The task is the mask: solving the riddle of being person centred

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‘Quality of life matters and is the only real indicator of quality of service.’ David Sheard

Holding up a mirror

Facing the truth is never easy. It takes a certain kind of courage to hold a mirror up to oneself. It is a brave step to see ourselves on the inside as others see us. Holding a mirror up to dementia care is equally difficult. In care work it is a given that people come to work to do their best. Many people in care services are already striving hard to radically improve people’s lives. Yet improving dementia care begins with accepting the truth. For too long the emphasis on quality of service has been over-focused on policies, procedures, systems and standards that consume staff in what matters least. Holding up a mirror in many care settings, to the real lived experience of people with dementia, is profoundly disturbing. This was demonstrated so powerfully in the BBC 2 series ‘Can Gerry Robinson Fix Dementia Care Homes?’ (The Open University, 2009) where poor leadership, a confused model of care, meaningless targets and institutional responses to both people working and people living with a dementia were witnessed widely across the UK.

Removing the mask

The truth is that dementia care has produced unparalleled levels of boredom, lethargy and staning into space, evidenced in a hundred qualitative observational audits of care homes (Sheard, 2008). This lack of emphasis on quality of life, combined with the maintenance of an institutional ‘us and them’ culture – examples being uniforms, separate staff toilets, staff not eating with people, has left the support of people living with a dementia rooted in the past. We all know the truth. We all know it doesn’t have to be like this. It’s as if we are all too lost in bureaucracy or too scared to examine closely what outdated models of care really look, sound and feel like. There’s no point looking in a mirror whilst wearing a mask, the truth will never be seen. The mask of bureaucracy at senior management level in health and social care powerfully protects those most accountable, for commissioning, regulating, inspecting and managing dementia care, from the truth. The mask of false detached professionalism (Sheard, 2009), where people divide the personal and professional protects professionals from their own emotional labour creating emotionless care. The mask of task orientation for nurses and care workers is a deliberate creation to protect staff from truly being person centred where feelings matter most at work. The key to solving the riddle of person centred care lies in the removal of these masks.

Institutionalising person centred care

Person centred care, as a term, originates from the work of Carl Rogers in the field of psychology and therapeutic counselling. The emphasis on being person centred was on being treated as a whole human being, as Carl Rogers called it ‘On becoming a person’ (Rogers, 1961). Professor Tom Kitwood (1997) drew on Rogers’ work applying this to the field of dementia care. More recently Professor Dawn Brooker has defined four key ingredients of person centred care in the VIPS model (Brooker, 2007). Anyone involved with health or social care services today will come across the term ‘person centred’. Throughout the sector the term ‘person centred’ has become in itself institutionalised, attached to glossy brochures and statements of philosophy, yet remaining invisible. Person centred care as a term has been around long enough in the care sector for us to know we’ve got a problem. Yet speaking about this can be treated as heresy. The truth is it has come to mean nothing – any old care can call itself person centred. It has indeed become a case of The Emperor’s New Clothes (Sheard, 2004). Where are all the crowd of people shouting out ‘Person centred care, it’s an illusion, it’s naked, there’s nothing to be seen’? Person centred care was never meant to turn into a task to be learnt. Turning person centred care into a task is the deliberate institutionalisation of a concept that many masked professionals have found too personally challenging. Even the idea of providing person centred care is flawed in its terminology. This concept is not something services can provide but instead is something that has first to be felt.
‘Being’ versus ‘doing’

Being person centred is a life philosophy. Being person centred is not something we do but something we feel. Yet a whole ‘industry’ of dementia care training focuses staff misguidedly on how to ‘do’ it rather than how to ‘be’ it. The idea that ‘Feelings Matter Most’ in care work challenges the whole basis and structure on which care has been delivered for decades. The psychological threat which being person centred poses to professionals leaves so many of them to run for the cover of their mask. If dementia care is anything at all it is all about emotional care. It is hard to believe that people can hide from this fact. People living with a dementia eventually rely less on facts, logic and reason; coming to rely more on their feelings. That people living with a dementia become more unmasked themselves, become more of a feeling being than a thinking being, must be known by anyone supporting people with a dementia. People experiencing a dementia search out other people i.e. staff to be feeling beings in order to feel reached. However, it is this very acceptance of feelings over facts, transparency over the mask that is so threatening to many masked professionals. Being person centred requires a person to have congruence in their life. A person with congruence has no separation of being and doing – they have their feelings, passion and their actions in a sympathetic flow. McDermott (2000) a consultant in the field of neuro-linguistic programming describes people who are congruent as people who live their passion and use their energies to have a driving force in their life. People who ‘get’ being person centred feel at ease with themselves in joining up the personal and the professional. For them, throwing away the mask is liberating. People who need to retain separation in their lives between the personal and the professional (the old culture professional) fight to hold on to their mask as its removal threatens their very core. As one nurse put it to me ‘Who will I be, David, if you get rid of the drug trolley and bring in individual locked cupboards?’! This nurse clearly felt standing for two hours at a drug trolley administering medication not only validated her as a nurse but also as a person. The challenge was for her to see and accept that leading person centred care as an exceptional nurse would be far better validation of her as a whole person. The masked old culture professional defends the barriers that separate people because they themselves need this separation from facing themselves in the mirror. The negative energy and forces against real person centred care are not to be underestimated. It is staggering to see the amount of misdirected energy put into defending the maintenance of an ‘us and them’ culture. So person centred care becomes another form of institutionalised care – a lost opportunity.

Believing feelings matter most

The reality is that there are no imperatives other than basic morality to practise being person centred. Organisations will go unchallenged and even receive three stars from the inspection process as long as minimum standards and legislative requirements are met. We are a long way off ‘outcomes’ being the standard measurement and of ‘quality of life’ mattering more than quality of service. That feelings matter most for all of us in life is self evident but not yet in the commissioning, regulation, inspection and management of care settings. So it remains a climb for passionate mountaineers to take on the challenge.

The ‘Feelings Matter Most’ model of care promotes five key steps to help focus those people committed to making person centred care a reality.

- **BEING** - focused on staff ‘being’ person centred rather than ‘doing’ it
- **ENABLING** - regular qualitative observations of the service being the key learning tool
- **INSPIRING** - real leadership using a measurable checklist
- **NURTURING** - staff’s emotions at work and supporting emotional labour
- **GROWING** - training that focuses on coaching and modelling real action

Training on Being

If the foundation to a person centred approach is all about being before doing (Sheard, 2007) and the turning point is realising that staff who ‘get it’ do so because of who they ‘are’ rather than what they ‘do’ this then has profound implications for learning and development in dementia care. It means shifting from developing competencies in a staff team to developing people’s self awareness and levels of emotional intelligence. Care services that ‘get it’ realise that being person centred has to start with each other before it can transfer to people ‘receiving’ care. This involves staff sharing their feelings, their emotional journeys in life, their own feelings of vulnerability with each other as the route to mirroring what they want to achieve in dementia care. From this comes the recognition that feelings matter most to all of us in life. Taking staff on this journey is about enabling a team to share its sense of ‘being’ in the team. This involves focusing individuals right back to their core of why people come to work in dementia care. It requires staff to make the links between this work and their own life history as a dementia care worker. The foundation of being person centred is to understand the fact that learning has to be an inward process of self reflection on being person centred and then applying this first to each other as a staff team before even beginning to try to ‘provide’ this in dementia care.
Opening the door

Sometimes in life we cannot see what is staring us in the face. We walk around with our eyes closed to the obvious. Our daily working lives are filled with images of people needing physical and emotional support that often do not equate with what we would expect for ourselves. We move these images on in our mind convincing ourselves it’s not really like this. Deep down we know truth but the truth is overwhelming. Being person centred begins with opening up a service to being observed, recording a day in the life of people and feeling the shock of boredom (Dean et al., 1993). Enabling a care service to see, hear and feel the lived experience of people with a dementia should not be underestimated in its power. It involves going through a pain barrier of acknowledging personal responsibility for being part of the old culture of care. It is this acknowledgement which enables someone to move on from the past. Regular qualitative observations of the lived experience of people and involving all staff in these observations is a more effective learning tool than any training workshop or DVD can provide (Sheard, 2008).

Removing controlling care is the first step in creating high levels of positive social interaction. This removal of words or actions that control people frees staff up from the rules and task orientation. Removing controlling care takes away the mask and opens up real potential to reach, connect and support people’s emotional needs. Organisations that enable their staff to see, hear and feel things as they really are will empower people living and working together. This feeling of empowerment will create a powerful imperative to decrease negative care and to be part of supporting lives that really matter.

Centring on inspiring leadership

Not everyone in life would dare to be so presumptuous as to feel they could inspire other people. Yet many people feel they could be a manager. Dementia care is drowning in management. It has been noted that some dementia care services have acquired the language of ‘being person centred’ but the ‘them and us’ culture is as strong as in the asylums. Equally person centred services’ exist in care homes that are as restrictive as any locked hospital environment. Alongside this, a large number of services have care environments looking like soulless hotel settings. Something has gone radically wrong with the management of person centred dementia care when these stark examples go unchallenged.

People experiencing a dementia need inspiring people to change the course of dementia care. Heartfelt leaders create emotional warmth, not just policies and procedures. Inspiring leaders project a new vision and set of beliefs with an infectious passion. Inspiring leaders have a determination to change uninspiring organisations. The Feelings Matter Most model (Sheard, 2008) guides leaders through a seven section, 50 point Checklist which focuses in priority order on:

- Removing ‘them and us’ barriers
- Evidencing Feelings Matter Most
- Ensuring physical and emotional freedom
- Creating meaningful ways to occupy people
- Focusing on a positive mealtime experience
- Writing strengths based care-plans
- Adapting the environment to compensate for the disability of dementia

Leadership involves helping staff, families and people living with a dementia to see what the pieces of the person centred jigsaw could be like if they were put together with passion, spirit and clarity. Leadership is about being unstoppable.

Tearing up the old rules

We live in a world that doesn’t ‘do’ feelings very well. Bound by the stiff upper lip, holding onto the hypocrisy of hidden emotions, displaying false niceness we waste so much time negotiating our lives by covering up. It should not then come as any surprise that the health and social care sector is a reflection of the national moral compass. The care sector avoids naming, recognising and expiring the impact of emotions at work because the rest of society does. ‘Detached professionalism’ where maintenance of the divide between the personal and professional are maintained has not worked and has delivered clinical, antiseptic lethargy. ‘Attached professionalism’ involves naming, valuing and supporting emotions at work and recognising that if staff are to be truly person centred this involves the giving of emotional labour. The suppression of staff’s emotions at work is a sign of a weak care organisation. Services that ‘get it’ create an emotion led organisation and implement positive, structured and focused ways to support staff well being.

NOSE – Nurturing our Staff’s Emotions is a new tool in the publication Nurturing which gives voice to the lived experience of staff and evidences being person centred with staff by focusing on their well being. If staff are to be encouraged to be person centred and to give of themselves in terms of providing other people with emotional support, this will only occur when staff truly believe that this giving of emotional labour is balanced by them receiving real emotional support themselves from their employers.

Shifting training into action

So what does all this mean for training, learning and development of staff? In the last ten years we have seen significant growth in the belief that training is the answer
to increasing the number of care services that are person centred. Without much evidence of what works or preparation of the ground training, like seeds, are thrown to a bare plot of soil, with the misplaced hope that something will flourish. The connection must be made that to turn dementia care awareness training into action mentoring, coaching and modelling is required. Any training opportunity is only as good as the impact it has on improving the quality of life for people within the care service.

The whole model of dementia care training must reverse the current cart before horse approach. Creating a real learning environment in dementia care is always about ‘us’ and never about ‘them’. Staff only understand the real meaning of being person centred when they have the space and opportunity to reflect on the meaning of this for themselves in their own lives. Training in ‘skills’ in dementia care will never be turned into practice without this training being linked into people’s core beliefs and feelings. Real evidence of how being person centred changes people’s lives can only be achieved with the backup of reflective learning. This reflective learning also means trying things out for ‘real’ with supportive coaching. When dementia care trainers grow in confidence, alter their methods and move out into really improving people’s lives directly in lounges and dining rooms so too do staff learn.

**Maintaining momentum matters**

If removing the mask is all about ‘being’ person centred not ‘doing’ person centred care, is all about seeing hearing and feeling the truth, is all about inspiring attached professionalism not detached management, is all about working to a clear model of rule free care and is all about growing learning through developing self awareness with coaching turning skills into action, then yet more energy is going to be needed to take this on. How is momentum in improving dementia care going to be kept up?

Think of a time in your own personal life when you persevered and kept going. Thinking about that time in your life what can you feel? What can you see? What can you hear? What can you transfer from that time in your life to keep dementia care improving now? Person centred care is about maintaining personal momentum. Person centred care requires a national ‘driver’ to sustain momentum. Person centred care was never about people living with a dementia. Being person centred needs to move out of the dementia care arena into the wider world of a belief system about life. Person centred care is not really about people living with a dementia at all but about how we would all wish to be with one another. When this is accepted, person centred care will be in with a chance. Like people living with a dementia, person centred care remains marginalised – it needs to become mainstream. Person centred care needs to move from being a nice ‘tack on’ when everything else has been done to becoming core business for everyone in an organisation. This requires a care organisation to sign up at Board level to a clear model of care, to set a clear commitment to quality of life being its main quality of service measure. Organisations need to become accountable for being person centred. This would involve measuring general managers on their capacity to ‘get it’, involving implementing appraisals for staff in being person centred and demonstrating regular action arising from qualitative observations. It’s time for dementia care to harden up. If the mask hasn’t yet been removed, if task orientation is still alive then it’s time to get tough. As one general manager commented to me: “We need to be belligerent about moving forward, to stop being nice and friendly, to be more honest and less sensitive about those who fail to make and sustain improvements.” It’s time for the world of dementia care to stop being so coy. Do you ‘gerrit’?

**References**


The Open University. (2009) ‘Can Gerry Robinson Fix Dementia Care Homes?’ www.ouw.co.uk.