Working with people experiencing chronic loneliness

Insights from Ageing Better Middlesbrough

AGEING BETTER MIDDLESBROUGH

COMMUNITY FUND

Teesside University

This paper is based on a review of published material, and research carried out by Teesside University that specifically relates to Ageing Better Middlesbrough. The primary research encompassed survey responses, 'stories of change', depth interviews with beneficiaries, and focus group discussions with front-line staff.

Key Messages

- The distinction between social isolation (objectively, not having people around) and loneliness (subjectively, feeling a lack or loss of companionship) is increasingly recognised. Within either dimension, people will have diverse personal experiences, differing in intensity and duration for every individual affected.
- Most people experience loneliness at some stage in their lives. This may be temporary (transient), perhaps relating to a major life event (moving away, relationship breakdown, bereavement). For others, loneliness is long-lasting and life-disrupting (chronic); it can even be so all-encompassing to call into question their very being (existential).
- Distinctions between different types of loneliness are potentially important when it comes to devising appropriate interventions. Ageing Better Middlesbrough aimed to address a full spectrum of needs: raising awareness of available activities; establishing specific community activities to attract people; providing outreach and befriending support to overcome barriers; and offering therapeutic support if this was warranted.
- Therapeutic support offered by Ageing Better Middlesbrough has typically been offered to people with complex, difficult life histories and substantial needs, often related to mental health. This mirrors established characteristics of 'chronically lonely' people. For some, an accumulation of issues had taken them to a place that could be described as 'existential'. Conversely, transient loneliness was less prevalent amongst recipients.

Key Recommendations

- Facilitate consistency and continuity in staffing when developing contract specifications or deploying care and support staff. For people experiencing loneliness, seeing a familiar face can be important in and of itself. Facilitating such meaningful personal relations does not need to compromise maintaining appropriate professional integrity.
- Avoid fixed specifications that fail to take account of individual needs. Recognise that for some people, especially those experiencing chronic or existential loneliness, there is unlikely to be a 'quick fix'. However, this does not mean that investment in their needs is not worthwhile nor that progress cannot be made.
- Recognise the importance of the overlap between physical and mental health. If a single service cannot address both, ensure that commissioning and delivery decisions consider in detail how coherence between services can be promoted, and fragmentation avoided. This is likely to require flexibility and imaginative thinking.

Alison Jarvis, June 2020

Types of loneliness

The distinction between social isolation and loneliness, despite their overlaps, is now well established. Social isolation is commonly understood as the absence of social contact. Whilst it can lead to loneliness, it is not the same thing. Perlman & Peplau (1982) provide a commonly used definition of loneliness, describing it as: *"A subjective, unwelcome feeling of lack or loss of companionship. It happens when we have a mismatch between the quantity and quality of social relationships that we have, and those that we want."*

Beneficiary perspectives

Having a sense of community does not necessarily protect against feelings of loneliness. For example, one focus group participant talked with great pride and passion about where they lived and about their family, friends and neighbours. They regularly went out and about into the local community and often helped others, yet also commented... *"but in reality, I am lonely".*

Source: Focus Group with Beneficiaries

Less understood, perhaps, are distinctions within loneliness. There is growing interest in distinguishing loneliness that is transient (temporary, often situation-dependent) or chronic (persistent, sometimes regardless of context). Increased health risks pertain to both, but for chronically lonely people it is higher (Shioitz-Ezra and Ayalon, 2010, cited in Harris, 2014; O'Súilleabháin, Gallagher and Steptoe, 2019). For some people, loneliness is marked by deep disconnection and overwhelming feelings of isolation. At the extreme, people have been described as 'existentially lonely'; disconnected from a larger meaning or purpose in life (Bellingham et al., 1989; cited in Townsend & McWhirter, 2005).

Ageing Better Middlesbrough has engaged successfully with many people who might be classed as 'situationally lonely'.

Examples of 'situational loneliness'

- **Relationship breakdown:** *"I've just joined after the break-up of my marriage, so I feel the need to try to escape from feelings of isolation and depression. I think in the long run it will remove the feelings of self-pity."*
- **Moving to a different area:** *"Having moved to Middlesbrough from the London area this year I have found it difficult at times, I have been pleased to know about ABM."*
- **Bereavement:** *"When my wife died 2 years ago, I lost the self-confidence to mix with other people, to give local history talks and to write an article for the Gazette. I have now been able to achieve these goals..."*

Source: Survey respondents' 'open' comments

Even where such 'transient' loneliness has been long-lived, the project has been able to achieve positive results.

Chris's story

Chris, a previously sociable individual, became chronically lonely upon losing his job. He explained that for several years, his only social contact had been with Job Centre staff. Coming upon Ageing Better by chance, he received the encouragement and support he needed to start volunteering at a local heritage venue. This has revitalised his motivation, confidence, and social skills. Not only does he enjoy the role, he believes the experience may ultimately help him find work.

Source: Survey respondents' 'open' comments

Pearl's story

"I have found it difficult to engage in my local community, since a family bereavement. I have lots of interests, but I didn't realise how isolated and unconnected I felt towards the outside world... Since joining Ageing Better Middlesbrough, a constant thought of mine is "I'm living again". I've met new people, people who are interested in me and what I have to say and offer... I was isolated, and now I feel insulated, protected, optimistic and valued."

Source: Survey respondents' 'open' comments

Ageing Better Middlesbrough has also encountered chronic loneliness, particularly through those aspects of its service (outreach support and therapeutic engagement) which have engaged people on a one-to-one basis.

Carla's story

"I have depression, which blocks my thinking, I was lonely and isolated and also have physical health problems, these can become worse when you cannot get out of the house. I cannot thank you enough for getting me through my struggles. When you visit me, I feel as though my spirits have been lifted. The sessions have helped me with depression and anxiety."

Source: Survey respondents' 'open' comments

Loneliness and Health

Causality and statistical significance are not always established in considering the relationship loneliness has with physical health (Bekhet & Zauszniewski 2012). However, there is evidence that suggests the relationship might well be two-way; poor health leading to loneliness, and loneliness leading to poor physiological health including frailty and functional deterioration (Yanguas et al, 2018; Larsson et al, 2017). Sioberg et al (2018) conclude that when illness and physical limitation affects access to the world, and people are unable to share thoughts and experiences, a sense of worthlessness is reinforced, triggering the experience of meaninglessness.

There is less divergence in views about the relationship between loneliness and mental health. McWhirter (1990) identified the following variables as correlating with loneliness: *"depression, anxiety, suicide, alcohol and drug abuse, [and] personality traits like hostility, passivity, poor self-image, and low self-esteem".* Association with mental health may be particularly pertinent to chronic and existential loneliness (Schnittker, 2007) although some research has found that adjustment and acceptance of 'now' can push existential loneliness into the background. Existential loneliness is often linked to people facing impending death (Sand & Strang, 2006) but studies have also found experiences of disconnection and abandonment are shared by those living with severe mental illness (Bolmsjo et al, 2019).

Individual life histories may also play a part. Research suggests that chronic feelings of loneliness may be rooted *"in childhood and early attachment processes".* Chronically lonely individuals are more likely to lack affectivity, be socially withdrawn, lack trust, feel little control, and be dissatisfied with relationships (Ernst & Cacioppo, 1999). More recent research has also found that positive life events can buffer the association between loneliness and psychological maladjustment (Chang et al, 2015), and that older people's perceptions of loneliness may be heavily premised on psychological processes.

Complex lives and difficult histories

In recent months, the impact of Covid-19 has led to a telephone befriending service taking up some of the time of administrative and community development staff, giving them first- hand exposure to the overlap between loneliness, health issues, and difficult circumstances.

Chronic and complicated

Project Staff shared examples of their encounters with chronic loneliness, including someone who had experienced multiple bereavements; someone whose previous experience of physical abuse had left them haunted by recurrent nightmares; and several people with depression, anxiety or other mental health problems. Telephone befriending had had mixed results. One contributor had heard from a client that *"if didn't hear, I wouldn't be here".* Another felt that her reassurance was received positively but was simply not enough to address 11 years of intense loneliness.

Source: Focus group with front-line staff

Ageing Better Middlesbrough's psychological therapy service has routinely engaged with people with deep-seated problems, with difficult life histories, or facing complex current challenges.

The case studies that follow give a flavour of beneficiary profiles:

Case Study: Gavin

Gavin has been in touch with secondary mental health services for nearly four decades. In and out of hospital for many years, he has had no in-patient stays since a change in diagnosis and medication. Although happily married, with children, grandchildren, and friends; Gavin has felt increasingly isolated in recent years. This is partly as a result of sensory impairments which make it difficult for him to navigate space and traffic or follow conversations. His confidence declined and it became easier to 'stay home'. Gavin has been involved in the full spectrum of Ageing Better Middlesbrough: he has attended advertised events, engaged with the outreach team, and tried out specific community development activities. Most important to Gavin, however, is the therapeutic input he has received. The following themes stand out from his interview:

The value of a therapeutic approach: Gavin had long thought that he would benefit from one-to-one input, but for many years, either the option had not been open to him, or he had not been in a place where he felt able to take it on. He has received counselling in more recent times but although this has helped to some extent, it had been limited in scope ("I talked a lot, only talked") and scale ("when the six sessions... [ended]... I was a bit taken aback at that").

The interplay of physical and mental health: Ageing Better's therapeutic input focussed on the cross-over between Gavin's mental and physical well-being, giving him techniques to manage negative thoughts and feelings and helping him to devise coping strategies. Gavin had suffered with disturbed sleep patterns for many years which affected his mood and concentration during the day, and led him to ruminate on his past during the night: [My] "mind was like in a, in a jumble, it was just all jumbling up". Having started sleeping and drinking diaries and learnt about theories like 'fight or flight', Gavin now has different expectations and behaviours.

Letting go of the past: Finally, therapeutic input has allowed Gavin to 'move on'. In his words: "Well, one of the main things is, not to look back on what happened, and not to think of myself, what I was like years ago... I used to lay awake in bed for hours and hours [with] a jumble of different things coming in... that doesn't happen so much now... I have a few thoughts [but] they don't seem as jumbled as what they were... I get up, I might go and get a glass of water, I might put the tv on, I have my writing book... I don't like to dwell in the past now, I want to go forward".

Source: Individual interview

Case Study: Jenny

Jenny came upon Ageing Better when the carers' group she was supported by closed. Jenny had been engaged in health-related work, paid and unpaid, before family responsibilities became too pressing. Now widowed and retired, she cares for her disabled daughter. Jenny herself has significant physical health issues and has intermittently used secondary mental health services. She experienced abuse-related trauma in younger years which has triggered flashbacks. When she engaged with Ageing Better, she described her social circle as "virtually nil". The following themes are illustrated by Jenny's story:

The impact of service withdrawal: When their support service ended, Jenny describes herself and other carers as feeling: *"... very frightened and very alone. We felt like we had been dumped... to this day we still can't work out why it has been taken away from us... For me it was just like 'Well, that's it. Who do I talk to? Do I just go around the bend?'"*

The experience of 'loneliness in company': Jenny had constant company at home from her daughter but lived a very lonely life. She craved privacy and independent connection: *"It sounds horrible but sometimes I just want a break to do it on my own. But then I'd feel bad because I would ask her at the time and she would say, 'Why can't I come?'"*

The complexity of people's lives: As well as spousal bereavement, the strain of caring, and physical health problems, Jenny faced other pressures. A granddaughter, who she had brought up from teenage years, lived nearby with her baby, having split from her partner due to domestic violence. In addition, Jenny had been contacted by the police about the historic abuse she had endured: *"I didn't think I could do it but because there were two younger girls involved in the last 12 months, I just felt I had to..."*.

The value of a therapeutic approach: Jenny was initially in touch with an outreach worker who sought to engage her in community activities but, after a few weeks, they both felt that a therapeutic approach would be beneficial. Jenny described her state of mind on entering the service as: *"I was at the point where I just didn't want to live ... I am not saying I would have carried it through... but the point I had got to was 'If I don't get some help, I don't want this life.'"* Jenny described her therapist as 'gentle', 'trustworthy' and 'non-judgmental', and outlined the following positives from receiving therapeutic support.

- **Overcoming despair:** *"It has really helped massively... the depression was like really, really bad... I won't say it's completely gone as you get the odd day where everyday life will depress you. But I have learned how to deal with it differently and how to cope with it."*
- **Dealing with feelings of guilt:** *"I was the eldest and if I had stood up then, and had the courage to stand up and say something then, it would not have happened to the others... So all those kind of feelings and things she has supported me with... [It was] good to be able to talk about it and recognise that I have couldn't have done it and why I didn't do it... "*
- **Confidence and assertiveness:** *"I shock myself sometimes... I will say something that needed saying and I think afterwards, 'Where did that come from? Did I really say that?'... My confidence has grown a lot and I have learned I've got the right to say 'No'... without feeling guilty and without beating myself up for a few days and making myself ill..."*
- **Self-care:** *"But what I have recognised I can do is I can... take myself away into my bedroom or something... And sometimes just a good cry does me good, but I will sit and think about some of the work we have done and try work out or recognise ... where it [the feeling] is coming from. I have kind of managed to get through it just by* [that]."
- **Freedom for contact:** *"It is different for the fact that my head space is different around it, so I know that I do have a right to go out and do something... I will go into town sometimes if I have a doctors' appointment and go and sit and have a coffee... And the other thing I have done... is I have gone to the gym [through] Get Active on prescription."*

Source: Individual interview

Connectedness, flexibility and time

Research suggests that if older people can no longer maintain social contacts, care or support workers have the potential to act as a 'relational anchor', someone connecting the individual with the wider world. However, this can be undermined if contact is too brief, or if the person providing care is not consistent (Larsson et al, 2017). Sjöberg et al (2018b) found that being the focus of someone's concern and having meaningful exchanges of thoughts and feelings could ease the experience of loneliness. Ageing Better Middlesbrough's practice reinforces such findings:

The importance of getting to know someone

Front line Staff explained that value was added by really getting to know an individual. In one example, making telephone contact with someone whose life had been taken up with caring for an elderly parent had gone from brief catch ups to real, two-way, full conversations. The overall view amongst staff was that if contact was not meaningful, benefits did not accrue. Accounts picked up on how unhelpful it was to people's experience of loneliness if the visitors they did have – typically paid carers – were constantly changing, preventing beneficial relationships to develop.

Source: Focus group with front-line staff

The capacity to tailor the length and frequency of support to individual needs was hugely valued by staff. Rather than fitting the person into a fixed format, the approach was able to fit itself around the needs of the person. This did not mean fostering long-term constant dependency; it meant that staff could respond as and when needed, whilst allowing people to navigate their own lives.

Flexibility without dependency

One therapist described how Ageing Better Middlesbrough had enabled them "to find new, creative ways of working… Due to the flexibility and long-term support that we can provide, we are able to spend time with people and see them as individuals rather than labelling them with the condition that they have. My knowledge has improved from the people who engage, allowing me to avoid assumptions that people necessarily need you to do things for them. The reality is they just need someone to spend time with them, helping them to help themselves."

Source: Stories of change

The approach is also validated by the experiences of Jenny and Gavin, the subjects of the case studies cited above:

Keeping someone on board, not casting them adrift

In the aftermath of her husband's death, Jenny realised that the past abuse had surfaced. A mental health professional, recognising that she was facing issues that went deeper than bereavement, referred her for independent counselling "but it was six weeks, so you just get the courage to talk about it and it ended. And I found that was worse because you know you took it away. And I did for a little while pay for the counsellor that I had there privately… but I couldn't afford it…". Jenny's therapeutic support through Ageing Better had an end point, but it was not time-limited from the start. Whilst apprehensive about 'going it alone', Jenny felt "a lot more optimistic", and believed the consistent therapeutic support had given her "an inner strength".

Gavin, on the other hand, was open in his disappointment that the sessions were coming to an end. However, there was no suggestion that he expected continual support; he simply wanted to access help when he judged it was needed: "I do believe every now and then I've got to offload to someone, who… is in the position to help me… someone who has got the knowledge."

Source: Individual interviews

Journeys and progress

Finally, but importantly, Ageing Better Middlesbrough's psychological therapy service has achieved positive results. Whilst to some extent, quality might have been achieved at the expense of quantity, the progress made – from a very low base – has been impressive.

Ageing Better Middlesbrough: Outcome Measures (up to June 2019)

Psychological therapy is concerned with intervention, rather than prevention. Unsurprisingly, therefore, people engaging with the service had a different profile to that of Ageing Better Middlesbrough overall. Analysis carried out in 2019 established that they were more likely to live in a disadvantaged area, and more likely to have long-standing physical or mental health issues.

The tables below give an indication of the degree of need at the point of entering the service, and the value of the psychological therapy received.

Psychological Therapies: distance travelled by score (mid-2019)

		Mean scores		
Measuring...	**Validated measurement tool used**	**Entry**	**Exit / latest**	**Change**
Depression	PHQ-9 (scored between 0 and 27) higher scores indicate higher levels of depression	15.5	6.1	-9.4
Anxiety	GAD-7 (scored between 0 and 19) higher scores indicate higher levels of generalised anxiety	13.2	5.4	-7.9
Loneliness	DJG (scored between 0 and 3) higher scores indicate higher levels of **emotional loneliness**	2.6	1.3	-1.3
	DJG (scored between 0 and 3) higher scores indicate higher levels of **social loneliness**	2.2	0.9	-1.3
Wellbeing	SWEMWEBS (scored between 7 and 35) higher scores indicate higher levels of wellbeing	16.5	25.00	+8.4

Psychological Therapies: distance travelled by category (mid-2019)

		% of beneficiaries in the categorisation	
Validated tool	**In a category suggesting...**	**On Entry**	**On Exit**
PHQ-9	Moderately severe or severe depression	58%	15%
GAD-7	Severe anxiety	54%	8%
DJG	High levels of loneliness	67%	18%
SWEMWEBS	Low or very low levels of well-being	84%	19%

Conclusion

The analysis above points to the complexity of loneliness, to its interplay with health (mental and physical), to the importance of human interaction, and to the value of truly person-centred care. This, and the model for Ageing Better's outreach and psychological therapy services, tally with recommendations of the British Geriatrics Society and Royal College of Psychiatrists (2019). This highlights the need to be responsive to loneliness amongst people living with complex and longstanding physical and mental health problems and/or with complex social needs and calls for a greater focus on older people for whom socialising itself is a challenge, and who may need one-to-one support.

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