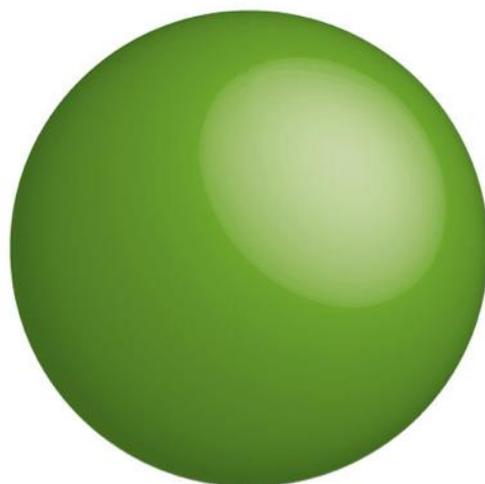




Circles of Support for People with Dementia

Summary Evaluation Report

July 2014





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Introduction

Circles of Support for People with Dementia was a 3 year project, funded by the Department of Health, 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, what support they need to do these things (including any changes to current support arrangements) and then support them to make these things happen. We believe that when this work started, in 2011, it was one of the first initiatives to apply this approach with people with dementia in the UK.

The Circles project was delivered by a partnership of two organisations, the National Development Team for Inclusion (NDTi)¹ and Innovations in Dementia². These organisations also worked with a range of other local organisations in the 4 project sites: Devon, Dorset, Hampshire and West London.

This report shares a summary of the outcomes and lessons from a retrospective evaluation of the Circles of Support for People with Dementia project. The evaluation was carried out between March and July 2014, by the research and evaluation team at NDTi, and the full report was written in July 2014.

¹ <http://www.ndti.org.uk/>

² <http://www.innovationsindementia.org.uk/>

Method & numbers involved

The aim of the evaluation was to capture and share the important, transferable learning from the Dementia Circles project. It used a Realist Logic Modelling /Theory of Change methodology to ask: Did the project achieve the expected outcomes? If so, how? If not, why? Evidence sources included 27 individual and group stories / case studies, and a series of interviews with people with dementia, family members, staff from partner organisations and project staff.

36 organisations were approached and engaged by the Circles project team, approximately half of which went on to become active participants in the project.

Through these contacts, 48 people with dementia went on to be supported through the project to develop a Circle of Support, either as individuals (23) or through their involvement in a Circles group (a further 25). We also worked with 36 family members and 2 friends who were involved in people's Circles, bringing the total number of those directly supported through the project to at least 86 people.

Outcomes achieved

A wide variety of outcomes have been achieved through this pilot programme, for different stakeholder groups:

- **People living with dementia** (total 48) are doing more, and in particular more of what they want to do (e.g. 46 people with dementia have increased and/or strengthened their networks through this project). 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.

We have more friends now. Relationships are better, better, better.

It really worked, she'd never have got to the group otherwise....She had been really unhappy...It made a really important difference to her life. It was because of the [Circles project team member] getting involved and wanting it to happen that made it happen....

The person centred planning tools really enable us – and A herself – to identify what would help her to live well.

I feel completely supported, days, hours. Having people I know and trust.

- **Carers and family members** of people with dementia (at least 38 people) are feeling more supported, experiencing greater peace of mind and more respite and

time to themselves. In at least two cases this support helped to prevent escalating problems that would very likely have had negative knock on effects for the person with dementia.

This Circles project – it was really good, it brought the family together.

[The volunteer Circle member] was special – plenty of experience. She helped A, and she helped me; she helped me understand A's behaviour – she said "that's not A, that's just the dementia" – it's been a long journey for me to understand.

- **Staff at partner organisations** (16 organisations), and in some cases family members, are thinking and acting differently; more broadly and creatively, focussing on networks, and having different conversations about people's lives.
I think differently about how I support people – now I think about wider networks. (Dementia Support Worker)
- **A wealth of wider learning** has been created as to why and how Circles of Support have worked for people with dementia, when they don't work so well, the challenges faced while using the model for the first time in this way, and the ways in which some of those challenges have been overcome.

In terms of how these outcomes were brought about:

Key enablers included:

- **Being led by the person with dementia and ensuring they are central to all discussions and decisions**

The focus has to be on person with dementia, not what everyone else thinks is important for them

- **Starting as early as possible, being led by the person with dementia and starting small:**

It can be helpful to start by finding a solution to one priority thing. The positive change seen through this can help the momentum of the circle.

- **Involving a range of different people** in Circles of Support, and 'sharing the load' (e.g. employers, faith groups that are often familiar with 'getting involved' in people's lives and building community, family members, friends and neighbours)
- **Pursuing a range of support options**, including 'natural' community support options as well as dementia specific support (where available) and opportunities for peer support
- Finding **support for carers**, which is often needed in order for Circles and community support to be viable

- **Commitment, determination to make it work** (including commitment to really good communication)
- **Allowing time** (e.g. allowing relationships to develop over time, not being put off at the first hurdle)
- **A handbook of Circles tools** and resources to dip into as and when needed (but not to be ruled by)

Key challenges and barriers included:

- **People with dementia lacking connections** and people in their life with whom to form a Circle of Support. A range of factors seemed to be contributing to this including:
 - Stigma – both expressed by other people e.g. community groups, friends, neighbours and family members - communities and also the stigma expressed by people with dementia who were fearful of telling other people about their situation. This stigma and fear prevented some people from accessing all kinds of opportunities.
 - People with dementia not wanting to ask for help:
 - The idea of asking other people to help her was initially very upsetting to Mrs T, as she felt she had always been someone who helped others.*
 - A lack of volunteers willing or feeling able to get involved in people's lives, especially on a long term basis
 - Lack of support at diagnosis, including to help people overcome the above barriers and maintain connections
- **Unfamiliarity with Person Centred Approaches** (a pre-requisite to building really effective circles of support) and this style of support – within support services as well as the general public.
- **Limited range of support options, and logistical barriers to accessing them** (including a lack of welcome from community groups; blanket rules such as a volunteer car service insisting that people with dementia have to be escorted; and a lack of support options designed around the needs of men and younger people living with dementia)
- **System boundaries** to ongoing and consistent support
 - The system, including the way that some services are funded, means that it can be difficult to continue to support someone when their circumstances change.*

The Theories of Change (assumptions that were identified at the start of the evaluation as having underpinned the logic of the programme design) were broadly supported by the evidence examined through the evaluation:

1. It is clear that **Circles of Support is a viable and potentially very helpful model of support for people living with dementia**. This is largely due to the flexibility which the 'model' allows, and with which it was applied, as well as the structure of the model itself and the person centred focus at its heart.

It's good for opening people's minds – "I can have a circle set up" – can take the pressure off the carer, they are not the only person who has to do everything.

I've noticed with befriending that this often becomes more about the befriender, what they want. [Circles of Support team member] was very focussed on M, that was very special. ...

While the project in general struggled to engage a broader cross section of people & public in individual people's circles (for the reasons described above), there were also examples where this has happened very successfully, helping people overcome stigma and promoting a positive alternative to life with dementia.

2. The concept of **bringing together 'natural' and 'professional' support** and involving a mix of people in the circle, though sometimes hard to achieve, was felt to be important by the project team members. The project supported a diversity of types and sizes of Circles; most involved both 'natural' and 'professional' support, although the professionals tended to be third sector support workers rather than health or social care professionals so there was a limited amount of linking between these sectors. Wider community input to circles was less common, although there were some good examples e.g. an employer who became involved. The networks created tended to be virtual rather than physical, with individual members talking to each other / other services on a one to one basis; and in many cases it was a drive for action by one key person in the circle (sometimes a carer, sometimes a support worker) that seemed to lead to changes.

Another key learning point in the project was about the **important role of circle groups**; 4 of these were supported to emerge and develop, highlighting that peer support is highly valued, and seems to have been lacking in the lives of many individuals involved, across all project sites. However peer support and groups are not the only kinds of support needed - there is also a clear call for more natural, mainstream opportunities for friendship, activities and support to be welcoming of people with dementia.

3. In terms of **avoiding crises and the need for more intensive professional support**, while much of the support provided through the Circles project was very 'upstream', there were also examples where the support made a direct and crucial difference; in at least two cases there were clear signs that crises had been avoided due to critical support or respite being found for the principle carer.

One of the key learning points from this project is that Circles tend to work best when developed soon after diagnosis, when there is still time to initiate and develop effective preventative support.

4. (Theories relating to the project journey):

Working with and through local partner organisations in general proved more difficult than anticipated, relating to a range of contextual factors around site/organisational readiness.

People need lots of conversations for it to become real.

Where partner organisations had been more actively involved, they experienced associated benefits, and were more likely to continue using and promoting the Circles approach beyond the lifetime of the project. In these cases it was a key person, or people, within the organisation who had made it happen, through leadership, flexibility and determination to see past obstacles and organisational boundaries and 'find a way in'.

The role of Circle Guide was recognised as being key to developing successful Circles, though engaging and training volunteers to fill this role (as had been anticipated) proved tricky. There remains a question over the issue of who is most suited to carry out this key role; suggestions about how it could be managed in future include the possibility of a professional paid facilitator. Finding someone who can hold this all together, and help that person (and carer/s) to feel the circle is also supporting them is clearly important.

Conclusions

The project has given rise to numerous stories and examples that can be shared and used to illustrate what is possible, which is a helpful starting point for understanding and spreading the person centred approaches that are at the core of the Circles model. A family member described the difference that this approach made:

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.

Meanwhile efforts to challenge stigma are still very much needed in order to help people with dementia raise their aspirations and expectations, as well as to help create communities (and community organisations) that are more understanding and welcoming – and less scared – of people living with dementia.

A common struggle experienced in this project was around people with dementia lacking the existing connections and people in their life with whom to build a circle. Circles can be particularly powerful if the approach is adopted at an earlier point, before people lose their connections (assuming they were well connected to begin with), and when existing natural supports can be harnessed.

Circles of Support are not intended to be a stand-alone alternative to other kinds of support, but rather a way of harnessing, in an individualised way, a wide range of options and opportunities for support (such as is envisaged in the Care Act 2014). This project illustrated that, although Circles of Support have the potential to work very successfully, such a range of support options is still not in place for many people living with dementia in local communities.