

In March 2019 projects within the BAB programme came together with other organisations working with older people in the city to **learn more about reaching and engaging older people who are carers**.

Research tells us that people who are carers are at particular risk of loneliness and isolation; this group is therefore a particular focus within the BAB programme. We want to ensure that staff and volunteers working with older people in Bristol feel equipped to identify older carers, to make their projects inclusive for older carers, and to be more aware of the support available for them.

Two workshops were run by [Carers Support Centre](#) in conjunction with [Bristol & Avon Chinese Women's Group \(BACWG\)](#) and were **co-designed and co-delivered with carers**. This Learning Digests presents the key learning and ideas from these two workshops.

## Context



### Who is a carer?

The definition of a carer used by Carers Support Centre is someone who **provides support** to family or friends who **could not manage without this help**. This could be caring for a relative, partner, friend or neighbour who is ill, frail, disabled or has mental health or substance misuse problems. All the care they give is **unpaid** and there is **no minimum or maximum number of hours** that quantifies someone as a carer.

This support might involve **practical household tasks** (e.g. cooking, cleaning), **personal care** (e.g. bathing, collecting prescriptions) or **emotional support** (e.g. listening, offering advice). They may live with or near the person they care for, but **may also live in a different city or country**. The caring role may begin suddenly (e.g. following an illness or operation) but may also involve a gradual increase in caring responsibilities over time. Many people do not see themselves as a carer.



### How many people are carers?

According to Carers Trust<sup>1</sup>, there are approximately 7 million carers in the UK, which is around 1 in 10 people. This number is increasing and it is estimated that the number of carers will increase by 3.4 million by 2030. **Among those aged 50-64, 1 in 5 people are carers**. 42% of carers in the UK are men and 58% are women. **The proportion of male carers in particular is often underestimated**.

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<sup>1</sup>.

There are many different types of carer, for example 'sandwich carers' who care for someone older (e.g. a parent) at the same time as also being a carer for someone younger (e.g. a child), or 'co-carers' who are two or more carers who provide care for each other.

<sup>1</sup> Carers Trust: Key facts about carers and the people they care for - <https://carers.org/key-facts-about-carers-and-people-they-care>

## Key issues and barriers affecting older carers



### Finding the relevant information

Older carers may find it **difficult to navigate the field of services and entitlements** for the person they are caring for, as well as what they may be able to access themselves as a carer. One example is Carers Allowance, which is a very complicated benefit - not all carers are entitled to it and, for a variety of reasons, those who are entitled to it do not always claim it. Another example is when the person being cared for does not have a diagnosed illness, as this also affects entitlements and support.

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. This **can mean that some older carers do not apply for certain entitlements** or do not question decisions they feel are incorrect, as they do not feel comfortable enough with the terminology and are worried that what they have may get taken away when further assessments are done. There is a particular distrust of assessments among carers from BAME communities.



### Changing relationships

Becoming a carer can **significantly impact other relationships**. For example older carers may find they have less time to maintain friendships, or may feel they have less in common with other people now as a result of the caring role.

Similarly, it can impact the relationship between the carer and the person being cared for; **they are now no longer just their partner, child, sibling or friend, but their carer as well**. This can sometimes cause tension and have other **emotional consequences** (e.g. feelings of shame, guilt, frustration or anger). The person being cared for may not perceive them as a carer, particularly if they are a relative, and therefore may refuse external help because they assume that they will be happy to help out as part of the family role. Similarly, **the carer may not necessarily get on well with the person they care for** or have had a positive relationship with them before the caring role began.

Tensions can also arise when multiple people are involved in making caring decisions, especially if there are **disagreements about the best course of action**, or if there is resentment about people not putting in equal levels of effort.



### Identity

Being an older carer can **impact personal identity**, particularly as it is common for carers to **overlook their own needs in order to provide support** for the person they care for. They may have less time and energy to undertake the hobbies and activities they enjoy, or feel that they **do not have their own individual identity separate to the caring role**.

Many people do not see themselves as a carer, particularly if this role emerged gradually over a period of time. For some people **perceiving themselves as a carer can be empowering** as it provides a language for the activities they are doing, yet for others it can be a **daunting** prospect.

Similarly, identity changes again when that individual is no longer a carer, for example if the person they care for moves away, goes into residential accommodation or passes away. Their personal identity as a carer is likely to be affected by **loss and change**.



### Emotional impact

As suggested above, being a carer has an **emotional impact**. This will be different depending on the individual but may involve feeling stressed, anxious, frustrated or not in the right state of mind to reflect clearly and make decisions. They may be **scared to seek help for fear that this might jeopardise the level of care** the person receives. Older carers may also have their **own physical and mental health conditions to manage alongside their caring role**.

### Spotlight: Older BAME carers

For some older BAME carers there may be a **cultural expectation for family and the community to provide care** rather than external services. **These expectations can make it difficult to seek support or to decide not to be a carer**, especially if seeking support is perceived as a sign of individual or family weakness. These expectations also mean that individuals may not see themselves as being a carer, particularly women who may face stronger cultural care expectations than men.

There is **sometimes a distrust of external services among some BAME communities**, for example a reluctance to give out information about their personal situation through fear of how this information will be used (e.g. fears about being forced to go into a care home). This is added to by perceptions of some support services as 'not for' certain communities. Similarly, **health conditions such as dementia are perceived as shameful in some communities** which reduces the likelihood of seeking external support.

If there is a **language barrier**, it can make it even more difficult to navigate the field of caring support and entitlements. **Those who do not have English as a first language may access support at a later stage** than others, and may find it more difficult to describe their feelings when seeking emotional support.

Sometimes the carer might speak English but the person being cared for cannot and therefore the **caring role might also involve translation**, for example during GP appointments. This can cause tensions as it involves the carer hearing personal information that the person being cared for may otherwise not wish to share with them, which can in turn impact their relationship.

## Possible indicators of being an older carer

Each caring situation is unique and therefore there are many possible indicators to suggest to community workers and volunteers working with older people in Bristol that someone they are working with might be an older carer. Some possibilities from the workshops include...

- Have they **disclosed** it on a form? When asked the question, not everyone will perceive themselves as a carer. Carers Support Centre therefore instead ask "do you look after someone who couldn't manage without you?"
- Have they become more **rushed**, busy or withdrawn?
- Do they **talk about someone else** (e.g. partner, family member, friend) more than they talk about themselves?
- Do they arrive late or leave early at **short notice**?
- Are they making **decisions** based on someone else's calendar?
- Are they **tired**, anxious, stressed or depressed?
- Are they often **accompanying someone else** to meetings and appointments?
- Are they **neglecting their own social life**, hobbies and interests?

## What can community workers and volunteers do to reach, engage and support older people who are carers?

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.

Be aware of organisations and groups that you can signpost or connect carers to where relevant.

Add a question onto your forms asking if someone is a carer, so that you are aware of who you are working with.

For paid groups and activities, offer a financial discount (or free) for carers.

See the individual beyond their caring role, with their own interests and experience.

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.

Ensure carers are aware of the [Carers Emergency Card](#).

Be flexible and considerate when people need to arrive late or leave early. Try not to schedule something for too early in the morning.

Visit communities rather than expecting that carers will come to you, especially if you wish to reach older BAME carers.

Ensure venues are accessible, welcoming and well-known within the area.

If indicators suggest someone might be a carer, explore this with open questions so they have a chance to disclose if they wish to.

Offer to provide transport for carers in order to reduce the time they are away from the person they are caring for.

Ask specialist organisations for advice when needed – working together and sharing expertise.

Reflect on who else in your organisation would benefit from learning more about older carers.

Work with organisations and community groups who already work with carers to invite people to your groups or activities this way.

## Further information and resources



Carers Support Centre  
Bristol & South Gloucestershire

### Carers Support Centre

Carers groups, Carersline, one-to-one support on a range of issues affecting carers, telephone counselling.

[www.carerssupportcentre.org.uk](http://www.carerssupportcentre.org.uk)

0117 965 2200

[carersline@carerssupportcentre.org.uk](mailto:carersline@carerssupportcentre.org.uk)

Sign up for the Carers News e-newsletter [here](#).



### Bristol & Avon Chinese Women's Group (BACWG) Care Support Service

Provide a team of support workers from the Chinese community who visit the person being cared for in their own home while the carer has a break. They also offer advice and support for carers

[www.bacwg.org.uk](http://www.bacwg.org.uk)

0117 955 3330

[carers@bacwg.org.uk](mailto:carers@bacwg.org.uk)

### Bristol Carers' Emergency Card Scheme

If a carer has an accident or is taken seriously ill, carrying this (free) card will ensure the person they care for continues to receive the support they need.

[www.bristol.gov.uk/social-care-health/carers](http://www.bristol.gov.uk/social-care-health/carers)

0117 352 1668

### Bristol Black Carers

Offer one-to-one support for carers, plus groups and activities.

<http://www.bristolblackcarers.org.uk/>

0117 379 0084

[manager@bristolblackcarers.org.uk](mailto:manager@bristolblackcarers.org.uk)

### Carers UK

National organisation providing advice, information and support for carers including information about Carers Allowance and other entitlements.

<https://www.carersuk.org/>

0808 808 7777

[advice@carersuk.org](mailto:advice@carersuk.org)

### Dhek Bhal

Provide support and advice on a range of issues for people (including carers) in the South Asian community.

<http://www.dhekbhal.org.uk/projects/carers-project.html>

0117 914 6671

[dhekbhal@yahoo.co.uk](mailto:dhekbhal@yahoo.co.uk)

### Headway Bristol

Provide carers groups and advice for carers of people affected by brain injury.

<http://www.headwaybristol.org.uk/services/carers>

0117 414 3222

[info@headwaybristol.org.uk](mailto:info@headwaybristol.org.uk)

**Rethink Bristol Carers Support**

Support carers of people with mental ill health. Run carers groups and provide one-to-one support and have a newsletter.

<https://www.rethink.org/carers-family-friends>

0117 903 1803

[bristolcarers@rethink.org](mailto:bristolcarers@rethink.org)

**Shining Care: Support for Somali carers**

Provide home care to enable carers to have a break and information and advice to Somali carers.

<http://www.shiningcare.co.uk/index.html>

07931 125 143

[info@shiningcare.co.uk](mailto:info@shiningcare.co.uk)