

Staying connected, with Circles of Support



Alison Macadam (top) is a project manager with the National Development Team for Inclusion (NDTi). Nada Savitch is a co-director of Innovations in Dementia CIC. To follow up on this article email alison.macadam@ndti.org.uk

Alison Macadam and **Nada Savitch** share some of the key findings from the recently completed Circles of Support project for people with dementia

Loneliness, social isolation or just plain boredom can be debilitating and frightening experiences, which block people's efforts to live well with dementia. At the same time, stigma and lack of awareness and confidence around dementia can block people within communities and families from welcoming and including those living with dementia. The Circles of Support project investigated a new approach to supporting people with dementia to voice and achieve their aims through connecting with people and their communities.

About Circles of Support

The concept of Circles of Support is not new. The first documented Circle of Support (also known as Circle of Friends) was developed in the 1980s in Canada, to support Judith Snow, a woman with disabilities, to move out of a nursing home and live in her own apartment (Forest & Snow 1983). Since the 1980s, the idea has been put into practice in many countries (including the UK) with different groups including disabled people, ex-offenders and older people. It usually involves a small group of people (usually between 2 and 10 people which can include family, friends and paid staff) who come together to support a person, helping them to identify what they would like to do or change in their life and then supporting them to make this happen.

This project built on the previous work of the National Development Team for Inclusion (NDTi) developing Circles of Support with older people, which was undertaken during projects carried out between 2003 and 2011 in local areas in the south-east of England. Through this work we found that Circles of Support could be an effective way of enabling people to achieve their goals and dreams and make positive changes in their lives (for more information see Macadam *et al* 2009).

The Circles approach

Traditionally, Circles of Support have involved a circle facilitator working with the person plus their supporters through a series of regular, pre-arranged meetings to identify the person's goals, then working together to help to achieve these. Early on in our project we realised that this was not likely to work for many people with dementia, as the idea of larger, more formal meetings (even ones

including those closest to them and wanting to help) was not attractive. We soon learned that we needed to be very flexible in our use of the Circles approach – reaching out to people in different ways, linking up remotely rather than trying to bring people together for regular meetings, also recognising and supporting the roles already being played by partners and families.

Encouraging people with dementia themselves, their families and friends and the professionals who support them to really think about the person's wishes and to see the person in the context of their wider lives is absolutely central to making Circles of Support work well with people living with dementia. This involves identifying:

- who is in that person's life – and who they would like in their life
- what the person does – and what they would like to do
- where the person goes – and where they would like to go
- what makes the person happy or unhappy
- how they can contribute and how other people can support them.

And then, crucially, the Circles approach tries to build on this knowledge to make connections with people who can contribute to making the person's life better.

How the project worked

The NDTi and Innovations in Dementia worked together on this project from 2011 until 2014, with people with dementia and other organisations, to test the development of Circles of Support and associated person-centred tools and approaches for people living with dementia. The aim was to work with people to find out what would help them to live well, and work towards achieving this with the support of others in their lives. We set out to develop shared support to help people carry on living in their local communities and tackle some of the issues faced by people with dementia and their partners and families.

The project took place in four areas in the south of England: Devon, Dorset, west London and Hampshire. We worked with many organisations across those areas, including Age UK in Kensington & Chelsea, Portsmouth and the Isle of

Wight, local Alzheimer's Societies in Dorset, Hampshire and West London, Nubian Life in London and Upstream in Devon.

We worked with 48 people with dementia to support them to develop their circles and widen their connections: 23 people on an individual basis and a further 25 within various group settings. Where we worked with people individually, this involved a member of the project team and / or a member of staff from a partner organisation having conversations and action planning discussions with the person with dementia, alongside their families and friends (where possible and appropriate), using the established person-centred approaches described below. In our work with groups, we also used person-centred planning approaches to determine what people wanted to do or change. We then worked with groups of people with dementia and partner organisations to support the formation of new groups – or to strengthen existing groups – to help people achieve their aims, while also making connections and achieving peer support. An example of this is where a group was set up which brought together a number of people with a love of poetry. This was inspired by one of the individuals we had worked with, who identified that she wanted to read and write poetry with a group of like-minded individuals.

Individual, group and site stories were developed to record the experiences, changes and outcomes achieved for individuals and groups of people and also to document the work which took place and the progress made within each area (site). A project evaluation was carried out by NDTi's Evaluation Team which involved identifying outcomes and themes from the stories and through fieldwork (interviews) with people directly involved.

Key findings

Working in a person-centred way really works

Person-centred planning tools were adapted and used by members of the project team and staff in partner organisations, when working with people with dementia and their families and friends, as part of the project. Many of these proved very useful and enlightening when used in an informal and supportive way. For example, we used tools to help with:

- recognising and capturing what people like and admire about the person living with dementia so that their true self remains at the centre of all discussions and decisions about their support
- identifying what's working and not working in someone's life, what makes a good day and what makes a bad day (and how to ensure people experience more good than bad days)
- understanding people's pasts in order to support them well in the future
- identifying key relationships and networks to whom that person is or could be connected
- understanding people's hopes, dreams and wishes to ensure that their aspirations and sense of self is known, understood and acted upon

- knowing what's important to someone and making sure that support focuses on this rather than what others see as important
- understanding how people communicate and ensuring that those involved in supporting them know this.

Being flexible and open to meeting the different needs, preferences and aspirations of people is key, ensuring the focus remains on the person with dementia and what they want to change – not what everyone else thinks is important for them. Circumstances and consequently priorities change over time, often very quickly for people with dementia and their families. Circles can be helpful within this context, bringing families and support networks together and being flexible enough to support people in different ways through uncertain and often difficult times. One family member described the positive impact of Circles in their lives as follows:

The Circle of Support joined up the dots for us...[it] kept my dad at the centre, never forgetting that he is a person with feelings and needs like any of us rather than just a patient. Thanks to Circles of Support, my dad attends a walking club, Singing for the Brain, and has met new friends – and all this gives my mum a much-needed break.

This approach can really help people with dementia to increase or maintain contact with personal and community networks

For many of the people with dementia who were part of this project, their natural networks are very small or remote: friends and family had often drifted away or died. We found that involving and linking people is not always easy, but the majority of people with dementia involved in the project (46 out of 48) were able to meet new people and strengthen existing connections. People are doing more of the things they want to do, such as regular walking and visiting local attractions. In many cases this has come from bringing people and information together to connect to new people and opportunities. Other outcomes have included enabling mutual and peer support, strengthened voice, support to continue living at home and sustainable employment (for one person).

Support from a Circle can also make a crucial difference to carers, helping them feel supported and that they don't have to be left to do everything. As with many approaches to good support for people living with dementia, it seems that the earlier a Circles approach can be adopted, the more likely it is to be beneficial. It also helps when people are open to change and trying new things; seeing or hearing about another person's circle can show what's possible and help people to believe that this approach can work for them.

It is helpful to have someone who can hold the circle together, for example coordinate diaries, look into different support options and so on. Sometimes a carer does this naturally, but it may be that a support worker, volunteer or other circle member needs to take on, or share out, this role. ➤



References

- Forest M, Snow J (1983) The Joshua Committee: an advocacy model, *Journal of Leisureability* 10(1) 20-23.
- Macadam A, Bowers H, Easterbrook L, Smith C (2009) Using circles of support to improve well-being in later life, in Poll C, Kennedy J, Sanderson H (2009) *In community: practical lessons in supporting isolated people to become part of community*. Stockport: HSA Press.

Some resources to help you to use the Circles approach

- A film, some stories and reports from the project to inspire you to take this kind of approach.
- *Keeping Your Connections* leaflet – for people with dementia and their families, written with the help of people with dementia and their carers who were part of the project.
- Person-centred planning tools to help you to really get to know the person and their whole lives, not just the bit you see that's related to your role or the services you provide.

All these resources can be found on the NDTi website (www.ndti.org.uk/circles).

► People find it really difficult to ask for and offer help – but if this is done in the right way it can make all the difference

Both people with dementia and their carers can be reluctant to ask for help. This can be mirrored by an equal reluctance on the part of families, friends and wider communities to offer or provide it. A number of issues seem to contribute to this. There may be awkwardness and embarrassment on both sides. People may fear losing their independence and friends may not want to be seen as interfering or 'taking pity'. For many, the nature of dementia means that they are unable to imagine what a person's future support needs might be or what sort of commitment might be involved. Many people worry about how to communicate effectively with someone who has lost their speech or who communicates in non-verbal, non-linear ways.

However, if this is approached in a positive way, it can work and circles of family, friends, neighbours, employers, healthcare professionals and so on can really support people with dementia (and their families) to live well. We found that an open and proactive approach – starting small, identifying a few things which are important in life, and talking to people about specific roles they could take on to support someone to keep doing these things – can be very helpful in overcoming some of the issues mentioned above. The *Keeping Your Connections* leaflet was produced as part of this project to help people to do this (available at www.ndti.org.uk/circles).

Organisations can change their approach, but it's not always easy

Circles of Support is not a service – it's an approach to working with people with dementia and their wider connections, including families and communities. While the concept of Circles was very well received, for many organisations the approach was unfamiliar and putting it into practice proved difficult. There was a perception from staff that it would require more time and greater involvement in someone's life. Services are often configured to work with individuals on a short-term basis, and struggle to reach out to others in their lives.

However, we found that the Circles approach to support is something that can fit into different services and roles, such as existing befriending schemes, volunteer support services, third sector and health and social care provision. Individual

staff and managers need to be committed, inspired and supported to adopt this approach for people living with dementia. It needs staff to think in a different way, to really listen to what people want, and be determined to make that work, rather than offer a list of services. Thinking creatively, reaching out to other people in someone's life and helping them to make new connections are vital to this approach.

Most of the staff we have worked with in partner organisations have advised that they have adapted their approach and intend to continue working in this way as a result of their involvement in the project. "I think differently about how I support people – now I think about wider networks," one dementia support worker has told us.

Sadly, a small number of people with dementia who were involved in this project have died and a few more have moved location. However, many of those involved are still being supported by staff in our partner organisations or still take part in the groups we have worked with in the project and benefit from ongoing support to identify and do the things they want, while also maintaining and increasing their connections.

People with dementia are often some of the best people to support other people with dementia

We found that a Circles approach can be very useful in group situations. It helps people to identify and share what they would like to do within the group and work together to make this happen, strengthening their connections with each other, getting to know more about each other and developing relationships over time. In groups, support can be experienced in a less formal, mutually beneficial way which can be more comfortable for people than the perceived intensity of an individual circle. As groups develop they can give rise to further, valuable one-to-one support links between different members. However, peer support is only part of the picture, and people with dementia also want to participate in and be included in mainstream community opportunities, and to keep and make friends beyond their diagnosis.

Often communities just aren't that dementia-friendly, but where they are...

We found big differences between areas, in terms of the range of options for support and opportunities for people with dementia to take part in community life (both dementia specific and general opportunities). Where the range of support options is wider, it is easier to develop circles that can successfully support people with dementia to reach their goals or make changes to help them live well. We found, however, that most places had very limited opportunities and sources of support for people with dementia to take part in things within their communities and a lack of readiness for welcoming people with dementia, and supporting them to take part in general groups and activities – particularly independently of their carer. ■