Identifying the ‘S’ Factor in dementia care

‘Doing’ person-centred care never works and a greater focus is needed on ‘being’ person-centred, says David Sheard. He argues that the ‘S Factor’ is the missing ingredient in care.

What are the common factors that unite people who get what being person-centred is? In celebration of our twentieth anniversary last year, Dementia Care Matters held a series of events titled ‘The S Factor in Dementia Care’ to look at the answer to this question.

The title was, of course, a spoof on the X Factor and each event commenced with care workers in role playing characters we have all come across over the years working in the care sector (see box, right). As each character is booed off the stage the S Factor judges become desperate to find a care worker who truly has the special factor in dementia care.

Finally on comes a care worker who talks about her own personal experience in life of having epilepsy. She describes feelings of disorientation that can occur, the fear, the need for closeness and how this personal experience has not only defined her identity but, she believes, has helped her to reach and connect with the experience of the people she supports of living with a dementia. As the audience sheds tears and cheers, the S Factor judges sigh with relief and say she will go far working in dementia care.

Nurturing our emotions at work

Behind this spoof is a serious rejection of a model of care that in the past was based on the domination of health and safety, routines, patronising attitudes and detached professionalism. The laughter the spoof creates, however, has within it a degree of discomfort with the fact that these characteristics are still familiar and recognisable nearly 20 years after Professor Tom Kitwood wrote his seminal work on person-centred care, Dementia Reconsidered: The Person Comes First (Kitwood1997).

Since 1995 we have promoted our philosophy that ‘feeling matter most’. Our work has centred on the key concepts that a) quality dementia care is about sensitive emotional care, b) the primary competency to work in dementia care is emotional intelligence and c) person-centred care will only be fully realised when care organisations at a strategic level commit to becoming congruent, emotion-led organisations able to practise being person-centred towards staff as their core driver in workforce development. In 2009, my book Nurturing: our emotions at work in dementia care was strongly endorsed by Pam Smith, GNC Trust Professor of Nurse Education at University of Surrey. “It is a must for those who dare to care,” she said of the book, which encouraged organisations genuinely interested in person-centred care to look at what constitutes the effective recruitment, appraisal, support and retention of staff.

The book examined the impact of emotional labour in dementia care and the ways in which staff manage their feelings, arguing for the necessity of care organisations giving emotional labour more priority. It published the findings of our UK survey of staff working in dementia care and their responses to naming emotions at work. The publication then went on to to promote Dementia Care Matters’ new concept of attached professionalism and identified how care organisations could develop and nurture an ‘Emotions at Work’ framework alongside support strategies.

Compared with high sales of the other 19 publications in our ‘Feelings Matter Most’ series, this publication has hardly ever sold. It raises a fundamental question still of whether the care home sector truly grasps what being person-centred is and that this is not only a life philosophy to be adopted by managers, nurses and care workers but is also a core strategic requirement for organisations. Few human resources departments seem to realise that they need to examine their own strategic responses to the emotional labour that person-centred care exacts from staff.

Reflections on ‘BEING’

In the light of this concern, as we prepared for the S Factor events and the presentation we gave at them called ‘The Feeling of Being’, we re-examined the core themes of our work over the last 20 years and in particular our belief that ‘Being is the Essence’. In summary, we concluded that the problem of successfully spreading on a large scale what person-centred practice is rests on the fact that many people still don’t know what BEING person-centred means. We believe the implementation of person-centred dementia care still depends on people’s understanding – or otherwise – of: What does it mean to ‘BE’?

Carl Rogers (1961) laid the early foundations for
answering this key question and we have built on Kitwood’s work by promoting the following view of what it means to ‘be’ as a person:

- **BEING** real, genuine and authentic
- **BEING** feeling based
- **BEING** more emotional
- **BEING** connected
- **BEING** close.

This has been the heart of our learning and development approach. We have also extended this concept of what it means to ‘be’ to include application to leadership, where we define being a leader as:

- **BEING** inspiring
- **BEING** an attached professional
- **BEING** able to face the truth
- **BEING** dogged and determined.

Equally the concept of what it means to be, in our sense, is relevant also to the skills of being a nurse or care worker in dementia care, where we assert that they are developed by:

- **BEING** an observer
- **BEING** free and not controlling
- **BEING** an interpreter
- **BEING** a ‘Butterfly’ (transforming lives, creating colour, flitting between people and being still)
- **BEING** in the moment.

As Tom Kitwood himself pointed out, this issue of ‘being’ may be the fundamental problem in achieving person-centred care. If the emphasis needs to shift from ‘doing’ person-centred care to ‘being’ person-centred, this may be a psychological threat to people who have never had the personal resources, time, opportunity or support to explore or know what their own BEING is.

**Philosophers on BEING**

To re-examine the theory of BEING and to identify what makes many people who seem so natural have the ‘S’ Special Factor in Dementia Care, the work of Martin Heidegger (Heidegger 1927), Jean Paul Sartre (1943), Ken Wilbur (2004), Brené Brown (2012) and Atul Gawande (2014) is worth considering.

Heidegger (1927) identified some key concepts which are very relevant to practising being person-centred today. In summary he proposed that ‘being is not a state of what but a state of who.’ He concluded that:

- it is possible to identify what being is
- human beings instinctively recognise the human being who knows what being is and one who doesn’t
- the fact that we are asking the question of what being means, means that we have some understanding of its meaning, and we should look for it in ourselves.
- being means we form our own essence separate from our existence
- being – that which is most familiar to us – is for that very reason especially hard to grasp
- it takes work to understand your own being.

These points resonate so clearly for us when we think of all the people we have met over the last 20 years who were such naturals working in dementia care. Knowingly or unknowingly they epitomised Heidegger’s points. It poses therefore a central question for dementia care training – how can this sense of being be enabled and explored in staff development? We believe that only through dementia care awareness training shifting to a model of emotional intelligence training will this be achieved (Sheard 2008).

Jean Paul Sartre explores the concept of what it means to become an authentic being in his book Being and Nothingness. He says that:

*Being requires a person to accept authentic impulses, to not allow the will of another person to change your action and to not accept conventionality. Being is about viewing oneself as we now are and not allowing the past to negate our current self.*

The concept of authenticity, we feel, is still the lost concept in implementing true person-centred practice and needs to become core in any dementia care learning and development. Sartre also
raised the interesting idea of ‘bad faith,’ in which people live a life that separates their existence from who they really are, ie their identity. People subject to bad faith play at BEING and live their lives within falseness.

This issue of authenticity and bad faith resonates in searching for the S Factor within staff in dementia care. It demonstrates that the essence of dementia care – where people living with a dementia are instinctively acting on their authentic impulses, not wishing to be controlled and able to live more in the moment than many other people – requires in all of us a similar level of authentic responses. Sartre’s work equally suggests that if we are to respond to the sense of being in people living with a dementia, then we have to first connect to our own sense of being. This will mean avoiding recruiting staff who, however unconsciously, are living in a state where their true identity is separated from their daily living and working existence.

Present ideas on BEING
As our search to identify the ingredients of the S Factor continued, we turned also to present day writers who confirm that the core of being person-centred is an acceptance of one’s own vulnerability, being able to access one’s own spirit inside and focus as a person on everyone’s well-being.

The old culture in dementia care of detached professionalism, which sought professional distance, led to a sterile, clinical approach disconnected from the real practice of reaching people. We have always proposed that real person-centred care comes when people through their own vulnerability can make parallel connections to reach other people.

This is supported by American academic Brené Brown who explores the concept of vulnerability, stating (Brown 2012):

"Vulnerability is not weakness and the uncertainty, risk and emotional exposure we face every day are not optional. Our only choice is a question of engagement. Our willingness to own and engage with our own vulnerability determines the depth of our courage and the clarity of our purpose: the level to which we protect ourselves from being vulnerable is a measure of our fear and disconnection."

Every person I have ever admired working in dementia care has always displayed a level of open vulnerability, has been someone who also instinctively knew how to use this vulnerability as a strength and yet instinctively was fully aware of how to keep within attached professional boundaries. The dementia care sector still seems to shy away from facing its own vulnerability and perpetuates the ‘them and us’ culture when in reality everyone in life is vulnerable. Dementia Care Matters believes a more open approach to vulnerability would close the gap in the care sector between people living and working together.

Ken Wilber, in his book The Simple Feeling of Being, suggests that tapping in to this vulnerability as the very essence of each person is the only way to be with one another. He asks:

Quality dementia care in the future will depend on our ability to BE person-centred and to identify, recruit, replicate and sustain the S Factor in special people

Don’t you already feel the simple feeling of being? Don’t you already possess this immediate gateway to your ultimate spirit – which is nothing other than the ‘simple feeling of being’. Don’t you already have an integral understanding of being in the world?

I would suggest that more exploration of the concept of the simple feeling of being and of each person’s vulnerability through dementia care training may be far more productive in the next 20 years than a focus on mechanical skills and competencies.

Finally, Atul Gawande in his book Being Mortal (2014) challenges us all in the care sector to shift from a medical model which has kept us in check to a model of being. He comments:

Being mortal is about the struggle to cope with the constraints of our biology, with the limits set by genes and cells and flesh and bone. We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that, it is to enable well-being. And well-being is about the reasons one wishes to be alive. The role of caring professionals and nursing homes ought to be aiding people in their search for well-being.

Being is the essence
Over the last 20 years I have observed dementia care grasp at any approach which focuses care on ‘doing’ things to people, be it reminiscence, reality orientation, dementia design, music therapy or snoezelen sensory rooms. All of these still have an important contribution to make. However, the core essence of being person-centred in dementia care has been lost in a desperate attempt to do something with ‘them’, through doing-type approaches, rather than to ‘BE’ person-centred in ourselves.

In our search for the S Factor in dementia care, and in looking at past and present philosophers and writers, many transferable messages can be drawn on to help us reflect on the future of dementia care training. The future lies in dementia care training being human. People who get what being person-centred is, may not be able to articulate it or have cognitively processed it in the same way as philosophers, but they just ARE...
person centred through their very being. Dementia care trainers have to believe that, where people are not natural at being person-centred, it can still be fostered with the help of mentoring so that carers develop these essential attributes:

• being able to join their identity with being authentic
• being able to have the courage to be vulnerable
• being able to project the essence of their spirit inside
• being committed to the search for well-being in others
• being mortal, wishing to be at peace with being in the now

Dementia Care Matters has focused all these elements of the S Factor in dementia care into an appraisal form called ‘Being Person Centred.’ This can be used to help staff and managers to rate each other on 12 ingredients of being person-centred. Additionally, we have produced a new dementia care reflection tool that rates people wanting to work and be in dementia care by focusing on five key factors of BEING.

There is no mystery as to whether the future of person-centred care is secure. From our early beginnings working at Merevale House to create the first Butterfly Care Home, to working with large care home companies here and overseas to spread the concept as we do now, on every occasion a person-centred care home has always been down to the quality of one person BEING this and BEING infectious with everyone around them. That there is an S Factor is not in doubt.

Quality dementia care in the future will never depend just on wonderfully designed dementia specific environments, nor on elaborate dementia care methodologies, cost benefit audits or any other new-fangled ideas. It will always depend on our ability to BE person-centred and to identify, recruit, replicate and sustain the S Factor in special people.

At the S Factor events the dreaded Health and Safety Sally comes on to the stage and recites:

You’ve nothing to fear with Sally
You’ll be safe in your chair all day
Though you may want to dilly and dally
We can’t let you roam or stray
The home will be totally tidy and clear
So you really have nothing to fear
Flowers are an absolute ‘No, no’
Scarves can strangle you know
All kitchen utensils must go!
But not a minute too soon
You’d be surprised what they can do with a spoon!
[Sally discards flowers, scarves and spoons]
Sweep the corridors clean
Lock the doors [She holds large key]
Ban all animals [Throws toy cat in bin]
Empty drawers!
You won’t have to worry about anything my dear
You can’t choke, trip or flounder here
If you are wanting a Riskbuster supreme
Safety Sal – capital ‘S’ - is your absolute dream!*

Routine Rita, Patronising Petal, Detached Deborah and Health and Safety Sally are far from the dream and are the nightmare of the last 20 years in dementia care. Let’s hope over the next 20 years, across all dementia care home organisations, everyone finally gets to the essence of what being person-centred really is.

* With thanks to Sally Knocker for her poem ‘Safety Sal’