Working and engaging with older people with poor physical health – learning from Ageing Better

Introduction

Ageing Better is a test and learn programme. It is collecting information and insights from across 14 partnerships to identify learning that will be useful for other programmes and organisations delivering activities aimed at reducing social isolation in people aged 50+.

We have grouped our national learning from Ageing Better into three themes:

- CONTEXT - We know from Ageing Better that the reasons for social isolation are many and varied and happen for a myriad of reasons including macro issues such as inequalities and deprivation as well as personal circumstances. These often occur in combination meaning people's situations are complex.
- CONNECTIONS – The people who are most socially isolated (where isolation is entrenched and embedded) will need some level of one-to -one support to help address their isolation.
- ECOSYSTEM – The Ecosystem is fundamental to addressing social isolation as it is the space where individuals connect with the community. It works preventatively to keep people socially connected and steps in when social isolation occurs. It includes interventions that people 'need'; activities and groups people 'want' to engage with; opportunities and provision for people to set up their own groups and community development, that includes age friendly activity.

This paper focuses on our learning around working and engaging with people living with poor physical health. It links into our national learning in the following ways:

- Understanding the CONTEXT – understanding why people who have poor physical health can be at risk of social isolation and loneliness.
- Developing the ECOSYSTEM – identifying ways to develop an offer that people with poor physical health can and want to engage with.

It is based on the learning and insights from five Ageing Better areas : Birmingham, East Lindsey, Leeds, Middlesbrough and Thanet.

The paper provides learning for third sector organisations who are working with people who have poor physical health and highlights the specific considerations that need to be made when working with this group.

Purpose of this paper

We have found across our Ageing Better learning that there are a set of common themes and approaches relevant to tackling social isolation and loneliness. These include working in a person centred holistic way to build a relationship with an individual, taking time to find out their interests and strengths, identifying any specific barriers they may have and then supporting them, through a variety of means to make meaningful social connections. This applies equally when working with older people who have poor physical health.

The purpose of this paper, however, is to outline some of the additional information, steps and approaches that need to be borne in mind when developing wrap around services for people with poor physical health in order to reduce social isolation and loneliness. Periods of poor physical health or declining physical health are risk factors for becoming socially isolated. It is therefore important to be aware of the particular risk factors and barriers that may impact the individual you are working with. Trying not to make assumptions and instead taking time to build a relationship of trust so as to understand an individual's particular challenges.

As in so much of Ageing Better learning, the role of a connector can have a particular part to play in supporting people with poor physical health and we outline some of the additional elements to consider. The rest of this paper seeks to highlight those factors and links to our previous learning to maximise support and access to activities that can help develop and maintain vital social connections.

Context

Poor physical health as a risk factor for social isolation

Having poor physical health covers a broad range of situations. This can include having a chronic condition or experiencing an ongoing deterioration of physical health. It can also include situations that relate to a specific (short or longer) period where someone may not be able to do what they were used to doing. So, for some, poor physical health may be an ongoing condition that they are learning to live with. For others, poor physical health may be transient and represent a period of their life when their normal circumstances change.

Within Ageing Better nationally, 59% of participants who completed our Common Measurement Framework (CMF) questionnaire said that they had a longstanding mental or physical illness. Please see Appendix 1 for more information on this CMF data provided by our national evaluation partner, Ecorys.

Our learning from across Ageing Better highlights how transitions in our lives can represent a risk factor for social isolation and loneliness, although not everyone with poor physical health will necessarily go on to experience social isolation or loneliness. But however poor physical health is "caused" it represents a key life event which can significantly impact on a person's social connections and support networks.

Impacts of poor physical health on social isolation and loneliness

Our insight from Ageing Better suggests poor physical health impacts on social isolation and loneliness in a number of ways:

- As a direct result of the condition – Reduced mobility, energy and overall wellbeing can mean people feel less able to connect in their "usual" ways. We have also found there is an interrelationship between someone's deteriorating physical health and the psychological impact. As well as the practical barriers people face, some people don't feel psychologically able to get out and about, attend things, meet with friends or interact at local bumping places and so lose social connectedness resulting in a spiral that can lead to social isolation and loneliness becoming entrenched.
- Finance – As well as the direct costs of having poor physical health which can include a reduced income or becoming more reliant on benefits, our learning work also identified some of the hidden costs. We heard that for some this means having to choose between their health and other needs resulting in being unable to afford the costs associated with attending groups or social activities so increasing their social isolation and feelings of loneliness.
- Transport - Transport can be a barrier for people with physical health needs living in both urban and rural areas. Even where transport is affordable, journeys can often involve multiple buses or taxis. Where multiple modes of transport are required this can mean waiting at stations or bus stops which for people with poor physical health can be an additional challenge.
- Hospital Transport - Hospital transport is often provided for people in poor health to access medical appointments. But this too can have its challenges with the timings of the transport organised around meeting the majority of user's needs rather than those of an individual. This can mean people waiting for several hours following completion of their treatment for the bus to take a group of patients home at the end of the day. This in turn can impact on an individual's ability to remain connected as part of their usual groups or activities due to time constraints or tiredness.
- Loss of control - Our insight from delivery in Ageing Better areas is that experiencing periods of poor physical health can lead to people feeling that they lack control. The diagnosis and period of poor health can, in itself lead to feelings of growing dependency with a perceived loss of independence and control. People can feel that the ownership of their own health now sits with health professionals. This feeling of disempowerment can lead to feeling less in control, less certain or confident and so more isolated, all of which can act as a negative spiral on mental health and so overall health deteriorates.
- Care interventions – Medical appointments and care packages are an essential area of support for people with physical health conditions. We heard that, the feelings of loss of control could be particularly prevalent at the stage when a care intervention was introduced. We heard that some people in effect felt bound rather than supported by the administration of their care package.

Because people needed to be at home to receive the care intervention this often meant that they stopped interacting with the groups and people they would otherwise connect to. Where someone is not given a specific time for a support or health visit and has to wait in all day then they are having to choose between the health appointment or attending a group or social activity that they enjoy. Ideally that shouldn't be a choice someone has to make on a long-term basis.

Covid-19

Covid-19 has clearly had a range of impacts on people with poor physical health. These include the immediate requirements and implications for people who were asked to shield as well as the reduction in respite and other support services and networks available during lockdown. Less immediately obvious has been the impact of the suspension of non-emergency services such as chiropody resulting in a deterioration in people's foot health with a linked impact on mobility.

At the same time, the switch to groups meeting virtually and the explosion in online and telephone activities has meant an increase in social connection for some people. This gateway for people for whom accessing groups or social connections outside of the home is challenging, has opened up a world for some. As the slow recovery from Covid-19 takes place with a transition back to face to face opportunities, it is important this gateway is not forgotten. We discuss the importance of this in our "Positives of Digital" learning report (link below).

Key Message: Poor physical health is a risk factor for social isolation and loneliness. Poor health can lead to feelings of loss of control. Elements of support services (e.g. care package) can act as a barrier for some in maintaining social connections and people are often unwilling/unable to challenge what has been offered. Transport can be a huge issue linked to both cost and availability. Covid-19 linked support has opened a gateway for some people with poor physical health to connect more with their local community through digital and telephone support.

Connections and the ecosystem

Our learning from across the programme is that social isolation and loneliness can be mitigated by having an active ecosystem that helps a person stay connected to their community throughout the life events and transitions people experience. But we know that where social isolation and loneliness has become entrenched a period of one to one more intensive support for an individual is often needed.

As we have already set out, not everyone with poor physical health will become socially isolated or lonely but it is a risk factor. Some people will need help setting new goals and targets based on their new circumstances, with some needing help to manage a crisis situation. Others will move in and out of periods of fluctuating health and their attendance at groups or activities may be more sporadic as a result.

It is important to develop, facilitate and support the social opportunities that people with physical health needs can and want to engage with. The considerations required include tailoring the activities for people to dip in and out of, as well as to take part in different ways depending on the state of their health at any given time.

Building connections

For people where social isolation and loneliness has become entrenched or where poor physical health is severely impacting on an individual's ability to make connections a period of more intensive support may be needed to support them through this phase. Within Ageing Better this initial one to one support is often carried out by a "Connector". Often the key referrers for this support come from Primary Care e.g. GP through a specific health referral following initial diagnosis or deterioration. Ageing Better areas have funded a wide range of "connector" activities. These have often relied on referrals from primary care to "identify" people in need.

We heard through Ageing Better that this referral process with primary care can be more effective for connecting with people in poor physical health than secondary care (e.g. via hospital or outpatient clinics). Ageing Better areas have been involved in a number of interventions and projects linked to Social Prescribing and so it could be argued that there is more of a developing culture and referral network being established between primary care providers and "connectors".

Where Ageing Better areas piloted work to explore referrals directly from a secondary care setting, we heard that they had experienced problems. For example, one proactive initiative with the aim of helping to link people into previous or new community connections such as lunch clubs as soon as possible following their discharge from hospital struggled to get the health referrals. This was as a result of paperwork blockages, closure of files once someone left a hospital, people's roles, awareness of the service and a lack of understanding of the totality of the "patient journey" and need to join things up.

Ageing Better areas have found that for some people with poor physical health what starts as a physical health problem can also translate into a mental health impact. A deterioration in physical health can lead to a reduction in confidence and mobility contributing to a situation where for a variety of reasons someone may not feel either psychologically or physically able to get out and socialise or meet people in their local "bumping places" such as shops and parks. Poor physical health can therefore quickly impact on an individual's ability to engage with groups or to connect with people socially. Poor physical health is also linked to a wide range of other factors which are in themselves risk factors for social isolation and loneliness. These include depression, loss of self-confidence, poverty and financial worries with the potential to impact on an individual's willingness to reach out and ask for help and support.

As we set out in the previous section a period of poor physical health can lead to feelings of loss of control and helplessness. But Ageing Better areas identified that people could feel so disempowered by the experience and impact of poor physical health that even when working in a person centred way it was hard to "draw out" or help them to identify the steps that could improve the quality of their life and their ability to make connections. This can be the case where someone's physical health is deteriorating or fluctuating so adding to the cycle and mix of emotions.

Ageing Better areas told us the value of using a *recovery focused model* when working with people who have poor physical health. This encourages people to think about where they want to get to with their health and recovery and then plots a pathway to get there. Ageing Better areas also identified how important it was to help people articulate what they wanted and to not make assumptions about what those might be. This relates to the importance of working with an individual on an individual basis to establish what they wish to achieve and the support that may be

required as a result.

Ageing Better areas have continued to evolve the tools and techniques they use to connect with people with poor physical health. This includes making home visits as well as speaking to people on the phone or during community sessions. During Covid-19 many of the same tools and techniques remained but with the addition of outdoor interactions. Some continued to make home visits, making use of PPE as well as undertaking garden visits and short walks to help build and maintain connections and rapport. These short walks are something that many Ageing Better areas plan to continue as they have proved to be highly successful.

Ageing Better areas have also made use of telephone befriending as another way of building a relationship on which to identify and help tackle some of the practical barriers people with poor physical health can face. This building rapport is key as people in crisis or in difficult situations may also be feeling anger and frustration. Building rapport helps unpack this anger and frustration and so can help people move forward.

Overcoming the barriers to making connections

There is a clear need to identify and build up an understanding of the specific, potentially complex barriers each person faces and then to work, often via a connector, collaboratively with partners to find ways to help overcome them.

One of the issues highlighted was that of organisations and agencies working hard to deliver within their sphere of influence but in effect delivering within a silo. There was not always an understanding of the need to look at how well (or at all) the offer delivered on the identified needs and wants of the person involved or how that impact could be further maximised by linking and working with other partners.

We heard that in some cases it was relatively simple blockages such as waiting for a grab rail or ramp to be installed that were stopping people from being able to get out and re-engage socially. These seemingly simple things are important not only in their own right but because the longer a person can't get out as a result of not having a ramp etc., the less social connection they have and the greater the spiralling impact on a person's self confidence resulting in them needing greater support. Having a "connector" intervention could help navigate the partners involved in a practical and timely way.

We also identified some of the more complex problems often linked to social care support not always working as part of a person centred approach. This could affect someone's willingness to take up support that would help them feel connected. We identified examples where the care on offer didn't always meet the "wider" holistic needs of an individual sometimes leading to the care support being declined. Often we heard that the care offer took place at a time which in effect meant that people thought they had to choose between receiving essential care or taking part in activities. For many people with physical health requirements there may already be a limited number of activities that they can engage with. Building connections with people can help identify the source and reason for a lack of engagement. The "connector" can then work with partners to overcome these practical solutions.

Ageing Better areas identified that even when working in a person centred way it was not always possible to overcome the barriers to engaging with and receiving the social care that worked for them. But we found that even when people did not take up an offer, going through the process of engaging with social care helped them understand what support would be available at a later point when they needed or felt ready to accept it.

We heard how grateful people are for the support they receive so don't feel that they want to impact delivery in any way or "make a fuss". Often people don't realise they can change the day, time or even the location at which care visits take place. This was one of the key areas of support that areas told us they may be involved in working with people. People can miss or not appreciate just how much the delivery of a care or treatment package is impacting on an individual's ability to develop or maintain a socially connected life and so leading to greater experiences of social isolation and loneliness.

Ageing Better areas highlighted how important this "advocacy" role was in empowering people to know who and how to contact if there was a particular blockage in their own care and support. As described above, the issue may not be a blockage but could be the way in which the delivery of a care package is not meeting an individual's needs. Changing the day a District nurse visits may mean an individual now being able to attend a group regularly again. This involves providing practical information and assistance, but it also involved recognising that confidence was often also a barrier. Often people needed support to advocate for themselves with those providing the care.

Keeping connections going

Across our Ageing Better learning we have identified the important role that groups can play in helping people stay connected. Groups can provide a regular opportunity to connect and play a hugely important role in the ecosystem that supports people to remain socially connected. Our wider learning paper on Groups highlights some of the key considerations when running groups. But for people with poor physical health, or those who have a fluctuating health condition there are three key components which groups and those organising groups need to especially consider.

First is the balance between fixed and flexible. Sessions should take place at the same time each week so that people can arrange appointments, personal care or care for others around this time. Changing times can cause a ripple of challenges for those attending. But it is also important to build in degrees of flexibility. Groups need to create an environment where members can dip in or out, depending on their own availability and any fluctuating health conditions without damage to the group dynamic. This also helps the group and social connections it provides remain a "constant" for an individual even where other external, physical and mental conditions may be in flux.

Second is having an experienced facilitator who can manage different physical abilities regardless of who attends the group or what the main focus of the group is. We heard that it was better to try and integrate different abilities as far as possible to encourage and share skills and experiences. This was particularly true in the case of physical activity classes or groups where we heard how an individual's own perception of their capability could be a barrier to engage and how having mixed ability groups helped foster an "I'm not as bad as I thought I was" mentality. Additionally, not "grading" a class or group by ability meant that people could continue to attend even if they had a "bad day" or their condition deteriorated. We heard how important this was in fostering connections and supporting meaningful friendships to develop.

Thirdly, the importance of taking a person centred approach and exploring with an individual their specific support needs. This includes not making assumptions but thinking carefully and asking people about what could help support their participation. One such example was checking whether the taxi company that an organisation used was actually large enough to fit a mobility scooter.

The importance of digital

We highlighted in our Positives of Digital paper, how important local digital offers are and in particular the importance of considering the needs of people with poor physical health when designing opportunities for people to connect with their local community. One of the issues raised by social prescribers pre-pandemic was the lack of face to face opportunities available for people with physical health needs and we heard that the increase in online opportunities has opened up more opportunities for some as a result.

The transition to digital platforms, has been hugely beneficial for some groups of people. It has allowed people with physical health challenges to be a more active participant in groups and activities and therefore be more connected. We have learnt that working to reconnect with people takes time, needs to be done in a person centred, holistic way often through the development of a relationship built on trust. A distinct feature of the digitial interactions created through Ageing Better is that they are promoting meaningful connections. This means creating opportunities for people to get to know one another and to connect in a way that is meaningful to them.

As we have already referenced, people who have poor physical health have benefited from the increased digital offer that has been created by Covid-19. Ageing Better areas have funded and facilitated people to access technology so they can access what they need. Covid-19 has also provided a motivation to get people digitally connected. This has had an unexpected benefit to people managing a health condition as by engaging with the digital offer they are in a better position to manage their health and condition. This includes making use of particular Apps for particular conditions (e.g. COPD) or simply helping them manage their prescriptions online. This engagement with the digital world has helped some people with a feeling of regaining control of their condition.

Key Message: People with poor physical health are likely to have interlinking barriers that limit their ability to make a connection. These could be practical or psychological. Building a rapport is key to helping unpick and unpack these barriers and ensures people get to a place where they want to be. Delivering effective group sessions and wellbeing opportunities involves using skilled instructors or ensuring one to one support is available to help people regain confidence about their health. Digital has been an important lifeline for some people with poor physical health during Covid-19 and should continue to be an important feature of delivery in those organisations seeking to work with this group.

Further information

Ageing Better national learning reports

- Positives of Digital
- Positive Mental Health
- Bridging the Digital Divide

- Groups
- Economy and Personal Resources
- Role of Connectors
- Social Prescribing - Health Referrals
- Telephone Befriending

- Time to Shine (Leeds) - Supporting Wellbeing and Independence for Frailty

More information on the Ageing Better Programme including insights from across the programme are available at Ageing Better

Appendix 1

Ageing Better participants with a longstanding illness.

Introduction

The following analysis is based on data from the Ageing Better Common Measurement Framework (CMF) Database. Participants have been included in the analysis if they responded that they had a long-standing illness. This is defined as a physical or mental health issue that has lasted or is expected to last for at least 12 months[1]. Data presented were collected between 23rd October 2015 and 23rd March 2020 (pre-lockdown).

Data relates to participants completing a CMF questionnaire, so is self-reported by participants. The data might not be fully representative of all Ageing Better participants because taking part in the survey is not mandatory and is not suitable for individuals who are unable to consent to taking part (such as participants with dementia). There is an accompanying methods note with more information.[2]

[1] CMF question: "Do you have any long-standing physical or mental illness, or disability? By 'long-standing' I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months."

[2] https://www.tnlcommunityfund.org.uk/media/documents/ageing-better/prog_fulfilling_lives_ageing_better_learning_report_4_annex.pdf?mtime=20200313105423&focal=none

Demographics

Overall, 59% of Ageing Better participants (n = 23,420) responded that they had a longstanding illness. Participants with a longstanding illness had a mean age of 70 years-old.

Gender	Without longstanding illness (%)	**With longstanding illness (%)**
Male	31	**33**
Female	69	**67**
Base: total sample	*(9,457)*	*(13,461)*

Ethnicity	Without longstanding illness (%)	**With longstanding illness (%)**
Asian/Asian UK	16	**13**
Black/African/Caribbean/Black UK	7	**7**
White	73	**76**
Mixed Ethnic	1	**1**
Other Ethnic Group	3	**3**
Base: total sample	*(9,319)*	*(13,259)*

Living arrangements	Without longstanding illness (%)	**With longstanding illness (%)**
Live alone	42	**54**
Live with family	18	**15**
Living with spouse/partner	38	**27**
In residential accommodation	1	**3**
Other living situation	1	**2**
Base: total sample	*(9,016)*	*(13,151)*

Sexuality	Without longstanding illness (%)	**With longstanding illness (%)**

Heterosexual	96	**96**
Gay/lesbian	3	**2**
Bisexual	1	**1**
Other sexuality	<1	**<1**
Base: total sample	*(7,866)*	*(11,507)*

Carer status	Without longstanding illness (%)	**With longstanding illness (%)**
Carer	21	**21**
Not carer	79	**79**
Base: total sample	*(8,995)*	*(12,877)*

Wellbeing and loneliness

On entry to the programme, 59% of participants with a longstanding illness had high loneliness[3] and 54% had low wellbeing[4] .

Variable	Without longstanding illness (%)	**With longstanding illness (%)**
High loneliness (UCLA)	36	**59**
Base: total sample	*(6,697)*	*(9,680)*
Low wellbeing (SWEMWBS)	30	**54**
Base: total sample	*(6,686)*	*(9,948)*

[3] A score of greater than or equal to 6 on the UCLA Loneliness scale.
[4] A score of lower than 20 on the Short Warwick–Edinburgh Mental Well-being Scale (SWEMWBS).