

Caring for Carers

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Summary of talk today

- Introduction
- Why is it important to consider carers?
- Why work with community members?
- Useful definitions
- How we approached setting up support for carers
- Meaningful collaboration with carers
- Carers Experiences
- Tips for running successful peer groups
- Tips for setting up courses/what is peer learning
- Interviews with Carer Champion, CPS volunteer



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Why is it important to
consider carers?



- One in seven people is a carer
- An average person has 64% chance of providing care in their adult life (factors such as gender influence this)
- Carers have poorer health outcomes than their peers who are not carers
- Socioeconomic status impacts the experience of a carer

Why work with community members?

- People with experience of living with or through something have insight and expertise others don't
- People should have the opportunity to address and solve issues they face
- End of life is over-medicalised which suggests we need to encourage social responses to it
- Communities are under-consulted which misses the huge expertise and interest they have
- We need lots of different voices to come up with solutions that work for us all



Useful definitions

- **Peer support** – people with something in common or shared supporting each other
- **Lived experience** – knowledge through first-hand and direct experience of something
- **Co-produced** – when people with this experience are involved and able to design models and services that work for them
- **Strengths and assets** – what works for people, what do they do well? What do they offer?

How we approached setting up support for carers

Our offer for carers aimed to be

- Consultative and co-produced
- Informed by lived experience
- Delivered with volunteers/ community support
- Driven by peer support and learning from existing skills which people have already
- Free to access



Carers have assets and strengths to share

Commonly identified strengths



I know my person very well



I am committed to them



I am proud of the care I give

Carers have shared challenges

Commonly identified challenges



I need more knowledge
My knowledge is ignored



I am invisible



I am looking after him.
But who is going to look after me?

Peer Groups

An outline of our peer groups

- Time to Talk
- Create and Chat
- Neurological Peer Group
- Healthy Walks
- Wellbeing Group/Carers



Peer Support Groups

Groups for carers to come together

Facilitated by a volunteer, often with caring experience

A space to speak about issues and challenges

Topics can be pre-decided the week before, or arise in the session

Community Peer Support volunteer –reflecting on experience



Caring for Carers Courses

What is Peer Learning?

Peer learning can take many forms, such as:

- **Group discussions**
- **Problem-solving exercises**
- **Role-playing**
- **Feedback sessions**



The benefits of Peer Learning

The feeling of being together with other people who understand what it's like to experience social or emotional distress makes it easier to open up and help one another.

Many peers talk about the relief of feeling that they're 'not the only one'. This can be comforting and reassuring, especially if someone has been struggling alone for a long time

Where people are able to feel empathy and mutual understanding, they are able to build trust with each other.

When talking with each other, knowing that someone may have been through similar problems can help people to feel empathy with each other.

Our courses are:

- For unpaid carers caring for someone at end of life or with a life limiting condition
- Facilitated by a trained volunteer (often with lived experience)
- Cover common topics identified by carers to be important
- Designed to allow for carers exchanging and developing knowledge



Case Study – caring for carers course participant

- Gwen is the primary carer for her husband. She was initially interested in the courses to explore important topics about caring and meet new people.
- After attending them she shared:

“it has allowed me to step back from my caring role and reflect on the journey so far. It has reminded me of some of the feelings I had initially and shown me how these have changed. It has been good to touch base with those feelings, especially as I am hoping to support other carers.”



Carer Champions

1-1 matching programme

Why a Carer Champion

To improve carer wellbeing

To engage them with ongoing support

To make carers feel as if their needs
matter

To discover what it is that carers feel
they really need

**Supports carers early in their journey and
prioritises their wellbeing**

**Space to speak openly, reflect and identify
challenges and opportunities**

**Explore opportunities for support as well as
personal opportunities to improve
wellbeing**

**Pursues carer's commitment to wellbeing
and provides degree of accountability**

The Process

Referral comes into the Community Action Team



Staff will have initial conversation, and set a time to speak with Carer Champion



Staff contact Carer Champion and inform them of time and background information



Carer Champion contacts carer and begins relationship



Inform staff when relationship ends

Hearing from a Carer Champion



Support after caring and when bereaved

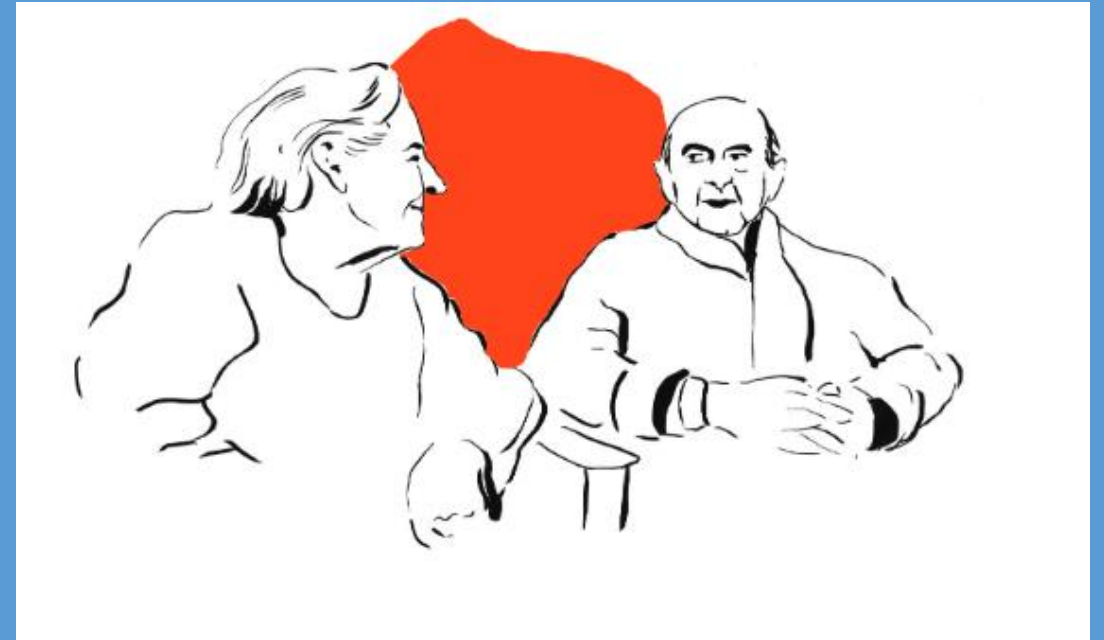
Continuing support for Carers

Bereavement Buddy - social and community support

Bereavement Buddies are volunteers with lived experience who are matched one-to-one for a short period with carers and family members to offer company, social support and a listening ear **pre and during early bereavement**. The match will last up to 4 months.

Who we are supporting when and how?

- Anyone who is caring for a person who is actively or imminently dying
- Any carer/family member who has been very recently bereaved
- Particularly if they say they could do with some company and support
- If they are lonely, socially isolated or do not have social support networks



What is Bereavement Help Point

- BHPs are weekly drop-in peer support sessions that aims to provide bereaved people with a place where they are able to access information and peer support, talk to others and share their emotions with flexibility of it being locally based and accessible whenever they need support.
- Visitors support each other and often visit regularly in order to meet up with others who share their feelings and understand what they are going through particularly in early grief when formal services are not available generally.



[Bereavement Help Points - St Christopher's Hospice](#)

Our work with Lived Experience & the Lived Experience Advisory Panel

- St. Christopher's hospice has developed a Lived Experience and Participation Policy which recognises the importance and supports the active participation of people with lived experience as expert advisors on all aspects of the hospice and the service we provide.
- Lived Experience Advisory Panel (LEAP) is part of this and will have a significant guiding input.
- We have recently started speaking with carers with lived experience from diverse local community groups to take part in the LEAP
- LEAP members will use their lived experience to consult our organisation, give recommendations on strategic aims and policies, and help us identify opportunities and issues

Questions and Reflections

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Thank you for your time today!

For more information, please contact Ella: E.Newman-Greaves@St.Christophers.org.uk

