

An activity project for carers of people with dementia



Background on Network Partner

The Carers Centre for Brighton and Hove is situated on the south coast of England in the county of East Sussex. At the last census in 2011 it had a population of 273,400. According to the Index of Multiple Deprivation 2015, out of 326 authorities across England it is ranked 102nd most deprived. According to the Carers Hub Brighton and Hove there are an estimated 23,000 **unpaid carers** in the area.

The Carers Centre celebrated its 30th anniversary in 2018. Since 1988 it has been providing carers with emotional support, advice and much-needed breaks from their caring role. The Carers Centre is a Network Partner of Carers Trust.

Since October 2017 the Carers Centre has been delivering a Carers Hub model which provides a 'front door' access point to all carer support services in the city. The Hub has become an effective and efficient single-entry point for carers to get information, advice, support and services through agreeing a series of pathways delivered in partnership with:

- Alzheimer's Society.
- East Sussex, Brighton and Hove Crossroads Care.
- The adult social care team.
- Children's services.
- Other voluntary sector organisations.

Within the three-tier system, the Carers Centre provides a dedicated phone line and a website with online resources, in addition to the support outlined on pages 2–3.

The Carers Centre for Brighton and Hove services for adult carers include:

- Emotional support.
- Information.
- Guidance.
- Peer-support activities.

These are offered to a wide range of carers, including carers of people with mental health issues, learning disabilities, physical or sensory disabilities and life-limiting illnesses.

As part of support for adult carers the Carers Centre provides a range of projects including:

- A Reablement project (support to achieve positive change by learning a new skill or reconnecting with an old hobby).
- An End of Life support project for carers of people with a range of life-limiting illnesses (including one-to-one sessions, support through a monthly group, and support for bereaved carers. This is delivered in partnership with other local organisations, for example Martlets Hospice and Horizons Cancer Centre).

Between April 2018 and March 2019, 1,452 adult carers received information, support and services from the Adult carers team (828 in the previous year). During this period 250 carers of those living with dementia were referred to the Carers Centre for advice and support (17.2% of all carers supported in 2018/19).



Local provision for carers caring for someone with dementia

Currently, most of the support for carers of people with dementia in Brighton and Hove can be accessed through the Carers Hub. Carers can be referred to the Hub either by a professional or they can self-refer. Initially, carers are offered a carer's assessment to look at the impact that their caring role has on their own health, wellbeing and daily life. Following an assessment, carers can receive a Carers Discount Card offering a range of reductions on products and services. An option to have a further in-depth assessment from the local authority, for example to explore respite options is also available.

As part of the Hub, Alzheimer's Society can offer one-to-one support for carers from a Dementia Support Worker. This can include:

- Emotional support.
- Improving understanding of living with dementia.
- Help with planning for the future.

The service also provides regular monthly peer support groups for carers of people with dementia, and a six-week dementia specialist information course for carers, known as the CrISP course (Carers Information and Support Programme).

The Carers Centre works closely with the Memory Assessment Service in Brighton and a significant proportion of referrals for carers of people with dementia come from this service. A Memory Assessment Link Worker co-facilitates a monthly peer support group with Memory Assessment Support Workers for people who are newly diagnosed with dementia. Carers can attend with the person they support and a separate space is provided for carers to access peer support. This group is currently available through the Memory Assessment Service for the first year after someone is diagnosed.

The Carers Centre for Brighton and Hove has also been working in partnership with Age UK and the Dementia Engagement and Empowerment Project to set up and facilitate a peer support group known as DMob. The impetus for this group came from the carers and people with dementia who attended the monthly Memory Assessment Service group. They felt strongly that an ongoing supportive, social space for both people with dementia and the people who care for them was key and should be available without a time limit. The group now has over 30 members and the Carers Centre is working to set up a second group in the west of the city.

Throughout the city there are a number of dementia specific activity groups provided by a range of third-sector organisations. These include:

- Impact Initiatives which runs a regular dementia friendly activity day in Hove on Fridays, which carers can also attend.
- Several day centres which help with respite for carers and provide activity and stimulation for people with dementia.

- Alzheimer’s Society which is currently running information courses for carers (CrISP) and Cognitive Stimulation groups available for people living with dementia.

Other available activities include coffee mornings and peer support for carers, and gardening, cooking and singing sessions which carers can attend with those they are supporting.

Addressing gaps in provision

A clear gap emerged in services for carers of people with dementia in Brighton and Hove. There was no service or group focusing specifically on in-depth guidance for carers in meaningful activity. Carers reported that they would like guidance about activities they can participate in together with the person they are supporting.

This identified need is also recognised and supported by recommendations in the National Institute for Health and Care Excellence guidelines, published in 2018, for the Assessment, Management and Support for People Living with Dementia and their Carers which advises that carers should be given: ‘advice on planning enjoyable and meaningful activities to do with the person they care for’.

Current guidance for people who have received a diagnosis of dementia emphasises keeping physically active, mentally stimulated and occupied with activities that interest them. The project was designed and delivered with the aim of addressing this gap in services.



The Carers Centre is also aware that carers of people with dementia from black, Asian and minority ethnic (BAME) groups, and from LGBTQ and Traveller communities are underrepresented in its services. The future aim is to link with other local organisations and communities to find ways to improve the support for these groups of marginalised carers.

Description of the project for carers of people with dementia

In April 2019, Carers Trust invited applications from Network Partners for grants of up to £500 to support the costs associated with providing groups of carers with structured, one-off activities or a series of activities that provided an opportunity to access a break from their caring role, a chance to relax and socialise or learn a new skill.

Through this programme, Carers Trust provided £448 to the Carers Centre Brighton and Hove to deliver a series of activity workshops for carers supporting a person with dementia.

Four workshops were delivered to 16 carers providing them with the chance to experience a range of activities and learn how they could adapt these to meet the needs of the person they support.

The workshops were centred around four different themes:

- Arts and crafts.
- Mindfulness and relaxation.
- Music.
- Reminiscence.

The main aim of the project was to:

- Increase carers' confidence and skills in planning and enjoying meaningful activities with the person that they are looking after.

Secondary aims were to:

- Reduce carers' isolation by providing an opportunity to meet peers in a similar situation.
- Enable carers to connect or re-connect with interests and hobbies that are therapeutic and relaxing for themselves as well as the person that they are caring for.
- Provide carers with time out from their caring roles.

Project planning

Several key issues needed to be considered during the design phase of the project:

- **Staffing:** Ideally the sessions should be run by an Occupational Therapist with the support of a volunteer. This provides both the expertise and support needed to deliver an effective project.
- **Timing of the sessions:** Feedback from carers identified mid-afternoon as a good time to hold the workshops, but it could be worth running sessions at a range of times/ on different days or on evenings or weekends depending on the carer target group, for example to reach more working carers.
- **Venue:** It is important to choose a venue which is accessible, has clean, safe facilities, enough space to host the workshops, located centrally and close to public transport/a car park.

- **Preparation and closure:** It is important to allow time when booking a venue to allow for setting up and tidying up. This project allocated an hour before each session and 30-45 minutes after the session.
- **Transport:** As there are several resources to transport to and from workshops it is helpful to have access to a car or small budget for a taxi.

All of these elements need to be captured within the project budget. The total budget required for the project was £448 across the four workshops delivered. This included the cost of:

- Venue hire.
- Resources (£30 was allowed per workshop for resources. Some workshops required more than others and some resources were free).
- Refreshments.
- Carer transport.

Staff costs were not included in this total as the Occupational Therapist was already employed by the Carers Centre. If a consultant Occupational Therapist had been employed they would have cost approximately £35 an hour (depending on local availability and going rates). The budget would also need to allow for the Occupational Therapist's time for planning, booking venues, reminder calls, setting up and travelling per workshop. Funds for volunteer support and supervision would also need to be factored in on top.

Below are examples of resources used or purchased for each workshop:

- **Music:** Record player and old records and online music resources (for example, Music Memories website) appropriate to the age of the people with dementia.
- **Mindfulness/Relaxation:** Facemasks and small pots of moisturiser for carer pamper packs, word search and crossword books (in large print if possible), mindful colouring books, jigsaws (from a charity shop), wool and knitting needles, seeds, bulbs, compost, flowerpots, gardening gloves, trowel, print out/book with of mindful breathing exercise script for facilitator.
- **Art/Crafts:** Acrylic paint and paintbrushes, glue and glue spreaders, felt pens, pencils, card, plain scrapbooks, terracotta flowerpots of varying sizes, ceramic coasters, mindful colouring books, pictures from old books and magazines, tablecloth.
- **Reminiscence:** Pictures from old books and magazines, plain cardboard boxes from a craft store of varying shapes and sizes, plain scrapbooks, access to websites such as YouTube, Spotify and Music Memories.

Top Tip:

To minimize costs:

- Ask colleagues, volunteers and carers if they have access to any appropriate materials.
- Check resources available in local charity shops.

Project delivery

The four two-hour long workshops were facilitated by the qualified Occupational Therapist with the support of a volunteer. In order to reach the highest number of carers each carer had the choice of attending two out of the four workshops.

Within the sessions, carers had time to experience a range of activities, for example in the art and craft session there was mindfulness colouring and painting flower pots. There was also time for group members to share examples of activities that they have tried and enjoyed, and problem solve any barriers they encountered when engaging the person they supported, for example poor motivation levels. Within the session the therapist was also able to offer more tailored advice to individuals.

The sessions also provided an opportunity for the Carers Centre to share information about the Carers Hub and other organisations and groups available locally which offer support, activities and social opportunities for carers of people with dementia.

Project evaluation

Evaluation of the sessions was commensurate with the size of the project and included a basic survey with the following questions:

- What did you like about the session?
- Will you take away any new ideas of activities to try with the person you support?
- Is there any further support you feel would help in planning/organising activities?
- Is there anything you would add or change about the workshop?

In addition, informal feedback was gathered from carers in the form of quotes.

Impact of project on carers including carer feedback

The feedback from the sessions was overwhelmingly positive, with great enthusiasm about the activities provided. All carers reported that they had enjoyed the workshops and would attend regular sessions if they were available.

The carers' quotes, detailed below, clearly highlight that the secondary aims of the project (reducing isolation, meeting peers, relaxing and having time out from the caring role) have been met. They capture the positive results of meeting other carers and sharing experiences:

“It was nice to have time to relax with other carers ... to chat about memories and swap information.”

“It was great fun completing a jigsaw as a team.”

A few carers specifically referred to the workshops as being positive time out from their caring role:

“Complete relaxation without any interruptions.”

“A very nice peaceful afternoon.”

“So nice to relax and do something away from the pressures of caring.”

Since the workshops have finished a couple of carers fed back about specific activities they have tried with those they care for as a direct result of attending the workshops, thus meeting the primary aim of the project (Increase carers’ confidence and skills in planning and enjoying meaningful activities with the person that they are looking after). One carer reported that he has been working with his partner and daughters to put together playlists of significant songs from his partner’s life. He found this has sparked conversations about past times and previous memories. He also feels that in the long run it will help them to have some more enjoyable times together.

Another carer emailed to say that having enjoyed painting flowerpots at the workshop, she and her husband planned to buy some flowerpots to paint for Christmas presents. Her husband really enjoys gardening and will be able to plant some spring bulbs in them. She feels that it will particularly provide a meaningful focus for them during autumn months when they are not able to go out as much.

Post project feedback

Feedback from five carers who attended a post project focus group clearly highlights the positive impact of the project and that the primary and secondary aims of the project were achieved:

“A friendly welcome. The first time we went in it was very warm. I suffer from anxiety so having that welcome really helped.”

“I realised others are dealing with a lot worse [situations] than me. Made me realise I am not alone.”

“It was nice to do something totally different and not focus on dementia. I hadn’t painted since God knows when.”

“It was a bit like being back at school, it was brilliant, you can just switch off and it was lovely.”

“So relaxing just colouring, space for myself.”

“I learnt tunes trigger certain memories ... it can trigger a mood change. I never associated how much music has a bearing on moods and memory.”

“I like playing [arts and crafts] it takes me away from everything else.”

“The groups have been very good for [techniques] of stimulating memories.”

When asked what they had learnt from the session, carers responded:

“Having a session where people can give help is fabulous.”

“A problem shared is a problem halved and that’s what these groups give us.”

“Talking to people who understand reduces the stress. It’s like a breath of fresh air for an hour or two and then you go back and put your carer outfit back on.”

“Colouring is very relaxing. Brings the blood pressure down.”

“We have got to look after ourselves. I am trying to be more careful with my health. I have gained most from the sessions listening to other people.”

“The companionship and safety [of the sessions]. I can talk about worries and it’s not going to get back to the person I care for.”

“I can sit round the table for half an hour and get more from talking than all the booklets.”

“It’s nice you can say I have had a rotten day and could kick something, and nobody would judge.”

“So many of the good ideas that have helped in our caring roles have come from groups.”

“Attending the peer support group is a key to opening other doors.”

Key project learning points

A few challenges were encountered in the delivery of this project:

- **Respite provision:** Carers not being able to attend workshops due to the difficulty of leaving the person they support for a couple of hours. To help address this barrier, free respite care was offered in partnership with East Sussex, Brighton and Hove Crossroads Care.
- **Travel:** Carers with significant mobility issues struggling to access the venue. To mitigate against this a small travel budget was included in the funding application to pay for taxi fares.
- **Events outside of a carer’s control:** Reduced carer attendance at some sessions due to carer illness or issues relating to their caring role. These were often last-minute changes which are difficult to mitigate against.
- **Timing:** Reduced carer attendance due to the date of the workshop (holiday time). On reflection, different dates could be chosen outside of summer holiday season or the sessions could be more widely publicised to increase attendance with other local charities, for example LGBT Switchboard and Mind, and details circulated to local Carers Champions at GP surgeries around Brighton and Hove.

What worked particularly well in setting up and delivering this project was:

- **An appropriate structure:** Getting the right balance when delivering the sessions between giving information and suggestions without overwhelming people or adding to the stress and anxiety that carers may already be experiencing, and providing them with time to enjoy and experience the benefits of the activities.
- **Ambiance:** Creating a very informal, relaxed atmosphere in a pleasant venue with no pressure to try anything carers didn’t want to and allowing a time for carers to chat among themselves over refreshments, to share stories and have the opportunity to experience valuable peer support.

- **Support:** Having volunteer assistance in the sessions to help with setting up and tidying away and supporting with making drinks during the workshops so that the sessions ran smoothly and were relaxed.
- **Partnership working:** Working in partnership with local organisations.
This included:

- The Memory Assessment Service, Alzheimer's Society and Age UK in order to spread awareness of the workshops to the target group of carers.
- Liaising closely with the Brighton and Hove Council Carer's Assessment Workers who form part of the local Carers Hub.
- Linking with the local care and respite partner East Sussex, Brighton and Hove Crossroads Care in order to offer the option of free respite to those carers who felt that they could not leave the person they care for alone in order to attend.

Things that could be done differently to improve the project include:

- **Increased referral agencies:** Extending the number of networks/organisations to circulate the workshop flyers to. Specifically, asking GP surgeries to display posters to increase engagement and other local third sector organisations supporting carers particularly those supporting people from minority groups such as the LGBTQ community, BAME groups and Traveller communities.
- **Expanding topics:** Merging the music and sharing memories sessions into one and trying out a new topic – Ideas for Keeping the Mind Active. This would link in with current recommendations for people who are newly diagnosed with dementia to maintain and stay involved in activities during the day to keep their minds active and stimulated.



Further information

For further information on the project please contact:

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About Carers Trust

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners and through the provision of grants to help carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

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