



Developing a Dementia Carers Group

Summary

Alzheimer's Society Lambeth and Carers Hub Lambeth plan to launch new groups specifically for Lambeth dementia carers. The aim of the meeting on 18th April was to capture the views of dementia carers on what the group could look like, what they would want and how it might run. The meeting was attended by carers as well as staff from both Alzheimer's Society Lambeth, Carers Hub Lambeth and Age UK Lambeth. We asked the similar questions on a survey sent out to dementia carers. This document summarises both the discussion and online responses.

We focused on three questions:

1. What does a dementia carer's group look like to you?

- Carers attending wanted a group that **balanced peer support with information provision**.
- There was a high value placed on **learning from others** who had experienced similar situations, especially in **dealing with social services** and **managing the stresses** of caring for someone with dementia.
- Carers would like the **chance to listen** to each other and **share stories**
- Carers would like to meet with **diverse carers from all backgrounds**
- Carers also wanted **to learn about new services**, wanted **guest speakers** and a chance to **engage with service providers**. A variety but relevant professionals should be invited.
- The online survey echoed the above with "To **discuss concerns, worries and problems** related to my caring role" and "**To learn more about dementia**" being the two most popular choices.
- Those attending **agreed the meeting should meet monthly**, which is backed up by our online survey which showed 83% preferring a group running monthly
- In order for the group to be affective there should be **a regular venue, time and date which didn't clash with other carer groups**.
- They expressed the need for a **private environment** rather than in a coffee shop or public venue, as this would create a safe space and allow confidentiality.
- Group to develop leaflets
- Carers would like to review the group with what works what doesn't and how members are engaged

2. How will the group benefit you?

- Learn from others
- Get to know others
- Learn about new services & gain information about services
- Address isolation

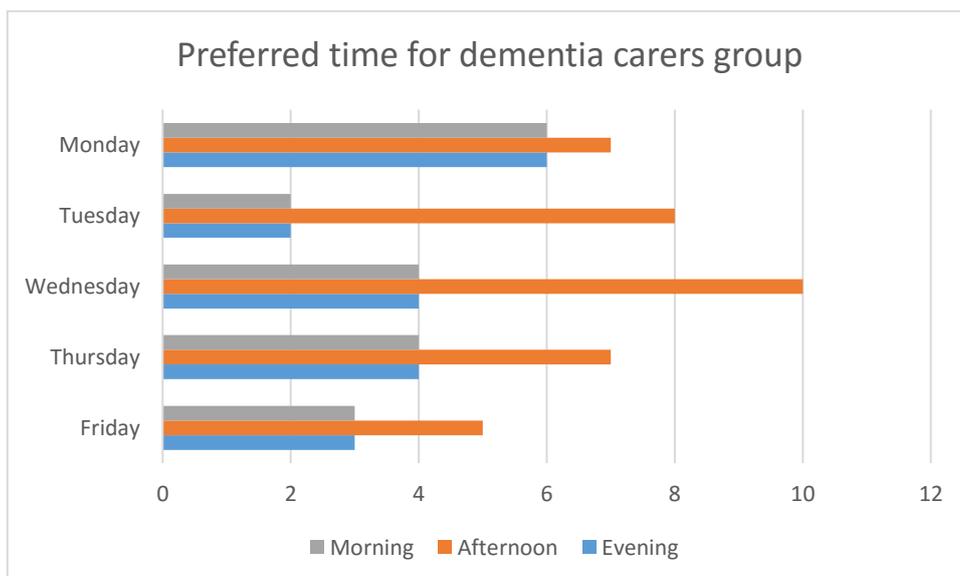
- Offload and de-stress
- A reminder to look after yourself
- Peer support
- Sharing ideas and picking up tips
- Feeling validated
- Navigating social services
- Good to have male carers attending for different perspective and learning
- Self-advocacy
- Learn assertiveness
- Transparency of services
- Address stereotypes

3. What would stop you attending?

- The main barrier in attending a group was the difficulty in leaving the person they cared for. It was discussed how the Healthy Living Club offered a space for carers to meet whilst the person they cared for attended the club.
- Appointments
- Being uncomfortable with group members or facilitator
- Feeling isolated
- Location or time unsuitable
- A clash with other groups
- If the group identity is different to my own carer role

Preferred time of group

Using feedback forms in the meeting combined with our online survey, these are the preferred times for attending the group.



Comments/feedback from the initial focus group

- “Found a new group of lovely people that it would be helpful to meet with regularly to talk about the difficulties of caring for someone with dementia.”
- “Very friendly group and I feel comfortable sharing about my mum.”
- “Perhaps someone from the unforgettable team to share ideas on the latest gadgets available.”
- “High hopes as it’s a relatively small group and not overwhelming.”
- “Too early to say given me hope maybe.”
- “I realise I am not alone as a carer.”
- “I have learnt a lot from others.”

Comments/feedback from the online survey

- “What I need is somewhere where I can pick brains and get tips about how to cope or get things done and end up feeling like it was worth giving up time escaping my home to be there.”
- “Make it light hearted, user friendly, but informative. That would help with building bonds of friendship.”
- “It would be good to have a mixture of ages, experiences and a variety of themes. Also a day trip once per year might be helpful to. Perhaps an annual local conference too?”
- “I would like a group where I am able to meet new carers and share our experience of living with someone with Dementia.”
- “We need speakers who have been carers rather than people who don’t know what is like to have lack of sleep not seeing or talking to anyone but the person you care for and I think it might to have solicitor or legal person sometime for legal advice without the charge if you need advice”
- “It should not all be about the caring. We should meet in nice uplifting places experience new things and debate issues like living in someone else's reality, confidence, fear and money”
- “Monthly speakers with first-hand experience of all the various stages of Alzheimer's/dementia”

Next Steps

We plan to launch the new group on Tuesday 22nd during Dementia Awareness week. At this group we will plan with the carers attending how the futures will run, by making a group agreement, choosing subjects for future groups, and giving the group members a chance to get to know one another.

We propose that the group then runs on Wednesdays at 1-3pm, as this was the most popular time from our feedback. This will be at 336 Brixton Road as this venue is available for the rest of the year and is accessible with good transport links. However this can always change, and we will continue to consult with the carers involved as to how the group works best for them.