Bringing relationships into the heart of dementia care

We’re going down to the bottom and coming back up. It’s rare to have this.”
- group member, Hounslow Alzheimer’s Society

Traditionally dementia care services have tended to be provided separately for people with dementia and their partners. Services seem to have been formulated on the basis that respite for and from people with a dementia is the main objective. Consequently people with a dementia living at home have attended day centres/ clubs without their partner while separately their partner has attended a carers’ support group.

With earlier diagnosis, the presence of anti-dementia drugs and the increased empowerment of people who have recently developed dementia, this way of organising services is becoming outdated. Support groups are being set up for people with an early diagnosis and these are proving invaluable. Many of these groups, however, still continue to provide a service model that separates couples; these groups miss out on the opportunity to explore couples’ shared experiences of Being Together with Dementia.

Clearly both the person with a dementia and their partner experience this next journey in life together. Presently little opportunity appears to exist to explore what ‘being together with dementia’ really means for both people in the relationship.

Relationship-centred care

Significant progress has been made in the last 15 years to begin to understand the perspectives of people with dementia. The model of person-centred care has rightly shifted the balance in provision of care from providing a menu of ‘set’ services to focusing on the uniqueness of individuals.

However, it is increasingly being recognised that person-centred care can potentially lead to a narrow focus that highlights people’s inner subjective states and neglects their relationship with significant people such as their partners and health and social care professionals. Everyone’s identity, including people with a dementia, is shaped by significant people in our lives. I would argue that practice in dementia care needs to develop an inclusive approach that sees the person with dementia within the context of important and significant relationships. This inclusive approach has important implications for dementia care, not least to people who are beginning to experience dementia and are entering into the process of diagnosis-sharing.

Professor Tom Kitwood’s injunction to “focus on the person not the disease” has importantly underpinned thinking which sees the person with a dementia as an individual first and the fact of having dementia as secondary to this.

More recently, various writers have advocated that dementia care workers need to recognise the importance of relationships in the assessment and delivery of dementia care. Adams (1999) understands this approach in terms of ‘partnership’, whereas Fortinsky (2001) has emphasised the ‘triadic’ nature of dementia care relationships. Nolan et al (2004) develop a similar approach based on the idea of ‘relationship-centred care’ and more particularly the ‘Senses Framework’. These approaches collectively may be seen as relational approaches towards dementia care and may be distinguished from person-centred care because they assert the importance of relationships in the construction, assessment and delivery of dementia care.

Trevor Adams at the European Institute of Health and Medical Sciences, University of Surrey, has described relational approaches towards dementia care as “characterised firstly by the idea that three agencies are frequently involved in the provision of dementia care: the person with dementia, their carer, and care workers; and secondly that each relationship affects the other”.

In association with the institute, Dementia Care Matters has been developing a model which extends Kitwood’s key statement to a new approach of “focus on being together with dementia, not experiencing it alone” – the Being Together project.

Relational approaches challenge

Group members’ ideas for the sessions

- not feeling alone
- controlling memory loss
- stopping the worry
- embarrassment
- getting rid of wishful thinking
- telling others
- getting on with living
- being together.
dementia care services that separate the person with a dementia from their partner rather than on facilitating being together. New services are needed which enable couples to explore what ‘being together with dementia’ means for them individually and as part of their relationships. For people who are not in a partnership, the idea may include other significant relationships such as those with adult children and long-standing friends. This new approach emphasises the idea of ‘being together’ and sees that relationships which arise in dementia care settings are likely to have a more significant long-term impact upon the delivery of care than the dementia itself.

“The emphasis should be on being together – not dementia. Don’t let it dominate.”

– group member, Hounslow Alzheimer’s Society

**Getting on with living**

Cathy Baldwin, training coordinator in the Alzheimer’s Society, identified the need to explore a new ‘training’ initiative that directly involved people with experience of early dementia themselves. This developed out of feedback from people who had a dementia and were attending a consultation group within the Peterborough branch. Cathy found that: “The group expressed a wish to be better informed and to be provided with an understanding of how best to live with the limitations they experienced.”

Initial funding was identified to commence a pilot project with two Alzheimer’s Society branches – Peterborough and Hounslow. Dementia Care Matters was commissioned to design, author and deliver this new project.

The aim of the project is to pilot the Being Together philosophy and training materials and to consult with the key members of each branch group, consisting of couples and branch staff, on the design of the sessions and their impact. An initial pilot session identified some key issues from couples about the design of future sessions.

**Designing the project**

Working alongside couples who are experiencing dementia together has raised a number of important questions, including:

- What experiences can ‘training’ as a method appropriately explore?
- Is training the right term or are the sessions a mixture of training, group work and informal ‘counselling’?
- What are the ethical implications of the training and what risks are involved?
- What level of competency is required to facilitate the sessions?
- How do you prepare couples to attend?
- Does the project include people who do not live as a couple?
- What practical and emotional support needs to be given prior to the programme starting?

Sally Trippetree and Jennie Whitford at the Hounslow Branch commented: “This is tough emotional stuff; trainers would need to understand that this is very different work.”

The eventual design format for the sessions that has evolved is shown in the box below. These sessions:

- Create an opportunity for couples to listen to one another
- Enable couples to share their experiences and what works/does not work for them individually and as a couple
- Draws couples to revisit what Being Together means for them both

Gill Lintott, branch manager at Peterborough, comments: “The project provided an opportunity for couples to share feelings and have an understanding of each other’s needs that may not have previously been discussed – a vast breadth of emotions were felt by group members, including much laughter.”

Indeed, a significant finding from facilitating the sessions was the confirmation from couples that issues discussed within the group had not been broached together as a couple at home.

**Key features of the project design**

- Focus on ‘being together’ as the overall purpose
- Significant preparations with couples to join the project
- Individual sessions with groups of people with a dementia and groups of their partners held first
- Joint sessions with couples present together are then held.

**Delivering the sessions**

Examples of the content of different sessions include:

- The experiences of people with a dementia
- Working with emotional identification
- Understanding the brain and reasons for behaviour
- Feelings about going round in circles
- Advice couples would give to others
- The most difficult thing about one another

The design of the sessions can be particularly complex and time consuming, as there is a need to create material that is flexible, fun and focused on feelings more than facts. The use of imagery, metaphors and pictures often works better than mere words. The shared involvement of learning needs to be reflected in handouts that use inclusive language such as ‘you’ rather than ‘they’ with clearly presented layout and which pays attention to size of text that is helpful while not patronising.

The facilitator needs to be orientated towards people’s feelings and create trust, and confidently balance input with facilitation. The facilitator also has to know how to pace, match feelings, create rapport, reflect words, use repetition and to constantly link the group members together. The sessions require more than one ‘facilitator’ with clear roles and someone to transcribe notes, as a record and aide-memoire of the session for everyone, is crucial.

Length of time spent on topics and appropriate length of video footage used require careful thought and planning. With no accepted expert knowledge on the design and delivery of these sessions, every decision on approach can create doubts and uncertainty. In the end you have to trust your instincts and believe you can work on the spot with anything directed to you by the group members.

**Feelings arising**

As a facilitator preparing for these sessions, this raised strong emotions around my own confidence and capability, the rawness of the material, the closeness I felt to group members and the closeness shared with me from them as participants.
On the train on the way to the sessions I would be gripped with self-doubt on all aspects of the material and on my own skills. During the sessions I would feel the most profound experience in my 24 years of working with people with dementia. On the way home I would feel fine until walking in the door and a team member or my partner asked me ‘how it went’ and every time to my surprise I would feel huge waves of emotion and tears welling up from deep inside at what I had experienced and for group members to have shared with me such deep personal feelings about their relationships.

Both branches’ staff commented on this:

- “This day was the most profound experience both of us have had for a long time. How can we have let these real feelings and anxieties gone without being heard?”
- “I feel privileged to have been involved – participants continue to ask for more sessions”.

Cathy Baldwin summed up her feelings saying: “For me, what felt so powerful was the feeling that the couples were able to ‘put the dementia down’ for the duration of the sessions. It could not be made to leave the room but it highlighted that there were ‘three people in this marriage’ – the couple and dementia – and this emotion for me is the one that has been most profound. Whenever I meet a couple in this situation now I can almost ‘see’ the third party.”

What have we all learnt from the experience? Group members identified a range of benefits:

- having your relationship recognised
- empowerment
- increased well-being
- being listened to
- holding onto handouts as a symbol of being in control
- joining together with others
- seeing each other’s perspectives
- focusing on skills
- being honest
- unity and strength from the group
- equilibrium in a safe environment which helped to readjust the balance as a couple.

“We’re being so honest about everything – this is a real tonic.”
- group member, Hounslow

While it is clear that for people with a dementia the actual content of the session is not retained, the feelings of having had the experience are, and this is what matters most. In a world too focused on memory we need to appreciate that the memory of the session’s content is not necessarily important but that the positive feelings the sessions elicit most definitely are. Gill Lintott commented that: “Although the value may not be long lasting, the immediate effect gave the couple a sense of being valued.”

Sally Trippette and Jennie Whitford felt: “These days are more about a sense of empowerment, shared experience and not feeling alone. Unpacking the learning process appears not to be important but hearing the person’s story does.”

Future development
Dementia Care Matters continues to develop its ‘being together with dementia’ philosophy and to seek ways in which it may be used to enhance dementia care. The Alzheimer’s Society has commissioned Phase Two of the project.

Cathy Baldwin indicated that as the nature of the ‘training’ provided necessitates a higher level of skills base than that required for general trainers the next steps in the project are:

- some group members presenting their experiences at JDC’s Memory and Cognitive Care conference (London, July 2004)
- feedback to be sought from current group members on the transcripts and videoclip of their sessions
- production of an advanced course for selected in-house Alzheimer’s Society trainers
- pilot of eight branch trainers/facilitators delivering Phase Two of the project
- commission of an interim independent evaluation
- developing aspects of this service within the Alzheimer’s Society’s Living with Dementia project
- future consideration by the society as to externalising this work to other providers

Couples want to talk about

- every imaginable feeling
- being controlled by my partner
- not being looked at in the face
- boredom
- the brain
- changing roles
- thoughts of suicide
- keeping your diagnosis from other members of ethnic communities
- not talking and arguments at home
- not losing the relationship
- fighting for life - coping is not enough

Together highlighted the partnership as needing to come first rather than the diagnosis.”

As Gill Lintott notes: “The work will provide a basis for future projects/ training for couples to undertake together.”

Couples participating in the project were asked by Jennie Whitford to complete the sentence “We took part in the Being Together programme because...” and two comments in particular sum up the experience from couples:

- “We found it helpful and comforting to talk to people whose situation is similar to ours. To hear how they manage to cope with the day-to-day problems incurred by dementia and because we appreciate that Being Together helps to prevent feelings of isolation.”
- “It was interesting to find out how our partners felt about things, about one another and also how we can help to make life better and easier for both of us.”

The final words for now on this project rest with a couple in Hounslow:

“He couldn’t be without me and I couldn’t be without him. In spite of dementia we are still together.”

Acknowledgements and contacts
The Alzheimer’s Society and Dementia Care Matters sincerely thank all of the group members in Peterborough and Hounslow who shared their experiences, feelings and insights as couples in order that they could influence other peoples thinking and development of services. Dementia Care Matters would be very interested to hear about similar projects. Please contact us with details or for further information on our work: Dementia Care Matters, 29 Bloomsbury Place, Brighton BN2 1DB, Tel/Fax 01273 242335, email DMSheard@dementiacare matters.com

Further reading


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