
Person-Centred Dementia Care

A featured speaker at CapitalCare Edmonton's Annual 'People and Progress Continuing Care Conference' was David Sheard, a renowned advocate for person-centred dementia care. The gist of his address is presented, including a description of the Merevale House in England, considered the epitome of person-centred dementia care.

By Bernadette DeSantis, Manager, Corporate Communications, CapitalCare Edmonton.

Contact: <info@capitalcare.net>

Dementia care in the UK

The pursuit of a person-centred dementia care philosophy

Thirteen years ago, David Sheard revolutionized dementia care in the United Kingdom when he set out on a journey to put person-centred dementia care into practice. This past February, Sheard shared his novel approach to dementia care at the annual *People and Progress Continuing Care Conference* in Edmonton.

The theme of the conference, sponsored by CapitalCare Edmonton was "Linking Culture to Care."

Culture shift

Sheard's address focused on shifting the culture of dementia care from what he calls "the social warehousing of seniors" to one of true person-centred care.

His approach, which focuses on "being" person-centred, advances the ground-breaking work of Professor Tom Kitwood who introduced the concept in the early 1970s. "Being" is also the title of Sheard's book, published by the Alzheimer's Society of the United Kingdom, for whom Sheard is a consultant.

In his address, Sheard stressed that being person-centred is not something we do, but something we feel.

"We spend life as a human being, not as a human doing," Sheard told delegates. "Being feeling-based starts with ourselves. We need a real connection so people have a sense of who we are, to feel how we are affected. This shift from *doing* person-centred care to *being* person-centred is the way out of the current muddle," Sheard said.

No meaningful interaction

The "muddle" that Sheard describes is the current state of dementia care in many countries, including Canada. He described some continuing care centres as "hospital-like environments dominated by multi-tasking, harried staff at medication carts watching over people with dementia who spend their days staring into space." He described other centres as "soulless, hotel-like facades emphasizing customer service, tidiness and all-you-can-eat menu choices - but rarely providing any meaningful interaction between staff and people with dementia."

To the shock of many delegates, Sheard described LTC centres that have secure dementia units as prisons, and those that use physical or

chemical restraints as asylums. "We're killing their souls with this confused model of prison/asylum/hotel and home," Sheard said.

His outspoken remarks about the current state of dementia care, as he sees it, took conference delegates by surprise. Some even admitted that they took offence at his remarks, describing his presentation style as "negative and blaming," while others said he "pushed some buttons to see practice change."

A passionate advocate

Sheard is director of *Dementia Care Matters*, an independent team of professionally trained consultants based in the Division of Health and Social Care at the University of Surrey, U.K.

Sheard does not apologize for his passionate advocacy for person-centred care. His belief that dementia care in the U.K. could be radically different and better set him on a journey to espouse it to as many as possible.

He even admitted to very nearly giving up on the journey after trying for five years to get policy-makers in the U.K. to see that what was needed was not more standards

and policies, but rather a retraining of staff - and management - in being person-centred. "We're still getting there in the U.K.," Sheard told approximately 500 delegates at the Edmonton conference, the majority front-line dementia caregivers from across Western Canada.

Sheard pointed out that many dementia care services in the U.K. have been working hard to develop person-centred care, and although many pockets of inspirational practice exist, "it is not on the scale required to guarantee the quality of care for the majority of people with dementia."

Merevale House, U.K.

Sheard went on to describe the person-centred dementia care practices he and his team introduced in 1995 at Merevale House, a private care home for 35 residents with dementia.

The Merevale facility is a converted detached Victorian-era house with an enclosed patio and garden area to the front, and landscaped gardens to the rear. Located in Warwickshire in Central England, the home is situated between a canal, train tracks, and a main street, yet there are no secure units. Although doors are discreetly alarmed, Sheard points out that Merevale House does not have an issue with elopement: "When you feel free inside yourself, you don't want to leave," he explained.

The staffing ratio at Merevale House is 1 to 5. The non-unionized staff do not wear uniforms or name tags - nor do they always perform tasks according to their work classifications. Rather, they are trained to be "butterflies," flitting about the centre, interacting with residents, and being with them in whatever headspace the residents are currently living in.

'Soft skills' and competencies

Medications are kept in locked cupboards in residents rooms and dispensed by whichever caregiver is engaged with the resident at the time.

"Being person-centred," Sheard said, "means focusing on the 'soft skills' rather than competencies." The competencies are there, he explained, but they're in the person. What we have to do, he continued, "is strip off the professional mask and unleash the emotion in ourselves."

Moving 'junk' around

On a regular basis, staff bring in various objects, what Sheard refers to as "junk" - mops, sponges, handbags, gardening tools, photographs, hats, and anything else that will stimulate a conversation, a memory, or an activity among the residents.

At Merevale, residents spend their days moving this 'junk'. For some, the junk relates to a job they performed at some time in their life. For example, a former accountant explains to a staff member why he is moving the numbers from one column to the next; a former housekeeper polishes the brass, while a former secretary bangs out letters on an old typewriter; and a mother is seen cuddling a baby doll.

"People with dementia need to nurture, feel, and be treated as an adult with responsibilities. The staff are there," he points out, "to support residents in their choices."

Sheard went on to explain that when residents at Merevale want to wake up, they do; when they want to eat, they can. "We have to stop the task orientation - getting everyone up at the same time, feeding residents when they're not hungry, dispensing medications from a trolley... Caregivers have to make time for 'being' with those with dementia," he stressed.

"No staff, only people"

At Merevale, there is minimal distinction between staff and residents. In fact, as Sheard explained, "there are no staff, only people who work there and people who live there." Mealtimes are enjoyed together because conversation and social interaction improve the residents' appetites.

Also, there are no "staff" washrooms. There is no 'us' and 'them' mentality. "There is just congruence. Everyone is family... It should feel as if coming to work is to be with family," says Sheard.

Families and volunteers are also part of the mix; so are pets and farm animals. Further, there is very little evidence of tasks, routines, schedules, policies, systems and risk assessments, even though they exist at Merevale.

Feedback and assessment

Conference delegates appeared to be in awe at what Sheard was describing. One delegate said of his presentation: "It gives you a desire to want to work at one of his homes."

Another called it "a really exciting vision for how dementia care can be so much better."

Others disagreed with certain aspects of his philosophy of care. For example, several maintained that they were not convinced that people with dementia will want to be around other people all the time; others called the approach "dogmatic."

An inspection in 2007 by the National Care Standards Commission in the U.K. shows that Merevale met or exceeded all the national minimum standards required. The report goes further in commending the centre for maintaining "high standards" and makes no requirements or recommendations for improvement.

In terms of what the home does well, the inspector wrote: "Merevale House provides a relaxing, comfortable, supportive and stimulating environment. On the day of the (unannounced) inspection, all the residents appeared to be relaxed, (with) staff observed supporting the residents in a sensitive and discreet way that promoted dignity and independence.

"Residents are able to participate in a broad range of activities that reflect their personal preferences, that promote their independence and that they enjoy. (Continued...)



From Left to right: Marguerite Rowe, Vice President and Chief Operating Officer, Community Care, Rehabilitation and Geriatrics, Alberta Health Services; David Sheard and Peter Priednieks, Dementia Care Matters; and Iris Neumann, CEO, CapitalCare - Edmonton Area, at the 23rd Annual *People and Progress Conference*, Fantasyland Hotel, Edmonton, Alberta.

“All of the documents seen were well ordered, easily accessible and up to date. Recorded information about service users is detailed, person-centred and provides staff with clear guidance on residents’ needs, goals and wishes.”

“Residents’ health needs are monitored and well met with the support of the staff.

“Staff receive a high level of training and support to ensure residents’ needs are met safely and consistently.”

Self-awareness

Sheard admits that the glowing inspection report didn’t happen overnight. He warned listeners that changing the culture of a complex organization requires “leaders who can lead from the heart, and staff who want to connect with the people they care for.”

He stressed the importance of recruiting the right kind of staff. “Being person-centred requires the caregiver to be self-aware. Self-aware people live with passion and use their energies as a driving force in

their lives. For these people, the job they do is seamless with who they are and where they work. . . . Being person-centred feels natural - a joining of all the elements of oneself.”

Sheard admitted it took an alignment of all stakeholders to bring about the dramatic culture change experienced in the U.K. “13 years after being introduced (1997), person-centred care is finally starting to catch on.”

“For any large organization, changing a culture is difficult and takes passion, commitment, teamwork and substantial time,” Sheard said. “Most training sessions in person-centred care tend to focus on what to do and how to do it. ‘Being’ is not something (care) services can provide; instead, it is something that has to be felt.”

For the person receiving care, person-centred essentially means being treated as a whole human being - as an individual, Sheard stated in the January issue of the *Journal of Dementia Care*.

“Providing person-centred care involves feeling the experience from

the perspective of the person they are supporting. For nurses and personal support workers, being person-centred involves ‘wearing’ someone else’s shoes. This means respecting each individual’s past life and being supportive of their current feelings.

“For an organization, being person-centred is about creating a culture where the (care) service brings out the best in individual staff and those receiving the service. This involves enabling people, and living and working together to develop a feeling-based service, almost like a family or a community. . . . It is 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 feeling, boundless energy and will power to be truly person-centred in this way. People who have these attributes simply ‘get it.’ They are not threatened by feelings, but share the philosophy 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 their very being.”

Evaluations

Sheard’s passion for person-centred dementia care was clearly infectious. Evaluations from delegates at the conference were overwhelmingly positive. Iris Neumann, the CEO of CapitalCare, sums up the prevailing mood after Sheard’s address:

“David has tremendous passion and knowledge about helping residents with dementia live their lives as fully as possible. His presentation will inspire many of us to search for better ways to interact, connect, and, hopefully, provide better care for people with dementia.” ■