

NDTi Insights give you the most important bits of learning from a piece of work by the National Development Team for Inclusion (NDTi). We aim to make them quick to read; they point to more detailed materials for those who want more information.

Circles of Support for People with Dementia – A Summary of Learning from the Project to Date

Who should read this?

Anyone who has an interest in supporting people with dementia to live well, including:

- People with dementia, their families and friends
- Anyone who is part of an organisation or group which represents and supports people with dementia
- People involved in planning and developing Dementia Friendly Communities
- Commissioners and providers of support and services for people with dementia

Anyone who is interested more widely in Circles of Support.

Background

NDTi and Innovations in Dementia are working on a 3-year project (from 2011 to 2014) to develop Circles of Support for people living with dementia. The project is funded by the DH Innovation, Excellence and Service Development fund and is being delivered in 4 local areas: Dorset; Hampshire; Mid-Devon and West London.

Plain English summary

This project is working with people with dementia in 4 areas in the South of England to help them develop Circles of Support. A Circle of Support is a group of people who help the person to think about what they would like to do in their life, then support them to make these things happen. We believe that this is one of the first projects to work in this way with people with dementia in the UK and learn whether this can help them to live well and remain connected to communities. This is a summary of the findings and lessons emerging so far (roughly the first half of the project), based largely on the experiences of people involved in around 20 Circles developed to date. A key finding is the need for flexibility – both in supporting people with dementia to make a difference in their lives and in how the project is developed in local areas.

Main findings (so far)

- We began in each of the 4 areas by engaging with a local ‘Hub’ (partner) organisation, which was either currently supporting people with dementia, or interested in doing so. The intention was to work with local people, including staff and volunteers in each Hub, to introduce them to Circles and support them to use this approach to work with people with dementia.
- As the project developed, we recognised that we needed to engage with a wider network of individuals, organisations and groups in each area in order to promote Circles more widely and encourage more people with dementia and their carers to get involved. This has led to a much better understanding about what people living with dementia need and aspire to, and how the organisations and groups within their communities can work together to support them in a more holistic way. There are also wider benefits of connecting people and groups in local areas, helping people with dementia to live more inclusively in their communities.
- Circles can be very small – as few as 2 people. For people with dementia and their carers, asking others (even close family and friends) to join a Circle can seem daunting. The idea of larger ‘formal’ Circle meetings is not attractive to many people and is often unrealistic. Family and friends (if they exist) are often spread out - linking up remotely (by phone, email etc) is often more realistic.



Further NDTi Insights:

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Families and Personalisation

Independent Living Strategy Projects

Prevention that Works

Increasing Voice, Choice and Control for Older People with High Support Needs

www.ndti.org.uk/publications/ndti-insights/

For more info

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Main findings – continued

- Flexibility is vital. The pace needs to suit the person at the centre of the Circle and it takes time to develop trust. Everyone’s priorities and hopes are different (and often change). What’s important to and for someone can appear minor to others – including those in their Circle. We have found that thinking about one or two (sometimes small) things that the person with dementia wants to change or do is often a good starting point for developing Circles.
- Traditionally, Circles of Support have a facilitator to help establish the group and focus it on supporting the person to meet their needs. We initially envisaged that volunteers would take this role on for many Circles, however this has not been the case and this has mostly been carried out by paid staff in the project team or partner organisations. Carers or other family members often perform a similar role, however they find that the support of someone with local connections and access to the right sort of information is very useful. Volunteers have been engaged as part of the project, however we have found that they tend to prefer to take on more defined tasks such as regular ‘befriending’ visits.
- Most people we have worked with want to increase their social circles, sometimes through meeting new people or by doing more of the things they used to do and enjoy eg. walking, watching sport and socialising.
- Introducing people with dementia (and their partners and carers), who are in a similar situation, or who have shared interests, into each other’s Circle has been very positive.
- Groups don’t always work for people with dementia – especially for some of the men we’ve worked with. Joining a new group can feel particularly daunting, however there are very few opportunities for people with dementia to meet other people on a one to one basis and potentially form friendships. People with dementia want to continue to contribute to family and community life. Opportunities to volunteer, get involved in research and other projects really help people to live well and feel included.
- Barriers which stop people with dementia from achieving things they want are very common and we believe these are often caused by fear, stigma and ignorance. These exist across many local services and supports and can take different forms, from complete exclusion ‘we can’t deal with people with dementia here’ to the more practical situation of people with dementia having difficulty in getting along to a group or activity (through lack of transport or appropriate support to get there).
- Opportunities for people with dementia and their carers to do things independently of each other can also be very hard to find, but are often much needed and appreciated if these involve activities which people really want to do. Although the Circles being developed are focusing on the needs and wishes of the person with dementia, it is also vital to consider the needs of unpaid carers, especially those with a full time role.

Next Steps

We will continue to work with the people already developing Circles and with new people interested in trying this approach. Individual stories will be published on our website. We will continue to work with new and existing partner organisations to identify how we can develop this approach to best support people with dementia to live well.

