Case Study: Younger People with Dementia Support Group.

A weekly peer support group for Younger People with a diagnosis of dementia, living in the Borough of Richmond Upon Thames.

This is a group of younger people (under 65 years) diagnosed with dementia that meets each week to discuss how they feel the diagnosis impacts their own lives and their loved ones. It is the only group in the Richmond upon Thames borough aimed specifically for this age group, which is essential as younger people’s needs differ from older individuals with dementia.

The group is run by Alzheimer’s Society (South West London Office) which is the leading support and research Charity for people with dementia, their families and carers. The group has recently formed as a result of some short term funding, which was provided to identify younger people with dementia living in the borough to establish their needs and develop peer support opportunities. The group:

- creates a safe environment to explore with others in a similar situation the difficult emotions linked to a dementia diagnosis, and to provide information and advice about the disease.
- makes links with other specialist services, leisure activities and support groups for people with dementia and their families.
- helps form a networking system to prevent isolation, apathy and reduce the risk of depression.
- explores and discusses with the group their different forms of dementias (atypical presentations which include posterior cortical atrophy, primary progressive aphasia, and front temporal dementia) and other rare and early onset syndromes.
- provides information factsheets which can be read and understood over a period of time (many of the participants have complained that they have been told to research these themselves by health professionals).
- shares memory strategies to help maintain independence and to discuss coping with dependency.
- investigates what would be helpful and share this with relevant organisations to heighten public and professional awareness around younger people with dementia living within the borough of Richmond Upon Thames.
- gives the group an increased understanding of their diagnosis to enable them to plan for the future.

Demographics
90% White British
10% Other/mixed.
Age range: under 65 years.

Facilitation
One Dementia Support Worker who is also a qualified group psychotherapist (employed by Alzheimer’s Society).
One Alzheimer’s Society volunteer.

Funding
Currently funded by CCG.

Joining the group is free and is subject to an assessment of need by the group facilitator.

Member Comments

“I no longer feel I am alone, I feel so much safer and feel relaxed knowing I can talk about my feelings and everyone will know how I feel”

“I was worried when I first came along, my sister brought me to the group and I was scared to speak but by the end of the session I was able to say how scared I felt, everyone was so supportive and now I will not miss a session as I get so much out of it”

“I have made a couple of friends who happen to live quite close to my home and we have started to meet up outside of the sessions”

“I love the group - we can have a cry and a moan about well-meaning friends and family who take over and between us come up with ideas of how to deal with these issues. One of the group members gave us a lovely tip the other day, he told us that he puts in a [permission to remember later] request himself when he cannot remember something and eventually his request comes back and it stops him worrying. I really liked this idea and I have started using it to.”

Facilitator comment

“The group has really benefitted from this weekly space as it provides a space to network with others in a similar situation.

There is a real sense of shared emotions. The issues and needs that are often explored includes, the diagnosis and what it means for them and their families, financial issues, care, and who to turn to in different situations”

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