



Changing roles

Key messages

- **People with dementia may not want to continue to be part of an influencing group for ever.**
- **Groups work well if they make adjustments to accommodate people's changing needs.**

Groups that are part of the DEEP network operate in a variety of ways. Some are campaigning groups, some are awareness-raising and training groups, some work on consultations and local practice or policy development, some are working to create dementia friendly communities, while others get involved in opportunities as they arise, such as making films. What connects the groups is a notion of people with dementia being engaged in discussions, decisions and interesting work.

For people with dementia within the group, there can come a time when they want to move away from being an active campaigner or influencer. This may be because:

- they want to prioritise other things in their life
- they want to slow down and not be involved in an active way
- their dementia changes and they find it harder to stay involved in an active way.

Some groups put a time limit on membership so that people can regularly review their involvement in the group.

In this guidance note, groups from the DEEP network share some of the adjustments they have made within their group to accommodate people's changing needs.

Retirement from the group

Some groups have organised retirement parties, with a card from all group members. This is a public way of acknowledging the contributions that a person with dementia has made to the group.

The reality is that the person may have stopped coming to organised meetings prior to this. And it is this lack of attendance that has prompted the group to realise that the person's circumstances have changed. Identifying the additional support needs of the person can sometimes encourage them to return to the group.

However, where it is agreed that withdrawing from the group is the best solution, then this can be recognised through a formal 'retirement' process. The person may or may not attend any retirement event.

A formal way of marking retirement (such as a party, card, or gift) is also useful for other group members. It allows them to say 'goodbye' to a group member. It also raises awareness that the influencing group is not always the most appropriate type of group for someone.

The Scottish Dementia Working Group describes this process as "handing on the baton" to the next generation of people with dementia. This future process is discussed regularly. There is group awareness that being a member of a DEEP group does not have to last forever.

Setting up a parallel group

Many DEEP groups have set up parallel groups as people's needs change. For example:

EDUCATE have set up a Reading Group. Here, people read prose and poetry out loud and discuss it as a group. The group is supported by an EDUCATE buddy (volunteer). The group includes EDUCATE members who were finding the more formal 'business' meetings of the group more difficult.

This EDUCATE-linked group still provides peer support to members. People still feel that they are members of EDUCATE. They can also take part in involvement/influencing activities, at their choosing.

The FIT group had become very large. A number of people were no longer participating in the core influencing work of the group. However, they were

benefiting from peer support, and enjoying talking about life. The FIT group have set up a parallel 'reminiscence' group - which had been the main focus of people's discussions. This group can still be consulted about issues that are relevant to them.

Dementia Voice, a group of younger people with dementia and carers, have also set up parallel groups. They noticed that a number of people with dementia were struggling to take part in group discussions. However, the peer support element of group meetings was still vitally important to people. They have set up two alternative groups:

- a connection point service (which includes a 45 minute session that focuses on discussions of particular issues).
- an activity group.

The core DEEP group continues to meet, but now at 3-monthly intervals. New members, who want to be activists, have been recruited to join this core group. The three groups now interlink. Opportunities developed by the core influencing group can be shared with the other groups where of interest.

Involving carers

Where a group includes both people with dementia and carers, carers may be able to appropriately represent the views of the person with dementia. This is not without its challenges but an explicit discussion with people about these changing roles can help to highlight the important role that carers can play as advocates.

This guide was created by working with all the DEEP mentioned

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email rachael@myid.org.uk or telephone 01392 420076.

March 2016

