Person-Centred Care for people living with a dementia

This thematic briefing was written by Professor Dawn Brooker, Association for Dementia Studies, University of Worcester UK, for the first WHO Ministerial Conference on Global Action against Dementia, March 16-17 2015

Person Centred Care is about seeing the whole picture. Who do you see?

<table>
<thead>
<tr>
<th>Do I see a label?</th>
<th>OR do I see a person?</th>
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<tbody>
<tr>
<td>A frail elderly patient?</td>
<td>OR a helpful great-grandmother?</td>
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<tr>
<td>A DEMENTIA sufferer?</td>
<td>OR a PERSON with Dementia?</td>
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<tr>
<td>A person with DEMENTIA?</td>
<td>OR a PERSON living with dementia?</td>
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Person centred care aims to maintain and nurture personhood. Personhood is what makes us essentially human. It is what human-beings recognise in each other and engenders feelings of trust, security and well-being between people at whatever age or ability level. There is a high level of risk that people living with dementia are treated as if they are “non-persons”. The risk of this is greater when the level of impairment is more advanced. The historical narrative that “dementia is the death that leaves the body behind” has been vigorously challenged over the past 20 years but is still prevalent in many societies and communities. It may sometimes be difficult to see the personhood in others who have advanced dementia but the assumption is made that it is always there to be found.

What does person centred care look like?

With the onset of dementia individuals are very vulnerable to their psychological defences being broken down. As the sense of self breaks down, it becomes increasingly important that the relationships that the person with dementia experiences remain strong. As verbal abilities are lost, the importance of warm, accepting human contact through non-verbal channels becomes even more important. In all interactions, four reflective questions can help caregivers1 to assess if they are practicing person centred care:

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1 The term “Caregiver” is used in its broadest sense to denote professional, paid caregivers or caregivers who are family and friends
• Does my behaviour and the manner in which I am communicating with this person show that I respect, value, and honour them?

• Am I treating this person as a unique individual with a history and a wide range of strengths and needs?

• Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by this person?

• Does my behaviour and interactions help this person to feel socially confident and that they are not alone?

In health care situations these principles can apply in every interaction. They apply when giving someone an injection, helping someone use the toilet, assisting someone to complete an advanced care plan or in running a music group. It is not the task itself that is person-centred but the way in which that task is done that can make it person-centred or not. Providing care in a way that really values people living with dementia can be a challenge where front-line care-staff and families themselves may not feel their own personhood is valued.

Language and communication

The language that is used to describe people living with dementia has a powerful impact on those affected by dementia and how they are viewed by society or in policy terms. Referring to people as bed-blockers, wanderers, aggressive, shouters or dements undermines the humanity of people. Even terms such as the elderly (rather than older people) or dementia sufferers (rather than people living with a dementia) promote a certain image that most people would prefer not to be associated with.

Caregivers can do a great deal to provide the structure that people with dementia need in order to communicate, even when time is limited. The approach to communication will depend on the level of and type of cognitive impairment. Also, if the person is communicating in a second language this often deteriorates more quickly than the mother tongue so communicating in the correct language is important. Courtesy, respect, friendliness and kindness are usually communicated by non-verbal actions and tone of voice.

Asking the person’s opinion

People living with dementia are increasingly being included in direct discussion about diagnosis and treatment but this is still relatively rare world-wide. Often people living with dementia are not asked their opinion at all. Evidence shows that, although people may lose the capacity to make truly informed choices about abstract decisions as dementia progresses, most people can make reliable decisions about their preferences well into their dementia.
Even if the capacity for understanding language is severely impaired, the non-verbal behaviour that accompanies being asked for permission or opinion will not go unnoticed and will do much to convey to the person with dementia that their personhood matters. Although there may be a decline in cognitive abilities over time, there is no decline in depth of feeling or the range of emotions that people with dementia experience. Indeed in many situations, emotions appear stronger than ever.

**Dementia Friendly Communities**

Some countries have developed *dementia friendly communities* programmes. People living with dementia want to remain independent for as long as possible, and to have choice and control over their lives through all stages of dementia. The dementia friendly communities programme improves awareness and understanding so that people can continue to enjoy the same facilities as everyone else such as going to the shops, spending time with friends and family and using financial services. Alongside this work at community level, organisations from different sectors, such as banking, retail, transport and the fire and police services, are working together to help make their own sectors more dementia friendly through activities such as improving awareness of dementia, training for staff and changes to their business processes.

**Personalised care**

Every person’s experience of dementia is unique. It is shaped by the dementia itself and how that changes over time, but also the person’s life history and personality play a part alongside family and community context. Individualised assessment, analysis and case management focus on this area of person-centred care. As dementia progresses, it can be difficult for the person themselves to remember important information and to tell others about this. This is true for information about health, preferences and wishes as well as the key stories of one’s life and identity. The provision of easily accessible information both about the person’s health and preferences as well as life stories are helpful here.

Understanding a person’s past history and preferences is crucial to providing person-centred care for people with dementia. Using positive memories can be helpful in improving self-esteem and to maintain an identity in the face of increasing confusion. Familiar touchstones of our cultural identity, our spirituality or religion, food, drinks and music are likely to have a calming effect. Vulnerability, anxiety and alienation are more likely to increase if those elements are missing.

**Knowing what’s important to each person**

It is often difficult to access this life-story information once dementia has progressed although there are an increasing number of tools to help with this. Families and friends can be good sources of knowledge in some instances. It is better still to have the person make a record of important events and preferences at an early stage following diagnosis so that this
information is accessible to others when needed. This is an emerging area of work as people are receiving earlier diagnosis. It can engage the person to record information about lifestyle preferences as well as advance decisions about end of life care.

**Understanding difficult behaviours**

Within the person-centred approach all behaviours are seen as communication. If a person is shouting out, or crying, or withdrawn, the person-centred response is to try to understand why this is happening rather than seeking to manage the behaviour with medication or physical restraint. People with dementia are prone to having physical health problems that can go undetected for a long time if caregivers are not vigilant about investigating causes of any sudden increase in confusion or distress. The majority of so-called behaviour problems are the result of untreated physical health problems, untreated pain, poor nutrition and hydration, boredom, unmet emotional needs, the care provider’s lack of understanding of cognitive capacity, poor communication, lack of knowledge about the person’s history, and poor general care.

This is the arena in which skilled care really counts and really makes a difference. Trying to understand the perspective of someone living with more advanced dementia is a core skill in person-centred dementia care. There is growing evidence base that the provision of general person centred care has an important role in minimising the likelihood of distress behaviours occurring and in improving quality of life.

**In conclusion**

Christine Bryden was diagnosed with dementia at the age of 46. This is her advice to caregivers:

“How you relate to us has a big impact on the course of the disease. You can restore our personhood, and give us a sense of being needed and valued. There is a Zulu saying that is very true. ‘A person is a person through others’. Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. It is very hard for us to be who we once were, so let us be who we are now and realise the effort we are making to function.” Christine Bryden (2005).

There is evidence that suggest that staff groups who have received training and on-going support in delivering person centred care demonstrate positive outcomes and beliefs about the personhood of people with dementia they support. Studies have also reported that person-centred interventions decrease job stress and strain as well as increase personal and professional satisfaction. There is a lot of knowledge about how to provide skilled person-centred care, support and assistance but there is a disconnection about getting this into regular practice. This is a global challenge and demands a global response in the same way as finding a cure for dementia. The need for person-centred care will not be eliminated even if we find a good pharmaceutical solution. The process of being diagnosed and being treated (just like that for cancer) require high standards of care, now and into the future.
Further reading


