

Dementia Carers Active Support Group



Redbridge Carers
Support Service

healthwatch
Redbridge

Dementia Carers Active Support

Introduction

This successful project, working with carers of dementia and their dependents came to an end in February 2018. We set out to work with carers of someone with dementia not accessing many social opportunities or support services and at high risk of mental and physical ill health owing to the stress and isolation associated with full time caring. We were also acutely aware, through our experience of working with this particular group of carers, of the many barriers they face in engaging their communities. We also set out to capture feedback from carers of dementia to inform how we develop support for them in future and to give them a stronger voice with decision makers throughout the difficult Health and Social Care Transformation programme and in the current climate of austerity.

We consulted with the 300 carers of dementia registered with RCSS, using a simple questionnaire to gauge how they were coping, what services they were accessing and what barriers they faced. The results demonstrated that existing provision did not meet need, particularly the traditional day centres. Carers were either unable to or did not want to leave their loved ones in day services or with sitters. They wanted to reconnect with those they cared for, particularly spouses and do fun and stimulating activities together. We had the idea of a joint peer support group including an activity for the person with dementia led by a former employee of the Alzheimer's Society. Sufficient and appropriately trained volunteers were already in place and the ideal venue – IRDSA Hall – in Barkingside was available to hire and we knew at least 30 carers were interested in participating. The next step was to fund the project. We made an application to the Community Cash Fund and on 18th October 2017 were awarded a grant of £650 to deliver 4 monthly support groups and activities between November 2017 and February 2018.

Methodology

To ensure the success of the project our methodology was underpinned and informed by carer feedback:

- **Choice of venue** – we asked the carers who expressed an interest where they would be able to and prepared to travel to attend the group activities. The IRDSA Hall in Barkingside was known and preferred by all participants as it is close to transport links, adjacent to a car park and is fully accessible.
- **Timing of Activity** – our experience of providing activities and events for carers showed us that we needed to choose a suitable time and duration. Too early or late in the day and too long would be off putting for carers as they would be concerned about getting there on time and/or their dependents becoming restless if the activity lasted for more than 2 hours.
- **Staff to Carer Ratio** – we ensured we had sufficient staff, volunteers and tutors to successfully engage the carers and safely entertain the carees. We ensured that the volunteers were trained and had the relevant experience to

work successfully with the dementia carees and that the activity was planned and led by an experienced tutor – in this case a former employee of the Alzheimer’s Society. We knew that the carers would be concerned and worried about whether their loved ones would enjoy and benefit from the activity. This was a pivotal element of the project and of similar activities in future, if the carees were unwilling to attend or did not enjoy the group, the carers would not attend future meetings and would be at high risk of social isolation.

- **Activities** – The activities were planned in advanced and included 3 peer support groups with speakers for the carers, (as outlined below) and one outing to the Redbridge Drama Theatre to see an interactive show. The latter was chosen by the participants from a selection of opportunities. The activities provided for those with dementia were based on a pre-selection questionnaire called ‘This is Me’ devised by our tutor. The questionnaire completed by the carer and caree together was designed to provide detailed information about the caree including their likes, dislikes, abilities and any support needs. The completed form was invaluable in deciding whether an activity was suitable if for example someone did not like loud noises or music. The resulting chosen activities were Art Work, Reminiscence, using film photography and soft ball and board games, (e.g. skittles), during the group meeting on 14th February the carees made Valentines Cards for their husbands and wives.
- **Evaluation**
As set out in our grant application, we already had the base line date obtained through our questionnaires and also the person centred planning that we complete with all carers as they join our service. Participants also completed formal evaluation forms and provided anecdotal feedback during our day to day contact with them. We also filmed elements of the Christmas Party event and Costa Del Trotter show.

Project Delivery

We provided dedicated peer support and activity groups for carers of dementia and their dependents. Including an activity for the person with dementia delivered by a former employee of the Alzheimer’s Society assisted by specially trained RCSS volunteers. We used the group meetings as an opportunity for carers to bond, form friendships and gain peer support and to learn about relevant services they could access to improve their health and wellbeing. We also used the group as a means of giving carers a voice encouraging them to engage with consultations on statutory services and from our perspective to feedback on our services to inform future development and delivery.

Outcomes

The project overall accorded with 4 Healthwatch Redbridge Priorities:

- **Ensuring people have access to the right health and social care services they need to stay well:** - carers received information and heard from professional speakers including: Anxiety Care, Talking Therapies, dementia befriending scheme, (One Place East), Living Well Resource Centre and Redbridge Respite Care. In terms of social opportunities – we provided information about Redbridge Drama Centre, Kenneth More Theatre and Vision Do More. We also delivered a mindfulness session at the January group encouraging carers to take time for themselves and relax. Our December group featured singing and dancing and was a fantastic opportunity for the group to bond and have fun. This led to us arranging a trip to the Drama Centre to see a comedy play ‘Only Fools and Horses’ as one of the peer support group meetings.
- **Supporting people using Health and Social Care Services to have a voice** – We provided important information to the carers on the remodelling of day services, changes to charging policies and other key issues within the Council’s Transformation Programme. We used one of the support groups as a workshop helping carers to complete consultation forms.
- **Accessing local mental health services** – by including the dependents with dementia in our group activities this project provided a vital mental health service, currently not available for those with moderate to advanced dementia. This addressed a serious and emerging need for both service users and carers. We also ensured that carers received information about other relevant MH services and were referred onto them where help to access them was needed.
- **Ensuring that Health and Social Care organisations comply with Accessible Information Standards** – this group enabled us to provide information to carers and dependents in different ways to meet their accessible needs e.g. spoken, written in large print or easy read formats and in different languages using our bilingual staff, volunteers and carers. For those with dementia our experienced professional delivering the activity was able to communicate in a way that enabled meaningful engagement, ensuring they were included and we were able to meet their needs

Findings & Conclusions

In summary, 35 carers and 6 volunteers participated. Carers reported feeling more included, better supported and more informed about local services. They said their health and wellbeing had improved and they felt less mentally exhausted and depressed. They also said the groups were a rare opportunity for them to do something fun with their loved ones and reconnect as spouses or family members during a singing or dancing activity.

They also said that it was vital to have a dedicated group where they could receive key information about local services and changes and that otherwise they may not have known about the changes to health and social care e.g. remodelling of day services etc.

Carers were also encouraged to consider their own health needs and unequivocally, all participants wanted to learn more about techniques to improve their own health e.g. diet, exercise and relaxation.

Overall, the project has given us an opportunity to engage with one of our hardest to reach groups. We have learned much about the barriers they face and how we can help them to overcome these and be more active in their communities. We also witnessed the developing friendships and enduring bonds within the group that will help to minimise the risk of acute isolation. We are currently seeking funding from Carers Trust for another social trip to Redbridge Drama Centre as the group have said that they would like to do this on a regular basis as well as continue to meet as a peer support group.

We have also been successful in achieving 20 weeks of Fit for Fun funding to run a Dementia Movement and Dance Group at the IRDSA hall every Tuesday for 20 weeks running until September 2018. The activity is aimed at carers and carers of dementia, using similar methodology described above and the findings of the Community Cash Fund project to evidence the need and the benefits of this type of joint activity. There is no doubt that the impact of the Dementia Carers Active Support project has been significant and its legacy i.e. the new Fit for Fun project will continue. RCSS are grateful to the Community Cash Fund and Healthwatch for the opportunity to make such a difference to the lives of this particular group of carers.