanliness Institute... devised a cleanliness curriculum, with clearly stated objectives, that stretched from the earliest grades to high school. Ashenburg op cit p257.
[b] Roland Simmons works on a project managed by Orbit to address the problem of hoarding and he started a self help group for hoarders in 2012.

Asset based approaches

Best practice involves a person-centred approach, listening to the person's views of their circumstances and building a therapeutic relationship[653] within a multi-agency and multidisciplinary context[654].

This demands a focus on strengths such as by complementing the person for wearing a favourite shirt, tie and jacket or putting on make-up, or spending time together admiring magazine pictures of well-dressed celebrities. This is illustrated by the story of Amou Haji who has not washed for 60 years but uses a mirror from time to time to adjust his appearance[655]. We seem to dislike the sensation of our fingers being dirty or sticky things on our face, and so many of our gestures, such as licking our skin, scratching our head, rubbing our eyes, straightening a garment or brushing off a speck of dust, are grooming activities[656] that can be recognised and built upon. It is then possible to use the positive recognition of any small effort to be smart as a starting point to address unkempt or dirty aspects of personal care. Sometimes self-neglect begins as a positive asset, such as pride in self-sufficiency or an independent, free-thinking approach to social norms, but that functional approach becomes dysfunctional over time or is reframed as service refusal.

It is interesting to note in passing that while the neurology, chemistry and psychology of disgust has been under examination since about 1990, as we have seen, but there has not yet been a parallel examination of delight – the opposing 'strength'[a].

By focusing upon strengths, staff can advocate on behalf of the person and recognise their interests, through seeking informed consent where possible before any intervention. Uncovering the person's preferences and ambitions may help, as when the person simply wants to be left alone and may engage in self-care behaviour if they understand that it will stop unwelcome visits from staff.

Indeed, what appears to be self-neglect may in fact be a demonstration of power, as revealed by the ancient custom whereby housebreakers leave a foul deposit behind in an act of defiance[657].

The Health Resilience Model

This approach employs 'adaptive distancing'; or 'cognitive reframing' techniques which teach the person how to resist negative pressures from family, school or elsewhere and withdraw from unhealthy situations through reflective thought[658]. This is expected to teach the person to abandon old bad habits and beliefs and adopt new ones, leading to better self-care. Others may be encouraged to retain their positive habits rather than let them deteriorate.

[a] Some work has been done to examine the responses of delighted customers who are especially satisfied with their products, but the core emotional response of delight does not appear to have been extensively studied in its own right. Perhaps it is a more diffuse response in contrast to the specific response of disgust.

Addressing traumatic experiences

Self-neglect may be related to low self-esteem, perhaps due to traumatic events in the past, even in early infancy[a]. Traumatic histories and life-changing effects are often present in individuals' own accounts of their situation."[659]

Within the Kleinian school of psychoanalysis, Winnicott[660] explains that healthy touching, holding and body care helps the infant to 'indwell the psyche-soma' and therefore engage positively with the external world and physical activity. Bick[661] and Anzieu[662] describe the function of skin as the boundary between the internal and external worlds. Where traumatic events take place, Bick and Anzieu use the concept of skin metaphorically to describe the development of a kind of psychological 'toughened skin' that helps the infant survive but impairs formation of relationship and may subsequently lead to physical skin-scarring behaviour, such as cutting, while Turp[663] suggests an alternative version of damaged skin that she calls porous, in which the inner self is insufficiently formed, leading to 'unadventurousness and an air of drifting and incomplete presence', that includes self-harm by omission. Among the variety of acts that fall under the umbrella term of 'self-harm by omission' she includes neglect of personal hygiene.

Olson[664] and colleagues interviewed 20 older people who were self-neglecting (many of whom neglected their personal appearance and hygiene), matched with 21 controls. The self-neglecters eagerly told their stories, in which three quarters of the group had one or more traumatic incidents in the past, compared to only one quarter of the control group. Traumas included being orphaned, childhood physical and sexual abuse, incest, wartime experiences, struggles with sexual orientation, mental ill health, substantial caregiving responsibilities, violence and alcohol misuse.

Dyer and colleagues[665] reviewed 538 people referred to the Texas Elder Abuse and Mistreatment team for self-neglecting behaviour and found that neglect by others was a feature in 28 percent of cases. Clearly abuse by others can be both a cause and a consequence of self-neglect[666].

As a kind of self-harm, missing out self-care rituals may be a way to acknowledge the pain of these traumatic events and perhaps blame, punish and shame oneself for their occurrence.

Similarly, a bereaved person may feel that their own life is over too and so there is no point in making an effort to maintain hygiene practices. Addressing historical issues may help the person to abandon the beliefs that sustain their self-neglect, although care is needed in linking antecedents with consequences, as, for example,

[a] Turp presents argues that poor relationships between the infant and their parent can lead to impaired self worth and hence self care. See Turp M (?) The capacity for self-care *Journal of Infant Observation.*

smoking, excessive dieting or extreme sports may be considered other forms of self-harm but may not be rooted in early trauma.

Self-neglect can be a way to punish the body and this raises questions about how the person views their relationship with their own body. For some, the body is to be feared, a source of shame, disgust, or something to be tamed[667] and so personal hygiene can be the place where these issues are fought out. Just as some people use tattoos to change their feeling about their own body[668], others may use dirt to write their self-loathing on to their skin or do the same with their living space; a kind of violent graffiti directed against the body and the home.

All these hypotheses may be eclipsed by a particular belief or memory that can only be discovered by getting to know the individual. A particularly extreme example of this principle was reported in Holland where an elderly gentleman in a psychiatric hospital refused to use the shower because he associated the cubicle with a Nazi torture chamber[669], but other, more mundane, but equally distinctive and individual explanations may arise, as when a person with poor balance has a fear of slipping on the wet floor and falling down.

Dirt and sex

There exist some complex links between dirt, cleanliness and sex. On the one hand, baths and showers, with their accompanying clean, sweet-smelling skin and hair are often viewed as aphrodisiacs, but, on the other, the frequent appellation of sex as 'dirty' is reinforced by those who find body odour[a], mud wrestling or dirty fetishes[b] sexually stimulating.

These links were familiar to the ancients as the Greeks coined the term coprophilia to describe the pathological or erotic love of dirt, and coprophagia, which describes the consumption of faeces, behaviour that has been observed in individuals without discernible mental illness and in a few isolated examples of people with depression[670], pica[671] and schizophrenia[672]. Coprophagia has been depicted on TV, such as in the animation *South Park*[673], as well as presented as a sexual fetish in literature by authors such as the Marquis de Sade[674] and William S Buroughs[675] and others hint at an unspoken sexual frisson in relation to dirt[676].

In contrast, ascetics like Saint Melania the Younger abandoned bathing after her two children were born in an attempt to make her marriage celibate[677]. However, before attributing motives to people without their knowledge, we must remember that many

[a] Most ancient civilisations matter-of-factly acknowledged that, in the right circumstances, a gamy, earthy body odour can be a powerful aphrodisiac. Napoleon and Josephine were fastidious for their time in that they both took a long, hot, daily bath. But Napoleon wrote to Josephine from a campaign, "I will return to Paris tomorrow evening. Don't wash."' Ashenburg op cit p6

[b] A man was arrested in a Cornish field on a cold February day in 2011, having been found naked, rolling in cow manure and masturbating. *Metro* newspaper 24 March 2011, page 13.

smells and behaviours are culturally interpreted. For example, the Dassanetch people of Ethiopia regard the odour of cows to be beautiful, and the men wash in cattle urine and smear their bodies with manure to enhance their status, while the Dogon of Mali prefer to rub fried onions all over their bodies as a desirable perfume[678].

A person who has never learnt or has forgotten that faeces are unhygienic may use faeces as warm play-dough or paint, while massaging the rectum may relieve physical discomfort caused by polyps, haemorrhoids or an enlarged prostate gland.

On the other hand, some learning disabled and other people who have been victims of sexual or physical abuse may respond to this by urinating or smearing faeces on walls or their own bodies[a]. Abuse by other people may sometimes be manifested by the victim through acts that reveal loathing of the self and the body, including both obsessional washing and poor hygiene. Understanding current behaviour in the light of past events may suggest a way forward.

'Making friends' with our own bodies, with their imperfections, changeableness and unreliability may help in moving from self-neglect to adequate care, even if the person does not develop an appetite for pampering. It is perhaps this idea that washing is far more than merely cleansing that drove Brecht to write[679] "I taught Carola Neher a number of things," he said; "she learned not only how to act, but also how to wash, for example. For she used to wash in order not to be dirty. There was no question of that. I taught her how to wash her face. She then brought this to such a perfection that I wanted to film her doing it..."'

The Senses Framework

This framework identifies six dimensions of care:

- a sense of security
- a sense of continuity
- a sense of belonging
- a sense of purpose
- a sense of fulfilment
- a sense of significance.

[a] This may be as a symbol of self loathing or a simple defence against further aggression. See www.ddmed.org/pdfs/26.pdf accessed 20 March 2011. Also Cooper C, Katona C, Finne-Soveri H, Topinkova E, Carpenter GI & Livingston G (2006) Indicators of elder abuse: a crossnational comparison of psychiatric morbidity and other determinants in the Ad-HOC study *American Journal of Geriatric Psychiatry* 2006, June; 14(6): 489-497.

Irrespective of the cognitive and physical abilities of the individual, it is possible to address these issues[680], leading, it is believed, to improvements in self-care.

We note here that lifestyle changes, such as moving out of the parental home, the 'empty nest syndrome'[a], redundancy and the departure or death of a partner can disrupt these six senses, interrupt the continuity of personal care habits and lead the person to abandon self-care behaviour.

Creative activity

Engaging in creative activity has been shown to offer opportunities for self-expression and lead to improvements in self-esteem, sense of purpose and meaning[681] which may result in people leaving behind their self-neglecting behaviour.

A secure home and a routine that includes meaningful activities will offer opportunities for creative self-expression. Where these things are missing, it becomes harder for individuals to maintain self-care. Moreover, the purposeful life also forms an important driver for people to wash and groom themselves, so that they can continue with satisfying activities.

Many Occupational Therapists will use the Model of Human Occupation[682] as a framework for exploring environment, volition and performance as it relates to self-care, hygiene and grooming. Self-neglect occurs when the person is unable or unwilling to perform activities of daily living or to recognise unsafe living conditions even if the need is understood. In this context, assistance with learning or deploying the skills and routines needed to maintain daily living, housing and health can be helpful[683].

Reflection time – Chapter Eleven

- What is the big idea or theory that is shaping how you are trying to help the person?
- Have you made the most of this theory by fully understanding it and applying its recommendations for action?
- What alternative theories might explain what is happening?
- Is your intervention working? Do you need to find another theory that fits the facts and is more effective at predicting

[a] The sense of loss experienced by some parents when their children leave home.

what will lead to success?

12. Arrangements between workers, teams and organisations

Case Study Thirteen

Agonisingly slowly, one extra step every few weeks, Reuben found his way down the five flights of stairs. It had taken two years. Two years of snail-paced encouragement. But he had done it. Reuben stepped outside briefly, smelt the air, and then returned inside. He hadn't done it alone. Alone would have been impossible. His support worker had urged him on, painstakingly. But now the two-year limited allocation of support had been withdrawn and thirty-year old Reuben was on his own again.

He had always used a personal budget to get help with the cooking and cleaning and he continued to do so, but the isolation inevitably returned. Despite his mental capacity to arrange his day to day circumstances, including the cancellation of appointments, his agoraphobia took hold. His leg muscles finally atrophied and he lost the ability to walk. Reuben's world closed in until a bucket became his toilet.

Engage a diverse team

Once self-neglect has been identified, collaboration can identify what, if any, interventions and supports are required to meet the person's needs. Drawing in a wide multidisciplinary group of staff to support relatives, friends and neighbours can aid decision-making and optimise access to health and social care services and wider resources[684].

The range of possible agencies that may become involved and form the team around the person include: adult protection services; general practitioner and psychiatrist, neurologist and occupational therapist as well as adult social care services; substance misuse services; environmental health officers; housing services; voluntary agencies; money advice and budgeting services[685].

Indeed, the list may be even broader as, for example, religious organisations may offer intensive social support and help individuals to recover their sense of self-worth[686], while some barbers and hairdressers[a] have been provided with mental

[a] Some hairdressers don't seem to need training. Two hairdressers spent a total of 10 hours with a depressed teenager, gradually cleaning, untangling and cutting the hair that had become matted through neglect in a period of depression. See the story at http://www.bbc.com/news/world-us-canada-40887208.

health awareness resources so that their interactions with the public become more supportive[a] and even the jobcentre may be able to help on rare occasions[b].

An American initiative in the 1970s[687] engaged just this kind of wide network of community members as 'gatekeepers' to help with the identification and referral of isolated, vulnerable people – postal workers, meter readers, bank and post office staff, fire fighters[c], police, neighbours, phone installers and landlords. Even refuse collectors have the potential to take up a distinctive surveillance role in local communities[d]. The UK's National Institute for Health and Care Excellence has recently suggested[688] that plumbers and meter readers could report homes that were particularly cold, while people from faith groups and others who visit people to socialise should know what action to take if the house is dangerously cold[e]. This is intended to reduce the number of excess winter deaths. Projects in Jersey[689] and Liverpool[690] engage postal workers in this sort of community surveillance.

The review carried out by Braye and her colleagues[691] did not produce a definitive checklist of agencies that might be involved, but this is widened right out in Texas and Kentucky[692] where *all* citizens have a mandatory duty to report possible cases of self-neglect and abuse.

Teamwork rather than hierarchy

When a diverse group of people are drawn together from many different backgrounds, agencies and traditions there are many opportunities for status to be asserted, and so it is especially important to listen carefully to those who might be ascribed with a low status. As Curtis[693] notes: 'Individuals whose work involves contact with body products, hair, feet, sewage, used clothes, waste and dead bodies

[a] Some 5,000 hairdressers in the eastern region of England were provided with anti-stigma materials in a mental health initiative during 2010. Barbers in Gloucester received mental health awareness training in 2020 - https://www.bbc.co.uk/news/uk-england-gloucestershire-53336997.

[b] Jobcentre Plus have in the past used funds to pay for interview or job-related clothing and this may extend to presentation or grooming issues, although funding is very limited and a specific job opportunity needs to be in view.

[c] Every Fire Station in the West Midlands has a Vulnerable Person's Officer, who can help with the provision of fire-retardant upholstery, carpet and bedding, as well as other management approaches to fire prevention.

[d] David Hobbs, Environmental Health Officer, wrote on 7 Nov 2011, 'I'm not aware of any referrals from bin men, but it may happen. It is often others such as nurses, social workers, housing officers, neighbours etc.'

[e] "People who do not work in health and social care services but who visit people at home, for instance: to carry out housing repairs, to read or install meters (including the installation of smart meters), or to provide general support or to socialise. This includes: faith and voluntary sector organisations; energy utility and distribution companies; housing professionals; installation and maintenance contractors." See https://www.nice.org.uk/guidance/ng6/chapter/who-should-take-action#who-should-take-action-in-detail.

tend to be poorly rewarded and suffer low status, perhaps because the nature of the work is perceived to contaminate the individual.'

This can be exacerbated if the task of supporting people who self-neglect is seen as unpopular work within the care team and shunted on to the least competent staff who ignore issues or fail to involve their colleagues or supervisor. One Serious Case Review[694] expressed concern that assessments had been carried out by staff who lacked professional qualifications, but we do note that 'unqualified' staff may have more expertise and hope for change than some of their professionally qualified but jaded colleagues.

Where staff from diverse agencies become involved, each worker may be unaware of what others can offer the person or even how they are currently involved and so it is vital to have a clear plan and record for how everyone should communicate and work together[695].

Respectful attitudes and language

Underpinning assumptions and attitudes within a staff team or in the wider society can sometimes be revealed in the language that is used to describe people who neglect their personal hygiene – in the 1830s[696], the poorest residents of growing cities were described as 'the great unwashed', and in some staff teams the language has not moved on very much. Such attitudes appear early in child development[697]. Kutame suggests that the very term 'self-neglect' locates the problem in the person, rather than in the wider society, as well as implying that the self is a single non-divisible whole that is being neglected in its entirety[698]. As the anthropologist Mary Douglas said[a] about hygiene rules within different cultures:

> 'you must always ask who is being excluded. The only thing that is universalistic about purity is the temptation to use it as a weapon.'

This has been taken up recently in some parts of the United States, where people can be ejected from public libraries[b] and public buses[699] for being smelly.

Co-production

In the face of seemingly intransigent problems, it may feel easier to assume that the person has made a free choice to neglect their personal hygiene, use it as a justification for inaction and leave the person to 'rot with their rights on'. Paid staff

[a] Smith V (2007) *Op cit*, p35. Ashenburg op cit p236-7 quotes George Orwell who wrote in *The Road to Wigan Pier*, "*The lower classes smell.* ...and the bourgeois child "is taught almost simultaneously to wash his neck, to be ready to die for his country, and to despise the lower classes." Similarly, Tolaas comments that "disliking the smell or other classes, races and countries is a cheap and fatally easy way to bolster our illusion of superiority." (Ashenburg op cit p271)

[b] "A 2005 law allows the public librarians in San Luis Obispo County, California, to eject smelly readers." Ashenburg op cit p272.

must rather find an option which generates least harm and not misuse choice or self-determination arguments as a reason to abandon the person[700].

At the other end of the scale is an overly intrusive approach, in which safeguarding and 'best interests' obligations are used in a disproportionate way to deprive people of positive choices and adult responsibility.

Between these two extremes of withdrawal and excessive control lie co-production approaches, such as that adopted by West Sussex in their work with people who self-neglect, in order to create a framework for positive decision-making[701].

Protocols and training

Local guidance, agreements or protocols will reduce the amount of misunderstanding between agencies caused by variations in the threshold for intervention, as well as helping to ensure speedy access to support[702]. While common themes appear in situations of self-neglect, other circumstances and elements are unique to the individual, making the development of uniform protocols that support a flexible response a challenging task.

Cross agency training about self-neglect and related issues will help to bring the inter-agency agreements to life in each local area[703]. This may include providing barrier clothing and helping the staff member to balance issues of personal safety with the needs of the person – especially where occupational health and safety regulations may prevent professionals from even entering the dwelling[704].

Serious Case Reviews form powerful training tools that highlight pertinent issues. For example, the review of the circumstances surrounding the death of 'Ann'[705] offers some crucial messages pertaining to self-neglect, including:

- The importance of establishing a clear and consistent response to problematic behaviours across a number of departments and agencies. Ann wanted staff to set aside their normal lifting and handling rules, and as some team members did so in response to her wishes, the others were considered by Ann to be behaving unreasonably.
- The importance of effective support for staff in dealing with very challenging individuals. One highly respected staff member left her profession after working with Ann.
- The importance of establishing a plan with predictions of trigger events or circumstances that mark deterioration and a change of response.

Supervision and support

Working with people at risk of self-neglect can be particularly challenging, apart from the time and cost involved, and can take an emotional toll on staff[706], as witnessing the person's living conditions can be distressing or even shocking, along with the

difficulties of deciding what to do, mobilising other agencies and sometimes being unable to make a difference[a]. Without specific training and inter-agency support, staff may fall back on common sense and basic humanity[707]. Professional supervision should be used to explore each difficult situation and support the team in planning their response.

[a] It has been suggested that we sometimes engage in scapegoating the person by projecting all our negative feelings on to them and then allowing the disgust response to override our empathy. The resultant conflict of emotional responses can block our capacity to respond effectively and leave us feeling helpless. See Douglas T (1995) *Scapegoats: transferring blame* Routledge London and New York

Reflection time – Chapter Twelve

- Is everyone involved who has a potential contribution to make?
- Are things arranged to create or sustain a hierarchy or to form a 'partnership of equals'?
- How is the person's own voice being heard in discussions with professionals? Do they have any real power or influence over what is happening?
- Are staff hopeful that improvement is possible?
- Do the most experienced professionals get involved in planning support for self-neglecting persons?
- Do you welcome help with your personal hygiene or is it an intrusion on your privacy?
- Have local organisations worked together to develop a shared action plan and protocol for joint working with people considered to be self-neglecting? Have these arrangements been audited to check that they are being used and are working well?
- Is it OK to tell your supervisor about your disgust response and how you are handling it?
- What training is available?

13. Some suggestions for further work

The following steps may help to bring progress in this field:

- The development of a common definition of self-neglect that effectively differentiates these adults from the general population whilst recognising the characteristics that they share with us all
- Improved research, specifically paying attention to the views of people themselves. There appears to be no shortage of ideas for research on this topic[a].
- Development of model programmes[708] that successfully help people to manage self-neglect and demonstrate effective interventions through robust data
- Further education for staff to help them recognise and respond effectively to self-neglect. It is interesting to note that a recent seminar on self-neglect attracted fifty general practitioners[709].
- Development of new assessment tools
- Evolution of interdisciplinary and inter-agency approaches that provide consistency across the various agencies that may be involved
- Improvements in the working relationships between agencies and professional groups that remove the barriers caused by differences in language and culture,
- Better knowledge of self-neglect among policy makers[710].

Reflection time – Chapter Thirteen

- Which of these things can you do in your local area in collaboration with people who self-neglect and others?

[a] In one project, a total of 273 research ideas were submitted for work on self-neglect. Brown, T.D., Lachs, M.S., Pillemer, K.A., Murtaugh, C.M., McDonald, M., Wethington, E., Reid, C. and Pavlou, M.P. (2009) 'Concept mapping to create a research agenda in elder self-neglect', *Journal of the American Geriatrics Society*, vol 57 (Suppl 1), p S44.

Appendix One – a checklist of questions

Here are some useful questions for people working with individuals who neglect their personal hygiene and grooming.

Each of the items listed in this appendix is discussed elsewhere in the book, but is reduced to a series of brief questions here as an aid to systematic thought. Note that poor hygiene is driven by many issues working together, so a single solution is unlikely to work.

Getting to know the person

1. **Strengths.** What strengths, abilities, successes and rights does the person have and how are you upholding these? As part of a person-centred plan, are you clear about the kind of life the person wants to live and what hygiene standards that will require?
2. **Beliefs and emotions.** Does the person feel able to set goals and achieve them in any part of their life and have they done so in relation to self-care?
3. How does the person view past and present media representations of health, fitness and beauty? Does the person feel good about their bodily appearance or are they ignoring or punishing their body?
4. What is their own explanation for their circumstances and behaviour? How does the person's identity (age, gender, ethnicity, and so on) and stage in the life-course affect the person's personal hygiene and self care?
5. Who does the person feel most relaxed talking to? How does the person feel about hearing comments about their personal hygiene from you or other people? Are they angry, in denial, humiliated, ashamed, defiant, embarrassed, suicidal, obsessional or anxious? Do they mind causing offence? Do they withdraw from social contact?
6. Is the person aware of your concern about their personal hygiene and grooming? Can they see, smell or feel the problem for themselves and can they think it through? Have you used the right language and a respectful manner that is clearly understood and acceptable to the person?
7. **Experience of services.** Have the services that the person has used in the past sent out specific and consistent messages about personal hygiene?
8. **Disability and Health.** Is the person ill, disabled, visually impaired, experiencing mental health problems or taking any medications that might increase sweating or affect body odour, cause bad breath or make washing and caring for their clothing and appearance impossible, impractical or ineffective?

9. **Family, friends and neighbours.** Are neighbours, other residents or relatives at risk, complaining or punishing the person for their behaviour or circumstances? Might they help? What is the person's family and cultural history of self-care habits?

10. Is the person's choice of clothing and appearance a badge of membership of a particular group or a signal to others to keep away? What message is it intended to convey and what does it mean to others? Explore the same question in relation to people who are dressed by others.

11. **Changes.** Is the person's personal hygiene getting better or worse and how quickly? What is likely to happen if you do nothing? What would need to happen to justify you referring the matter to a more senior person or taking more decisive action?

12. Has anything changed, such as illness, bereavement, redundancy, loss of a home, relationship breakdown, trauma or abuse that might have led to a change in grooming habits?

13. How does the person learn? Are there things that the person could learn about the consequences of poor self-care, how to buy good clothes on a small budget, establish a daily routine, use laundry equipment, use cosmetics, eat a healthy diet, lose weight or avoid excess alcohol and illegal substances?

How serious is the problem?

14. **Squalor.** Is the person's home or room dirty, in poor repair, cluttered with hoarded items, unopened post, or infested with insects or rodents? Are there signs that the person has sores and poor healing, does not eat adequately, and does not visit the doctor or other helping agencies when appropriate?

15. **Risk and safeguarding.** Is there an immediate and serious health hazard to the person, perhaps related to broken skin, incontinence and other causes of infection, or to other people or animals in the house, neighbours or other members of the community?

16. **Facilities and equipment.** Does the person have effective and regular access to a safe, private and comfortable space where they can wash, shower or bathe, wash their clothes and attend to their personal presentation? Has the person been shown how to use the equipment and supported to do so?

17. Does the person have enough money to purchase cosmetics, grooming materials, natural fibre clothes and breathable shoes? If not, can anyone else provide money or these items?

18. **Legal duties.** Do any legal powers need to be used to save life, protect others or prevent nuisance by forcing entry, removing the person, cleansing their body, imposing healthcare or cleaning or destroying their property? How will

you assess mental capacity, obtain legal advice and choose the least restrictive option?

Teamwork, procedures and arranging help

19. **Treatment.** Does the person have a mental or physical health issue, substance misuse problem or body odour problem that can be treated by referral to a doctor, psychiatrist or dentist? Can a pattern of good sleep, food, activity and social contact be established to provide a healthy routine?
20. Does the person already have a diagnosis or a history of involvement with helping agencies because of a history of self neglect?
21. **Person-centred teamwork.** Have people from different teams and agencies got together to pool their ideas of whether to intervene and how to support the person? Has the person been involved as much as possible in this?
22. **Protocols and Assessment Tools.** Is there any local policy or an inter-agency protocol, perhaps as part of your safeguarding process? Does it need to be researched, written, disseminated, supported with training or updated? Have assessment measures, mental capacity and risk management tools been used?
23. **Services, community and informal support.** Do you have contact with a supportive mobile hairdresser and launderette, domestic help agency, chiropodist, plumber, infection control service, and house clearance agency that will help someone with poor hygiene?
24. Who else is involved? Have agencies withdrawn their services in response to the person's self-neglecting behaviour? Are relatives, neighbours, friends or telecare systems available to help establish a routine of personal hygiene?

Supporting and developing staff.

25. **Staff behaviour.** Do staff offer positive role models in their own personal hygiene, appearance and presentation?
26. **Staff attitudes.** Is the person surrounded by staff (or relatives or neighbours) who adopt an intrusive, controlling and overly critical stance?
27. **Theory.** What theoretical approach to self neglect informs your work?
28. **Supervision and training.** Is supervision and training available to help you to explore your own feelings, assumptions and responses to the person? Should someone else be helping or taking over from you?

Appendix Two – a checklist of perspectives

Here is an alternative way to address the issues that may arise in relation to self-neglect. Perspectives are listed in alphabetical order. Remember that in real life, each of these professions ask many more questions than the single one listed here, and some would claim to engage with *all* of these viewpoints.

Think about yourself as a...	Ask this question....
1. Advertiser	What impact does the culture and media have on the person?
2. Advocate	What does the person want to say? Does the person lack power to express their preferences? What are their aspirations?
3. Animal welfare	Are there any pets or other animals at risk?
4. Behaviourist	What does the person actually do that affects their personal hygiene? What are the antecedents and consequences?
5. Counsellor	What trauma or distress has the person experienced?
6. Dentist	Is poor oral health leading to halitosis?
7. Dietician	What food or drink might be increasing body odours?
8. Doctor	Is there an illness or disability that makes parts of the body smell or that means it is hard to get and stay clean?
9. Environmental Health	Is there a nuisance or hazard for other citizens?
10. Finance Advisor	Is there a shortage of money or equipment?
11. Fire Officer	Does living conditions constitute a fire hazard?
12. Geneticist	Do other members of the family share the difficulty? Is there a genetic problem causing body odour?
13. Historian	How was the person in the past, what influences did the family, neighbourhood and community exert?
14. Landlord	Are both landlord and tenant rights being upheld?
15. Lawyer	What formal rights should be upheld and what responsibilities does the person and other people have?
16. Occupational Therapist	What activities fill up and structure the day and where might self-care fit in?
17. Pharmacist	What is the effect of any prescribed or non-prescribed drugs?
18. Psychoanalyst	How might early childhood experiences have affected the person?

Think about yourself as a...	Ask this question....
19. Psychologist	What function is ‘poor hygiene’ behaviour serving for the person?
20. Public health	Is there a nuisance or hazard for other citizens?
21. Risk manager	What might go wrong?
22. Social Worker	Are vulnerable people safe? Who can help?
23. Speech therapist	What message is the person’s behaviour trying to send to whom?
24. Teacher	What has the person been taught? What could be taught?

References

[1] The bulk of the work for this document was completed around 2012. Since then, relevant material that has been found whilst focusing on other projects has been added, with the date of the most recent addition being noted on the front page of the document. A comprehensive update for a new edition of the work has not been attempted.

[2] A third of English local authorities responded to a survey on self-neglect – see http://www.scie.org.uk/publications/reports/69-self-neglect-policy-practice-building-an-evidence-base-for-adult-social-care/. For a review of social care interventions, see Martineau, S, Manthorpe, J, Woolham, J, Steils, N, Stevens, M, Owen, J & Tinelli, M (2021) *Social care responses to self-neglect among older people: an evidence review of what works in practice.* NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London, London. https://doi.org/10.18742/pub01-047.

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[13] http://www.mwcscot.org.uk/media/193171/final_report_-_mr_jl.pdf page 17.

[14] Price C (1 August 2013) Less than half of patients attend NHS health checks, show official figures *Pulse.* Available at http://www.pulsetoday.co.uk/clinical/therapy-areas/cardiovascular/less-than-half-of-patients-attend-nhs-health-checks-show-official-figures/20003835.article#.UfoJyZK1FtU

[15] An increasing number of people on limited incomes in England are failing to collect their prescriptions or asking the pharmacist which ones they can do without as the charges are prohibitive. See Patients in England not collecting NHS prescriptions because of cost | Health | The Guardian

[16] "Up to 80% of patients may be 'non-compliant' in their medicine taking." Carter S, Taylor D & Levenson R (3rd edition 2005) *A question of choice — compliance in medicine taking: A preliminary review.* Medicines Partnership. Page 9. See http://www.keele.ac.uk/pharmacy/npcplus/medicinespartnershipprogramme/medicinespartnershipprogrammepublications/aquestionofchoicecomplianceinmedicinetakin/research-qoc-compliance.pdf. A lower figure suggests that 30-50% of medicines prescribed for long term conditions are not taken as recommended is reported in National Institute for Clinical Excellence (2009) *Costing statement: Medicines adherence: involving patients in decisions about prescribed medicines and*

supporting adherence NICE CG76. Page 9. See http://publications.nice.org.uk/medicines-adherence-cg76.

[17] A recent study found adherence among children with chronic conditions could be as low as 25% - see http://www.nottingham.ac.uk/news/pressreleases/2013/may/staying-on-the-meds-involving-young-patients-in-the-treatment-for-their-chronic-illnesses.aspx

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[21] See the 2018 judgement by Lady Black in the Supreme Court at https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf

[22] Twigg J (1999) The spatial ordering of care: public and private in bathing support at home *Sociology of Health and Illness* Vol 21, No 4, pp381-400.

[23] See http://www.classicfm.com/composers/beethoven/guides/beethoven-biography-final-years-1825-1827/

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[33] Smith V (2007) *Op cit*, p343-4 notes that, when in Turkmenistan... 'love marriages' were made legal in 2000: cosmetic sales rose by over 200%.

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[37] Cox R 'Dishing the dirt: dirt in the home' in Cox R, George R, Horne RH, Nagle R, Pisani E, Ralph B & Smith V (2011) *Dirt: The filthy reality of everyday life* Profile Books.

[38] The historical picture is never simple and uniform, of course. At the same time as cleanliness was being advocated, the romantic movement sweeping through country estates resulted in the construction of grottoes and ruins, sometimes with their own resident, unwashed hermit. *"An estate owner in Lancashire promised £50 a year for life to anyone who would pass seven years in an underground dwelling on his estate without cutting his hair or toenails or talking to another person. Someone took up the offer and actually lasted four years before deciding he could take no more."* (Bryson 2010, op cit, page 373)

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[43] See https://www.theguardian.com/commentisfree/2017/dec/01/gender-neutral-toilets-better-everybody-rage-latrine-trans-disabled.

[44] The 'Can't Wait' card scheme asks local businesses to display a postcard in their windows, to show people that they allow card holders to use staff or non–public toilets, or to use customer toilets without purchasing anything. Can't Wait cards are distributed through trusted partners, which include: Age UK, the Alzheimer's Society, Bristol Area Stroke Foundation, community nurses, South Glos Disability Equality Network, Disability Action Group, Memory Nurses and GP surgeries. See Public facilities for safety, comfort and independence | South Gloucestershire (southglos.gov.uk).

[45] https://www.theguardian.com/commentisfree/2016/jun/11/gender-bathrooms-transgender-men-women-restrooms

[46] See Malcolm Shifrin's website on Turkish baths in the UK at

http://www.victorianturkishbath.org/_000HOME/HOMEPAGE.htm

[47] Pontius Pilate knew that Jesus was not deserving of death, but in an act of political cowardice, allowed it to take place, symbolically washing his hands of the matter before releasing Jesus to his executioners. (Matthew 27:24).

[48] Smith V (2007) op cit, p248, 285, 287, 298.

[49] Smith V (2007) op cit, p274.

[50] Ashenburg op cit p265.

[51] For an example of music, see In da tub, for poetry see Self-neglect and for novels, see David Walliams (2009) Mr Stink.

[52] Nagle, R 'The history and future of Fresh Kills' in Cox R, George R, Horne RH, Nagle R, Pisani E, Ralph B & Smith V (2011) *Dirt: The filthy reality of everyday life* Profile Books.

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[54] George R (2008) *The big necessity: adventures in the world of human waste* London: Portobello Books. Page 132.

[55] The flushing toilet was invented by Sir John Harrington (1561-1612), not Thomas Crapper (1836-1910) as is popularly believed. Forsyth M (2011) *The Etymologicon* London: Icon Books Ltd, page 55. Reyburn pins down the date of Harrington's invention to 1596 - see Reyburn W (1969) *Flushed with pride: The story of Thomas Crapper* Pavilion books, page 35.

[56] In 1901, Hubert Booth patented a vacuum cleaner that sucked air through a filter. His design was more suitable for industrial use, so was quickly superseded by the upright model developed by Hoover in 1908. Floors were far from clean in the medieval period – Bryson comments that "*In even the best houses, floors were generally just bare earth strewn with rushes, harbouring 'spittle and vomit and urine of dogs and men, beer that hath been cast forth and remnants of fishes and other filth unmentionable' as… Desiderius Erasmus… rather crisply summarised in 1524.* (2010, op cit, page 86): "

[57] Sources sometimes give different dates for these inventions, so Bryson dates the washing machine to 1909 rather than 1914. Other electrical devices invented in this period include the fan in 1891, the iron in 1909, the toaster in 1910, and the refrigerator and dishwasher in 1918. (Bryson 2010, op cit, page 200)

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[59] Smith V (2007) op cit, p55, 81.

[60] Ashenburg op cit p80.

[61] George R 'The blue girl: dirt in the city' in Cox R, George R, Horne RH, Nagle R, Pisani E, Ralph B & Smith V (2011) *Dirt: The filthy reality of everyday life* Profile Books.

[62] Ashenburg op cit p283.

[63] In the USA, when the first hospital ward was erected at the hospital at Fort Davis, Texas in 1876, the Surgeon General's directive was followed, giving each bed 1200 cubic feet of air. Generous spaces between beds and a high ceiling achieved the target and windows were generous too.

[64] Cox R, 2011, op cit.

[65] Between 2001 and 2017, the percentage of the world's population using safely managed sanitation services increased from 28% to 45% and the number of people practising open defecation halved from 1.3 billion to 673 million. See https://www.unicef.org/media/55276/file/Progress%20on%20drinking%20water,%20sanitation%20and%20hygiene%202019%20.pdf

[66] Ashenburg op cit p236-7. See also Winsberg ME, Cassic KS & Koran LM (1999). Hoarding in obsessive-compulsive disorder and related disorders: a report of 20 cases. *Journal of Clinical Psychiatry*, 60, 591-597.

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[68] Cox R, 2011 op cit.

[69] Commercially produced boot polish was first marketed in the 1890s. Bryson 2010, op cit, page 141.

[70] There were forerunners to the sophisticated bathroom. Reyburn notes that, towards the end of the nineteenth century, Queen Victoria's Lady-in-Waiting enjoyed a sumptuous bathroom at Sandringham. It had three sinks – the largest labelled 'Head and Face only', the second, 'Hands' and the smallest, 'Teeth'. Reyburn W (1969) op cit, page 35

[71] Bryson 2010 op cit, p526.
[72] The first hotel to provide a bath for every bedroom was Mount Vernon Hotel in 1853 but the idea did not catch on and when Sir Gilbert Scott opened his St Pancras Hotel in London in 1873, there were four bathrooms for 600 bedrooms. (Bryson 2010 op cit, page 524)
[73] Wiles R (1993) Women and private medicine. *Sociology of Health and Illness* 15, 1, 68-85.
[74] Chapman and Lucas, cited in Twigg J (1999) op cit.
[75] Reyburn reports that toilet rolls were marketed by the British Patent Perforated Paper Company, launched in 1880, while in America the Scott brothers from Philadelphia began to market toilet rolls. Hand torn squares of old printed materials were in use before then, often strung together and hooked on a nail. Crepe paper, the forerunner of modern soft tissue, was launched in the USA in 1907 and UK production was started by the Rosenfelder brothers in Walthamstow, but it was initially less popular than the traditional hard toilet roll. Indeed, in 1969, all government offices were still issued with hard paper. Reyburn W (1969) op cit, page 80.
[76] Smith V (2007) op cit. p317.
[77] Bryson (2010, op cit, page 487) mentions a house in ancient Pompeii that had 30 taps.
[78] https://www.theguardian.com/world/2018/jun/21/shimla-india-water-crisis-life-on-frontline
[79] A British survey in 2005 found 94% of men take a shower or bath each day. http://www.cosmeticsdesign-europe.com/Market-Trends/Less-is-more-for-British-mens-grooming-routine
[80] One survey found that 59% of men and a 67% of women take a shower of bath each day – see *The Week* 28 December 2013, page 17. Sourced from Siteopia/Mail. Also a YouGov survey in 2019 found no differences between men and women, with 55% showering or bathing at least once a day – see https://yougov.co.uk/topics/health/articles-reports/2019/01/07/three-quarters-brits-probably-shower-too-much.
[81] https://www.justiceinspectorates.gov.uk/hmipri sons/wp-content/uploads/sites/4/2015/02/Nottingham-web-2014.pdf Page 77.
[82] Carole-Anne Langford, 21 January 2013, personal communication. Carole-Anne questioned these arrangements (based on her personal hygiene regimen) and was reassured that the gentleman concerned was not adversely affected either in his personal hygiene or emotional wellbeing, and exceptional arrangements for more frequent showers could have been made if needed. One might question whether the problem is absolute staffing levels or deployment of staff. An inspection report of Cressington Court care home dated 24 May 2022 reported that one resident told inspectors that she had not had a shower or a bath for four weeks because the staff didn't have enough time – see cf2a6e2c-556d-46aa-98fe-b9418d4a15db (cqc.org.uk)
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[87] Curtis V, Barra Micheal de & Aunger R (2011) Disgust as an adaptive system for disease avoidance behaviour *Philosophical Transactions of the Royal Society Bulletin* 366, 389–401 doi:10.1098/rstb.2010.0117. Page 395.
[88] John 13:14 in the Bible.
[89] James 2:2 in the Bible.
[90] Bryson (2010, op cit, p489) tells us that Godric walked from England to the Holy Land without washing even once..
[91] Smith V (2007) op cit, p126-137. See also Ashenburg op cit p59, who refers to a number of saints who 'embraced filth enthusiastically'. Saint Eutychius, bishop of Constantinople in the sixth century was described as never washing, but nevertheless, his body was fragrant. See The Beautiful Bishop: Physiognomy and Holiness in the Life of St.

Eutychius of Constantinople. Bryson tells us that when "Thomas a Becket died in 1170, those who laid him out noted approvingly that his undergarments were 'seething with live'." Bryson (2010, op cit, p489)

[92] Margaret Marie Alacoque records in her diary an occasion when, in tending a sick person, she found great pleasure in cleaning up their vomit with her tongue. (Gauthey, L (1890). *La Vie de la Venerable Mere Marguerite-Marie.* Paris). Mme Guyon reports a similar experience - Knox, R. (1950) *Enthusiasm*. Clarendon Press. St John of the Cross has been said to have licked out the sores of lepers. Blessed Angela of Foligno swallowed a scab from a leper when she was drinking the water that she had bathed him in and said that it tasted like the communion host.

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[195] The *Changing Places* campaign has increased the number of large toilets for people with disabilities who may need a changing area and special equipment. Perhaps this group is perceived as worthy of investment, compared with those who are homeless.

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[378] Senate Select Committee on Intelligence (2014) *Committee Study of the Central Intelligence Agency's Detention and Interrogation Program* pages 415, 429, 490. Available at http://i2.cdn.turner.com/cnn/2014/images/12/09/sscistudy1.pdf

[379] http://www.express.co.uk/news/uk/518869/Patient-locked-in-cell-with-no-toilet-food-or-water

[380] http://www.icrc.org/customary-ihl/eng/docs/v1_rul_rule90

[381] The classic case is Price v UK. See http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-59565 . A commentary on how such unsanitary conditions makes patients feel can be seen at https://purplepersuasion.wordpress.com/2019/03/21/these-are-not-the-little-things-unsanitary-conditions-on-mental-health-wards/

[382] See Melnitis v. Latvia - decision of the European Court of Human Rights at http://caselaw.echr.globe24h.com/0/0/latvia/2012/02/28/case-of-melnitis-v-latvia-109289-30779-05.shtml paragraph 78.

[383] https://www.justiceinspectorates.gov.uk/hmiprisons/wp-content/uploads/sites/4/2015/02/Nottingham-web-2014.pdf page 5.

[384] Christopher Blackwell tweeted on 16/9/2022 "In prison nothing is free. Not even toothpaste. The cost of hygiene products increased again today. Toothpaste used to be $3.85 and now it's $6.10. That's over 14 hours working a prison job to afford one tube of toothpaste."

[385] See Stanev v Bulgaria http://www.bailii.org/eu/cases/ECHR/2012/46.html. Hygiene standards in the care home were very low (para. 23: 'Access to the bathroom, which was unhealthy and decrepit, was permitted once a week. The toilets in the courtyard, which were unhygienic and in a very poor state of repair, consisted of holes in the ground covered by dilapidated shelters. Each toilet was shared by at least eight people. Toiletries were available only sporadically'). There was a violation of Article 3 of the European Convention on Human Rights in this case.

[386] www.ccprcentre.org/doc/ICCPR/General%20Comments/HRI.GEN.1.Rev.9%28Vol.I%29_%28GC20%29_en.pdf

[387] In Bernard, 20 months without an accessible toilet was considered a violation of Article 8 (right for respect of private and family

life), but not Article 3 - see http://www.bailii.org/ew/cases/EWHC/Admin/2002/2282.html. Similarly, in McDonald v UK http://www.disabilityrightsuk.org/mcdonald-v-united-kingdom the removal of night-time support was a breach of Article 8, but only insofar as it was in breach of Mrs McDonald's care plan. When the care plan was reviewed and revised to not include night-time support, there was no violation.

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[505] Chlorhexidine 0.05% solution is an antibacterial and antiseptic solution available from pharmacies. Applied daily, it significantly reduces the number of bacteria, although it has no effect on sweating itself. Another remedy available without a prescription is 20% aluminium chloride solution (this is the active ingredient in most antiperspirants) otherwise known as Anhydrol Forte and Driclor. Applied to the sweaty skin before bed, it blocks the sweat glands and reduces the amount of sweating the next day.

[506] A dermatologist can offer iontophoresis, which is an effective treatment if sweating affects hands or feet. It involves submerging the hands or feet in a bowl of water and then a weak electric current is passed through the water. Each session lasts between 20 and 30 minutes and symptoms should improve after 4 to 10 sessions, after which occasional follow up treatment is required. Iontophoresis kits for home use are also available costing £300-500.

[507] Injecting botulinum toxin (Botox) into the skin near the armpit. Botox is only licensed as a treatment for excessive sweating from the armpit and is not usually available on the NHS. Although the results only last a few weeks, it's an effective and safe treatment.

[508] The removal of some sweat glands from the armpit, or destroying nerves that control armpit sweating.

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[531] The study was led by Professor Ron Cutler at Queen Mary, University of London and undertaken in collaboration with the London School of Hygiene & Tropical Medicine. See http://www.bbc.co.uk/news/magazine-19834975.

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[536] Nadeeem M (27 Nov 2013) Doctors' smartphones are source of hospital infections *NL Times.* See http://www.nltimes.nl/2013/11/27/doctors-smartphones-source-hospital-infections/

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