

Planning for Tomorrow

Supporting older carers who are bereaved or planning for their caring roles to come to an end across the UK



Overview

In February 2019 ten Network Partners (local carers' services that are part of the Carers Trust Network) across the UK were awarded grants of £2,500 to develop and deliver a programme of activities for older carers (aged 60+) in one of the following categories:

1. **Bereaved carers.** This could include sessions such as grief workshops, group therapy, and social activities for groups of bereaved carers giving them an opportunity to make friends and rediscover old hobbies.
2. **Carers planning for their caring role to come to an end.** This could include discussions with carers around end of life issues and how to talk about them with the people they care for, and workshops on topics such as writing a will and establishing a Lasting Power of Attorney.

We were especially keen to work with Network Partners who would be focusing on supporting groups of older carers from **Lesbian, Gay, Bisexual, Transgender (LGBT+), Black, Asian & Minority Ethnic (BAME) or rural communities.** We know that relatively low numbers of carers from the first two community groups access services from Network Partners, and in rural communities there are additional challenges in delivering services. We therefore want to support services that are accessible and suitable for these groups of carers. The table below shows which Network Partners were funded, the category of carer they chose to support, and the community they planned to work with.

Network Partner	Category	Amount Awarded	Target community (if applicable)	Total no. of carers supported
Blackburn with Darwen Carers Service	Bereaved carers	£2,469	BAME and Rural	32
Carers First	Bereaved carers	£2,500	BAME	21
Swindon Carers Centre	Bereaved carers	£1,960	BAME and LGBT+	46
North Argyll Carers Centre	Bereaved carers	£2,500	Rural	136
Carers Trust Carmarthenshire Crossroads Care (Sir Gar)	Bereaved carers	£2,500	Rural	13
Sutton Carers Centre	Carers planning for their caring role to come to an end	£2,500	LGBT+	0
Carers Support Centre	Carers planning for their caring role to come to an end	£2,460	Rural	16
Northamptonshire Carers Centre	Carers planning for their caring role to come to an end	£2,486	BAME	25
Bridgend Carers Centre	Carers planning for their caring role to come to an end	£2,500	Rural	20
East Renfrewshire Carers Centre	Carers planning for their caring role to come to an end	£2,500	n/a	182
Total number of older carers supported:				491

Supporting bereaved carers

Five Network Partners chose to work with bereaved carers. This could be carers wishing to access support very soon after they were bereaved or some months or even years post-bereavement. Carers Trust were not prescriptive about how long after the bereavement had taken place a carer could access support, Network Partners were enabled to work to a timescale that fitted with their overall organisational approach to supporting former carers.

Blackburn & Darwen Carers' Service

The service ran three, 6-week Life After Caring courses. Each course incorporated the Life After Caring outcome star measures listed below, with an activity related to the topic.

- Managing distress and emotions
- Exploring grief and managing wellbeing
- Meaningful use of time
- Economic wellbeing
- Hope, motivation and empowerment
- Self-confidence, Self-esteem and self-care

Activities included arts and crafts, mindfulness, meditation, massage, reiki, and visits from guest speakers on topics such as benefits and welfare, holistic therapy, and fitness. At the end of each course was an overnight residential where carers had the opportunity to reflect on the course and make future plans. At every session there was a time for group conversation, "the round". Some carers were more comfortable than others about sharing their feelings but as the weeks went on this became an important part of the session, where everyone got an opportunity to talk.

The project lead describes one carer "who was absolutely desperate, she attended each session and in the first two sessions, just listened and did not take part in any of the exercises. On the third session we did a memory walk and she began talking about how her partner had loved the outdoors, and this broke the ice. The sessions afterwards became a lifeline for this participant and she grew a little more positive each week. To see her now is a joy as she presents a totally different outlook from when she had started the course, to see her smile on the residential, laugh and take part in activities was an amazing transformation". The carer said about the course: "I don't want to think about what I would have been like without it. It's going to be a long road but not a lonely one".

North Argyll Carers Centre

A range of activities and workshops were held across the Oban, Lorne and Isles area. Sessions included afternoon tea and reminiscence sessions where carers could share stories and remember the people they had lost. "Let's talk about death"

sessions were held in partnership with Marie Curie where carers were offered information on dealing with death and bereavement, and a number of bereavement peer support groups were established on different islands.

A group of six carers attended a residential trip to the Isle of Tiree, called “To Absent Friends – Reminiscence and Bereavement Retreat”. The carers took part in walks on the beach, a ceilidh, and a number of “to absent friends” sessions. The project worker leading the project explains what this involved:

We asked everyone to bring something with them that had belonged to someone they’ve lost, for our ‘To Absent Friends’ session. It was very moving listening to stories, and the group were very supportive and understood each other’s feelings well...the group discussed the loneliness after a death, and ways to get used to the grief.

Some of the group had initially had reservations about going away on a residential trip, but by the time we left Tiree everyone was very glad to have been part of the visit. Since returning to Oban the ladies have been meeting up regularly to support one another on their bereavement journey.

One carer said: “The Tiree trip was a much needed opportunity to rest and reflect in a safe and held space, amongst other people who had experience of loss and bereavement. It was deeply healing and greatly appreciated”.

Swindon Carers Centre

The PATH (Planning an alternative tomorrow with hope) group has been established to support bereaved carers, offering them the opportunity to come together for social and peer support events. They could also choose to access bereavement counselling. The Network Partner Staff member leading on the project says: “Carers are given an opportunity to socialise, empathise, make new friends, ‘get back out there’, re-ignite or find new hobbies and experiences and reduce feelings of loneliness and isolation”. Carers attended fortnightly ‘cuppa and a chat’ meetings and activities such as theatre trips, yoga and pamper sessions and meals out. A small cohort of carers also met weekly for a course of ten group counselling sessions.



Carers attending the PATH group said: “It has been a wonderful outlet for making friends with people who understand your loss and it gives a purpose to your day to socialise. When you are down, it can be a really cheerful experience”.

“It’s so lonely by yourself, this group gives me company that I need. I look forward to us getting together”.

Supporting carers planning for their caring roles to come to an end

Five Network Partners developed a programme of activities for carers who were planning for the end of their caring roles. This could include carers who are planning for the end of life of the person they care for or carers who are considering the end of their caring role for other reasons. They could be planning for their own end of life and are concerned about what will happen to the person they care for when they die, or perhaps their caring role is changing as the person they care for is going into residential care, for example.

Carers' Support Centre

Carers' Support Centre delivered a programme of six sessions aimed at carers aged 60+ to think about planning for their future:

1. Introductory session
2. Death Cafe
3. Legal Matters & Financial Planning
4. My Future Care Plan
5. Role of a Funeral Director
6. Life After Caring

Carers could pick and choose which sessions they wished to attend, they did not have to commit to all six sessions and could attend the ones which felt relevant to them. A counsellor was on hand at every session for carers to speak to if they got upset, particularly during discussions on more sensitive topics. The Carers' Support Centre worked in partnership with a number of local organisations and health professionals to deliver these sessions including a local solicitors, a Macmillan End of Life Lead Nurse, and a Funeral Director. Carers were encouraged to complete a "My Future Care Plan" form, where they and the person they care for could write down their wishes as far as their future care is concerned.

One of the sessions was a "Death Café, a safe, welcoming place in which people share their ideas, concerns, fears, and hopes about death as well as tea and cake". Whilst discussions about death and dying can be seen as being uncomfortable or difficult, the end of project evaluation found that 100% of the carers found attending a Death Café useful and felt very comfortable. All carers rated the structure and facilitation as very good or excellent. Carer comments included that it was "interesting and enjoyable".

I learnt the importance of planning ahead and preparing, both emotionally and practically

I feel I can plan for the future with a lot more knowledge now.

We have made a will and increased priority of other financial arrangements and Lasting Power of Attorney for other family members.

Bridgend Carers Centre

Carers in 3 different areas, one of which was a very rural community, attended a course of 4 workshops. Each workshop was facilitated by a different expert on the topic being covered. The workshops were:

- 1. Meaningful Conversations** facilitated by the Carers Centre counsellor. Carers were given a number of tools and materials to facilitate conversations about end of life issues with the person they care for e.g. photograph albums, cards, and memory books.
- 2. Legal Matters** facilitated by a local solicitor. This was an informal session where carers could ask questions about all sorts of legal matters relating to end of life care and death e.g. wills, lasting power of attorney and housing issues.
- 3. Practicalities around arranging a death** facilitated by a bereavement officer from the local hospital. The bereavement officer explained what happens in both a hospital based death and a death in the community, how a death certificate is issued, documents needed to register a death and which organisations need to be informed about a death. At the end of the session carers took part in a tai chi session and were given a hand massage to reduce any stress caused by some of these difficult and emotional conversations.
- 4. Coping when caring role ends** facilitated by the Carers Centre counsellor. Discussion about the stages of grief, support mechanisms and coping strategies. Signposting and referral to organisations to support carers to move forward and explore future opportunities.

Jane is a carer for her father who is living with Dementia. She advised that she had been struggling for some time caring for her father and wanted to get some practical tips and emotional support. Through attending the workshops Jane identified that she needed support from social services in her caring role. She was referred to the Carer Link Worker at the centre who completed a Carers Assessment and an Anticipatory Care Plan. The result of this assessment was that a package of care was put in place for her father which allowed her to have a break from her caring role.

Through the four week course Jane was able to access legal advice regarding issues around power of attorney and continuing health care funding and she started to look at options regarding residential care homes for her father in the future.

Jane was also equipped with the knowledge that a Bereavement Officer was in post at the local hospital. Jane advised this eased her concerns regarding what the processes were in regard to a death.

At the end of the course Jane said she were able to:

“Come to terms with the fact that it is okay for me to think about myself and my caring role. I made friends with other carers and they understood what I am dealing with on a daily basis.”

Outcomes

We identified 3 main outcomes for this programme; reduced isolation and anxiety and increased knowledge and confidence about the future. These outcomes were met in a variety of ways:

Carers experience reduced isolation

Caring can be a lonely and isolating experience. These feelings can be exacerbated with the end of a caring role. One carer attending a bereaved carers support group at Swindon Carers Centre said: “I could drive here but I choose to go on the bus, as it means I am longer out of the house because when I get back home, it is so quiet”. Another said “some days I only have my dog to talk to. The group means that I have a reason to go out”.

All Network Partners reported their projects having a positive impact on levels of isolation amongst attendees. The project lead from Blackburn with Darwen Carers Service said: “Individual members of the group did report that once the caring role had finished and they were on their own, isolation was one of the major issues they faced, and sometimes in between the sessions they did not see anyone. However, once they had become more confident and had had a taste of some of the activities, they were connecting a little bit more within the wider community”. Carers in Blackburn started meeting up outside of the Life After Caring course and one group even booked a holiday together. A support group has been set up by the carers as a continuation of the course, where they can continue to socialise and support each other and newly bereaved carers can also join.

The project lead from Carers First’s bereaved carers group reports that “The meals out were beneficial to the carers in reducing isolation. Several stated that they rarely went out other than to shop and fulfil appointments. Now though they were going out like others do and enjoying themselves, without guilt related to their loss”.

Carers taking part in the course about future planning run by Bridgend Carers Centre exchanged phone numbers for social support outside of the course and a group was established after the course to provide ongoing peer support.

Carers said...

We were all the same, we all so understood each other, that is what we wanted to know, we were not on our own.

I loved it all, and met some lovely people, did some lovely things. Before I was scared and lonely, and didn’t know what to do.

It’s so lonely by yourself, this group gives me company that I need. I look forward to us getting together.

Carers experience reduced anxiety

Carers can experience a great deal of stress and anxiety in their caring roles, and in planning for the future for themselves and the people they care for. Planning for a future after the caring role has ended can also be a very anxious time. One of the main aims of the Planning for Tomorrow projects was to take some of this fear and uncertainty out of the future by helping carers plan for what was to come and supporting them to talk about it with the people around them.

Some Network Partners, particularly those supporting bereaved carers, used the Warwick-Edinburgh Mental Wellbeing Scale to evaluate the impact their projects had on the carers taking part. This is a scale of 14 positively worded items for assessing mental wellbeing. Carers were asked at the beginning and end of the project to complete a short survey giving a score from 1-5 for statements such as “I’ve been feeling relaxed”, “I’ve been feeling cheerful”, and “I’ve been feeling optimistic about the future”. The Network Partners who used the scale all reported a positive increase in the carer’s scores by the end of the project.

The project lead from Blackburn with Darwen Carers Service reports “carers who participated in the course came with very low self-esteem and anxiety about themselves and the future...The Warwick Scale evaluation showed very low scores and highlighted areas that individuals needed more help around. Feeling desperate, unloved, isolated, not able to feel self-worth were very common in the carers initial evaluations. Each week I worked on feelings using the core stages of counselling, building rapport, listening, being congruent and providing unconditional regard. Most participants found the sessions as a lifeline, a safe place to come from week to week where they could get the support and motivation to carry on for another week. Slowly over the sessions the mood and feelings became more positive”.

Bridgend Carers Centre combined their practical information sessions with activities such as tai chi and mindfulness, and carers were referred to the Carers Centre counsellor after the sessions if they wanted to discuss any particular anxieties or worries further.

The project lead from East Renfrewshire Carers Centre said: “Knowing that procedures were in place, i.e. Powers of Attorney, wills, etc. was a great relief to many carers who attended the workshops. Being able to have information about choice around planning funerals for themselves and loved ones also greatly reduced anxiety”.

Carers said...

I was anxious, weepy, not able to cope or sleep. I’ve started feeling more confident, the group is so helpful, I have made friends that will last.

It’s been great to adapt to coping with my grief, it’s been nice to be distracted as I’ve had an emotional breakdown and been so lost, I felt like I had no hope at times. I’m not alone there’s others who have lost, talking has been great for us all.

Carers have increased knowledge and confidence about the future

The projects helped carers to feel more confident about the future in a variety of ways. Those supporting carers planning for their caring roles to come to an end equipped carers with knowledge and information to help them to plan for the future. Projects supporting bereaved carers enabled attendees to envision a future beyond their caring role, facing it with more confidence and, in many cases, a group of peers who understood what they were going through.

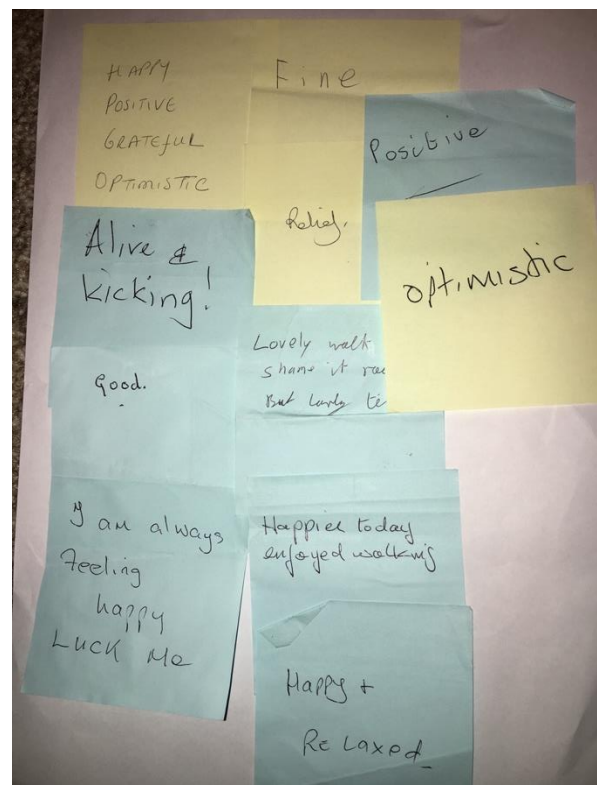
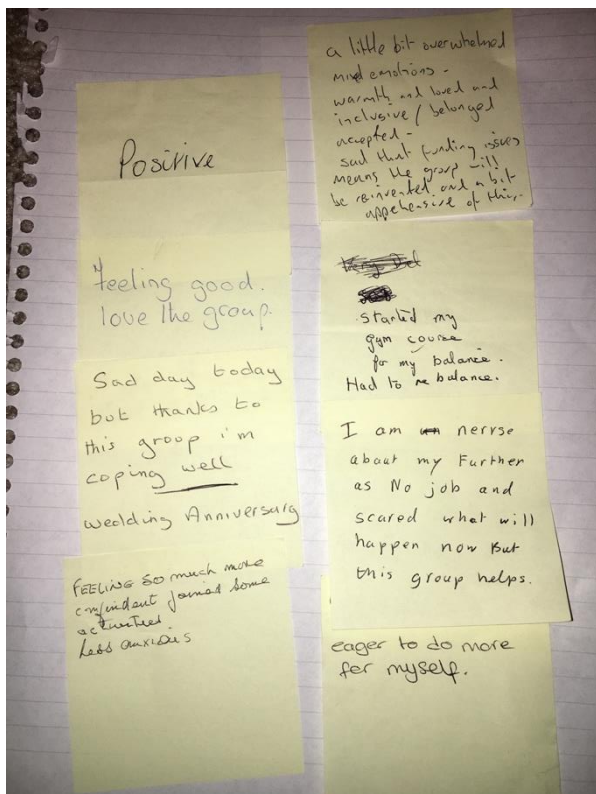
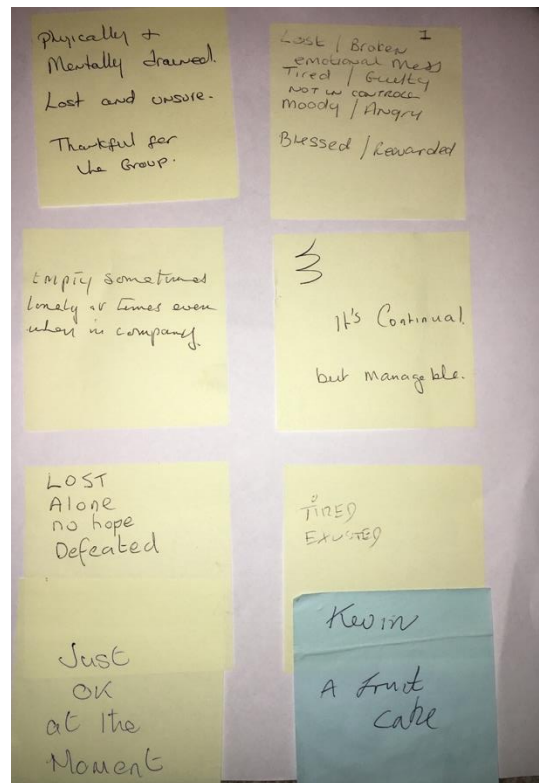
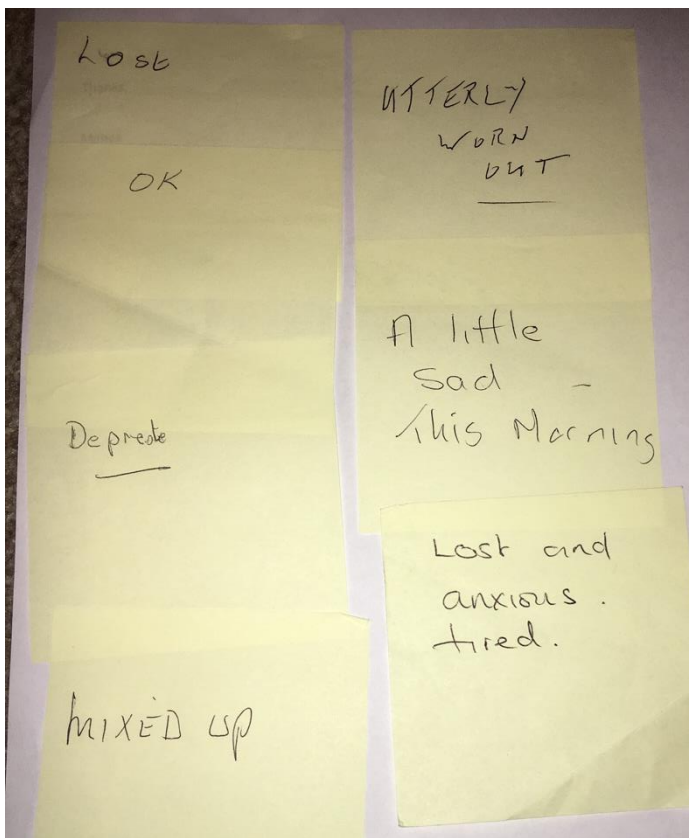
Many of the Network Partners worked with a range of local partners to deliver their project. Carers were signposted to local organisations and businesses that could help them when it came to making difficult decisions for themselves or the person they cared for, as well as accessing support from other carers in similar situations. The project lead at the Carers' Support Centre described the situation of one carer who had concerns about the future care of her husband:

Over the course of the sessions the carer shared her experiences of her caring role and found she bonded with two other carers, as they realised they had more in common than first thought. They all were thinking about the future, residential care for the person they cared for and what might happen if they pre-deceased the person they cared for. They found that each other completely understood their specific situations and were able to give each other better focused support. This was especially around the feelings of guilt when the person they cared for goes into respite care or a nursing home, if it is acceptable to not visit every day, how they are still a carer but in a different caring role and how they maybe need to try to make for time for themselves as they know the person they care for is being well looked after. The carer said she was grateful for having the opportunity to discuss her feelings, receive valuable advice and support which has helped her to see things from a different perspective.

The project lead at Carers First's bereaved carers group said "The cohort were in different stages of the grieving process, both in terms of length of time from the bereavement and how much support (if any) they had received initially. The more recently bereaved gathered strength from those whose bereavement was more distant". At North Argyll Carers Centre the project lead reported "by bringing people together and sharing there was a real sense of peer support that increased confidence and belief in the future. Being with people "who just get it" made a real difference to carers and as people were at different stages in their loss, to hear from those that were embracing the change and were at a different stage really helped people". A member of the PATH group in Swindon said:

"It has been such a long time since I had an evening out, with no responsibilities. As a carer my world shrank. Thanks to the PATH Group, my world has opened again. I feel able to face the future with joy instead of sorrow and hold on to the good memories".

Post-it notes from carers attending the Life After Caring course at Blackburn with Darwen Carers Service at different stages of the project



Network Partners targeting seldom heard communities: successes, challenges and learning

We told Network Partners at the start of the programme that we especially wanted to work with projects focusing on supporting older carers from:

- Lesbian, gay, bisexual, transgender communities (LGBT+)
- Black Asian & minority ethnic (BAME) communities
- Rural communities.

Many Network Partners funded through Planning for Tomorrow recognised that they had a gap in service delivery to specific carer communities. To that end, they took the opportunity to use the funding to try to redress this gap by focusing their recruitment on carers from these seldom heard communities, which they have done with varying degrees of success.

LGBT+ carers

In July 2019 we organised a training day for some of our Network Partners with the charity Opening Doors London. The session aimed to raise awareness of the needs of **older LGBT+ people**, and four older LGBT+ Ambassadors (one of whom, Maggie, is pictured below) shared personal stories which gave attendees a real insight into the lives of older LGBT+ people. The day ended with a discussion around how Network Partner staff could take the learning back to their organisations and help embed LGBT+ inclusivity into the culture there.



Despite this positive session, when it came to engaging older LGBT+ carers in the projects Network Partners found it difficult. The project lead from Swindon Carers Centre said: “Due to the average age of members, disclosing that they are a member of the LGBT+ community is not something that they chose to do”. Other Network Partners reported no LGBT+ carers attending the project or listing the number as “unknown”. We have learned that there is more work to be done to ensure that Network Partner staff members are comfortable in having conversations around

sexual orientation and gender identity with carers, ensuring that the needs of this community group are met. There is also a need to create more links with local LGBT+ organisations or groups, such as Opening Doors London, through which Network Partners could engage carers and learn more about the needs of the community.

Sutton Carers Centre aimed to support older LGBT+ carers through their project and they formed a positive relationship with their local LGBT+ forum in the hope of establishing the group together. However, the project lead at Sutton Carers Centre reports “it proved far more challenging to work with the Forum, a group in its infancy and also struggling to attract and include members in this cohort. However, we hope that this professional relationship will develop over time”.

Despite being unable to engage any older LGBT+ carers for their project within the timeframe given, Sutton Carers Centre will nevertheless be taking this work forward. By the end of the project delivery period they report having “robust partnership commitment (from the local authority and local voluntary and community sector) and the foundations laid to successfully deliver this agenda in the coming year. It will remain on our work plans for 2020/21 even though the funding stream/project life will have ended...we are confident that the eventual positive outcomes for older Carers in the LGBT+ community will be even greater and more sustainable”.

Carers from black, Asian & minority ethnic communities (BAME)

Four Network Partners chose to focus on supporting **carers from BAME communities**. Network Partners in areas with higher populations of BAME people were able to engage more carers from these communities, with the project lead from Carers First saying “The carers’ demographics demonstrate the diversity of Haringey”. She went on to explain more about how they established the group:

We chose not to have a cultural specific group as Haringey is very diverse and has a large variation in different BAME groups. We choose to run the group in English and staff were aware to use graded language and simplify if necessary. They also were careful to ensure that carer’s input was summarised simply to ensure all carers could follow the group and carers who lacked confidence in English were included in any conversation and encouraged to participate. At the time they were bereaved some carers were involved in local community groups but reported that they did not feel safe to share personal information due to perceived confidentiality issues. Some came from communities which are tight knit and they felt that there were cultural constraints due to their gender roles which limited how they could express themselves and were also concerned about sharing some feelings of anger, etc. We felt that it is really important to create a space where there is unconditional positive regard and everyone feels safe and staff have expertise in working with a wide variety of people.

Some Network Partners highlighted the fact that practices around end of life care and bereavement can differ between communities and cultures. It was important to respect these differences, making services as accessible as possible, whilst recognising that some community groups and cultures would benefit from having a separate group that met their specific needs.

Northamptonshire Carers Centre had planned to establish a group supporting older carers of people with dementia, with an emphasis on carers from BAME communities. When they came to start the project they experienced real challenges in engaging carers from BAME communities. The project lead said “Engaging with varying cultural groups can be challenging but topics like dementia, end of life care and bereavement all have their own cultural norms which need understanding. Although it is dangerous to consider people from a particular group as the same, a deeper understanding of groups is arguably a topic in itself and not part of planning a particular project”. Research from the Alzheimer’s Society suggests that BAME communities often face delays in dementia diagnosis and barriers in accessing services so this could have contributed to the lack of carers from BAME communities being referred to the carer’s service by health professionals.

Rural carers

Four Network Partners focused on supporting **carers from rural communities**. North Argyll Carers Centre delivers services in some of the most rural and isolated communities in the UK. The project lead describes some of the challenges involved and how these can be overcome.

One of the biggest challenges is logistics and the difficulties of trying to bring people together when they live at distances, transport infrastructure can be patchy and people have expectations of where they feel activities should be held. We have tried as much as possible to place ourselves where people are and through established local groups we have been successful with engaging with people but at times it can be a challenge for people to get to one location. It was great on the island of Mull to experience carers sharing transport to get to and from groups. This was excellent as further peer support is gained within the journey and solutions are coming from the community themselves. We also placed ourselves within non-traditional locations such as a monthly community café in a very rural area to start conversations and capture people’s thoughts.

We have used intergenerational work as a way of engaging with rural communities, bringing schools and elders of the community together. We have committed training time for our Learning and Development Co-ordinator to learn new skills and incorporate this learning in approaches to bereavement work.

Other Network Partners delivering services in rural communities offered transport to carers who were unable to access group sessions, and held activities and workshops in a number of locations to ensure that as many carers as possible could attend. The project lead from Carers' Support Centre explains "once the carers in rural areas had expressed interest in the programme and travel and/ or location was an issue we were able to engage these carers by picking a central venue in the county, on a good bus route. Plus arranging transport with our volunteer drivers where required and advising carers who to contact if they needed to arrange alternate care for the person they care for".

Project workers leading sessions in very small rural communities explained that some carers expressed reservations in talking about sensitive or difficult topics because they lived in communities where "everyone knows everyone" and so it was particularly important to emphasise ground rules including the importance of confidentiality at the start of the sessions to ensure that carers felt safe and comfortable to open up during discussions.

Next Steps

We have learned a great deal from Round 1 of the programme and we have used this learning to implement some changes to Round 2. Network Partners will still be encouraged to support seldom heard community groups but rather than carers in rural communities we are asking Network Partners to focus on supporting male carers along with carers from LGBT+ and BAME communities. This is because Network Partners will continue to support carers in rural communities simply based on their location but male carers were under-represented in Round 1 of Planning for Tomorrow with some Network Partners reporting that no male carers attended their groups, or the numbers were very low if they did. Some of the Network Partners have made suggestions of what they might do differently in order to engage male carers so we would like to see some of these ideas put into practice in Round 2.

In Round 1 of the programme we were not prescriptive about how the Network Partners should monitor and evaluate their projects. We were interested to see a variety of methods being tried and tested. However, for Round 2 we will be asking all Network Partners to use the same impact measurement tool so we can collate and compare the results at the end. The tool will partially be based on the Warwick-Edinburgh Mental Wellbeing Scale which many Network Partners found useful to use in Round 1, with some additional questions which are more carer-specific. Evidence gathered from the project evaluations carried out by Network Partners in Round 1 suggests that the expected key target indicators (to date) of reducing isolation and anxiety whilst increasing their knowledge and confidence about the future have been met. However, carers participating in Round 2 of the programme will be asked to complete a short survey at the beginning and end of the project so we will be able to clearly measure the overall impact of the project in relation to the quantitative target indicators.

Five of the Network Partners funded in Round 1 of Planning for Tomorrow have been given additional grant payments to assist us with producing two toolkits for Network Partners wishing to establish services to support bereaved carers or carers planning

for their caring role to come to an end. The toolkits will cover all aspects of setting up the service, what works well, what the challenges can be and how they can be overcome, and how different communities of carers can be supported. Network Partners participating in Round 2 will be given the draft versions of the toolkits to help inform their delivery. At the end of Round 2, selected Network Partners will be asked to add to the toolkits if there are any gaps which have been identified, with the final versions of the toolkits being made available to the wider Network in 2021. In this way we will be able to share learning across the Network, ensuring that more older carers are supported through their caring and bereavement journeys.

Summary

The ten Network Partners funded through the Planning for Tomorrow programme delivered their projects in a variety of ways from short courses focusing on information, advice and signposting to longer programmes of activities involving counselling, wellbeing techniques and peer support. The common thread running through all the projects is that carers taking part reported feeling more confident to face the future, better equipped and more resilient to face what lay ahead, whether that was difficult decisions around end of life care, or life beyond their caring role.

