Life among the butterflies

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It affects more than 35 million people worldwide and costs government €460 billion a year to treat. By 2030, those figures will have doubled; by 2050, they will have tripled.

According to the World Health Organisation, dementia – the brain illness that affects memory, behaviour and the ability to complete simple tasks – is set to become one of the biggest public health challenges in the world over the coming years.

In the face of such a dramatic rise, an increasing number of those involved in caring for people with dementia are seeking alternatives to the institutional-style care that has become the norm.

Moorehall Lodge in Ardee, Co Louth, is typical of a new kind of care facility, one in which the goal of care is to create an environment that more closely resembles a home, not a hospital.

The staff don’t wear uniforms, the residents have an equal say in what goes on there, and there is a strong emphasis on treating dementia sufferers as people first. At first glance, the communal areas can seem chaotic – instead of clinical order, visitors are confronted with rummage boxes, domestic items, musical instruments, work items from residents’ past careers and more.

But amid the chaos there is a rational approach to caring for people with dementia that is meeting with significant success. Termed the ‘Butterfly Approach’, it is based on the belief that people with dementia are primarily emotional rather than thinking beings, and as a result nurses and care workers need to learn a new way of relating to them.

“People with dementia are living in a different reality than us, but it’s just as real to them as ours is to us. However, the conventional approach to dementia is to treat it as a medical condition.” Says David Sheard, chief executive and founder of British-based Dementia Care Matters.

“People have a disease of the brain and that disease causes symptoms that lead to behaviour that requires the sufferer to live in a hospital or care setting. That setting often replicates a hospital environment. It’s clinical and sterile, and while people receive good personal care, they have high levels of boredom and the culture around them has a high level of malignancy about it. The general attitude is that there’s nothing more that can be done for you.”

Sheard coined the term ‘Butterfly Approach’ to describe the way care home staff should interact with people with dementia. Like butterflies, staff aim to be colourful, to capture attention and create moments of connection, and to fill up the environment with what they wear, how they smell and what they say.

“Instead of running formal activities for 30 to 40 minutes that will collapse because dementia sufferers don’t have the attention span for them, we create lots and lots and lots of small moments.
where the staff connect with people and with the things around them to reach the person inside,” he says.

“The emphasis is not on activities per se, but on being occupied. This might be rummaging, stroking or simply fiddling with a doll. Every connection is geared towards giving the person with dementia a sense of belonging inside, which leads to a feeling that they are comfortable in their surroundings.”

Sheard believes that the problem behaviours exhibited by sufferers of dementia are more often than not caused by what he terms ‘care culture’ rather than the disease itself.

“You have to work on the basis that people with dementia are more feeling beings than thinking beings, and accept that they can’t work with facts, logic, reason and memory. What they have got is a heightened sense of emotions and feelings. They’re still there inside, but you have to reach their spirit. Although the disease will get worse, they can flourish and in many ways come alive again.”

To achieve this, facilities such as Moorehall Lodge which have embraced this approach turn the conventional care model on its head, and arrange the care given around the patient rather than the institution.

“We fill up the environment with tons of stuff associated with life – hooks with things hanging on them, boards filled with stuff to do with people’s past jobs, soft toys, dolls, household items. People with dementia can’t just be people with dementia; we need to help them find who they were before they started to suffer the symptoms,” says David Sheard.

“We need to help them re-experience the memories they have, because they’re living in their minds – being a mum, a cleaner, a housewife, a painter and decorator or whatever. We recreate their past lives through the environment. We find that once this ethos is established, there is no evidence of the behaviours that can sometimes match the public image of people with dementia.

These behaviours are not caused by a disease in the brain – they are caused by environment and disconnection.”

Sheard is 54 and has been advocating this approach to dementia for 17 years. He started his career at 22 as a social worker in Yorkshire, working with people with dementia and remaining in the British National Health Service until 1995, when he left his position as a general manager for old age psychiatry for the city of Coventry to become a consultant.

The founder and chief executive of Dementia Care Matters, in 2010 he was awarded an honorary degree by the University of Surrey for his contribution to the field of dementia care development.

“At 36 I decided I couldn’t do it anymore – I didn’t want to run dementia care factories anymore, as it had become increasingly far from what I believed could be done. I began with one care home, Merevale House, that has since become nationally recognised in Britain for the quality of its approach. I moved into that home as a consultant, and myself and the owner decided we’d start from scratch,” he says.

“At the time, I was just one consultant working in one care home and I struggled to get people to listen to my ideas.”
Today, Dementia Care Matters has 43 project homes located across Ireland and Britain, offers training courses in both countries and has 16 full-time staff. A second Irish care home the Castleross Nursing Home in Co Monaghan recently signed on to adopt Sheard’s methodology, and there is also a year-long diploma course being offered in Dublin and Cork in person-centred dementia care.

It was at one of the 50 conferences that Sheard was invited to speak at over the last year that he met Moorehall Lodge’s owner, Michael McCoy.

Moorehall Lodge was set up in 1998 as one of the first purpose-built care homes in the north-east. In 2000, McCoy opened a care unit specifically for people with dementia and since then the facility has grown to accommodate 81 people. Over the years, McCoy has travelled widely to visit other facilities around the world to attempt to fix a problem he saw in how care for people with dementia is typically delivered.

“We travelled and looked at different models of care before finding the Household Model, which was created by Steve Shields at a facility in Kansa called Meadowlark Hills. The principle is that anyone in residential care is cared for in a domestic rather than an institutional setting, and around four years ago we adopted that,” says McCoy.

“Moorehall Lodge has the same basic features and facilities that people might experience in their own homes. There is comfort, security, freedom to make choices, the normal smells and sounds you’d find in your own home – down to chatting over tea around a kitchen table.”

What impressed McCoy about Sheard’s Butterfly Approach was how neatly it fitted in with the Household Model, and the fact that culture change was deeply embedded in both.

“I heard David speak a few times and did his diploma in St James. What impressed me most was the idea that there’s no ‘us and them’ scenario between staff and residents. There are no uniforms and no name badges, we operate as one extended family where the resident’s voice is as important as the staff’s.”

The idea of connecting with people on an emotional level rather than on a thinking level means that there can be real quality of life for people who are typically written off.

“Take something you like the incontinence that can happen through dementia. It takes around 37 different instructions from the brain for someone to recognise the need to use the toilet, get up and fully go through the process. You have to decide you want to go, know where the toilet is, how to navigate the door and lock, work the toilet itself and so on,” says McCoy.

“People with dementia don’t have the ability to go through those 37 processes. What they do have is the ability to emotionally process things. Some may have the ability to say “I need to go to the toilet”, but may not be able to remember where it is or what to do next. They can become quite agitated through not knowing what to do.”

McCoy has found that by communicating emotionally, reading body language and recognising the person’s emotional state, it’s possible to help that person through that kind of day-to-day task.

“If the person caring for them is tuned into that individual, they can stay a step ahead of them – they can look for facial expressions, look at the way someone is sitting, see that they are becoming
agitated. They can read the signs, and not explicitly say, ‘Come on and we’ll go to the toilet’, which can cause stress, but rather something like ‘let’s go for a walk’, and then guide them there. Often people don’t understand that the person with dementia doesn’t have the ability to interact with the world in the way they used to. They expect them to be able to do things like go to the toilet on their own,” he says.

According to McCoy, making this emotional connection involves accepting the person in the reality they are living in, and realising that there are places within their mind that will trigger off memories and ideas.

“For example, we have a thing called a memory box, and we ask staff to bring in six things that are connected to strong memories in their own life. Then we ask them to pull something out of the box and explain why it’s significant to them, why it fires off a memory for them,” he says.

“This allows them to connect to how the same process works in people with dementia, and to realise how evocative and powerful memories like that can be. For example, there’s a man with us who has a towel with the logo of his favourite football team. To him, it’s a significant thing. When he came into care, that towel was just kept in his wardrobe and treated as you would any other towel, but if someone had used it to wipe up a spilled cup of tea, that would have been quite hurtful, and it would have driven him to a deeper place. Instead it’s now up on the wall and is given pride of place. It provides a strong emotional connection to something that means something to him.”

According to Dr Emer Begley, social policy officer with Age Action Ireland, there is cause to be concerned at the range of facilities on offer to people with dementia in Ireland.

“The most up-to-date figures we have suggest that there are around 40,000 people with dementia in Ireland, but that’s expected to triple over the next 40 years. It’s not a normal part of the ageing process, but there is a prevalence of the condition among older people and with people in general living longer than they used to, we will see an increase,” she says.

The breakdown of research in this area shows that the majority of people with dementia don’t live in institutions but in the community.

“About 26,000 live at home, and probably the majority of them may not have a diagnosis. There are a few possible reasons for this, and the first is that people may have some of the symptoms of dementia but not known that what’s causing them. There is a general lack of knowledge among the general public about what dementia is, and there’s also a stigma associated with it,” says Begley.

“People don’t want that label attached to themselves out of fear, so they put off attending a doctor. For the same reason, family members are reluctant to bring it up.”

The fact that the early stages of dementia can be confused with the natural effects of ageing mean that many people who have the condition live with it for quite a while before realising that something is wrong.

“There’s a lot of stigma about dementia, because typically the images we see of people with the disease on TV depict those in the later stages of the condition. The reality is quite different. You can
have dementia for a long time and not realise it. You don’t go from zero to 100 without progressing through all the numbers in between – there’s a whole journey,” Begley says.

“In Ireland, unfortunately, we don’t have a strong history or tradition of formal services to support people with dementia and their families. In the new dementia strategy the government has committed to in the Programme for Government, we will see an increase of funding into that area. As the population increases and ages, there will be an increase in the number of people with dementia. We need to see a huge investment to prepare for that, and we haven’t seen it yet.”

Age Action Ireland is campaigning for the creation of what it terms a dementia-friendly society. This would see attitudes to and treatment of dementia re-evaluated with a view towards maximising the person’s abilities, rather than focusing on what they can no longer do.

“We would like to see heightened awareness of dementia among the general public, and we would like people to see it as much as a social disability as a neurological disease. If this happened, there would be more understanding of how a person’s physical and social environment can influence the disease,” says Begley.

“It’s quite common for people’s life experience to change as a result of the diagnosis, not from the disease, but because of attitudes to the disease. But it doesn’t have to be like that. I spoke to one man who received a diagnosis of dementia who said that his friends didn’t treat him any differently when he told them about it. They still went to the pub, they still played golf. His experience was much more positive than somebody whose friends withdrew from them.”

In her doctorate study, Begley found that when people received a diagnosis they often consciously withdrew from social activity and from their circle of friends. In some cases they didn’t want others to find out, and in others they lacked the confidence to explain it.

“We would like to see more psycho-social intervention to support the person, so we wouldn’t necessarily focus so much on medicine and on dispensing drugs to make people better, but rather ask how we could help people to live at home for longer. We should be supporting carers a bit more – in an age-friendly society, there would be more support for the people who care for the elderly.”

Adopting a person-centred approach to dementia care in a residential setting is not an easy task. While the approach itself demands a lot of staff and management in residential settings, it can also be met with resistance from the families of people with dementia, as well as staff and other healthcare professionals.

David Sheard believes some of this is natural, and that particularly in the case of the families of care homes residents, there needs to be education on all sides.

“Initially people don’t know what to make of it. Some are shocked by what a care home that uses this approach looks like. Families would say to me that they don’t want their mother to have a doll that she thinks is a baby, or that they don’t want their dad walking around thinking he’s back at work at some point in his past. It offends the dignity of the memory they have of their parents before they suffered dementia,” he says.
“I would say to them, well you can visit your Mum or Dad and try to get them back by dragging them into your reality, but it won’t work – you’ll leave upset, when you get home you’ll feel bad that they’re in a care home, and when they’ve gone you won’t have good memories left of that time.

“Or you can go on a painful journey with them that involves learning to love them and connect with them as they are now. That way you will have good visits and you’ll be left with positive memories of your Mum or Dad, who were living well during their time in a care home.”

Reactions from other care providers to this method of care can also be mixed, according to Sheard, who says that if people have worked for an extended period of time in a clinical setting, adapting to a new way of doing things can be difficult.

“Initially, it can cause some difficulty. We want the staff to really reach people; we don’t want them looking or sounding like a nurse in a hospital,” he says.

“Some staff see it and immediately think: ‘Of course this makes sense, this is how I’ve always somehow known it should be’. But you also get people who are used to the old ideas and culture, and struggle a bit with it. Most get it over time, but there are a small number of people who fight hard against it. They justify themselves using a false notion of professionalism, and are quite threatened by the ideas.”

**What is dementia?**

Dementia is a broad term used to describe a progressive deterioration of cognitive function, usually noticeable as loss of memory, lack of ability to reason, loss of social skills and normal emotional reactions.

Not a disease in its own right, dementia is best understood as a symptom of other diseases, the best known of which is Alzheimer’s disease, or as a result of damaging the brain, such as a stroke. According to the Alzheimer’s Society of Ireland, there are around 100 diseases that can cause dementia.

Most affecting the elderly, it is possible for adults to suffer from the condition at any age and can take years to become apparent to the sufferer and those around them. Initially it affects the higher mental functions, but in the later stages the person may not know what day of the week, month or year it is, where they are or who the people around them are.

There is no cure for dementia, but drugs can be used to slow its progress and early detection is crucial to minimising its effects.