Advancing the Butterfly model in dementia care homes

Providing a springboard for culture change in care homes is key, says David Sheard. He explains why Dementia Care Matters’ 50 Point Checklist has been revised.

Surely checklists are the antithesis of a movement towards culture change in dementia care? Checklists foster a tick box culture linked to process management. This style of management has previously consumed the care sector in policies, procedures and systems that have had little to do with evidencing improvement in people’s lived experience in care homes.

In Dementia Care Matters we believe a new culture of care comes from focusing on a model of emotional intelligence where values, attitudes and passionate leadership transform care home cultures. It is now largely accepted that focusing energy on achieving outcomes is more likely to improve the well being of people living and working together.

Faced with commissioning and regulatory requirements, practice development initiatives, family expectations and competing models of care it can be difficult to bring these elements together into a cohesive approach. Care homes can feel overwhelmed by the existence of too many pieces of the care home jigsaw with no guidance on how to fit these together. As long as checklists are not used to foster a tick box culture they can act as helpful glue in bringing a model of care together.

Inspiring the ‘picture on the box’

In 2008, Dementia Care Matters authored Inspiring: leadership matters in dementia care as part of the Feelings Matter Most series of publications (Sheard 2008a). It set out a compelling vision of dementia care aiming to give care homes the ‘picture on the box’ in order to know how to piece together a cohesive model of dementia care. Back then, our particular model of dementia care was known as ‘The Butterfly Approach’. Inspiring gave practical examples from this approach of how to shift people from a detached management style to an attached leadership style where people led from their intuitive hearts and not just with their practical hands. The publication provided evidence for this vision with an example of a model service, ending with a 50-point action checklist for services to appraise their care culture and to give care homes practical elements to develop future action planning.

Over the last eight years thousands of these checklists have been completed in care homes across the UK, Ireland, USA, Canada and Australia. Now the time has come to align and revise this checklist.

Facing the truth

The original purpose of the 50-point checklist was to identify the key elements needing to be present in a dementia care home. The checklist collated these under seven headings:

- Removal of Them and Us Barriers leading to Culture Change
- Feelings Matter Most Approaches
- Evidence of Physical and Emotional Freedom
- Creating Meaningful Ways to Occupy
- Focusing on the Mealtime Experience
- Person Centred Care Planning
- Evidence of a Dementia Specific Environment

The checklist was written in priority order, i.e. the first element on the checklist was seen as the highest priority element to enable a new culture of care, with the last element being the lowest priority although all 50 elements were still valuable overall. Care home managers and staff who completed the checklist were asked to do so on the basis of working quickly from their gut reaction. People had to rate whether each element had been implemented within the home on the basis of ‘yes’, ‘no’ or ‘partly’. Here is what one trainer said about the checklist:

“It’s a great measure of the home’s quality of life and the team indicators we look for but it is only as good as the manager or team completing it. By that I mean if it’s completed with honesty, transparency and a total awareness of how people with dementia are experiencing their life in the care home, it will provide a sound foundation for development. However, it can create a sense of vulnerability and that can shape the responses given on the checklist with far too many ‘yes’ and ‘partly’ attributed. Gwen Coleman, consultant trainer, Dementia Care Matters

On completion of the checklist, the total number of ‘yes’, ‘no’ and ‘partly’ responses gave the home a clear indication of current progress achieved in bringing together different elements of care into one cohesive model. The results were always startling in conferences where the 50-point checklist was completed. Often when a room of 100 participants declared individually their total scores, 80% of them would score their care home as achieving fewer than 20 ‘yes’s on the checklist and 50% would even score their care home as achieving fewer than 10 ‘yes’s. The checklist was completed for the first time in Australia at six conferences in 2015 by 274 participants (Sheard 2015). The Australian care homes’ findings were:

- Total number of ‘yes’s achieved:
  - 112 care home participants stated their care home had only fully implemented up to five of the elements on the checklist.
  - 67 care home participants stated their care home had only fully implemented up to 10 of the elements on the checklist.
  - 57 care home participants stated their care home had only fully implemented up to 20 of the elements on the checklist.
  - 24 care home participants stated their care home had only fully implemented up to 30 of the elements on the checklist.
  - 14 care home participants stated their care home had fully implemented over 30 of the elements on the checklist.

Despite the last 20 years’ development of person-centred care approaches these results continue to be replicated now in the UK. They are a powerful indicator of the...
random methods of many care homes and the piecemeal way in which practice developments are adopted without any linkage to a cohesive model of care. As one UK care home manager stated recently: “There were elements that were hard and difficult to change such as relieving them of tasks and ‘going with the flow’, especially for staff with many years experience of institutional care.”

Checklist as catalyst
Many care homes report that the 50-point checklist has been instrumental in transforming their culture of care:

> It has had a major impact in turning the home from an institution to a truly loving, person-centred home. It helped us to focus on what were our priorities to work on, to identify easy, small wins and it was a clear vision for teams to see and understand the direction we were going in. Its effect in changing care provision cannot be overstated. Lesley Hobbs, home manager, Deerhurst, Brunelcare.

> When the checklist was first produced, a number of elements within it were and still are viewed as controversial. Using the same numbering, these are:
> 1. Uniforms have been removed and staff look like ‘best friends’ and not like nurses in charge.
> 2. All use of trolleys has been stopped – medication is given out individually from locked cupboards in people’s rooms.
> 3. Staff are not obsessed with risk prevention and health and safety – they meet legal requirements but evidence during the day that their approach is in the context of promoting rights.
> 4. Attempts are made not to mix up people with a dementia at different ‘points’ of experience who are fearful of one another.
> 5. Twenty-four hour visible food is out in public areas and hallways – changed hourly to meet Food Hygiene Regulations, with the aim of encouraging people to eat when they feel like it.
> 6. Hallways exist which are divided into coloured sections or divided up with objects and/or seating to prevent institutionalisation.

> The first eight elements on the checklist, under the heading ‘Removal of them and us barriers,’ continue to be the section in completed checklists that receives the most yes’s. We still have a very long way to go to create truly inclusive communities in care homes where Professor Tom Kitwood’s original vision of no ‘them and us’ is finally achieved (Kitwood 1997). Currently 44 Butterfly Care Homes exist in the UK, but many thousands of staff not in Butterfly Care Homes have implemented the 50-point checklist. The movement to get rid of what Kitwood called “malignant social psychology” continues and the checklist has played its part.

> Prior to implementing the 50-point checklist in my care home, I had heard it would free up the staff team’s time and improve the quality of life. What I did not expect is that the tool would empower the staff team and it’s impact can certainly be seen, felt and heard much more than I had hoped. Louise Collins, owner, Wisteria House, Plymouth

Moving towards households
In 2010, our Butterfly approach began to advance in adopting a household model of care inspired by examples in the USA and Ireland. Dementia Care Matters began advocating strongly for the adoption of household principles in both its model of care and in its dementia design features (Sheard 2013). Care homes that received our Butterfly Quality of Life National Accreditation Award, did so by achieving a positive outcome on three measures: level of positive social interactions assessed through a qualitative observational audit using QUIS (Quality of Interactions Schedule) (Sheard 2008b), the degree to which the care home had implemented household design features through Dementia Care Matters’ ‘Look’ checklist, and its success in achieving over 30 yes’s on the 50-point Butterfly Model of Care checklist.

> Since 2010 care homes that have adopted the new Butterfly Household Model of Care are increasingly encouraged to divide up the home into matched households in which people live together at a similar point of experience of a dementia. This matching is in order to reduce people’s ill-being and stress caused by placing together an inappropriate mix of people, who at different points of a dementia express themselves differently. People working in the care home are encouraged to develop and match their specialist skills to people living in a particular matched household.

> Alongside this, ‘household’ language is adopted and institutional terms such as ‘corridors’, ‘on the floor’ and ‘residents’ are removed. Instead the language of houses is brought in, i.e. ‘front doors, ‘hallways’, ‘living rooms’ and the term ‘people who live here’. The word ‘mealtimes’ is changed to ‘meal experiences’, moving away from the idea of routines and set times and towards the idea of a meal being an experience that can last throughout the day. Similarly the word ‘bedroom’ is changed to ‘personal room’ on the basis that people need to feel they have more in life than just a bedroom.
Improving the jigsaw

If in 2008 care homes were struggling to put together the jigsaw of care, then eight years on the jigsaw has developed more pieces. The revised Butterfly Model checklist has had to include in particular a new key section on creating households which has added 13 new elements.

New elements on creating households
- Home Like
- Households
- Domestic Size
- Own Front Doors
- Matching People
- House Leaders
- Housekeepers
- Lounge Diners
- The Household’s ‘Story’
- Personal Rooms
- ‘Later Stage’ Household
- Care Partners
- Sense of Community

Eight years of learning and implementing the Butterfly Household Model of Care has also resulted in a significant refinement of language use in the checklist to provide more explanation of the Butterfly principles. It is interesting to note that, separate from the new section on creating households, the revised checklist places a new emphasis on several more elements that were also not in the original version. This is a fascinating indicator of the growth of practice developments both in dementia care and Dementia Care Matters. Their inclusion comes from our own evidence base demonstrating the importance of the new elements in sustaining culture change.

Additional new elements
- Feeling Based Recruitment and Training
- Nurse Leadership
- Two-way Giving
- Qualitative Observation
- Night Clothes for Staff
- Homely Desks
- Staff Handovers
- Theatre Stage Setting
- Quality Personal Care
- Well-being Assessments
- Pain Assessments
- Closeness and Intimacy
- Rescuing Approach
- Quantitative Measures

Model first, design second

In eight years’ time will the care home sector have truly embraced the household model not only just in dementia care but throughout care provision? A worrying development in a large number of care home organisations is their claim to be offering and providing a household model. This is often without the radical transformation of approach to care and design which a true household model requires. We seem to be in danger of everyone talking the talk about household models in very much the same way that people have used the term ‘person-centred care’ seemingly to refer to any type of care.

In a back-to-front way, many positive dementia design features are increasingly becoming institutionalised as the ‘quick fix’ solution to transforming cultures of care. Our key message is that in order to benefit from good dementia design an organisation must design and build to a cohesive operational model of care first. Designing a care home first and then bolting on a confused operational model will mean that many of the vital jigsaw pieces of care are missing.

Imagining eight years’ time

Dementia Care Matters has been so encouraged and inspired by many care homes that have adopted the 50-point checklist. A care home owner commented a few weeks ago:

“When we first saw the 50-point checklist four years ago we said it was impossible to achieve. We now know not only is it possible, it is liberating. Our family members who live with a dementia laugh, have fun, tease each other, cry, protest, object, love – the simple beauty is that they can. Ros Heath, owner, Landermeads care home, Nottingham.”

We believe that a specialist model of dementia care is required to build on the care sector’s level of expertise. The Butterfly Household Model of Care and its revised checklist hopes to continue to contribute to changing cultures of care and to proving why living in households really matters. However, in eight years’ time, the success of the household model, with no further need for revised checklists, will only happen if the concept of true inclusion has really been embedded in the care sector.

Is it possible to dream that, eight years from now, things will have advanced to a point where specialist dementia care and matched households are no longer required? The need for specialist dementia care and matched households is a direct response to the levels of ill-being, de-humanisation and poor skill levels that have been a feature of ‘them and us’ cultures. Specialist dementia care and matched households offer for a time an opportunity to correct this imbalance, improve cultures of care and develop more specialist skills to reach people. The goal in the future will surely be to develop staff to the point where they are able to match their skills to each individual person.

Models of care have been at the chrysalis stage for a long time. Their eventual transformation into a more sophisticated model, similar to the Butterfly Household Model of Care, will arrive when people working in a care home are enabled to switch their skills effectively from person to person, where matched households are not needed and a person-centred and relationship-focused approach is applied to everyone living and working together.

References
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Bibliography