



Britainthinks

Insight & Strategy

July 2017

Strategic Research Programme | Final combined report

**Struggling to Cope with later life – qualitative research on
growing older in challenging circumstances**

Contents

Executive summary	3
Background to the project	5
Stage 1 report:	6
Objectives	7
Sample	7
Defining 'self-neglect'	9
The mind-set	13
The view from concerned relatives and neighbours	28
Stage 2 report:	31
Background	32
Defining 'self-neglect'	33
Working with people experiencing self-neglect	38
Appendix: Case Studies	45

Executive Summary

- ‘Self-neglect’ was a common term used by practitioners to refer to a behavioural condition in which an individual displays signs that may indicate an inability or choice not to look after themselves.
- Self-neglect is not, however, a term used by older people to describe themselves; their experiences of the phenomenon are complex and trajectories into this state are highly personal. Understanding of these experiences is important to providing appropriate response and support.
- The following signs and behaviours associated with self-neglect were identified:
 - Not keeping on top of household tasks;
 - Hoarding;
 - Letting their property fall into disrepair, not dealing with pests e.g. mice;
 - Not maintaining personal hygiene;
 - Not eating properly, and either losing or gaining weight;
 - Not taking medication;
 - Substance abuse including excessive smoking, as well as drugs/alcohol;
 - Social isolation and ‘shutting off from the world’, including not opening mail and having no interest in the outside world;
 - Depression;
 - Not keeping on top of finances, leading to debt or threats of eviction.
- The research revealed how the phenomenon of self-neglect exists on a spectrum, depending on the extent to which the patterns of behaviour are entrenched:
 - **Low levels:**
 - In which there are some changes in behaviour but few signs of this unless you are really close to that individual
 - May have recently had a change in situation (e.g. bereavement, divorce, stopping driving)
 - **Medium levels:**
 - Changes in behaviour are continuing and the signs of this start to show
 - Becoming a change in *daily* living (e.g. not going out as much)
 - **High levels:**
 - Behaviours have become entrenched and have an impact on one’s life and health as well as potentially impacting on others
 - **Safeguarding cases:**
 - Behaviours have become entrenched to the extent that the individual is a danger to themselves and/or others
 - Individuals meet the criteria for Section 42 of the Care Act

- The research identified four distinctive characteristics of the mind-set of someone at risk of, or currently self-neglecting:
 - **Low self worth:**
 - Feeling that one's life no longer has value/purpose and that they are a burden on others;
 - **Low motivation:**
 - The benefit/value in making a change is outweighed by the effort;
 - **Lack of agency:**
 - Not knowing how to, or not feeling able to, make change;
 - **Reluctance to ask for help:**
 - Not wanting to admit there is a problem linked to feelings of shame, resignation or in many cases pride, and a desire to retain independence.

- Friends and family – ‘concerned observers’ in our sample – were often deeply unsettled by signs of self-neglect in their older relative and can struggle to cope with it.
 - They find it difficult to talk about with the person because they don't want to cause offence.
 - They themselves have to overcome strong emotional barriers to having such conversations e.g. acknowledging a parent is changing as they grow older.
 - None had used support services to help them or the older person in their lives to deal with issues around self-neglect. Rather, they had all taken it on themselves to offer support to the older person, sometimes by covert means.

- Practitioners felt that working with older people who are self-neglecting presents some of the hardest cases that they have to deal with. While they have developed a number of effective approaches and techniques for working with such individuals, there was also a recognition that in some cases that there is a limit to the support/intervention that the older person will accept.

- Practitioners developed a set of broad guiding principles for how to work as effectively as possible with older people who are experiencing self-neglect:
 1. Build a relationship and rapport with that person
 2. Follow a person-centred approach
 3. Identify the key people around the person that you should be working with
 4. Effective partnership working
 5. Remember your responsibilities and limits regarding your professional practice

Background to the project

Background

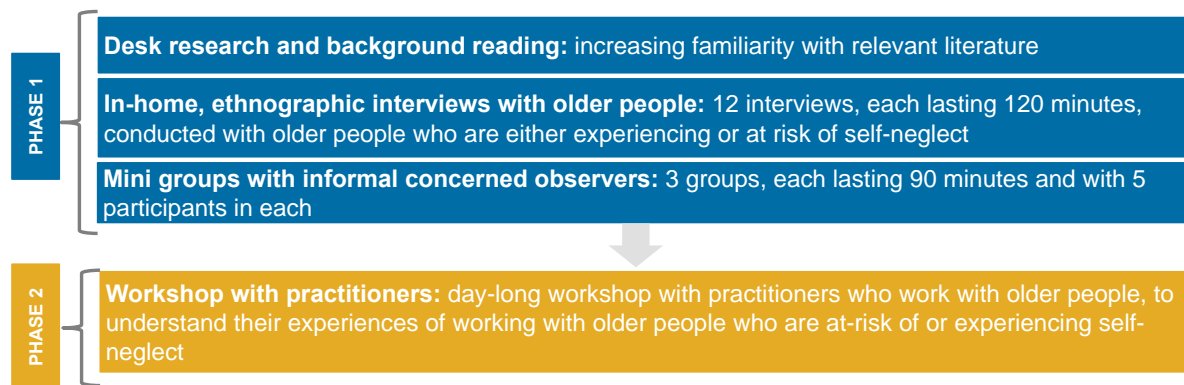
Age UK has commissioned BritainThinks to deliver a three-year, strategic research programme.

The first year of this programme has explored the lives, experiences and mind-set of older people who could be described as experiencing or at-risk of self-neglect. In addition, it has explored reluctance to ask for, accept or act on help, and the way in which this.

This report outlines the detailed findings from the project.

Methodology

The project was comprised of two-halves, with a period of absorption and reflection in the middle, as outlined in the diagram below.



This report is split into two halves, outlining findings from Stage 1 and Stage 2 of the project separately.

The logo for Britainthinks, featuring the word "Britainthinks" in a blue, sans-serif font. The "thinks" part is in a lighter shade of blue. Below the logo is a horizontal line with "Insight & Strategy" centered underneath it.

Britainthinks

Insight & Strategy

A blue-tinted, high-angle photograph of a busy pedestrian walkway. The ground is paved with light-colored tiles, and the silhouettes of many people are visible as they walk in various directions. Some people are carrying bags, and one person is using a bicycle. The overall scene is a dense, active public space.

Stage 1 report: Research with older people and ‘concerned observers’

Understanding ‘self-neglect’ and reluctance to ask for, act on or accept help

Objectives

The objectives for this stage of the project were split into two key areas of focus, as outlined below.

1 Gain insight into the lives of older people experiencing or at risk of self-neglect

- What are the main causes of self-neglect, and what are the trajectories that can lead to this type of behaviour?
- What is the lived experience of self-neglect?
- How can self-neglect be addressed?

2 Understand older people who display a reluctance to ask for, accept or act on help

- What are the barriers to considering and asking for help?
- What would motivate people with this mindset to ask for help?

Sample

We conducted 12 in-depth interviews with older people at-risk of or currently displaying signs of self-neglect, and three mini-focus groups with 'concerned observers'. Please note that all names have been changed to protect respondents' anonymity.

	Name	Gender	Age	SEG	Household	
Depth interviews	Daniel	M	61	D	Lives alone	Urban (London)
	Anne	F	87	C1	Lives alone	
	Sally	F	81	C2	Lives alone (Widowed)	
	Adam	M	61	E	Lives alone	
	Vincent	M	61	E	Lives alone	
	Rob	M	69	C2	Lives alone with guide dog (Widowed)	Rural (North West)
	Melvyn	M	78		Lives alone with dog (Widowed)	
	Jeremy	M	62	E	Lives alone with dog	
	Gail	F	63	E	Lives alone	
	Mary	F	65	C1	Lives alone	Semi-rural (South East)

Paired interviews	May and her husband	F	68	C1	Lives with husband, son and granddaughter	Urban (London)
	Leah and her daughter	F	74	E	Lives with daughter, son-in-law and grandchildren	Semi-rural (South East)

	Relationship to older person	Gender	
Mini-groups	Related	5 x M	Urban (London)
	Related	5 x F	
	Unrelated (neighbour or friend)	2 x M 2 x F	Rural (North West)

Defining 'self-neglect'

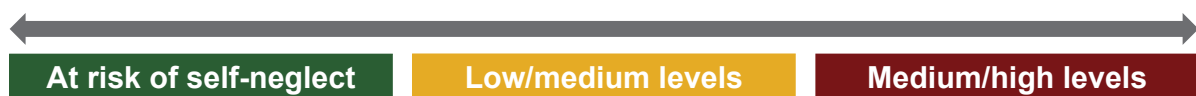
The starting point was a definition agreed with Age UK, which is outlined in the box below. This definition was used to underpin the recruitment process, and provided a starting point for specific behaviours for moderators to look for signs of, and probe on, during fieldwork.

'Self-neglect' is a term describing a behavioural condition in which an individual fails to take adequate care of themselves, even though they are physically and mentally able to do so, to the degree that they are at risk of harm.

It involves behaviours (conscious as well as subconscious) which lead to an adverse impact on wellbeing, and includes neglecting basic needs (e.g. personal hygiene, clothing, diet, management of long term conditions) as well as their overall environment (post/bills piling up, hoarding, clutter/dirt, debt).

'Self-neglect' exists alongside an attitudinal sensibility of **being reluctant to seek or accept help.**

The research built upon and added depth to this definition. Rather than being a single condition or state, the phenomenon appears to exist on a spectrum, from being 'at risk' at the lowest end, through to higher or more extreme behaviours at the other:



The spectrum, and the position of an individual within it, is dependent on four key factors:

1. **How visible the behaviour is to those outside the household:** for example, there is a distinction between maintaining parts of life that are visible to others in an attempt to 'keep up appearances' versus neglecting even those elements of living that are easily visible to others, such as hygiene and personal appearance.
2. **How harmful these behaviours are to physical/ mental wellbeing:** individuals at the more extreme end of the spectrum are likely to have developed a set of behaviours that are increasingly harmful to health and wellbeing, such as having poor personal hygiene, failing to clean and tidy their home or being socially isolated. Patterns of behaviour gradually becomes the 'new normal' and individuals increasingly struggle to imagine anything better for themselves.
3. **The specific drivers behind their reluctance to ask for or accept help:** those at risk of self-neglect tend to be reluctant to ask for help due to a fear of becoming a burden (especially on family and friends) and so tend to down-play or refuse the help they need. For those experiencing self-neglect to a greater degree, feelings of shame act as a powerful barrier to seeking help and support. Those at the most extreme end of the

spectrum have often reached a point of resignation about their situation. Low levels of economic security can add to this sense of resignation.

4. **The role of family or “concerned observers”:** family plays an extremely important role and can reduce a person’s likelihood of progressing along the spectrum. Those at risk of self-neglect will often be increasingly reliant on others to boost their levels of motivation and help them complete tasks. In line with this, within the sample consulted in this study, the majority of those experiencing self-neglect to more extreme levels were living alone and with no close family nearby.

	At risk of self-neglect	Low/medium levels	Medium/high levels
Overview	An individual whose behaviour is not currently causing harm. These individuals may have recently experienced a change in their life (for example, sudden reduction in mobility) and are struggling to adapt.	An individual who is neglecting the parts of their life that are not easily visible to others, whilst prioritising the maintenance of outward appearances.	An individual suffering from entrenched self-neglect in parts of their life that are easily visible to others, in a state that has become normal.
Type of behaviour	Examples sit within the more superficial aspects of lifestyles such as not painting nails or not wanting to get a Christmas tree in the winter.	Examples include not eating enough, taking medication or keeping on top of finances, whilst at the same time keeping a clean house/ tidy front yard, or dressing up when going out.	Examples include poor hygiene, lack of care in appearance, having a home that is dirty, in disrepair or infested.
How harmful the behaviour is	Behaviours may have an impact on mental wellbeing, but otherwise will not cause physical harm.	Behaviours will have a bigger impact on mental wellbeing and some may also cause physical harm (for example, not taking prescribed medication).	Behaviours are likely to cause s harm to the individual, both mentally and potentially physically as well (for example, neglecting personal hygiene).

Reluctance to ask for help	Growing concerns about being a burden on family and friends, can lead to denial, increasing social withdrawal and a reluctance to ask for help.	Feelings of shame at their situation, leads to an increased reluctance to ask for help.	Resignation about their lifestyle and struggle to imagine anything else increases reluctance to ask for help.
Role of family	Family likely to be playing a crucial role in boosting mood, levels of motivation and stepping in to complete tasks that have become too difficult.	Family likely to be uncertain how to communicate on the issue, especially in instances where the older person is attempting to hide self-neglect.	More likely to be living alone and with no family support network.

The spectrum of self-neglect does not appear to be an inevitable series of stages, with those in the ‘at risk’ category destined to self-neglect in the future. Rather, it is entirely plausible that they could stay in this position. It was, however, a relatively common experience amongst participants in our sample, or amongst the relatives/those known to the ‘concerned other’ participants, that the situation had worsened over time, in some cases spiraling quite rapidly.

Differences across the sample

In our sample of 12 older people, self-neglect behaviours manifested across gender, SEG, age, location and family/household composition. There are some observable patterns in the way that severity of self-neglect fell out across the 12, but given the small sample size we urge caution on drawing a strong conclusion from this. We outline below some of the differences in the sample:

Gender: in our sample two of the women and none of the men were allocated into the ‘at risk’ category’. Only men were allocated into the most severe category of self-neglect.

SEG: self-neglect was evident in participants from different socio-economic backgrounds. There was evidence to suggest that those on lower incomes had a greater range of problems to deal with and were more restricted in the options for solutions e.g. it was harder to socialise. Those in the most severe category were in socio-economic groups D and E, living a hand-to-mouth existence and in poor housing.

Age: there was no strong link in our sample between older age and higher levels of self-neglect. Some of those in the most severe category of ‘self-neglect’ were in their early 60s and those in the ‘at risk’ category were in their 80s. There was a mix of ages in the low/medium category. There was, however, some evidence that quality of life (physically and emotionally) had gradually decreased over time on an individual trajectory.

Location: participants in both rural and urban locations were manifesting behaviours that could be described as self-neglect – there was no evidence to suggest that one type of location was more or less likely to create conditions under which a person could begin to self-neglect. The only discernible difference was that those living in rural areas were more restricted if they could no longer drive which could have an impact on ability to access services.

Family/household: having close family support clearly had an impact on individuals, who were less likely to self-neglect to such a severe extent if they had regular practical and emotional support. In our sample, those individuals who fell into the most severe category of self-neglect were men who had never married and who did not have children.

A note on using the spectrum

There will always be an inevitable element of subjective assessment when assessing an individual and their levels of self-neglect. For example, the person may be neglecting a part of their life that they have always taken great care in, even if this is a relatively minor behaviour change. In the research sessions with family members, one respondent described how concerned they would be if their mother no longer coloured her hair – which would not necessarily be categorised as a harmful behaviour in general.

“In the case of my mother, I think the first sign for me would be the day that she doesn’t colour her hair and personal cleanliness. They would be the big alarm bells for me.”

(Concerned Relative, Male, London)

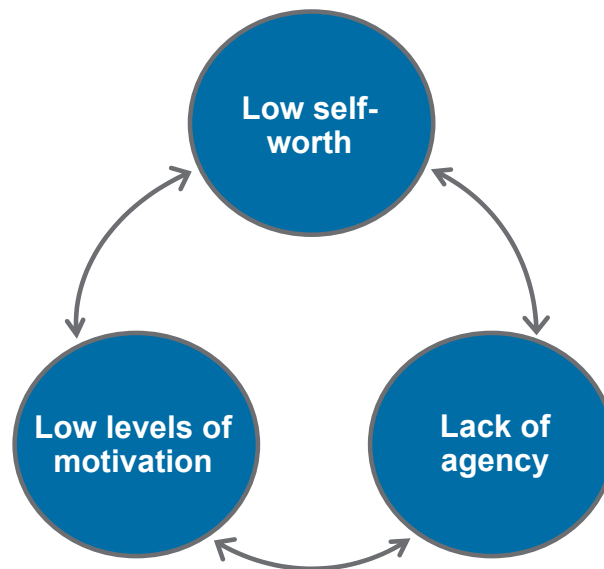
Conversely, a behaviour that might seem in line with more extreme levels of self-neglect may be unimportant for an individual, or something that they have never done. For example, Melvyn, one of the older people interviewed, acknowledges that his home is untidy but it is not something that he sees as important.

“I don’t bother with the house. It’s not important to me, it might be to other people.”

(Melvyn, 78, E, Rural, North West)

The mind-set

The research points to three interrelated characteristics common to older people who are self-neglecting. These mind-sets feed into each other and were each experienced, to varying degrees, by all the older people interviewed regardless of where they sat on the spectrum.



- **Low self-worth:** feeling that their life no longer has value or purpose and that they are a burden on others.
- **Low levels of motivation:** being unwilling to maintain the health and wellbeing because the benefit/ value in making a change is considered to be outweighed by the effort. This is often connected to an unwillingness to ask for or accept help.
- **Lack of agency:** not knowing how, or not feeling able, to make a change.

Each of these characteristics is explored in detail in the following sections.

Low self-worth

Having feelings of low self-worth was common amongst the older people in our sample, indicating a link between this and a propensity to self-neglect. Some participants spoke explicitly about their lack of confidence and low self-esteem; for others, their low opinion of themselves was evident more *in the way* they spoke about themselves and their lives, rather than something they talked about objectively. For some, low self-worth had been something they'd struggled with their whole lives; for others, it had developed in later life as their professional role and personal relationships had dwindled.

"I hate looking in the mirror. I don't see who I really am. I see a really fat, ugly person that isn't me...and I'm constantly pulling the corners of my mouth up, what would I look like without these droopy bits...My hair went silver but it also was speckled with dark grey and brown, it was horrible."

(Leah, 72, C2, Semi-rural, South East)

"I think depression, and losing interest in taking care of yourself, seems to be a bit of a theme when people get to a point where either they don't feel that they've got anything left"

(Leah's daughter, C2, Semi-rural, South East)

The impact of personal relationships on self-worth

Low self-worth amongst older people in our sample was very much tied up with the feeling that on a personal level, *they were no longer of value to others*. This was especially salient amongst individuals without a strong social network – those who lived alone and who did not have children, siblings or close friends. These participants were more likely to live isolated lives and to say they felt lonely. And very often this type of isolation was self-perpetuating – such individuals tended to say they weren't really interested in seeing people anymore or reported feelings of anxiety or frustration when they did socialise with others.

Daniel, an older man from London who was self-neglecting to quite a severe extent, was someone for whom loneliness had affected his sense of self-worth. There were indications that low self-worth was something that Daniel had struggled with his whole life, but also that the problem had grown in later life, as the number of people in his social circle had diminished. Both his parents are now dead, he has a sister who lives on the other side of London and he said he doesn't have any neighbours he knows well. He says he has few friends who he sees regularly and the death of a close friend in the past year was a real blow. He no longer has regular employment, so work does not provide him with any opportunity to interact with others.

"I've kind of run out of people who I have continuous contact with. I had a really good friend who was my best friend for about 35 years. He died fairly recently...Since then I've not really got any friends that I keep in regular contact with."

(Daniel, 61, D, Urban, London)

The upshot of this is that Daniel doesn't have any close personal relationships with people who make him feel good about himself or on whom he can easily draw on for emotional support. The relationships he does maintain were often fraught with tension – he says he argues with his sister and his only close friend is someone with whom he struggles to assert himself.

"I have a friend who I have to deal with - she's always getting me to help her with her problems, or telling me about them, or ringing me in the middle of dealing with them in a not very constructive way. So I end up getting shouted at as well as her kids...We have this kind of cat and mouse game where she's trying to trap me into making decisions for her so that I will be responsible for the consequences. That's stressful."

(Daniel, 61, D, Urban, London)

Daniel's main regular source of social interaction is on social media sites, where he says he spend a lot of time arguing with people about politics. He said he didn't ever invite anyone round to his flat anymore, which means he feels no compulsion to tidy up or maintain his personal hygiene. He also said that he can find socialising outside his home a bit daunting.

"If I had somewhere nice to live that I could be proud, show to people, it would make a lot of difference. It's kind of a vicious circle really."

(Daniel, 61, D, Urban, London)

"I've planned to go [to an open mic night] sometimes and I think 'who is going to be there? Is anyone even going to talk to me?' Because a lot of the times they don't. By the time I get there, it has gelled into these cliques."

(Daniel, 61, D, Urban, London)

Whilst social isolation was often a key contributor to feelings of low self-worth, it is notable that even older people *with* a close social network expressed concerns about being a burden on their friends and family i.e. that they felt their 'value' to others was decreasing over time and that they were taking more from these relationships than they were able to contribute.

"I'm so restricted and reliant on my daughter. Although she says she doesn't mind, for me that's not the point"

(Leah, 72, C2, Semi-rural, South East)

"I miss going out, I've got young grandchildren... and I used to take them down the park and I miss all that now, because I'm just not able to..."

(Sally, C2, Urban, London)

One woman in the sample, Gail, who was well supported by friends and family, nevertheless expressed her anxiety about the dynamic of those relationships and revealed that she had feelings of low self-worth tied up with this. Gail had poor health and limited mobility, but was ineligible for professional support, which meant that she was heavily reliant on her partner, her son and a close friend for help with daily tasks and household chores. Her immense guilt about

being a burden on those closest to her, belied a self-perception that she was no longer 'of value' to those around her. Her particular worries about 'holding her son back' revealed a fear that her role and status as a parent and guardian to him was being lost.

"It's being limited to what you can [physically] do. and I find that more frustrating than anything. I want to be able to do what I did 10 years ago. and I can't. And some days I could just sit here and cry. And if anybody asked me what was wrong I couldn't tell them... I get annoyed because I can't do what I want to do. I can't just get my coat on and walk into the shop...[it makes me feel] horrible after. Because you're relying on somebody's good nature to do things for you...Some days I think 'I don't want to be here'. I feel life would be easier for my son ... I do rely on him a lot... It breaks my heart to think that he feels as though his life is on hold for me...I didn't bring him into this world to look after me."

(Gail, 63, E, Semi-rural, North West)

The fear of becoming a burden was something that relatives of older people also picked up on, especially when it was seen to feed into a reluctance to ask for or accept their help. For some participants, the attitude of their older relative was simply frustrating, but there was a general understanding of what a sensitive topic this is. For instance, several participants in the mini-groups said they felt awkward or uncomfortable handling the changing dynamic and nature of their relationship.

"My mum would never ever ask and she's always worried that she's putting me out. She thinks it's such a big burden on me."

(Concerned Relative, Female, London)

"They always used to be part of something, they don't want to be a burden now."

(Concerned Relative, Male, London)

"Often it becomes reverse parenting, which isn't easy on both sides, neither of you likes it."

(Concerned Relative, Male, London)

Another way in which feelings of low self-worth manifested, was when individuals down-played their own needs relative to others. In the mini-group with men, all of whom had an older relative about whom they were concerned, one participant described how his mother-in-law increasingly prioritised her husband's needs above her own. Whilst she was at pains to make sure her partner was comfortable and well-fed, the participant in the group had noticed that she was neglecting her own diet and had started to lose weight. He felt that her focus was so squarely on caring for her husband that she was under-valuing her own needs, not recognising the fact that she too needed help and support.

"My mother-in-law frets and worries about the father-in-law so much she doesn't eat herself... she's lost an awful lot of weight... she doesn't bother for herself, just cares about her husband... she doesn't realise the strain she's putting on herself"

(Concerned relative, Male, London)

Aside from having some negative feelings about their personal relationships, older people with a low sense of self-worth also tended to lack a positive identity or purpose in their lives. For many, this was something that had developed as they had got older. Participants often spoke of their previous professional or family role as having been a great source of pride and self-worth as well as being a key part of their identity. Without these responsibilities in their lives any longer, many older people had suffered a blow to their self-confidence and sense of self-worth.

"I was reluctant to retire ...when you have a success it's a tremendous feeling that you've intervened in someone's life and made it better....but I had to give it up, so there we go."

(Jeremy, 62, E, Rural, North West)

"Since [her son] died it's been hard. She was needed – she cooked his meals and did stuff for him."

(Concerned relative, Female, London)

Whereas once their identity and status had been tied in with their job or role in the family, now, many of the older people in our sample had become defined by what they *could no longer do*.

"Once you pass a certain age, you're written off aren't you. People don't want to employ you. [You're] too old. Not very nice is it...the sooner you die, the less of a burden you are to society... that's what I am in reality"

(Adam, 61, E, Urban, London)

"I started out as a laboratory assistant. I then went back to college to do my A-levels and ended up doing a lot of casual, industrial work. Eventually I got into computing and did IT. I ended up doing book-keeping, which I did for a fair chunk of 20 years. I'd quite like to be actually employed and productive....That would be nice... [but the main thing stopping me from working is] the availability of opportunities really"

(Daniel, 61, D, Urban, London)

Many felt that as they had grown older their capacity to enjoy life had diminished and their daily routines had grown mundane and repetitive. Without a hobby or interest to pass the time or structure the day, older people in our sample often lacked things *to do*, things *to be good at* or things *to talk about* – things which we all use to build our sense of self-identity and self-worth. These participants spoke about their lives being merely an 'existence' or 'survival' rather than anything more meaningful.

"I get up, I don't get dressed, I wander about, I do get a cup of tea and some breakfast, and then just, basically sit on the bed. Go on my phone, go on Facebook. Spend much of my day on social media arguing with people."

(Daniel, 61, D, Urban, London)

“I was a ballroom dancer when I was young, and I loved it. And I thought that keeping busy and dancing, would make sure I didn't have any mental or physical illnesses... It started when I couldn't walk very well... you just end up by sitting, and not doing much. and the less you do, the less you want to do”

(Leah, 74, C2, Semi-rural, South East)

Rob was a 69-year-old man in our sample, who started losing his sight over 20 years and is now registered blind. The way he spoke about himself conveyed how the quality of his life had decreased as he has grown older, but most notably since his wife died about a year ago. Without her support, Rob struggles to manage everyday activities, but beyond that he feels aimless, unfocussed and very often, bored. His confidence has taken a blow and he no longer feels comfortable eating out in public or going somewhere new.

“It's the same thing every day. There's no variety...before, I had a life. Now, it's an existence. That's how I'm looking at it. I'll probably sit there, have a cup of coffee. I won't want to eat... so it'll just be in the kitchen, come in here, on the settee, put the radio on, and that's it - .that'll be it until about four o'clock. Feed the dog again, then think, what shall I have to eat? And normally I'll just have a bowl of cereal. And that'll be it”

(Rob, 69, C2, Rural, North West)

Low levels of motivation

Along with feelings of low self-worth, another common theme amongst the older people interviewed was having low levels of motivation. Many of the individuals in our sample spoke of a sense of weariness and lack of energy, or to a pessimism about the world more generally. Many also reported a lack of motivation to making a change in their lives – that is, the effort required to change their situation was simply felt to outweigh the benefit of doing so.

A low level of motivation was often seen as the most important warning sign to family members that their relative was slipping into self-neglect. The things that participants in the mini-groups said would look out for in older relatives were often linked to a lack of interest in social activities or low motivation around maintaining one's appearance or household. Similarly, a break in their normal routine was considered another red flag – if the older person could no longer 'be bothered' to do the things they always had done.

“If he fell out of his routine. If it was nothing to do with his health and he didn't go on the bus to Sainsburys.”

(Concerned relative, Male, London)

My mother-in-law would never go to the door with a stain on her or anything like that. He house isn't immaculate but it is tidy and clean, so that's where I would notice it. If her house started getting filthy and her physical appearance.

(Concerned relative, Male, London)

“If she stopped going to all her clubs that would worry me”

(Concerned relative, Male, London)

“In the case of my mother I think the first sign for me would be the day that she doesn’t colour her hair, and personal cleanliness. They would be the big alarm bells for me.”

(Concerned relative, Male, London)

In instances where concerned relatives and neighbours participants had already noticed low motivation start to emerge, they spoke of the distress this had caused them, but also often of the frustration and impotence they felt to be able to do anything about it. Having conversations with the older person on the issue was typically considered to be very sensitive and awkward – it was only thought appropriate that blood-relatives rather than in-laws could broach the subject – but even then it wasn’t clear what should be said to really make a difference.

“She says ‘I don’t think I can be bothered’ whereas before she used to look forward to going to her clubs or out with her friends. It makes me feel more despondent than her to tell you the truth, because I’ve seen how active she’s been and for her to turn round and say I don’t think I can be bothered to go”

(Concerned relative, Male, London)

She says ‘what’s the point in painting my nails now?’

(Concerned relative, Female, London)

“Like mum, as she gets older, she has low moods and she seems to just want to shut herself away and not bother with how she looks”

(Leah’s daughter, C2, Semi-rural, South East)

“You’d go in there and the clothes weren’t as clean as they once were, her hair wasn’t as tidy. I think the motivation had gone, she was so uncomfortable and in pain.”

(Concerned relative, Male, London)

“My father-in-law if he had a doctor’s visit he would always dress up and make sure he was smart. Now if they come round he’ll stay in his pyjamas. Sometimes he won’t get dressed all day.”

(Concerned relative, Male, London)

It is worth noting that there were some participants in the sample who suffered from an ongoing illness or condition, or who had limited mobility, meaning they often felt tired and weak. It was not easy for these individuals to galvanise their resolve to make a change when there were very real physical barriers to simply ‘getting up and going’. Bouts of mental ill-health, most commonly depression, was also mentioned by some participants as a contributing to their apathy and lethargy.

"It's very much a 'why bother, just give up' feeling. It's a feeling of defeatism. It's exacerbated by a feeling of tiredness... It is a vicious circle... if you're defeatist, you get defeated"

(Victor, 61, E, Urban, London)

"Lack of energy is the worst... I find I don't have a lot"

(Anne, 87, C1, Urban, London)

"I can't see my life getting any better than it is now...for one I'm not mobile enough, and it's not because I don't want to be, it's because I can't breathe when I'm doing it. And I don't have the energy...I take every day as it comes"

(Gail, 63, E, Rural, North West)

For one of the research participants - Jeremy – this type of apathy characterised his outlook on life. He had struggled with alcoholism and depression over his lifetime, but having taken early retirement related to the onset of osteoporosis, he now found it harder than ever to motivate himself to 'get things done'. His way Jeremy spoke about himself, both in terms of what he said and the tone of his speech, conveyed a deeply pessimistic attitude towards his life.

"I think I've always been prone to depression. And I'm lazy. and I always have been lazy. And I think in a way I needed the discipline of work - it was very good for me. I used to get up at 7 in the morning and get home at 7 at night, and then make myself a meal. But I don't do that anymore because everything seems kind of - you know, I'm just waiting... I'm waiting for the end really"

(Jeremy, 61, E, Rural, North West)

Aside from these feelings in their personal lives, it was also common for participants to express their pessimism and despair at the state of society at large, or of their community at a local level. A typical refrain was that the world was getting worse and that there was no evidence or hope that that humans would be able to make positive progress. In terms of their local neighbourhood, participants who had lived in their area for a long time, often felt that a sense of community spirit or neighbourliness had grown weaker over time.

"[As I've gotten older] I'm less optimistic about things. I don't necessarily mean in my own personal life, I just think the world is going to shit, basically"

(Daniel, 61, D, Urban, London)

In terms of how participants experienced low levels of motivation to make a change in their own lives, there were indications that the specific driver leading to low motivation differed by the severity of their self-neglect – so, those 'at risk' of self-neglect were typically prevented from taking action by *denial*; those experiencing low/medium levels of self-neglect were held back more by *shame* and those experiencing medium/high levels of self-neglect were driven by a sense of resignation to their situation.

Those in the 'at risk of self-neglect' category were often finding it hard to come to terms with their decreasing capabilities and feared starting losing their independence. They were more likely to talk about their lives in way to suggest they were down-playing the benefits of making a change as a way to justify their inaction. For example, they might refuse to admit the extent to which they had started to struggle with day-to-day chores.

One participant, Anne, was determined to remain in her own home, despite health problems making this increasingly challenging. She had lived in the same house for 35 years and now lives there by herself since her children have left home and her husband was taken into residential care following the loss of his sight. She has leg ulcers which severely limit her mobility in and outside her home, but her mind-set is one that sets her against down-sizing or exploring other living arrangements. Anne rejected the possible benefits of moving to a smaller property.

"I'm not moving either. Everybody keeps telling me I've got to downsize, and I can't see any advantage in it... I went to look at one of the retirement homes, and I thought I'd go mad coming out of my door and into a corridor and I thought 'a life of corridors, I don't think I could stand it!"

(Anne, 87, C1, Urban, London)

Such sentiments were very often picked up by relatives, rather than something that older people themselves discussed openly. Some of the concerned relatives in the mini-groups described how the older person they knew chose not to take up offers of help or seek solutions to practical problems. These were not individuals who could currently be described as self-neglecting but their reluctance to ask for or accept help could be seen to put them at risk of harm over time.

"My husband suggested we get rid of the bath and get her a walk in shower. She absolutely, categorically refuses because the tiles will be ruined and it's all the upheaval... whatever you try and do to try and make their life easier, there's always an obstacle in the way."

(Concerned Relative, Female, London)

"She doesn't want us there, so we make excuses to go over there and check she's ok. We take her to the doctors and we sit there and she only gives them half the story – we have to fill in the rest."

(Concerned Relative, Male, London)

"I don't think she sees that there's a problem"

(Concerned Relative, Female, London)

Those living with low/medium levels of self-neglect, had started to lack the motivation to maintain their health, wellbeing or household to a more serious degree. They were also often lacking the motivation to get a handle of their situation or to make a change to their lifestyle. Behaviours such as not managing finances, not taking medication or eating properly were starting to manifest. Their coping tactics often involved hiding their behaviour, shutting people

out, or attempting to deal with the problem by themselves, indicating that feelings of shame were behind their reluctance to seek help or motivate themselves.

Melvyn was neglecting the upkeep of his home. Since his wife died 12 years ago he has lacked the motivation to do the house-work or make the necessary repairs to his house. He says he feels embarrassed at the state of his home, but manages the issue at the most superficial level - by simply avoiding letting people into his home anymore - rather than making any attempt to tackle the issue at its core.

"I just leave the house as it is...I don't do any work on it, I don't decorate. I haven't done any for a long time since my wife died... When somebody comes that you've known a long time and you know they're tidy, and your wallpaper is hanging off and it looks right rough, you're a bit ashamed...You would [want to be in a tidier house] wouldn't you."

(Melvyn, 78, C2, Rural, North West)

Adam was neglecting to deal with a pressing financial issue. He was adamant that he and he alone would deal with this problem even as he took a fatalistic attitude to his situation. The issue was that whilst he was living in sheltered accommodation, his benefits did not fully cover the rent. At the time of interview he was due in court for rent arrears and feared being evicted. However, he was not taking the time to properly read through the correspondence he had received from the council or to seeking help with his finances.

"I think I'm going to get slung out of here eventually... get my rucksack on and get my tent out. There's not much I can do about it...it's constantly on my mind, 'what's going to happen?', 'how much longer?'. There's not much I can do."

(Adam, 61, E, Urban, London)

Another aspect of self-neglect that those in the low/medium part of the spectrum showed, was having 'given up giving up' on harmful health behaviours such as smoking or drinking or eating an unhealthy diet. This often went hand in hand with a dismissal of medical advice or a lack of interest in taking medication properly.

"I smoke and I'm old, does it matter?"

(Mary, 65, C1, Rural, North West)

"[The doctors tell you to] give up smoking or give up drinking or give up breathing...I've smoked since I was 11 years old. I have to go visit the doctors now and again. That pisses me off. They'll give you more silly tablets, you know this that and that or a referral for this and that."

(Adam, 61, E, Urban, London)

The lack of concern about unhealthy behaviours felt by some older people, contrasted with comments we heard from concerned others who were typically really worried and even angered when they saw relatives taking risks with their health. They often felt frustrated and

unable to exert any positive influence over someone who had decided not to take the advice of the doctor.

“She won’t take her tablet, she won’t use her stick”

(Concerned relative, Female, London)

Those at the higher end of the self-neglect spectrum were more typically resigned to their situation and were at a loss to see a way out. They demonstrated strong feelings of despair, frustration and despondency, resulting in low levels of motivation to take care of themselves or make a change in their lives. For those individuals, the problems in their lives often felt complicated and intractable. Very often, they struggled to provide a clear or coherent account of their problems. Some elements of their self-neglect had become so entrenched that that had lost sight of what ‘normal’ was and were no longer able to engage with the idea of being able to live well.

“I don't think anything's really changed [in the last few years]. I'm still treading water, trying to find myself out of the rut I've got myself into. I don't really want things to be as they are, necessarily. There's a lot that I'd like to change. In particular it would be good not to be mired in debt. Not that I'm ever going to borrow money again if I can possibly avoid it. It's just I'd like my life to be more productive... I wake up everyday and nothing is any different. And then the next day, it's still no different. I don't know, I just feel that I can't think of a way to make it substantially different.”

(Daniel, 61, D, Urban, London)

These older people may also have had poor experiences of welfare/social care – some may have attempted to seek support and been refused or found the support on offer to have been inadequate at providing the help they really needed. Such experiences were liable to decrease motivation to seek further help and undermined their belief that a long term solution was possible for them.

Vincent, for example, had noticed that consultations with mental health professionals at his local drop-in centre had been cut. As a result, he attends the drop-in centres for distraction and access to free snacks, but claims he doesn’t find talking about his situation helpful.

" The professionals are getting scarcer and scarcer and scarcer. All the drop-in centres I go to in Lewisham are now staffed by volunteers..."

(Vincent, 61, E, Urban, London)

Lack of agency

Alongside feelings of low self-worth and low levels of motivation, it was clear that for participants in the sample, feeling a lack of agency was another strong theme in the mind-set of those at risk of, or currently, self-neglecting. Older people expressed this mind-set by saying that they felt trapped in their lives, or stuck in a rut, faced by various practical barriers that felt insurmountable. However, the specific ways in which individuals experienced a lack of agency varied across the sample:

Financial problems

Those participants in socio-economic grades D and E, were individuals on very low incomes. Making ends meet was a daily struggle for these people, who described being unable to heat their properties sufficiently or eat well on such small budgets. Furthermore, two of the participants had, many years earlier, fallen thousands of pounds into debt and were now on structured debt repayment programmes.

"Once a fortnight I go and pay little debts off, buy myself some tobacco, put money on the key meter for the electric, and survive. It's survival...The rent here is about £135-140 a week, and the council only allow me £127.50 so I have to make the [shortfall] and pay for electric and heating. That's why I have no heating on... I'm not a big eater, but I eat everyday, more or less..."

(Adam, 61, E, Urban, London)

"I do owe over £2000 on my credit card. Luckily it's still interest free, but I don't have £2000 to pay it with.....the minimum repayments are being deducted from my bank account."

(Vincent, 61, E, Urban, London)

"I live on such a tight budget...I'm banned from having credit because I got £15,000 into debt...I was working, I was being paid very, very little. Then suddenly that employment ended and my debt spiralled because I was still paying off bank loans and credit cards and stuff."

(Daniel, 61, D, Urban, London)

Living with such a small disposable income left such individuals feeling frustrated and trapped in their situation. It acted as a major barrier to socialising, pursuing a hobby or interest, or even enjoying a treat once in a while – Daniel, for example, said he could barely afford to go out in the evening and on the rare occasion that he did, he would buy one pint and make it last the whole night. And Adam could no longer afford to buy himself something nice for his evening meal.

"Once up on a time I could've bought steak but I can't anymore. It's well out of my price range isn't it."

(Adam, 61, E, Urban, London)

Financial restraints were also a source of stress and anxiety. Adam for example, as mentioned above, was living with the threat of eviction, as his benefits were not covering the rent on his flat. His inability to pay his rent and the looming court date were both weighing on his mind and were clearly having an impact on his emotional and mental ability to manage the situation effectively.

Being disabled

Being disabled or having issues with mobility were also often present in those at risk of, or currently, self-neglecting. Having experience of a physical impediment to carrying out daily tasks, leaving the house, travelling independently or communicating well with others, was frustrating and left people feeling trapped in their situation. It also contributed to low levels of motivation and self-worth, as mentioned above.

“My health? I think it's pretty awful. I'm always in pain. It's been a year now, and that's a very long time for an ulcer and it just won't heal... I used to be very active up until my leg got like this. I used to be an avid gardener.”

(Older person, Female, C1, Urban, London)

In the early stages of Rob's blindness, he was able to maintain an active lifestyle and in fact played in a number of golf tournaments around the world specially run for blind players. He had a guide dog to help him get about and he was supported by his partner Linda. As he has grown older, however, he has found it harder to cope with being disabled. He can no longer play golf because he has developed arthritis in his hands, and his partner died a year ago, leaving him alone. He feels he has lost the pleasure in his life as well as his confidence. It is hard for him to get things done, but also to find the motivation to try.

I like to do quite a lot of things, but roughly this time last year I lost my partner... You just try to carry on. But it's so hard. She basically did everything for me... I didn't realise how hard it would be, but it is. I find I get very, very frustrated. Mainly because the jobs that I used to be able to do that would take me 2 minutes, now take me 10-15 minutes. If I put something down, and I come to pick it up, I now think well where have I put that?...

(Rob, 69, C2, Rural, North West)

May similarly has suffered a knock to her confidence related to her ailing health. She had been diagnosed with diabetes and has also had a few falls. One particular incident, where she had a fall on a bus, really shook her and, as she explains, it has made her less willing to venture out of the house on her own:

“I used to go to church sometimes. And in the evenings I used to visit my sister in law. But not anymore. I get scared because of my diabetes. Once I had a bad fall on the bus. I was taken to hospital. that's why I don't go alone, I go with [my husband].”

(May, 68, C1, Urban, London)

Living in a rural location

For some, living in a rural area meant they faced difficulties with transport and access to services. Jeremy, who lives in a small village in Lancashire does not like to leave his home in the winter months, for fear that he will slip and fall on the icy roads – he says they are steep and poorly maintained. Gail, another participant living in a rural setting, said she felt she had access to fewer services than would be available in a town/city, either because they are less easy for her to reach, or because they are less well advertised.

Lacking skills

Others felt restricted by their skills they lacked – for example, if they were no longer able to drive or not able to go online to find out information.

“Not being able to drive, not being able to take myself where I want to go...it is very frustrating...I'm restrained really...I'd like to drive again, yes”

(Older person, Female, C1, Urban, London)

Sally was a woman in our sample who felt frustrated by her inability to use the internet. She had recently broken her hip but was determined not to rely too heavily on her children and grandchildren for support. However, her attempts at being self-reliant had been frustrated when she was told she needed to go online to access a local ‘dial a ride’ service. Lacking the skills (or the computer) to get online, she felt her independence had been undermined and was left disappointed and de-motivated.

“I hate it when you ring anybody and they say 'go online'...they presume you have a computer sitting there. The lady next door - she has dial-a-ride and she goes to Sainsbury's every Friday. The thing is, it would be nice for me to do that... but the driver said you have to go online...if only things were a bit easier. I think to myself 'oh I can't be bothered'... People at my age, perhaps they all have computers, I don't know, but I've never been interested”

(Sally, 81, C2, Urban, London)

Unable to access appropriate solutions

Aside from feeling unable to make a change in their lives, we also heard from the older people in the sample, that many did not have a clear account of *how* they could effect change in their lives.

We heard a common refrain amongst participants that they felt ‘in a rut’, unable to get a handle on their situation objectively or to strategise a way out. The mind-set of self-neglect actually meant that it was not always easy for individuals to recognise the type of support they needed. Certainly someone like Vincent, who was living in a derelict property and appeared to have mental health issues, was in no way able to coherently articulate the challenges he faced, make the necessary enquiries of local services or put plans into action that would improve his situation.

An additional challenge was that many were unaware of the options at their disposal. While doctors were the obvious first port of call for physical illness, it was less clear who to turn to for help with financial matters or social issues like loneliness. Participants assumed that there were no services or support available that would genuinely be effective at helping them change their lives.

There were a number of assumptions about the state of health and social services that put off those in our sample from seeking such support – some had had experience of public services and this had informed their view. Participants typically thought that they would be ineligible for services or that they would otherwise be difficult to access. There was a perception that cuts to public service funding, and specifically that of mental health services, had further reduced their chances of being able to access support. Finally, there were also concerns from some that the cost of services, especially social services, would be prohibitive.

Rob said he feels he has been poorly served by the social care system. He sought help from social services to help him cope better with his blindness, but says he has not been able to access the support he needs, due to budget restraints.

“They say there are gadgets out there for the blind... but you try finding them! They're all specialised places, and the cost is just ridiculous...I know for a fact social services won't be able to help me. I turn around and say 'I could do with a rail here', or something there or something there. And they say 'we can't really do that now, cos we haven't got the money'”

(Rob, 69, C2, Rural, North West)

The view from concerned relatives and neighbours

As mentioned above, friends and family are deeply unsettled by signs of self-neglect in their older relative and can struggle to cope with it. In some instances they felt more worried or upset about someone's behaviour than the older person themselves. However, this concern didn't necessarily translate into action as there were often emotional barriers to having a conversation with the older person, couple with uncertainty as to what to do.

"We've been round on at least one occasion when we're going for a family meal, and we'll get there and they've not even got dressed to go out, and said they didn't want to. And that used to be their thing – it was a big flag for us"

(Concerned Relative, Male, London)

"You would have to acknowledge the deterioration and therefore loss of somebody – might try to ignore it."

(Concerned Relative, Male, London)

They also recognised that on the part of the older person there is very often shame and reluctance to admit to a problem. This, coupled with awkwardness on the part of the family member, mean that things often go unsaid or that conversations focus too squarely on the offer of practical support.

"With the mother in law – it's not that I feel awkward, but I don't think its my responsibility to tell her. I just feel like it shouldn't be me. It should be her son or daughter talking to her."

(Concerned Relative, Male, London)

"I would have to sit her down and say 'right mum, why don't you want to colour your hair' and try to get to the bottom of it. And if that didn't work I would go down the medical route."

(Concerned Relative, Male, London)

Participants in our sample had not made use of any support services to help them/the older person in their lives. Their hesitance to take action was typically borne out of a concern they might cause offence, meaning they tended instead to take a more covert approach to help manage and support family members.

There were also indications that older people were attempting to actively hide self-neglect from friends and family – something which was a real cause for concern and often left relatives feeling uncertain how to deal with it. Several participants in the concerned relative mini-groups had examples where they suspected the older person in their lives was trying to cover up self-neglecting behaviour. In one instance, a male participant felt his mother-in-law was starting to lie about what she was eating; in another instance a participant's mother had decided not to attend Mass but hadn't told her son about it.

Friends and family members do play a vital role in pushing against the self-neglectful behaviour becoming worse/entrenched. In many cases this is carried out quite consciously with that

objective in mind. The main way they do this is to step in more to help their older person complete tasks that are starting to become more difficult.

"If you know what's important to them, you try to do those things for them - that helps...compensate for what they can't do"

(Concerned Relative, Female, London)

"If she's going out to her daughters she'll ask me to make sure her cardigans clean. I told her that her jumper wants washing"

(Concerned Relative, Female, London)

They also play a vital role motivating and encouraging their relative, providing emotional support and things to look forward to. The social interaction that family members provide give a sense of meaning and purpose to life and a reason for the older person to think about their appearance or tidy their homes. Having a valuable role in the family, such as looking after grandchildren, also seemed to have a positive effect on wellbeing and self-worth.

"I feel a responsibility to keep them involved"

(Concerned Relative, Female, London)

"He's looking at targets, he's thinking about Christmas, my first granddaughter is going to be born soon"

(Concerned Relative, Male, London)

For those participants in the mini-group of people not related to an older person they were worried about, but for whom a neighbour had given them some cause for concern, one of the main issues was not wanting to overstep the mark or come across as patronising. They may approach a family member if they felt there was an issue developing, but very often they too are left feeling impotent to really make a difference to that older person.

I find it difficult because she's so fiercely independent, I don't want to smother her
(Concerned friend, Male, North West)

"I rung up [his cousin] to say that he wasn't right. He wasn't doing his beard and he looked a bit unkempt."

(Concerned neighbour, Male, North West)

These participants also had concerns about the quality of social care. They felt the social care workers were not given enough time with the older person and the shifting rotation of staff was not good practice.

"They're not given the time to talk and that's it - they want to talk. They just want the company"

(Concerned friend, Female, North West)

"Having the one person who would be there for them, have the time to talk - not just half an hour - but having a regular person day in day out..."

(Concerned friend, Female, North West)

Britainthinks

— Insight & Strategy —



Stage 2 Report: Workshop with practitioners

Background

On 13th May 2017, Age UK and BritainThinks convened a day-long workshop with practitioners who work with older people to explore the topic of self-neglect. This workshop built on an exploratory phase of research with older people experiencing self-neglect, as well as ‘concerned observers’, and was designed to understand the perspective of professionals who encounter older people on a day-to-day basis.

Objectives of the workshop

The workshop had three core objectives, as outlined below:

1 Understand experiences of practitioners of working with older people who are self-neglecting

- Do practitioners have a way of identifying people at risk of/currently self-neglecting or those reluctant to ask for help?
- Do they have a specific approach to working with such clients?

2 Understand practitioners’ views on defining self-neglect

- To what extent do practitioners recognise the findings of the scoping research?
- Is there anything they would add to the mindset/definition?

3 Develop a set of principles for working with older people who are self-neglecting

- What are the **principles for language** to be used in consultations with people at risk of/currently self-neglecting or those reluctant to ask for help?
- What are the **principles for how to work** with people at risk of/currently self-neglecting or those reluctant to ask for help?

Structure of the workshop

An outline of the workshop agenda is summarised below.

- Discussion of professional experiences of supporting older people who may be self-neglecting.
- Presentation of findings from the exploratory research with older people and ‘concerned observers’.
- Responses to the presentation and discussion to develop the definition and mind-set of self-neglect.
- Discussing participants’ recommendations for how best to work with older people who are self-neglecting, and how to approach difficult conversations.
- Developing a set of principles for working with older people who are self-neglecting and reluctant to ask for help.

Practitioner attendees

A total of 17 practitioners attended the workshop. Attendees were recruited to represent a spread of professionals and sectors. An outline of participants' roles is included below.

Sector	Job title
Health practitioners	Community Services Team Manager for older people's mental health
	Deputy Team Manager in older people's mental health
	Deputy Manager of the memory service for older people
	District Nurse
	Lead Matron for Self-neglect and Safeguarding
Local authority practitioners	Designated Adult Safeguarding Manager
	HCPC Registered Social Worker
	Housing Manager - Sheltered Scheme
	Housing Manager - Sheltered Scheme
Other practitioners	CAB Advisor, specialising in income maximisation
	Sheltered Scheme Housing Manager for Family Mosaic
Age UK practitioners	Six practitioners from Age UK Croydon, East London, and Sutton. A range of positions including: <ul style="list-style-type: none"> • Community Health/ Home from Hospital • Director of Care and Services Management • Home and Care Service Manager • Information and Advice Manager

Defining 'self-neglect'

Initial thoughts on 'self-neglect' from a practitioner perspective

All participants were familiar with the term 'self-neglect'. It is a term they use professionally and something they recognise as affecting some of the older people they work with. Practitioners across sectors had a similar definition of 'self-neglect' which centred around a person **no longer taking care of themselves** in terms of personal care, their health, and financial wellbeing, with the potential for this to **cause significant physical harm**:

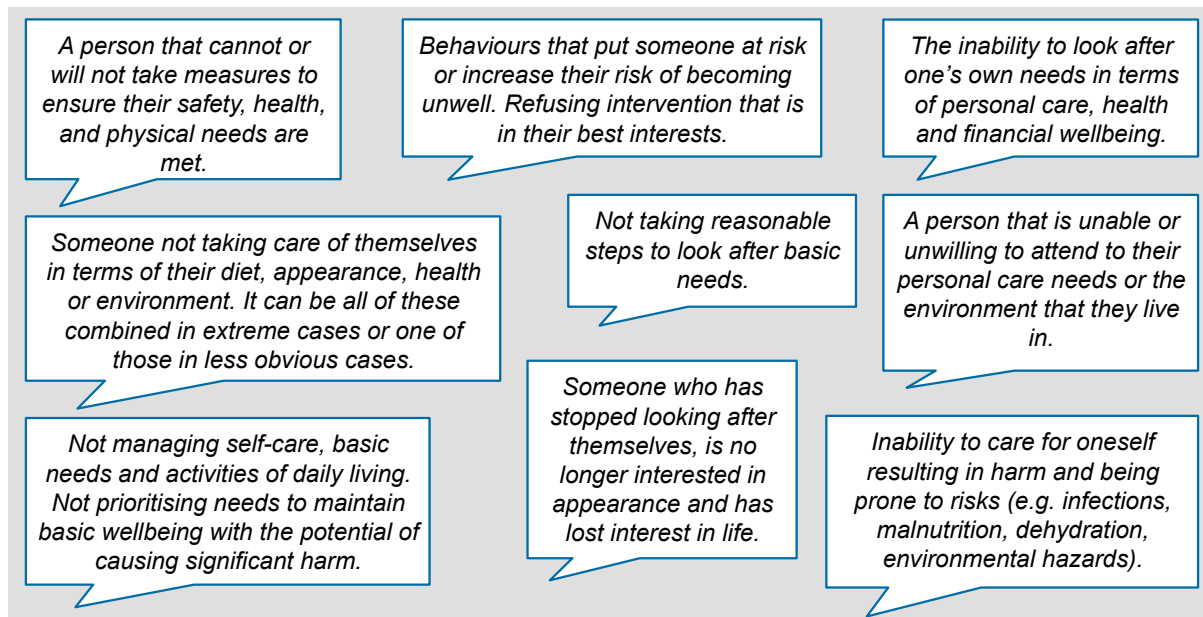


Fig. 1 Practitioner definitions of self-neglect written at the start of the workshop

Reactions to the findings from the scoping research

Participants responded positively to the findings from the scoping research, and recognised that the people we had spoken to were similar to some of their patients or clients. There was broad agreement with the definition of self-neglect and associated behaviours and mind-sets that had emerged out of the research, but there were also some really important builds and additional nuance that practitioners were able to add.

In terms of some overarching points:

- They felt that in most of the self-neglect cases they deal with, there had been a **'trigger'** that led to a change in behaviour. This trigger can include any number of things and is highly personalised, however, common examples are: bereavement, loss of a pet, retirement, children leaving home. Practitioners also mentioned the importance of spending time to hear an older person's story, so that you can understand their behaviours within the context of their lives, as well as gradually gaining their trust.

"There's always something. When I was working with people in their homes, I used to try and get them to tell me their story. If you can get them to do that then you can start to unpick where they're coming from [and what has triggered their behaviour], and it could be something like losing their dog."

- Practitioners recognised that **family often play an important role** in pushing against self-neglect, making sure that behaviours do not become too harmful or entrenched. But they built on this by pointing out that **family can play a negative role too**. This can include relatives covering up the extent of a problem because it is too distressing for them to acknowledge or deal with it, or even taking advantage of their relative – for example financially.

“...relatives don’t want to see the changes, it’s probably more the sons and daughters who don’t want to let go of who they are and won’t just let them age.”

“I once went to assess someone and her house was full of cat faeces. Her grandson was ‘taking care of her’. He was feeding her sandwiches and fizzy drinks and having his friends round to smoke weed.”

- There was agreement that self-neglect is **subjective** and that it is important to know the extent to which certain behaviours represent a change for an individual. However, practitioners were clear that **there is a point when self-neglect can be objectively identified** i.e. when the individual’s behaviour has created a danger to themselves and/or others.

“You can’t just assume that someone with a dirty home is self-neglecting...you’ve got to know that person...my residents who have been homeless will tend to be a bit dirtier.”

“We do have to check ourselves before we make a judgement. Hoarding for one person can be collecting for someone else.”

Developing the definition of ‘self-neglect’

Participants re-phrased elements of the definition of self-neglect. While they were clear that self-neglect is a behavioural condition, they pointed to the importance of making sure that there is no sense of ‘failure’ or ‘blame’.

They also felt that the definition should extend to **include older people who do not take care of themselves because they are unable to do so** (i.e. not just those who choose not to even though they are physically and mentally able to do so). For some this meant including older people suffering from dementia or other conditions affecting their capacities to cope in the same ways they used to.



In addition, participants mentioned instances of self-neglect, to the point of risking self-harm. This may be a way for patients or clients to receive attention or more support from services or relatives. However, it is very difficult to draw the line between these behaviours.

“It’s that contact isn’t it...I used to work with community nurses and house-bound patients would make their injuries worse so the nurses would keep coming round ...as a professional, if someone says they can’t do it there’s a challenge there to see what’s true.”

“I’ve seen quite a few people coming out of hospital and displaying self-neglecting behaviour because they wanted someone there to provide for them...it’s almost like they’ve become the person that needs help even though they could be the person that takes care of themselves and is independent.”

Behaviours and signs of self-neglect

The **behaviours** we had pulled out as signs of self-neglect were in line with those that participants had described themselves spontaneously. Practitioners added to this list so that it covered:

- Not keeping on top of household tasks;
- Hoarding;
- Letting their property fall into disrepair, not dealing with pests e.g. mice;
- Not maintaining personal hygiene;
- Not eating properly, and either losing or gaining weight;
- Not taking medication;
- Substance abuse including excessive smoking, as well as drugs/alcohol;
- Social isolation and ‘shutting off from the world’, including not opening mail and having no interest in the outside world;
- Depression;
- Not keeping on top of finances, leading to debt or threats of eviction.

“I went to her home to see what was going on and I found piles and piles of medication that they hadn’t taken...I had to remove three bin bags of medication and we then went on to find a freezer with food from 1993 in it.”

“Eight or nine years ago, I had a lady who lived in a ground floor flat and collected pigeons. She had been given an eviction letter so we went in to help, and it was to this day the worst case I’ve ever seen. We walked in and there were mice everywhere and there were so many pigeons in the place...but when you spoke to her, she was actually a really intelligent, nice lady. She was just very lonely and that’s why she had started collecting the pigeons.”

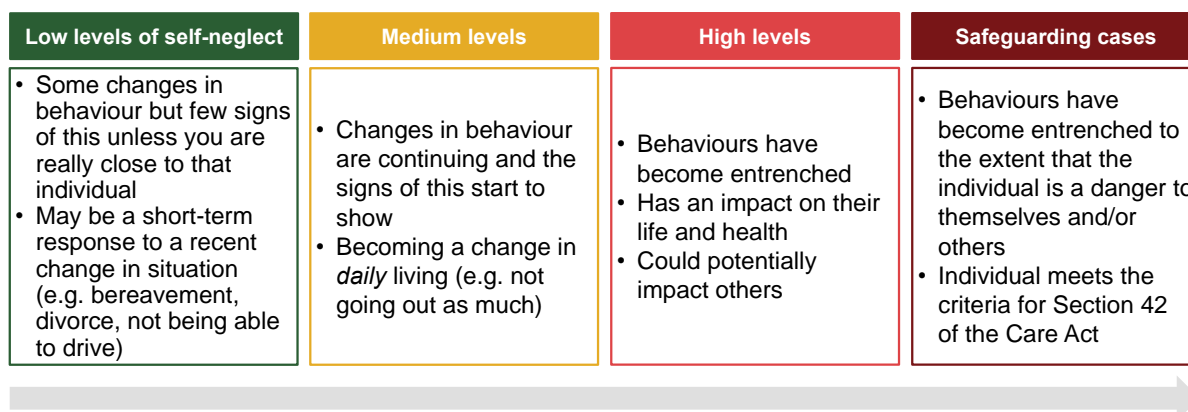
In particular, practitioners stressed the importance of a **lack of social interaction** in being a key driver to self-neglect and something that can make a big difference to the extent to which older people shut-off and disengage with the world around them.

“I know people that sit on their own all day and don’t actually do anything. If they had more social interaction then they wouldn’t be in the same situation.”

The spectrum of self-neglect

Practitioners agreed it made sense to see self-neglect on a spectrum and to identify the appropriate professional response in relation to this. They had three main builds and amends to the spectrum:

- Adding in a **fourth category** to separate those experiencing high levels of self-neglect from safeguarding cases.
- Amending the category originally labelled as ‘at risk’ to **‘low levels of self-neglect’**, in order to reflect the fact that an individual at this point of the spectrum has already started to change their behaviour.
- Finally, participants built on the way in which **behaviours map onto the spectrum**. Rather than categorising behaviours into different levels of severity, they felt that the important thing is instead how *entrenched* that behaviour has become, as outlined in the diagram below.

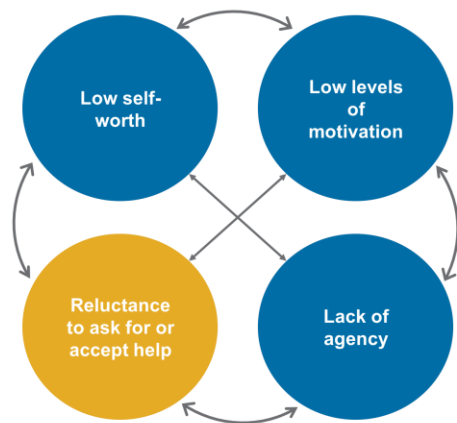


“For example, someone I work with has been banned from the supermarket because he smells and it’s almost like he? doesn’t value the consequence of not washing because he’s too far along.”

The mind-set of self-neglect

Participants built further detail into the mind-set of self-neglect, in particular:

- Adding ‘reluctance to ask for help’ as a fourth distinct element of the mind-set of someone experiencing self-neglect – this can be driven by pride, shame or denial.
- Building what we mean by low self-worth to include **loneliness and lack of purpose**. In line with this, they pointed to instances where self-neglecting can be a way of fulfilling a purpose, e.g. to get more social interaction and support.



Low self-worth: feeling that their life no longer has value/purpose and that they are a burden on others. Social isolation leading to loneliness can also be an important part of this

Low levels of motivation: the benefit/value in making a change is outweighed by the effort

Lack of agency: not knowing how to, or not feeling able to, make change

Reluctance to ask for or accept help: not wanting to admit that there is a problem linked to feelings of shame, resignation at the situation or, in many cases, pride and a desire to retain independence

“Someone who may be self-neglecting is very distrustful of social care or any health professional because they’re afraid they’ve got the power to move them and put them in a nursing home.”

“What is self-neglect giving them? You offer them everything but they still self-neglect, so that behaviour must have a purpose...it could be that self-neglecting means they get more attention from their family or their doctor.”

“They can be proud and self-reliant to the extent that it stops the person from accepting assistance even when they really need it.”

“They can be in a state of denial and feel able to believe they are managing OK. To refuse my support or help and be unwilling to accept that they are not really able to look after their own needs adequately.”

Working with people experiencing ‘self-neglect’

Overview

Working with older people who are self-neglecting is hard, and presents some of the hardest cases that the practitioners said they have to deal with. Participants described how they have developed techniques and approaches for working with clients and patients who are self-neglecting that they feel work well. However, there is also a recognition that these are tough clients and patients to help, and quite often all you can do is the best you can within each individual circumstance.

Several participants noted that they typically get involved with cases of self-neglect when they are at a more extreme stage, so often an individual’s self-neglecting behaviours have become entrenched.

- Healthcare practitioners in particular felt that they tend to come into contact with self-neglecting patients when their cases are already at the higher end of the spectrum. They felt that this often resulted from the older person hiding the extent of the problem from

others, but also that partners and family members sometimes had a role in ‘papering over the cracks’ to avoid outside agencies being involved.

“Because we haven’t seen the baseline and we don’t know where the person is coming from – so one thing we can do is approach their support network to try to figure out what has changed.”

- By contrast, those working in social housing were able to observe and pick up on a more gradual development of self-neglect because their relationship with tenants tends to be over a longer period of time. They are therefore more likely to have an idea of what their tenant was like prior to or at early stages of self-neglect as well as being more likely to be able to see inside their home.

“You can’t just assume that someone with a dirty home is self-neglecting...you’ve got to know that person...my residents who have been homeless will tend to be a bit dirtier but when it involves a change in behaviour then you’ve got to involve other agencies to stop it escalating because when they get to the high level it’s hard to go back.”

- Advisors often found themselves in more of a ‘detective role’ whereby they need to be alive to the fact that the person in front of them may be seeking advice on one thing but actually have other problems/issues they are less willing to admit or discuss. In these instances, practitioners have to think carefully about how they can open up new avenues of conversation in order to understand what the ‘root’ issue might be.

“You do that first thing and you’ve got their trust. I had a lady that came in who was clearly self-neglecting in lots of different areas and her husband was withholding money from her so there was a bit of safeguarding issue with that. She was upset that she didn’t have a phone so I went online and ordered her some SIM cards that came to her house and all she needed to do was put them in the phone. Now because I was able to do that thing for her I then managed to get a home visit to talk about another issue and then we opened up the spectrum to speak to the husband too. It turned out she did have a pension she was just a bit confused. So, by doing the smallest thing of getting a SIM card I had opened up all this other stuff.”

Challenges to successful working practices

There are examples of success, but for the most part participants find themselves frustrated that they can’t fix bigger problems.

- A key frustration is **having to accept that you can’t reverse the problem** if it’s not what the patient or client wants. As outlined above, it’s key to involve them in the process and if they are adamant that they do not wish to make a change then the best practitioners can hope for is to manage the situation they are in without resolving the problem.
 - N.B. There are occasions where practitioners find they can be, or are obliged to be? more action -orientated and take control of the situation. The line is when their patient or client is a safeguarding case, assessed to pose a danger to themselves and/or others, and legal duties are triggered.
- Other challenges are **a result of the system** they are working within. A key frustration for some practitioners can be the **lack of time** they are able to spend working with an individual, especially the health professionals consulted. For example, lack of time directly

impacts a practitioner's ability to develop a relationship and gain trust. In addition they highlighted instances where **certain policies can get in the way of an older person receiving the support they need**. For example, one participant described their frustration when one of their patients with dementia was refused transport to hospital due to a policy that someone had to accompany him.

- Another frustration highlighted was the extent of **silos-working**, which the practitioners consulted felt is detrimental to the wellbeing of individuals that may be self-neglecting and vulnerable – especially when breakdowns in communication result in problems not being noticed (e.g. a patient not taking their prescribed medication).

“You can't work in silos...there needs to be a team around each person.”

“Because each professional is going in doing their bit and then leaving again...I had someone who was bed ridden and I'd found bags of meds and one of my colleagues discovered that she had more than enough supplies to take the meds twice.”

- Finally, participants flagged the **length of waiting lists** that can prevent people from receiving the specialist care that they need (e.g. chiropody, physiotherapy, primary care or hospital appointments). This is especially a problem in the case of patients or clients who are self-neglecting and reluctant to accept help. Participants described how after taking the time to build the trust of an individual and persuading them to see a specialist, this can be reversed by a long waiting list and the trust lost.

Overcoming challenges

Participants highlighted some examples of strategies that have aimed to reduce silo-working, although these were often limited to specific local areas. For example, senior staff networking with others and passing on these channels of communication to others had worked well for in some local organisations.

“The whole integration agenda, we've been here before...The agenda worked for a while and we had the Hackney Project. I found it quite beneficial to have a link person working with me as a care coordinator.”

“Our Chief Executive [at a local Age UK], made the point to make sure we had connections with other people in different organisations in our area so that even though we can't share data, we know what's going on within their organisations. So, they will now come to us and say 'we dealt with this recently, but you can stop it happening by doing this'.”

There were calls for certain initiatives to be encouraged more widely, in particular, those in leadership positions taking the initiative to network with people working in other sectors and enable colleagues to do the same.

Finally, participants highlighted that awareness-raising for the public as a whole would be really helpful for identifying self-neglect cases before the behaviours become so entrenched that it is harder for professionals to help.

“One of the best things I’ve heard about communities coming together was a guy who started self-neglecting his personal care and eating. He was a regular at his local pub and the staff there had noticed that he was really hungry and had started eating food off of people’s plates. So, the pub staff befriended him went to his house and then contacted [Age UK] and the social worker. They knew that we couldn’t get a hold of him and so we went to the pub in the evening and found him. That’s how it should work: the voluntary sector, the community and social services working together. The more eyes there are around a person the more protected they are.”

Effective approaches

Building rapport and gaining a person’s trust were described as the most important steps when working with people who are self-neglecting.

- They are also able to **build an understanding of the older person** that may help them identify the trigger that led to their behaviour change, as well as **identify specific, person-centred ways of encouraging them to accept help and change their behaviour** (e.g. is loneliness an important factor? Are there any cultural or religious reasons why they may be more or less likely to change their behaviour?)

“When I started working with my gentleman, I started to try to understand his story. He had a photo of his parents on the mantelpiece and he said how he thought his mother was looking down on him through it and that she would be ashamed of the mess. And I knew that was it, it was the breakthrough I needed.”

- It is important to **find a way of letting the patient or client feel in control** of the decision to make a change and accept help. Within this, it is important to let the older person set the agenda themselves, so that the pace of change is at a level they are comfortable with.

“With one of my men who has dementia, when we first started working together his complaint was that after he came back from hospital his kitchen had been painted and all his things had been put in bin bags, and he said no-one had asked him. He had no memories of the room and felt lost in his own home...So he told the volunteer what area of the room he wants worked on and he’s now got memories of this because he’s involved in it.”

- Another important step is trying to **find a way to give someone their purpose back** in life. Participants spoke of a ‘light switch’ moment where self-neglecting patients or tenants can resolve underlying issues

“I worked with one lady when she was basically at end of life and had all but given up. Her house was such a mess and she wouldn’t let anyone touch it. When I got her talking, she told me that she had met a guy in the 1940s from Jamaica, they had a child and her parents made her have the child adopted. And her life ended there. Her biggest wish was to find the child and so I said I would see what I could do...In the end we tracked the child down, she was living in Canada, and said that she was willing to come to meet her. And when I told the lady that her daughter was coming to see her it was like a switch went on in her mind, and she looked at her home and said, ‘we have to get this place cleaned up don’t we?’”

Difficult conversations and language considerations

Starting a conversation about self-neglect was considered to be extremely difficult due to the high level of risk associated with offending the person and them disengaging with any attempt to put help or support in place. None used the term 'self-neglect' directly with clients or patients to avoid the risk of creating a sense of blame or failure. Attempts to discuss apparent self-neglecting behaviour were done on a personal, individual basis and always entailed taking time to establish rapport and hear the story from the point of view of the older person.

Practitioners noted an additional challenge when in some cases the person may not be aware of the problem. They also spoke frankly about the risk to themselves of getting this conversation wrong and being subjected to verbal or physical abuse from clients.

"Sometimes you've identified it but they don't realise there's a problem...there was one woman, she was very distraught. Her house smelt really strongly of urine, her bed was covered in urine...she said 'my brother says my house really smells of urine, does it?'. She didn't realise because she's never out of the house. My difficult conversation was saying 'yes it does smell'. It's really difficult to have to break it. She was upset, she asked me to leave..."

Practitioners shared their experiences of how they navigated this initial conversation and which included:

- Making points of connection with the person to communicate respect, shared goals and that 'you're on their side' e.g. agreeing with some of the points they make, saying you understand how they feel.

"I try and make them feel I'm on their side – I'll agree with them 'yeah I understand why you feel that way'."

- Easing into the conversation and preparing them by acknowledging that it is going to be a difficult conversation e.g. using the phrase: 'you're not going to like what I've got to say but I'm obliged to say it' or 'your GP has said they're concerned about you, why do you think that might be?'

"It's about being open and honest but in a gentle sort of way."

"I never start with the problem first. I always ask 'how are things? How are things at home?'."

"It's easier because I know the people. The first thing I say is 'how are you? I haven't seen you around...' I say 'I'm just a bit concerned, is everything ok? Is there anything I can do to help?...if they don't engage you have to take it up a level and say 'you seem to be struggling'...it's gentle...building it up slowly."

- Being honest but not brutally so – softening the edges of the issue and not feeling the need to press home every single point.

"There was like an inch of dust, but I let the person say 'oh my eyes are bad, I didn't see that' and we can agree between us that that's why, I'm not going to challenge it, we don't have to agree why, but as long as we can agree there's dust there."

- Providing them with the time afterwards to digest the conversation rather than force a response from them.
- Being mindful that the older person may have quite low self-esteem and be very sensitive towards feeling blamed. So not saying anything that could come across as judgemental as well as saying things designed to boost their confidence – e.g. talking about what they can still do, like doing.

“You make them feel good about themselves, like it’s not their fault and that you’re on their side.”

- Considering non-verbal communication to ensure engagement e.g. looking to make eye-contact with the person.

“You try and get eye contact, I get people avoiding eye contact.”

- Letting them know that any service or intervention that is put in place is not necessarily permanent and that they have some choice over whether to continue with it or not.

“There’s something about the perception of control... it’s about the skill set to be able to empower and give them the sense that they’ve still got control.”

“I say ‘can I get you some help? You don’t have to keep it and you can change your mind’.”

Guiding principles for professionals working with older people who are experiencing ‘self-neglect’

At the end of the workshop, participants developed a set of guiding principles for professionals working with older people who are experiencing self-neglect to follow.

1. Build a relationship and rapport with that person

Identify and prioritise the (potential) risk, using your judgement but without being judgemental.

Make every contact with them count to build your picture of them along with their trust: understanding *who* I am, to understand *why* I am.

2. Follow a person-centred approach

This approach should ensure that the person feels empowered to make a change and feel that they are responsible for setting the agenda themselves. Showing that you are listening and working together to identify common goals is crucial.

It is also important to see patients or clients experiencing self-neglect as *individuals*, including building an understanding of their attitudes, beliefs and values, and what is most important to them.

3. Identify the key people around the person that you should be working with

With consent, reach out to the people that are around the person and can influence them.

This could be friends and family, neighbours, carers, professionals, volunteers or other community networks (e.g. religious groups, local shops/pubs).

4. Effective partnership working

Communication between services (with consent) is key, and building professional networks can really help.

Establish strategic case management: think about who needs to be involved in the case, who should be the lead, and develop useful resources such as a 'this is me' book of preferences.

5. Remember your responsibilities and limits regarding your professional practice

There will be times where you have to accept that the person does not want to make a change and other times when you are obliged to act, in accordance with your professional codes of practice.

Appendix A: Case Studies

Those at the 'low end of the spectrum have made some changes to their behaviour, but there are few signs of this unless you are really close to that individual

Case Study: Sally, 81

- Sally has been a widow for over 40 years, and lives alone – but with family nearby. The day before her 80th birthday party, she fell over in her kitchen and broke her hip, and has since suffered loss of mobility and has had to stop driving.
- Sally lives for going out and about, and not being able to drive has really impacted her. She doesn't like to ask friends and family to take her places and sometimes declines when they offer – she doesn't want to slow them down – and at times feels quite low.
- Sally's daughter-in-law, Louise, plays a big role in her life and has taken it upon herself to complete the household cleaning tasks each week that Sally can no longer do for herself (hoovering, changing bed sheets etc). She also tries to make sure that Sally's sense of self-worth does not decline, for example, by saying that she needs Sally's help to 'babysit' the children – in the knowledge that they will really be the ones providing Sally with help with household tasks and ensure that she has the motivation to prepare and eat a 'proper' evening meal.

[A good day is when] I get to go out. It's nice because sometimes Louise works on a Sunday and John takes me to Trent Park with the grandchildren, which is very nice. I enjoy that. But I mean they've got their lives to lead, and they want some time with their children. I don't expect that every week, but that's what I enjoy.

She says 'what's the point in painting my nails now?' but I go round there and paint her nails for her and make sure she's got perfume. Last year she said she didn't want a Christmas tree, she said 'what's the point?' But I said to my husband, don't let her bully you into not having one. She wouldn't have said anything [if she hadn't got one] but she would have probably had a little cry and been sad about it. (Sally's daughter-in-law)

Case Study: Anne, 87

- Anne lives alone in the same house she has lived in for the past 35 years. Her husband had to move into a care home two years ago because of blindness, and around about the same time Anne developed a bad ulcer on her leg which has had a massive impact on her mobility.
- Anne feels her leg ulcer rules her life and she is very unhappy about this. She is always in pain and her son or housekeeper takes her to the doctors to have her

dressing changed three times a week. Aside from that, she feels she can no longer get out and about or garden – the one thing she used to love doing more than anything. Instead, she finds that she now spends most of her time listening to the ‘wireless’. She’s increasingly frustrated about what she can’t do anymore.

I miss not being able to drive, not being able to take myself where I want to go...it is very frustrating, I'm restrained really.

My health? I think it's pretty awful. I'm always in pain. It's been a year now, and that's a very long time for an ulcer and it just won't heal... I used to be very active. p until this leg got like this [I liked] the garden [most]. I'd rather go out and garden all day than do the housework. I used to be an avid gardener.

For those at the ‘medium’ end of the spectrum, their changes in behaviour are starting to show and are becoming a change in daily living

Case Study: May (67) and her husband (75), C1

- May and her husband are both originally from Goa and moved to the UK around 25 years ago. They live with their son and 14 year old granddaughter in a small ex-council housing flat in South London. The flat is messy and cluttered, and there is an odour of uncleanliness.
- The son has two jobs to make ends meet, and is out from 6am-10pm most days. He contributes to the family financially and picks up heavy items of shopping. May cooks big meals for the family and takes pride in this role. She also does the family’s laundry (although her husband will often help with the ironing). Her husband appears to do everything else, including the paperwork.
- Both were diagnosed with diabetes when they moved to the UK, and May seems to suffer most. She had a couple of falls, one of which was quite serious when she was crossing a road which they attribute to her condition, and she will not go outside without someone else to accompany her. Her husband tries to get out and about as much as possible and walks his granddaughter to school every day, but it appears May is much less mobile and, aside from a Thai Chi class every Friday, spends most of her time in the house.
- May takes little care in her appearance or personal hygiene. She is visibly dishevelled and has a large stain on the blouse she is wearing. However, neither recognise any problem, even when discussing case studies of people who were self-neglecting, which were presented as pen portraits [please refer to Appendix B

for information about the stimulus materials used]. Both attributed the scenarios to the person being 'depressed' and without family to look after/care for them.

- May seems forlorn and reserved during the conversation, which is largely dominated by her husband.

I used to go to church sometimes. And in the evenings I used to visit my sister in law. But not anymore. I get scared because of my diabetes. Once I had a bad fall on the bus. I was taken to hospital. that's why I don't go alone, I go with [my husband].

I don't like to sit at home, you see. I just go out. I'm the president of the village association. so I go out to visit friends and go to church. I keep plants to water them, it keeps your mind going...otherwise you're just watching the telly and you're not happy at all. (May's husband)

Case Study: Leah (74) and her daughter Lulu

- Leah is 73, and has lived in her house 32 years. She has been widowed 26 years, but her daughter Lulu, son-in-law and grandchildren moved in 2 years ago to care for her. The house is small and untidy, and they are looking to move into a bigger house all together. Leah calls her bedroom the 'box room', because it is very cramped, and cluttered with her belongings and memorabilia
- Leah has bipolar disorder which severely affects her lifestyle. When she has a bipolar episode, this can lead to a complete neglect in hygiene and appearance. She is also overweight, and suffers from limited mobility, diabetes and arthritis. She can no longer do the housework as a result, but admits that even when she was able, she found it hard to motivate herself
- Leah struggles with how her quality of life and independence have declined with the physical changes that have occurred as she has grown older. She was always very active, and feels guilty and frustrated at having to rely on her daughter as much as she does. Her best days are when she goes to her Creative Options activity group and can do things like cooking, as she gets bored if she is in the house. She also hates looking in the mirror as she doesn't feel like herself, and has dyed her hair purple as she hated the mix of grey and brown that her hair had become
- Leah has always been highly sociable, and Lulu notes that even when she completely neglects her personal care, her desire to socialise has never wavered. At times, Lulu even suggests her sociability and kindness gets her taken advantage of. Before Lulu moved in, she found that her mother was easily scammed into giving away money, or swayed into letting people stay in her house.
- A year ago, Leah's state worsened because of her disorder. Her previous Community Psychiatric Nurse had been replaced by a social worker who Lulu felt was not taking her mum's case seriously enough and she became frustrated. This resulted in a safeguarding report being filed against Lulu and her husband claiming

they were trying to get Leah's house and put her in a care home. The case was finally dropped, but Lulu is dissatisfied with what she sees as a severely under-resourced service

I'm so restricted and reliant on my daughter. Although she says she doesn't mind, for me that's not the point. I fully expected to be able to do everything I wanted to do. walk, drive, do everything... I was a ballroom dancer when I was young, and I loved it. And I thought that keeping busy and dancing, would make sure I didn't have any mental or physical illnesses.

It started when I couldn't walk very well... you just end up by sitting, and not doing much. and the less you do, the less you want to do

I think depression, and losing interest in taking care of yourself, seems to be a bit of a theme when people get to a point where either they don't feel that they've got anything left, or like mum, as she gets older, when she has low moods she seems to just want to shut herself away and not bother with how she looks. (Leah's daughter)

They said to her 'you're getting a new care coordinator, she just hasn't gotten around to seeing you yet'. This is someone with severe bipolar who is also old. And what she said later makes you even wonder why it took her so long to even see mum...I probably was getting a bit bullish which I can be - but this was my mum! (Leah's daughter)

Case Study: Mary

- Mary lives alone in a medium-sized house on a quiet, residential cul-de-sac. She left her previous house to her daughter and grandchildren 3 years ago. However, upon moving into her new, smaller house, found it had been poorly constructed and has been dealing with necessary repairs ever since. The house is tidy, with a large living room where Mary sits and watches TV in the morning, but her kitchen walls have been stripped bare for a several months because they need re-plastering and Mary hasn't been able to find a reliable plasterer
- Mary has always tried to set a good example for her 2 daughters and steer them onto the right path, but their relationship has been tumultuous. She took in her grandchildren a few years ago when they were taken away from her daughter for neglect. Today, she tries hard to manage and mend her family relationships but sometimes gets shut out
- Mary had an active social life when she was at work as a psychiatric nurse, and despite taking an early retirement, she went back to work part-time to feel she was caring for someone and was needed. She finds that people like her at work and it helps her maintain social interactions and a routine in her life
- However, outside her shifts at work she still struggles with how her social circle has dissipated, with most of her friends now only in contact through Facebook. Despite her inclination to help others, she is unable to think of anyone who does anything

for her. She has suffered from clinical depression twice in her life, and still dips in and out of depression, though she feels she is more able to manage it now

Times have changed. Years ago in the summer I would have a shower before I went to work and a bath when I got home. Now I bathe and wash my hair about twice a week...Other than that I might do a strip wash or baby wipes, that sort of thing. I would say I yes, I don't take as much pride in myself as I probably did 7 years ago...you just do it when you're younger but if there's nobody coming around I just think 'I can't be bothered'...I can be bothered a couple of times a week...I hate looking in the mirror. I don't see who I really am. I see a really fat, ugly person that isn't me. I look in the mirror in her car ...and I'm constantly pulling the corners of my mouth up, what would I look like without these droopy bits...my hair went silver but it also was speckled with dark grey and brown, it was horrible...recently, in the last 3 years or so, I haven't been able to be bothered to have a shower.

I wouldn't know where to ask for it...[I would want help] just with making decisions I think...just to take things away, lift them to the dump...my other daughter as well, they should come and do things for you because you're their grandmother. I think decision-making and finding the right people to do the jobs because they know I can't do them.

I smoke and I'm old, does it matter?

I was a bit of a social butterfly right up until about 7 years ago when I had to take in my grandchildren actually... I think that because I had them, my social life - going out to the cricket - had finished because I was looking after the children. And going out in the evening, anything like that - I just completely lost my social network, and haven't really been able to pick it back up again.

Case Study: Gail, 63

- Gail lives in a small bungalow in a small block of bungalows. Her bedroom is small and cramped, but her living room is cosy, decorated with lots of memorabilia and photos of family and pets. She has been there for 5 years, since moving out of the home she shared with her partner due to financial and mobility issues
- Gail was active her whole life; her biggest passion was horse-riding and she loved taking long walks with her dog. This all changed when she had a gastric bypass surgery 6 years ago due to life-threatening obesity. Since then, she finds that she in fact is able to do *less* since the surgery due to a number of subsequent health complications. She is no longer able to go out on her own, has developed IBS and suffers from COPD, sleep apnea and congestive heart failure
- She has a strong network of support: her son, her partner and her friend Pauline come around or call daily. But Gail struggles to accept her reliance on others, and sometimes lashes out at them out of frustration. She is plagued with guilt that she is burdening her son with her care since free care services have been cut, and on the darkest days, feels he would be better off without her holding him back

- Gail enjoys going out into town for lunch or a walk with her friend when she can. When at home, she tries to stay occupied making cards and jewelry, which help her feel she is accomplishing something
- Gail quit smoking in her 30s, but started again immediately after her father passed away about 20 years ago. She doesn't want to quit smoking now because smoking gives her a sense of control, since everything else she used to love, she feels has been taken away from her. Smoking is the one thing no one can force her to give up.

I could have a care agency in, where I would only probably have to pay a percentage. But I don't want every Tom, dick and Harry tromping through my home. Because you never get the same people... I don't want somebody different every day.

I've got to 63, stopping smoking isn't going to help my health now. Won't make it any worse but it won't make it any better. Because whatever damage has been done, it's been done. Plus I don't want to. It's the only pleasure I've got. If I'm making cards I don't smoke as much. If I'm making jewellery I don't smoke as much. But if I'm just say here watching the telly...[I smoke] about 20/30.

This Barcelona trip was only booked last week...It was my friend's [idea]. She said 'you're going. I'm sick of you in that house'...she said 'I promise you, we'll just do what you can do, and what you can't do, we don't do. But you need to get out of that house'...I just felt, somebody cares. Somebody wants to do something with me.

I can't see my life getting any better than it is now...For one I'm not mobile enough, and it's not because I don't want to be it's because I can't breathe when I'm doing it. And I don't have the energy...I take every day as it comes, and thank God for every day that comes.

But most days I'm just in here...I haven't been out this week, I didn't go out last week. I just didn't want to. I've bought all of my Christmas presents, apart from bread or whatever I don't really need to go out.

It's being limited to what you can [physically] do. and I find that more frustrating than anything. I want to be able to do what I did 10 years ago. and I can't. And some days I could just sit here and cry. And if anybody asked me what was wrong I couldn't tell them...I would like somebody to call and just say 'Are you alright Gail, is there anything I can do for you?'

Case Study: Melvyn, 78

- Melvyn lives in a large repurposed farmhouse on a narrow road in rural Lancashire. The house is very untidy, with canned food, appliances and other bits and bobs in different rooms which Melvyn no longer uses. The house is littered with cobwebs, including in the kitchen, which is the only room Melvyn uses and heats. In this room, the wallpaper is peeling off the walls and the surfaces are cluttered with food,

dishes and other products. There is a cosy armchair in which Melvyn spends most of his time, with a small television

- Melvyn is retired, and has been widowed for 12 years. He thought about downsizing, but his wife had always wanted them to stay in the house until they died so they could leave it to their children. So, when she died Melvyn decided to stay in the house. While he acknowledges it would be nice to have a clean house, he cares more about comfort than cleanliness, and isn't interested in doing housework
- As well as his household, Melvyn's diet has declined since his wife died, as these were both things that she used to look after. He has developed diabetes and is severely overweight, but doesn't take any medication and isn't interested in dieting. He feels he has lived a full life and is still able to go out and be active, therefore doesn't feel the need to worry about these things, even though he acknowledges he overeats.
- The most important thing to Melvyn is being active: being able to drive and go outdoors and see friend. He maintains quite an active social life, and so does take care of his appearance. To him, if he could no longer drive or get out of the house, he'd be better off dead

I don't bother with the house. I just leave the house as it is, I just live in it. I don't do any work on it, I don't decorate. I haven't done anything for a long time since my wife died. I'm not interested in housework at all. It's not [important] to me, it might be to other people. I do like it tidy but I'm not going to bother...When somebody comes that you've known a long time and you know they're tidy, and your wallpaper is hanging off and it looks right rough, you're a bit ashamed...you would [want to be in a tidier house] wouldn't you.

I never go out of [the kitchen] I don't have to heat the rest of the house do I, that's why I'm up in here... It's comfortable, I can watch television.

I was overweight but I wasn't as overweight as I am now when my wife was living. As you get older, you're eating the same but you're not burning it off the same... I think it's just normal.

Well I eat too much...it is a problem really...I don't bother dieting. I'm at the age now where I've had a good inning so I'm not very bothered. I've got to 80. Lots of people who I know who are a lot younger than me - they've died... It's no good worrying is it. It's a waste of time... I'm happy as I am.

Case Study: Rob

- Rob has been registered blind since 1987. He has endured a gradual worsening of his vision - today he cannot see anything. He used to play blind golf for England all over the world, which he loved. However his friend who used to take him died in 2012. This, and his arthritis, means he cannot play anymore.

- He relies on his guide dog to get around, although he says his current one is a bit difficult to work with. Although he doesn't feel particularly safe in his area, he tries to go out at least 3-4 times a week.
- His wife died last year, and he is struggling without her. Cooking is particularly difficult as he can only make sandwiches or use the microwave. He eats a lot of tinned soup which he doesn't enjoy much and on bad days eats hardly anything.
- A typical day involves walking the dog in the park and going to the local shops. He cannot really expand on this routine as he will be unsure of where he is and he doesn't trust the dog to adapt to a new place. He thinks his life is 'boring'. He gets frustrated very easily when he cannot complete minor tasks easily.
- He doesn't feel he is able to access the blind aids he needs to cope – the specialist equipment he says is too expensive for him.

It's the same thing everyday. There's no variety... it's everyday things that people take for granted, cleaning your teeth... dropping anything on the floor... everyday things that sighted people take for granted like picking up a pair of shoes. Are they the same shoes, or are they odd?

It's not the same. Before I had a life. Now it's an existence. That's how I'm looking at it.

And I just won't feel like doing anything. I'll probably sit there, have a cup of coffee. I won't want to eat... so it'll just be in the kitchen, come in here, on the settee, put cover on the settee. Put the radio on, and that's it. That'll be it until about four o'clock. Feed the dog again, then think, what shall I have to eat? And normally I'll just have a bowl of cereal. And that'll be it.

The only thing is now I can't cook what you would call 'a healthy meal'. I can't peel potatoes, I can't peel carrots. Believe it or not, I have worked as a cook! I'd love to make my own soup... I just can't do it now.

Case Study: Adam, 61

- Adam lives alone in a small flat in a sheltered housing block. The flat is warm, tidy and decorated with care – there are pictures on the walls and a desk in the living room where he says he sits and does drawings.
- He has been in the flat for less than a year. He became homeless after a relationship broke down just over 12 months ago – last winter he spent several months living in a shed on an allotment before he was offered the flat he currently lives in. He receives benefits which only just make ends meet. In fact Adam is currently in arrears on his rent. A court case is upcoming and he fears being evicted but the letters from the council demanding payment are piling up – he is resigned to his fate.

- Adam is in poor health and looks much older than his 61 years. He suffers from COPD and gout but has no intentions of giving up smoking or changing his diet to reduce his symptoms. He is drinking a can of cider at the time of the interview (mid-afternoon) but says he doesn't have enough money to drink to excess.
- His ex-girlfriend did all the cooking when they were living together and he says he doesn't eat so well now. Firstly he says he doesn't really have the money to eat 'good food' e.g. a steak, but on top of this he says he often lacks the motivation to cook himself a meal.
- He has some estranged family and a couple of friends he'll see infrequently. His attitude is very much one of self-reliance – he doesn't expect anyone to care/be able to help him out.

Payday. Once a fortnight. I go off and pay little debts off, buy myself some tobacco, put money on the key meter for the electric, and survive. It's survival.

The relationship broke down and she flung me out basically. So I became homeless....I lived in a shed on an allotment... It was very tough. And then the council slung me off because you're not supposed to live there on the allotment or whatever. But yeah I survived.

I went to Greenwich council and this is the first thing that came up...the rent here is about £135-140 a week and the council only allow me £127.50, so I have to make the shortfall and pay for electric and heating. I've got bundles of letters... it's this constant barrage of letters, bills, council tax. It won't stop. It's endless. It's obviously worrying...I've got a couple of letters, at least one came through the other day. In a pile of that crap. Can't even be bothered to read it all... I flicked through that one, I can't be bothered with that one telling me I've got to go to court. I've got a county court judgement in December at Woolwich [about] rent arrears I have to make up, which I haven't been able to afford. I don't know how it's going to pan out until it happens. I think I'm going to get slung out of here eventually. It won't be til the next year...get my rucksack on and get my tent out. There's not much I can do about it... It's constantly on my mind, 'what's going to happen?', 'how much longer?'. There's not much I can do is there?

I've smoked since I was 11 years old. I don't smoke as much as I used to - I can't afford to... I haven't tried to give it up because I enjoy it... I'd go mad without cigarettes. And the doctors have accepted the fact that I'm never going to give up smoking. It's my choice.

I don't stay in bed and feel sorry for myself all day. No I have to snap myself out of it, go out for a walk or a wander....There are days where I could spend hours painting or drawing, keeping myself amused. Sometimes time can fly by - I can spend hours doing a painting or a picture. Then I'll get fed up with that. You have to motivate yourself don't you. But it is hard sometimes. You just let it go, let it go.

For those at the 'high' end of the spectrum, their behaviours have become entrenched and have an impact on their life, health and wellbeing

Case Study: Jeremy, 62

- Jeremy has no children, has never been married and lives alone with his dog in a small council flat in rural Lancashire. The house has a strong odour, and the living is visibly unclean. He no longer cooks or uses his kitchen, other than to make tea, as he has let dirty dishes pile up past the point where he feels able or motivated to clear up
- He is a recovering alcoholic – since a bad stint in hospital he no longer drinks at all – he says he will never drink again.
- Jeremy suffers from chronic depression and lack of motivation which, coupled with osteoporosis as he grows older, means he claims means he feels lazy and rarely gets things done. He has always lacked the motivation to take care of his health or household.
- His diet is extremely poor – he says he often only eats bananas or granola. Recently, he was diagnosed with anemia which he feels is a direct result of his own lack of self-care.
- His job, while stressful, was very fulfilling. Since taking early retirement due to osteoporosis, he feels he has lost even more of his motivation due to the lack of routine. He has taken up photography and feels it has been a good way to try and regain his social circle.
- He doesn't have much of a family network, with only one older sister who lives in Scotland who he is not very close to.

I was reluctant to retire (...) when you have a success its a tremendous feeling that you've intervened in someone's life and made it better. But I had to give it up, so there we go.

I used to be out and about everywhere but I can't be bothered or I haven't got the motivation.

I've never really looked after my health. Bad diet and the heavy drinking. I used to be a heavy smoker, and then I thought 'if I can give up drinking I can give up anything', so I stopped... I've never looked back on giving up smoking or drinking...Addiction is a horrible thing. And I've got an addictive personality I think. So I tend to do excessive things.

I've always been an untidy person it's just gotten worse. I was thinking the other day - my kitchen's in a right state and it's just gotten to the point where it's a big job. ...I should definitely pay someone to do something about hte kitchen, and then I could cook more....If

I wanted to cook something it would involve cleaning up a greasy frying pan or griddle pan. the work surfaces are all dirty. It's not that pleasant...

I'm quite a good cook but I can't be arsed for one person

Motivation and depression - you think 'it doesn't matter what I do today',...So don't retire - it's no good.

I do get a disability allowance so I suppose that includes a bit for me to pay a cleaner. I should do I suppose... I could do with a cleaner but I just don't like the idea of someone coming in much.

I'm waiting for the end really, and in the meantime passing the time by photographing people.

I don't particularly mind living like this, but I suppose I'm slightly embarrassed about friends coming 'round... That's why I like bars and pubs - they're neutral territory. they're not your place, they're not my place.

Case Study: Daniel, 61

- Daniel lives in a small ground floor flat that he rents from the council. He has lived there for twenty years or so. The flat is extremely messy – the floors are covered in clothes and rubbish; the kitchen is full of dirty pans and plastic bags. Daniel himself wears a grubby t-shirt and tracksuit bottoms. His hair is long and unkempt – he clearly hasn't showered for at least a few days.
- He says he feels embarrassed at the state of the flat and never invites anyone in because he feels so ashamed. Even so, he says he just can't motivate himself to tidy up.
- He used to earn some money designing websites for people but hasn't had a job in a long time. Instead his only income is his benefits which are just enough to survive on – he budgets very carefully and has no money left over to go out. Years ago he ran up thousands of pounds worth of debt on a credit card – he is on a debt repayment scheme and can no longer access credit.
- He has little family - both parents are dead and he has a sister who lives in North London who he sees infrequently. His best friend died last year which he has found really hard. His only regular social interaction is arguing with people online.

I can go a couple of days, two or three days without bothering to shower or wash. I just forget to do it really... It doesn't feel important at the time, no... I think it has gotten worse over the last 10 years or so. I think my life has just got stuck in a rut really. And I don't feel so motivated about things.

It's been very difficult because I can't go out that often, as I have no money. I try to force myself out sometimes and make one drink last all evening. You get to chat to people and

interact with people...I've not been to an open mic thing for weeks now. I've planned to go sometimes and I think 'who is going to be there? Is anyone even going to talk to me?

Cleaning, tidying, washing up - that's the main thing [I find difficult]. I think it undoes itself so quickly, and then you have to do it again... I had a proper tidy up several weeks ago. but then I don't keep it tidy. It's very irregular, and usually driven by the fact that I've got someone coming round to do some work, like the council, and you'll get inspection or maintenance or whatever. I have let this slide for quite a bit now. I think the time for a good old serious clean up is approaching...I do feel better when it's tidy, I must admit, because it's tidy. I mean, I do actually care whether or not its tidy, it's just I have a capacity for ignoring it...if I can avoid [inviting people to my flat], I will...It's been a long time since people come round apart from council workmen...It is embarrassing if you think about it. Because it's not how I want to be seen. It's not how I want to be, and not how I want to be seen. It says that I can't look after myself, that maybe someone should keep an eye on me or something, which I don't want. I'm not helpless I just, I suppose you can call it lazy. I don't have a great sense of motivation and at some level I'm probably quite depressed. And I find myself rationalising things in a way that depressed people do... My physical health isn't bad, it's just that my emotional health isn't good.

A bad day, I don't even bother getting up... I get up, I don't get dressed, I wander about, I do get a cup of tea and some breakfast, and then just, basically sit on the bed. Go on my phone, go on Facebook. Spend much of my day on social media arguing with people.

I enjoy being on social media and arguing with people... It gives me someone to interact with I suppose... Because I'm stuck here on my own, it's a way to combat loneliness really, I suppose...[I argue about] politics, religion whatever. I do enjoy it, I must admit.

[I] live on such a tight budget...I'm banned from having credit because I got £15,000 into debt...I was working, I was being paid very, very little. Then suddenly that employment ended and my debt spiralled because I was still paying off bank loans and credit cards and stuff. [The bank] decided to close my account, default my credit card, and I had to go through the whole business of [asking] 'please cancel my interest and I can afford to pay you £1 a month on each of these', so that's what I've been doing... that happened about 12 years ago.

I feel bad about it, but I don't feel that bad about it because it's under control and because I had probably paid off the original amount of money I had borrowed. The rest of it is all interest and charges and things like PPI... It's not something that preys on my mind...[At the time] it felt like I was staring over a precipice. It would be nice to clear it - the joke has kind of worn thin that it would take 692 years to pay it off.

I'd quite like to be free of depending on benefits as well. That would be good. I've kind of got [my financial situation] under control in the sense that no one is going to come after me for a sum of money. I'm not likely to have bailiffs coming around - there's nothing worth taking anyway. All of my creditors understand that you can't get blood out of a stone...They just keep telling me to give them a pound a month... and I've managed to sustain those payments with no problem.

I've kind of run out of people who I have continuous contact with. I had a really good friend who was my best friend for about 35 years. He died fairly recently...Since then] I've not really got any friends that I keep in regular contact.

I have a friend who I have to deal with - she's always getting me to help her with her problems, or telling me about them, or ringing me in the middle of dealing with them in a not very constructive way. So I end up getting shouted at as well as her kids...We have this kind of cat and mouse game where she's trying to trap me into making decisions for her so that I will be responsible for the consequences. That's stressful.

[I would change] my social life, really. It could be better... The relationships that I have got, the friendship that I have got that seems to have become the central friendship in my life, I could maybe handle a bit better. I've actually had counselling about it. I've had assertiveness training in order to deal with being able to say no to people.

In safeguarding cases, behaviours have become entrenched to the extent that the individual is a danger to themselves and/or others

Case Study: Vincent

- Vincent says that he owns a small terraced house, but it is in such a state of disrepair that it is unclear what the situation really is – he says there hasn't been electricity or running water at the property for over 5 years and that his 'neighbours' are trying to push him out the house. However, there are signs that the authorities have condemned the building and that therefore he is living there illegally.
- He was able to speak lucidly but in some areas of his life was unable to make a rational assessment of his situation and certainly unable to strategise a way out. He displayed some delusions about who his 'neighbours' were and their motives – it was a term he applied to an amorphous group of people who he felt were persecuting him.
- He says the house is often broken into – he considers the trolleys he's collected in the front yard a protective barrier, putting people off from trying to get in. He says he carries all of his belongings around with him as another safety precaution and goes to the public baths to wash (although from his appearance this is probably very seldom).
- He is overweight but gives the impression he exists on cereal and sugar free fizzy drinks. He says he likes Subway sandwiches.



The [neighbours] they seem to be rather dodgy people. Never too clear as to what they do but they all have rather large Mercedes cars...they try and press me for money and make various threats and when I don't respond satisfactorily they arrange various stunts like my house gets took over... On the last occasion they pretended someone else had bought it, they stuck a note through my door to that effect. And when I went out, they arranged for my front door to be removed, and that paraphernalia about demolition, and they arranged for that grill with a lock on it to be there so I couldn't get in... With the aid of a hack saw and sledge hammer I managed to hack my way back in. they weren't too happy about that - they actually complained to the police.

I do owe over £2000 on my credit card. Luckily it's still interest free, but I don't have £2000 to pay it with... I just wonder, perhaps I ought to go for one of these ads that says if you switch to another card you can switch your debt interest free for another year... There's Money Advice and so forth...nothing [has stopped me from contacting them] at the moment because it's not a problem - I'm not paying any interest...the minimum repayments are being deducted from my bank account.

I tend not to like to talk. I think, but I'm not into talking. I tend to find that talking is not generally helpful. A lot of people I'll talk to will probably have worse problems than I've got, or they just want to talk to you about their problems...I've disciplined myself to feeling that talking is a lot of effort for little reward. I actually find it a strain... Talking about my problems doesn't solve any problems...So when I go to these drop-ins, I actually prefer a distraction and not to think about my problems. It's one way of running away from my problems.

I have access to public baths where I can wash myself. There's a swimming pool down the road... I like to do it about twice a week.

I don't have any electricity. I found that since I had no electricity, it made me harder to burgle because there's no lights... If you're a burglar would you want to go in there after dark?

Appendix B: Pen Portraits used in research sessions with older people

In the interviews with older people, we used a series of pen portraits as a moderation tool to encourage respondents to talk about their lives and experiences of self-neglect. We had two versions of the same scenario, one with a male character and one with a female character, so respondents saw a version that was the same sex as them.

The pen portraits are outlined in the table below:

Food and diet	<p>Over the last few years, Allan has become less able to cook and clean for himself. Many of his teeth have now fallen out so eating is tricky, and he has little appetite to eat anyway. Too proud to ask for help, he often skips meals. When he does eat, he microwaves porridge or packets of pre-cooked rice.</p> <p>Over the last few years, Anita has become less able to cook and clean for herself. She also has less and less of an appetite for food, and eating has become tricky because many of her teeth have now fallen out. Too proud to ask for help, she often skips meals. When she does eat, she microwaves porridge or packets of pre-cooked rice.</p>
Hygiene and appearance	<p>Over the past 5 years, Bernard has lost interest of taking care of himself. He pays much less attention to his hygiene and appearance – forgetting or not being interested in going to get a haircut or taking care of his nails. Most days he skips washing himself, preferring to distract himself with television.</p> <p>Beatrice has been struggling with growing older. She feels uncomfortable looking in the mirror and finds it hard to imagine positive things for the future. As a result, she has stopped taking care of her appearance. Most days she doesn't feel like taking a bath or styling her hair – which has grown very long because she hasn't felt like going to the hairdresser in a while.</p>
Household	<p>Because he now struggles to use the stairs, Martin has started sleeping on his sofa in the downstairs living room. He now rarely bothers to open the blinds in that room, and it has become cluttered with bedding, dirty laundry, dinner plates and unopened mail. He doesn't get on with his family very well and doesn't trust them enough to ask for help. But he struggles to find the motivation to clear up the mess. As a result, he doesn't invite people over anymore.</p> <p>Because she struggles to use the stairs, Maria has started sleeping on her sofa in the downstairs living room. She now rarely bothers to open the blinds and the room has become cluttered with bedding, dirty laundry, dinner plates and unopened mail. She feels embarrassed but struggles to find the motivation to clear up the mess and doesn't trust anyone enough to let them clean up for her. As a result, she doesn't invite people over anymore.</p>

Alcohol and cigarettes	<p>Alfred and his friend George used to have the occasional drink and play cards together at their local pub. But lately, Alfred has begun drinking whisky every evening at home until he falls asleep in front of the television.</p> <p>Agatha quit smoking 20 years ago, but in recent years she has taken it up again. Her children have told her to quit because they are worried about the effects smoking will have on her health, but she feels she is too old now for that to matter anymore.</p>
Finances	<p>Robert has always prided himself on staying on top of his finances. But lately he has been getting increasingly forgetful, and now piles of bills and unopened post have built up. Whenever he sees them, he feels so overwhelmed by the idea of going through it all, he goes in another room and tries not to think about it. His son has offered to help him get everything in order, but he hates the idea of admitting he is no longer able to take care of it himself so always refuses.</p> <p>Ruth has been feeling unable to cope with all of the different bills and financial matters to take care of. Piles of bills and unopened post have built up, and whenever she looks at them she feels overwhelmed and doesn't know where to start. She therefore prefers to try not to think about it, despite starting to have built up debts and unpaid bills.</p>
Medical	<p>Carl strongly values his independence and always refuses when family or friends offer help. He was diagnosed with diabetes several years ago and advised to control his weight, change his diet and do more exercise. He struggled to do this so now he has been prescribed some tablets. But lately he has started to wonder whether his medication really makes a difference, and takes his pills less regularly. His pharmacy has rung him to pick up his repeat prescription last month but he has yet to go.</p> <p>Carla strongly values her independence and always refuses when family or friends offer help. She was diagnosed with diabetes several years ago and advised to control her weight, change her diet and do more exercise. She struggled to do this so now she has been prescribed some tablets. But lately she has started to wonder whether her medication really makes a difference, and takes her pills less regularly. Her pharmacy has rung her to pick up her repeat prescription last month but she has yet to go.</p>

Social life	<p>Derek spends almost all of his time at home as he does not feel up for socialising or trying to meet new people. Many of his friends have now passed away, and his son lives far away. His son has offered to visit, but Derek doesn't want to see anyone, and often spends days at a time without leaving the house.</p> <p>Dina spends almost all of her time at home as she does not feel up for socialising or trying to meet new people. Many of her friends have now passed away, and her son lives far away. Her son has offered to visit, but Dina doesn't want to see anyone, and often spends days at a time without leaving the house.</p>
-------------	--