Working and engaging with carers – 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+.

This paper focuses on our learning from Ageing Better in relation to working and engaging with carers. It is based on the learning and insights from the Birmingham, Greater Manchester, East Lindsey, Sheffield, Isle of Wight, Leicester and Leeds Ageing Better areas who attended a workshop to explore this theme.

At the end of this report we provide links to specific learning reports from Ageing Better areas on this topic.

Context

Carers are the enormously important but often unsung heroes of the health and social care system. According to Carers Trust, there are approximately 7 million carers in the UK, which equates to around 1 in 10 people. This number is increasing and it is estimated that the number of carers will, by 2030 have increased by 3.4 million. The value of unpaid carer's support is estimated to be £132 billion[1].

The contribution made by carers is often overlooked. The focus of health and social care is often the cared for person but, 65% of carers aged 60-94 have a long-term health condition themselves. A similar percentage (69%) say that being a carer has had an adverse effect on their mental health. One third of carers in this age group say they have cancelled a treatment or an operation for themselves because of their caring responsibilities.[2]

Carers themselves need and deserve support to help maintain their caring role. We

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[1] https://www.carersuk.org/news-and-campaigns/news/unpaid-carers-save-the-uk-132-billion-a-year-the-cost-of-a-second-nhs
[2] https://carers.org/key-facts-about-carers-and-people-they-care

also know that carers themselves are vulnerable to social isolation and loneliness. Research by Carers UK[3] identified how 8 out of 10 carers have felt lonely or isolated as a result of their caring role. In the case of carers who have been caring for 10 years or more this rises to 84%. The reasons carers have these feelings of loneliness and isolation are varied but around half explain that they lack the time to take part in activities that would help reduce their social isolation. Around half also identified the difficulty they had leaving the home. Around a third felt uncomfortable talking about their caring role with friends and family and just less then a third identified finance as a barrier.

Across Ageing Better, projects have worked to deliver activities and interventions focussed specifically and targeted at carers. But it has also connected to carers through projects and activities aimed at the "cared for" person. Caring in itself can invoke a range and complexity of emotions - we heard that caring could be challenging, exhausting and anxiety inducing as well as providing love, accomplishment and value. It is important to remember that each carer is an individual and each carer's circumstances will therefore be different but across the work Ageing Better has done with carers we have found some common characteristics:

- The caring role is often characterised by feelings of anxiety – these include anxiety about the future, fear of being left alone, concern they are doing the right thing and concern over what it will mean when the caring role ends

- The role of carer can also lead to social isolation and loneliness – carers can become increasingly isolated from friends and family as routine opportunities for social interaction disappear with an increasing sense of loneliness for the carer

- Caring can raise challenges to an individual's identity – a carer may not wish to see themselves as a carer or accept the label of carer. We also heard that carers can also experience an increasing loss of self-confidence and self-esteem over time.

- Caring can also result in changes in relationships – this can be the relationship a carer has with the cared for person (especially if they are the partner of the cared for), but also their wider relationships with friends, family and professionals as a result of supporting the cared for person

- Post carer role – we heard a great deal about the additional challenges and support needs for people who have been carers after the cared for person dies.

> **Key Message:** Carers are an enormously valuable part of the social care system. However, a caring role as well as being rewarding, can be enormously challenging. Caring is a risk factor for experiencing social isolation and loneliness. Carers need both formal and informal support to help them maintain their caring role.

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[3] https://www.carersuk.org/images/News__campaigns/The_world_Shrinks_Final.pdf

Connections

What prevents the making of connections?

Connecting with carers and providing them with support has its own unique set of challenges.

Carers often occupy a position where they themselves prioritise the needs of the cared for person over their own needs as do also the services they connect with. This means they will often delay accessing the support they need in order to keep their caring role going. A further consequence is that any connection to a carers support organisation will often only be made once the carer is in crisis, when they don't know what else to do.

We heard that carers will often not have accessed support prior to entering crisis for a number of reasons including:

- Suspicion of or previous bad experiences with service providers or the statutory sector including the NHS and Adult Social Care. There is often concern that statutory services will become involved if a carer does access support

- The carer may not recognize themselves as or identify with the term "carer" and so will not recognize the support that is targeted towards them. People may be caring for someone and in employment and so not always appreciate that carer support also includes them. This can also be wrapped up in pride or duty, with people thinking they can or should be able to do things on their own

- There can also be specific cultural and language issues surrounding the carer role for some communities. Older carers may need to learn a new set of vocabulary and technical jargon, which can add to the challenges of accessing the relevant information, particularly if English is not their first language. Some BAME carers have to address unique challenges. For example, some people with dementia may lose their ability to speak English, especially if only learned in mid-to-later life. The carer may lose the ability to communicate fluently with their relative or will see a significant change in relationship due to this. Additionally, the term "carer" may not always translate effectively and amongst some cultural groups caring for a loved one is seen as just part of life's course. In some BAME communities there may be cultural taboos in identifying that individuals need support as a carer, especially with regards to respite. Sometimes a more active approach by a trusted organisation with a strong community identity may be needed.

- Lack of awareness around just what services may be available and how to access them as well as the complex surrounding bureaucracy. This can mean that some older carers do not apply for certain entitlements or do not question decisions they feel are incorrect, added to the worry that what they do have may get taken away when further assessments are done. A particular issue is where the person being cared for does not have a diagnosed illness. Added to which someone who is already isolated and lonely may find it difficult to access appropriate information sources.

- Anxiety (and sometimes guilt) on the part of the carer about leaving the person they care for whilst they access services for their own needs or for their own self-care. We also heard about the lack of affordable/free respite care for carers to access in order to be able to make connections.

- Household finances can be constrained with carers not accessing their full range of entitlements. There can also be hidden costs associated with accessing services particularly in rural areas where both transport costs and links can be a considerable barrier

- Employers can lack awareness and understanding of the caring role. This in turn creates barriers for the carer, who prioritises the care of the cared for person above their own needs.

One of the features linked to carrying out the role of carer can be the loss of their social connections. Making friends and some of the weak informal social connections that come from having an active social life can fall away. This in turn leads to the lack of opportunities to help connect the carer to local services or support networks or to raise awareness of the support that may be available.

Tools and techniques to help connect and engage with carers

Despite the very real challenges which carers face, the learning from Ageing Better is that there are a wide range of different tools to help connect to and engage with carers:

- Early links - Providing information and support for the carer when the cared for person first receives a diagnosis can help put support services on the carer's radar as they take on a caring role

- Develop a wide range of community connections including connections with GPs, hospitals or local services such as libraries. This will help raise awareness of support between all the services in the places and spaces that carers are likely to access. This increases the chances of the carer being made aware of information that is relevant to them. Social prescribing models can also be used to reach the carer as well as the cared for person

- Focus on offering practical courses and practical solutions that will help to meet some of the carer's problems or challenges. A carer's time is by definition limited so be very clear about what someone is likely to gain from a session you put on as carers are more likely to engage if they can see they will gain something specific from the session. This can then be used as a starting point for building further relationships and social connections

- Use ex-carers as volunteers for the service. This has a dual function of ensuring there are people who understand the carer's role and the journey they are on, as well as providing the ex-carer with a purpose and focus

- Raise awareness in as many locations as possible about the support that is available to carers. Ensure GPs are aware of the support that is there and the role they can play in connecting people to it. Create local partnerships to help the message to reach as wide a range of groups and people as possible. This will also help reduce any stigma felt about accessing the support.

- Present self-care for carers as important in enabling the carer to care better and for longer. Offer activities on different days and times so carers are better able to access at least something during the week

- See the individual beyond their caring role, with their own interests and experience. Try to support or provide activities for carers to attend either alone (e.g. for peer support or respite) or along with the person they care for if they wish.

- Offer at least some support and interaction with carers in their home. This

tries to reduce the additional stress of having to find care for the person they care for in order to attend a meeting. Develop on-line opportunities for people to connect as part of the package you offer for carers.

> **Key Message:** Connecting with carers can be challenging and they will often prioritise the needs of the cared for person above their own. However, there is considerable value in supporting carers to build social connections that will not only have long term benefits for their own personal wellbeing but also to their ability to maintain their caring role. Specialist organisations that provide support to carers can provide valuable support to voluntary sector organisations with a wider more general remit.

What works?

Types of activity

Through Ageing Better, a wide variety of different activities have been piloted and developed. Ageing Better has also helped carers support organisations to expand and further develop their existing services.

We heard that the following approaches have been successful at connecting and engaging with carers:

- Providing telephone support – for all the reasons we have outlined above, carers can often find it difficult to attend sessions and activities away from the cared for person. Telephone support is a way of providing carers with connections without needing to leave the home. Telephone support, however, benefits from an initial face-to-face meeting at the start of the relationship

- Supporting emergency planning – we found that supporting carers to consider what they would do in an emergency if something happened to them was a good way of engaging them in wider discussions about their own self-care and contingency plans for the cared for person. This can include helping to bring in social connections by stealth

- Offering a range of different groups, activities and networks for people – carers are not one homogenous group and as such the support and type of groups developed need to reflect this diversity and variety. Greater Manchester flagged that they had found a lack of carers support groups aimed at men and that also when offering support to people 50+, there are more groups aimed at carers aged 75+ than people 50-60 who may want totally different things and have different interests.

- We found groups targeting specific groups of carers could be particularly effective e.g. men only, ones with a self-care focus and creative workshops. Where feasible we also found it beneficial to open up existing interest related groups to carers, whilst being mindful of what support the carer will need in order to attend e.g. availability of respite care

- Providing sessions with a specific knowledge or information focus – we found carers worked hard to be able to attend sessions which included a skills or knowledge development focus. This included training on dementia, independent living and digital and IT activities

- Supporting carers to set up and develop their own groups – we found groups could be sustainable if carers were given responsibility for their management

and delivery. However, we found this needed to be managed carefully as current carers can feel they have enough organisation and management to do in their lives already. This can be a situation where there needs to be more support by paid staff to set groups up to meet the needs identified by carers. We found supporting not forcing or imposing expectations on people to take the lead was critical to the success of this

- Helping carers to use support services creatively – we found carers could benefit from support to help them use, access and fund unofficial respite. For example, hiring a cleaner or gardener to provide themselves with more time. At the same time do see carers as experts of their own experience by not assuming they lack knowledge about the support options available – it may just not be suitable for them.

Important considerations

We also found that there were important considerations for projects or activities looking to specifically support carers. These include:

- Consider the length of the course or activity as well as start times – ideally courses should be relatively short, around 6 weeks. If courses are too long, carers drop out as other commitments take precedent. We also found courses needed to start at a time when carers could make use of any subsidized transport

- Being clear on the outcome of the session or activity – we found this could be around self-care or fun, or something practical, like "lifting" training. It is still important to include a social element to the session but when promoting it is worth stressing the "focus" of the event. We also found that, particularly older carers, needed encouragement and education around the value of looking after themselves – in their own right but also in order to help them care as effectively as possible

- Making careful use of language – people do not always recognize themselves as carers or want to be seen as a "carer" which can have connotations with work or the statutory sector. We found organisations using creative ways of communicating what caring is, without using the word carer helped people connect to the organization e.g. "do you help look after" etc.,

- Flexibility is key – carers should not be excluded from groups because they may have missed sessions. Any course or activity needs to allow for carers to take part when they feel able. An open door, flexible policy supports this as does having had an initial face-to-face meeting early on to help build a relationship of trust so that the person can talk about what is important to them and how you can help support them to make that happen

- Recognizing the hidden costs, time and effort is required of a carer when attending a support service or activity and they are away from the cared for person. As well as the costs and time of the group there may be hidden costs such as the time taken to travel to the session and the implications this has for any "finite" respite care

> **Key Message:** The number of carers is going to increase and their contribution to the social care system will grow. We would encourage funders and commissioners to encourage and support collaboration between organisations working in this area and to provide long term support to those organisations that can evidence their success of working with and supporting carers.

Further information

Bristol Ageing Better - [Reaching and engaging older people who are carers](#)

Greater Manchester - How VCSEs can support older carers as employees or potential employees https://ambitionforageing.org.uk/VCSEcarers

More detail on our wider insights from across the Programme to date together with an overview summary of our learning to date are available at [Ageing Better](#)