

Struggling to cope with later life

Qualitative research on growing older in challenging circumstances



Acknowledgements

This research was commissioned to Britain Thinks, we are grateful for their expertise and sensitivity in dealing with such an important and challenging topic.

We also acknowledge, with gratitude, the older people, families, friends and practitioners who shared their experiences, opinions, insights and wisdom with us, enabling us to open discussion on this topic.

All names have been changed to protect the identity of research participants.

Introduction

Age UK has many years of experience of working with older people who are going through tough times – whether because of one-off problems triggered by a recent event such as bereavement, or issues that they have been wrestling with for far longer, possibly for most or all of their lives. What we have learnt is that simply offering support or information is sometimes not enough: older people who are in the worst place often feel there is no hope, leading to a vicious circle of low self-worth, lack of motivation and reluctance sometimes to ask for or accept help.

The purpose of this project was to understand more about older people in these situations, with a view to developing approaches that can help them to want to and be able to move on from them in a positive and sustainable way. We hope that this work will be helpful to Age UK and other organisations that work with older people in need, including the NHS, for which a key interest is understanding how to support people more effectively to look after their health. This project is relevant to that concern because it focuses on the older people who, usually for a plethora of reasons, are unable or, it may appear, unwilling to look after themselves properly. It could also be of interest to other organisations, such as the Money Advice Service, seeking to understand how to motivate people to manage their day to day lives effectively.

We know, from our Index of Wellbeing in Later Life, the importance of maintaining meaningful engagement with the world around you – whether this is through social or leisure activities, work or volunteering. Our starting point is therefore a strong belief that older people want and deserve choice and control over their lives, and to be recognised as the important contributors to our society that they are now and have been in the past. However, this project was focused on people who are furthest away from this ideal – those who are struggling to stay connected to the wider world, not really looking after themselves and in some cases running the risk of significant harm as a result.

'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.'

(Vincent, 61, urban, London)

Our research

We worked with Britain Thinks to interview 12 people who were in this situation, or approaching it. As well as these in-depth interviews we also ran three mini-focus groups with 'concerned observers' (such as friends and family) and a

workshop of practitioners who had experience of supporting people in this situation. The full research report is available on our website¹ where you can also see films of some of our interviewees describing their experiences.

What did we find?

We found a cycle of exclusion and self-exclusion from the world around them among the older people who were interviewed. Signs that the person was struggling included not keeping on top of household tasks, neglecting personal hygiene, not eating well or failing to take prescribed medications. How entrenched these behaviours were fell on a spectrum, ranging from low or temporary signs of ‘self neglect’ towards more immediately noticeable, habitual behaviours and culminating in situations where there was a risk posed to the individual or others around them, as in Figure 1.

Figure 1: Spectrum of behaviour

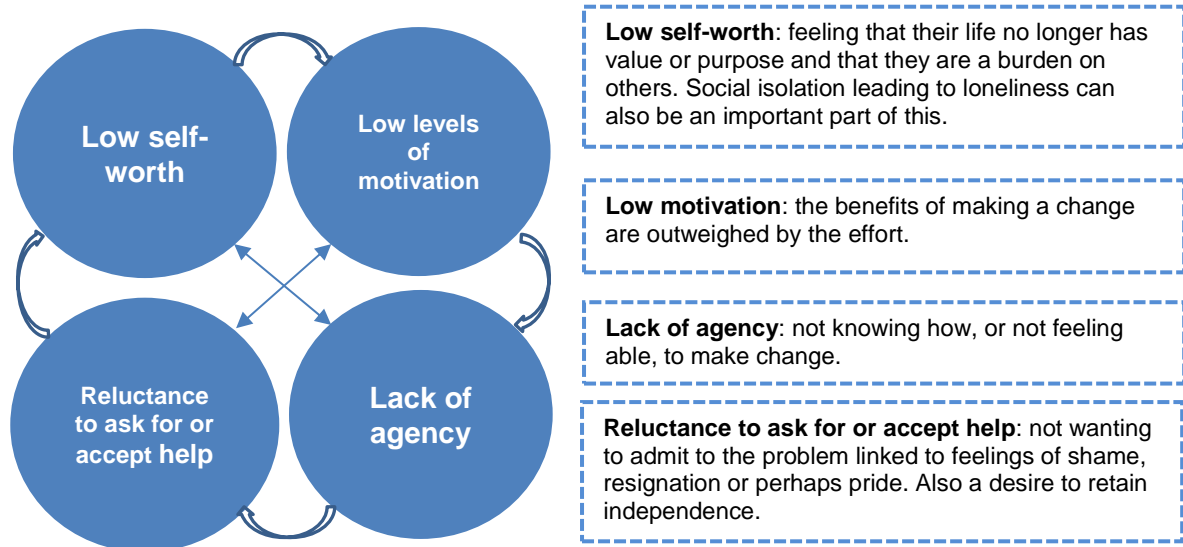
Low level	Medium level	High level	Safeguarding issues
<ul style="list-style-type: none"> • Some changes in behaviour but few signs of this unless you are very close to that person. • May be a short-term response to a recent change, e.g. bereavement, divorce, or even giving up driving. 	<ul style="list-style-type: none"> • Changes in behaviour are continuing and the signs of this start to show. • Becoming a change in <i>daily</i> living, e.g. no longer going out. 	<ul style="list-style-type: none"> • Behaviours have become entrenched. • Has an impact on their life and health. • Could potentially impact others. 	<ul style="list-style-type: none"> • Behaviours have become entrenched to the extent that the person is a risk to themselves and/or others. • The person meets the criteria for Section 42 of the Care Act

Underpinning these behaviours, as shown in Figure 2 below, were a lack of confidence, a feeling of hopelessness, and a reluctance to ask for help, accentuated by feeling a burden. Isolation became a way of life and people could move along the spectrum of behaviour described above. Behaviours included poor nutrition (e.g. living on biscuits), losing control of the housework, neglecting their appearance, failing to pay bills and, in the most extreme case we saw, an example of all these things as well as hoarding - to the extent that formal safeguarding processes had to be activated. In other cases there may have been unrecognised depression or other mental health issues, although it is difficult to disentangle cause and effect as to whether such factors predispose

¹ <https://www.ageuk.org.uk/our-impact/policy-research/struggling-to-cope/>

someone to enter such a negative cycle, or arise as a result of it. For some older people both things were probably going on.

Figure 2: Contributing factors



The practitioners to whom we spoke – health practitioners, social workers, safeguarding managers, housing managers and third sector advisers from local Age UKs and Citizens Advice – recognised this behaviour from their own practice. We are very grateful to all who took part in this research and particularly to those older people who were prepared to share their stories with us. This could not have been an easy thing for them to do.

In this paper we have built on their experience, together with that from across Age UK, to propose the following recommendations.

1. Listen to older people’s histories and value their contribution

‘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, urban, London)

‘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, semi-rural, South-East)

It is striking that interviewees who had previously led full and busy lives, making a major contribution to society, felt that this now counted for nothing. This was not necessarily a matter of family dynamics. In focus group discussions with concerned family and friends of older people who were struggling, it was clear that they recognised and valued everything their older friend or relative had done for them in the past and continued to value them today.

This sense of low self-worth in later life does, however, reflect a negative attitude towards older people that is sometimes given explicit expression in our society in the media and social media. Cultural change is, of course, easy to call for and hard to achieve, but there is no doubt that this societal failure to value older people – a form of ageism - does make life harder for those who are going through a tough time and already lacking self-confidence and hope for the future.

Against this context, giving older people space and time to tell their stories is important and practitioners such as social workers and others can help by including pen portraits in notes that say something positive about older people's earlier lives, not just noting illnesses and problems. The Alzheimer's Society's 'This is me' leaflet that is given to some older patients in hospital and their families to fill in is an example of good practice in this regard, helping hospital staff to see the whole older person for who they have been and are now, thereby enabling them to better meet their needs.

2. Understand the causes to spot the danger signs

The research suggested that the triggers for exclusion and self-exclusion are typically life changes like bereavement (both of family members and friends), children leaving home, the onset of a health condition that could limit independence or energy levels, acquiring caring responsibilities, or anything else that matters to people in terms of their daily lives. People in their sixties could also find themselves in this position following redundancy or divorce, a change of financial situation or retirement itself. All these changes could lead to loneliness and social isolation, and then to a loss of willingness and capacity to look after themselves and stay connected.

'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 it could be something like losing their dog.'

(Practitioner)

'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 just completely lost my social network, and haven't been able to pick it back up again.'

(Mary, 65, semi-rural, South East)

As well as life changes and physical problems, some of the people we interviewed may have been living with depression, while other research on brain ageing and wellbeing shows that cognitive decline can also have a part to play. In addition, as individuals we all have differing levels of resilience in the face of adversity. So it is vital to understand all the factors that may be contributing to someone's current position, and to look at each person as the individual they are.

3. Use a person-centred approach that starts where people are

A very clear message from the research was the importance of recognising individual choices and circumstances. Living in an untidy house, for example, might seem totally unacceptable to one person but be completely routine to another and the way they've always lived. The important thing is to understand the individual and recognise what is normal and acceptable for them.

'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. That would be the big alarm bells for me.'

(Concerned relative, male, London)

In the same vein, people at their lowest ebb may already have lost so much that keeping some element of self-determination becomes even more significant. It is important to make sure people feel in control of a decision to make a change and accept help.

'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.'

(Practitioner)

4. Understand the role played by family and friends

Family, friends and neighbours were clearly lifelines for many of those whom we interviewed, and some went to great lengths to ensure they felt included and valued as a way of maintaining their sense of self-worth, in addition to providing practical help.

For example, one daughter-in-law not only took on weekly cleaning for her mother-in-law but had also tried to buoy her up by asking her to ‘babysit’ her children – in the knowledge that this would be positive for her (hopefully she was right!) and that they would actually be helping each other. Nonetheless, there is a risk that help and support, especially from adult children, can exacerbate an older person’s sense that they are ‘a burden’:

‘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 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, semi-rural, North West)

Family members often found it very difficult to broach conversations about these issues and, if they did, could be puzzled and frustrated by their relative’s refusal to accept help.

‘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)

Of course, families can sometimes play a negative role too, perhaps covering up a problem because they find it too distressing or, far worse, taking advantage of their relative for their own gain, which was raised as an issue by some practitioners. In addition, several of the older people we talked to appeared to have nobody close to them at all as friends as well as partners or siblings had died, and they had no children of their own or had become estranged from them.

5. Find a way to return purpose to life

A common theme in our conversations with older people was ‘before I had a life, now it’s an existence’, but practitioners told us moving cases of ‘light-switch’ moments that helped older people to overcome their lack of hope and motivation, such as a visit by a long-lost child:

‘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?"

(Practitioner)

On a much smaller scale, family and friends also highlighted the importance of keeping up familiar routines that are strongly linked with people's sense of identity. As this suggests, professionals need the time to find out what's really important to individuals when trying to develop health and care plans.

'She would say "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.'

(Concerned relative, female, London)

One finding emerging from the research was that even people who were at an extremely low ebb could take pleasure in activities such as photography, drawing and crafts. This chimes with the findings of Age UK's Wellbeing Index, which found that the single biggest contributor to wellbeing is 'creative and cultural participation'.

We would very much like to see more opportunities to enjoy these activities made available for the older people who are in the greatest need of them, and peer support to help others to keep up their interests.

'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.'

(Adam, 61, urban, London)

6. Ensure that emotional support is backed up with practical action

Some older people faced very severe barriers to improving their situation because of ongoing poor health or low income, or debt. In these situations the first priority ought to be practical action to tackle these factors:

'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.... That's why I have no heating on.... I'm not a big eater, but I eat every day, more or less....'

(Adam, 61, urban, London)

Cuts to public services clearly had an impact on some older people's motivation and willingness to seek help, as did difficulties in accessing services for those who were not online at a time when more and more processes are becoming 'digital by default'.

'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."'

(Sally, 81, urban, London)

Some practitioners also reported frustration that, having built up trust and persuaded someone to seek help, they could be faced with a long waiting list which simply compounded the older person's sense of hopelessness and diminished their faith in any possibility of things getting better.

'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, rural, North West)

7. Give professionals working in this area the tools they need to help

The practitioners we spoke to had many valuable insights to share, although they were often frustrated by the difficulties of putting them into practice, usually because of lack of resource or poor multi-disciplinary working. Key barriers were the lack of time they had to spend with an individual; the extent of silo-working, with different professionals coming in and doing their bit and then going away again; and long waiting lists for specialist services, which could undermine their work in building up the trust to enable someone to ask for help or accept it.

However, support was sometimes found in unusual places:

'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 people's plates. So the pub staff... 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.'

(Practitioner)

Conclusion

We all have bad days when we feel down and demotivated and find it difficult to see a way forward. However, later life can bring specific challenges such as bereavement, ill-health and social isolation that may compound these feelings and make it harder for an older person to 'keep strong' and successfully overcome them.

The situations of the older people in our research were much more serious and it was much harder to help them to make things better because they had become entrenched in terms of their behaviour and their broader outlook on life. Just offering an older person like this information and advice is unlikely to be enough. Equally, being too quick to diagnose the problem and decide on solutions, without taking time to understand the issues and build trust, can make someone fear losing control and as a result seem uncooperative or unwilling to accept help.

Our research provides useful insights about how to spot the signs that someone may be at an extremely low ebb, or approaching it, and the support that they may well need if they are to move on from it. However, underfunding of statutory services and a struggling community sector may mean more, not less, of these types of stories as these people are hard to find, challenging to support and more likely to slip through the net.

The full research report from Britain Thinks is available on our website².

² <https://www.ageuk.org.uk/our-impact/policy-research/struggling-to-cope/>

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