Less doing – more being person-centred

David Sheard describes Dementia Care Matters' approach, Being, which takes a fresh look at what it really means to be person centred, and emphasises that feelings matter most in dementia care.

It's time to be honest
The evidence that person centred dementia care does not yet exist as a majority experience is a fact. In Dementia Care Matters, a study of 100 qualitative observational audits revealed people that people with dementia spend 70% of their time experiencing boredom and lethargy. This is compounded in environments where controlling care still exists, where a strong 'them and us' culture predominates between people living and people working in the service and where task based care rules the day.

Many care services have been working hard to develop person-centred care. Many pockets of inspirational practice exist, but on nothing like the scale required to guarantee any quality of care for the majority of people with dementia in the UK. Everyone knows deep down what ‘managed’ dementia care has delivered: a patchwork quilt of the old culture of restriction and control, and the new culture of dementia care focused on individuals and feelings, all muddled up together. The meaning of being person-centred is becoming lost.

Focus on being not doing
We must become the change we want to see.
Mahatma Gandhi

Doing something is not enough in life. Being person centred is not something we do but something we feel.
Being ‘feeling based’ starts with ourselves. Professor Tom Kitwood emphasised that it is a life philosophy - a set of fundamental beliefs about what it is to be a person. This emphasis is in danger too of becoming lost.
We need people who love or care for us to not just do things to us. We need a real connection, for people to have a sense of who we are, to feel how we are affected.
We can make an active choice to not just ‘do unto others’ but to be with others – in their sense of who they are. This shift from doing person-centred care to being person centred is the way out of the current muddle.

The need for congruence
The approach we call Being stresses a particular concept – that being person centred requires a person to have congruence in their life. Being demonstrates many parallels in the ideas behind being person centred and those of neurolinguistic programming (NLP), the study of excellence, leadership and ways to improve all our communication, in particular ideas promoted by Ian McDermott. It is this need for congruence in people that makes being person centred
Overall themes in Being

Being promotes a set of overall themes which are fundamental to achieving feeling-based support for people with a dementia, families and friends, managers and staff. These themes need to permeate an organisational culture and underpin best practice.

These ten themes are:

- A person enters and leaves this life as a human being not a human doing.
- The meaning of life is individual to each of us.
- Each of us has an inner spirit that needs to be kept strong.
- Having hope and a purpose in life is critically important.
- Feeling physically and emotionally free to express ourselves is fundamental.
- Loving relationships maintain our well-being.
- Everyone needs to feel a sense of togetherness and community with one another.
- Faced with difficulties in life, recovery of the spirit and the self inside is always possible.
- A person-centred approach has to look, sound and be heartfelt.
- Being person-centred requires congruence – a merger in life and at work between oneself and these overall themes.

What it means in practice

Whether as a person experiencing a dementia, family, friend, staff or a manager, none of us is separate from each other in our experience as human beings.

For someone receiving support, being person-centred essentially means being treated as a whole human being – as an individual.

For a family member or friend, giving person-centred support will involve feeling the experience from the perspective of the person they are supporting. It also means services should treat you as an individual and with respect for the role you are undertaking in supporting someone.

For nurses and care workers, being person-centred involves getting into someone else’s shoes. This means respecting each individual’s past life and being supportive to a person’s present feelings. At work it also means being treated yourself in the same person-centred way as those you are supporting.

For an organisation, becoming person-centred is about creating a culture where the service brings out the best in individual staff and those receiving the service. This involves enabling people living and working together to develop a feeling-based service, almost like a family or community. This is a service with no artificial boundaries, which does not create a ‘them and us’ culture, but is somewhere where people living and working together are like an extended family.

It takes a large amount of passion, a significant level of sensitive feelings, boundless energy and willpower to be truly person-centred in this way. People who have these attributes simply ‘get it’. They are not threatened by feelings but share (whether they know it or not) the philosophy of our organisation (Dementia Care Matters), that ‘Feelings Matter Most’. Such people have no barriers, no outdated ideas about professionalism and, most importantly, no pretence. They have not only learned to ‘talk the talk’ of person-centred care but they ‘walk the walk’ and it exudes from their very being.

The shift from doing to being

Many care settings are finding it difficult to fully implement a culture of person-centred care. A wide range of publications and training courses exists to promote this approach. Yet many managers are left wondering why training in these ideas is not easily being turned into action. For any large organisation, changing cultures is difficult and takes passion, commitment, teamwork and substantial time. Being an approach also suggests that it is essential.
to try a different starting point. Most publications and training in person-centred care have tended to focus services on what to do and how to do it. Being wants you to consider a different perspective.

Providing person-centred care as an approach is flawed in its very terminology. This approach is not something services can provide but instead is something that has first to be felt. Attaching the word care to person-centred is problematic. The word care suggests paternalism, knowing best what is right for others, whether on a personal or professional level. Services providing care have often been remote from people and lacking in feeling.

The word care has resulted in staff feeling confused about their role or the appropriateness of being loving towards people they are supporting. Equally the word ‘carer’ applied to staff, families or friends has had connotations of caring for someone rather than enabling and supporting them to remain in charge of their own life. Christine Bryden has spoken about this in her book Dancing with dementia – she prefers the term ‘care partner’:

We want not to be smothered by your care, nor isolated by your denial, nor cast aside as a victim of your grief but we want you to be a care partner walking alongside us to meet our increasing needs. Christine Bryden

Being promotes a series of moves in which all individuals, and therefore all organisations, managers, staff and families must acknowledge the need to:

• move from seeing oneself as a carer to being an enabler or supporter
• move from providing care to being a care partner
• move from delivering person-centred care to being person-centred
• move from sounding person-centred to being feeling-based.

A different angle

Dementia Care Matters in partnership with the Alzheimer’s Society Quality Care Team seeks to offer a way forward by offering guidance on:

Being – an approach to life and dementia

Enabling quality through real observation of people’s daily lives

Inspiring real leadership and not just management of dementia care

Nurturing support for emotions at work

Growing an effective learning and development approach to being person centred.

Feelings matter most

Feelings are the most honest things about us. They are the expression of our spirit untainted by logic, reason and the inadequacy of the spoken word. They are the conversation between our heart and the world around us. They express what is important to us. Stuart Wright, Brunelcare

Focusising on care services and training from this perspective will uncover the real meaning of being person-centred and being feeling-based. Starting from this perspective will uncover what a person-centred approach looks, sounds and feels like.

So, what does a person-centred approach look, sound and feel like?

Feels like home, sounds like being among friends, looks like fun. Feels warm, gives a sense of attachment, is secure and happy with contentment and love all around.

Eileen Wakeford, Guild Care

Bibliography


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Nurse education under review

Two major reviews of nurse education are being undertaken concurrently. The Nursing and Midwifery Council (NMC), is looking at how education programmes for student nurses might be shaped in the future. One of the key questions it asks is whether there should be separate preparation for the different branches of nursing (ie adult, children, mental health, learning disability) or if nurse education should be more general (and the same for all). A more general preparation for all might lead to mental health nurses (the branch where dementia education is traditionally addressed) being inadequately prepared for working with people with dementia and their families.

The Review of pre-registration nursing education can be accessed via www.nmc-uk.org/article.aspx?ArticleID=2641. The consultation can be completed online or downloaded. The closing date for responses is 5pm, 8 February 2008. Meanwhile the Department of Health is taking a lead on developing a framework for post-registration nursing careers, encompassing all stages including specialist and advanced practice. This consultation suggests that education should be built around these commonly followed patient and service user pathways: children, family and public health; first contact, access and urgent care; supporting long term care; acute and critical care; mental health and psychosocial care. The concern here is that people with dementia and families may cross a number of different pathways.

The closing date for this is 15 February 2008 and consultation can be completed online – see www.dh.gov.uk/en/Consultations/LiveConsultations/DH_079911 for details.

Both consultations will have significant implications for the shaping of nurse education, although neither provides much opportunity to ensure that education in dementia care is directly addressed.

Rachel Thompson, Admiral Nurse, for dementia