

The following guidelines are provided for information/assistance for Gu3a group leaders. Note that it is not our role to act as carers for people with dementia, and if a carer brings a member with dementia to a group meeting the expectation should be that the carer will stay throughout.

## Helping people living with dementia

Dementia is caused by changes in the brain that can result from many diseases so that people living with dementia might exhibit different symptoms. They will not all have the same symptoms as the disease progresses, and it will not progress at the same rate for everyone. The key symptoms of dementia include difficulty with the following:

- remembering things
- working things out
- learning new things
- finding your way around
- driving

It is important for anyone with dementia symptoms to get an early diagnosis of what is causing it because there are now treatments that can slow the decline of cognitive function so that if anyone tells you they are worried about dementia do encourage them to see their GP.

Find out how confidential their diagnosis is and if they want others to know. If they are open about it then a small group of 'supporters' can perhaps be identified who will keep watch over the person with dementia – making sure the person understands what is happening and can find what they need.

If we are with someone who is recently diagnosed, in a group for example, or doing an activity, what CAN we do that is helpful and appropriate? Here are some ideas based on what people living with dementia have asked for themselves. You can read more about the study that collected this information in the book 'Dementia' by June Andrews, published by Souvenir Press.

### **Be accepting**

Sometimes it may seem daunting to talk to people living with dementia – will they remember you? Can they hold a conversation? Often people with dementia are wanting to be included but find difficulty in joining in. There are ways of making this easier.

-  Find a way to introduce yourself and others – maybe by calling each other by your names. For example – Betty says 'Barbara and I were just chatting about....' And Barbara says 'yes and Betty was saying.....' - thus jogging a failing memory. Groups can introduce themselves.
-  Don't be afraid to repeat things that have not been heard or may be confusing. Leave time for questions and do not speak too quickly. At the same time try not to sound like a primary school teacher! Remember that the person with dementia might repeat things too and be patient.
-  Be careful with humour or sarcasm – the person with dementia might not be able to appreciate this any longer and it may be offensive and triggering.
-  A crowded room with a lot of noise will make it more difficult for a person with dementia to pay attention or even to hear. If you are running groups find a quiet spot and remind everyone not to speak over each other.
-  Ask the person with dementia if they would like to discuss their memory loss and how it affects them and what help they might like (for example in finding words or showing

them where the toilet is). This can all be done quietly making sure we preserve their dignity and confidentiality.

- ✚ Encourage the person with dementia to join groups and activities. They may be afraid to join because of memory loss or feeling they won't be accepted by others. Continued learning and socialising both keep dementia at bay (or slow its progress). Exercise is another beneficial activity so helping people living with dementia to continue with walking groups helps them through the social interaction as well as the activity itself.

### **Disturbing behaviours**

Sometimes people living with dementia exhibit disturbing behaviours that might include anxiety, aggression, or hallucinations. Mostly, people who are well enough to be attending group sessions will be well enough to present these behaviours but just in case you encounter them, here are some tips.

- ✚ Do not argue with the person with dementia because there is no point. Be in their reality.
- ✚ If they are being physically aggressive walk away and if possible leave them alone for a few minutes to let the aggression pass. Make sure they are in a safe space. When you return they likely won't recall what happened.
- ✚ If there is a loss of inhibitions that causes the person to use inappropriate or offensive language this may be because they are anxious or in discomfort. Validate their feelings by saying 'you seem angry/upset – how can I help'. Often a calm interaction will help them get past the storm.
- ✚ In all cases of disturbing behaviours try to think of a diversion – take them outside to see the garden for example. The goal is to restore calm for them.
- ✚ Make sure doors are labelled – so they can find the toilet or kitchen or where they are supposed to go.
- ✚ Keep the environment calm. Shouting, rushing around and a lot of unfamiliar people can all be unsettling.
- ✚ Be careful with touching and hugging. It can be interpreted as restraint which can also be a trigger for anxiety or aggression.
- ✚ Consider using essential calming oils in a room, such as lavender.

### **Stick with it**

Being willing to support people living with dementia to be functional for as long as possible is not always easy but it makes an enormous difference to them. Let Terry Pratchett, the actor and writer, have the last word. He has been diagnosed with Alzheimer's disease. This is what he said:

*'It is a strange life when you 'come out'. People get embarrassed, lower their voices, get lost for words..... It makes you feel quite alone.'*

### **Further information**

[dementia-uk-tips-for-better-communication-leaflet.pdf](#)

[My Choice: The information you need to help you to Live Well with Dementia](#)