

Inspiring action: checklist for culture change

David Sheard outlines his assessment of the state of culture change in dementia care in Australia, based on findings from the Butterfly Care Homes' 50-point action checklist

After presenting (via Skype) at the Australian Aged Care Quality Agency's Better Practices Conferences in 2014, Dementia Care Matters Director of Learning Peter Priednieks and I arrived in Australia in June 2015 for a six-city speaking tour to outline Dementia Care Matters' Butterfly Household Approach to culture change, with a view to introducing Butterfly Projects here.

Dementia Care Matters established the first Butterfly Household in 1995 at Merevale House in Warwickshire, UK. After a five-year trial there, the model expanded throughout the UK, through a one-year university-recognised course titled *An emotional journey*. This merged person-centred care principles with a culture change approach. Over the past 10 years, a network of Butterfly Care Homes has been developed by establishing Butterfly Projects in the public, charitable and independent sectors of dementia care in the UK, Ireland and Canada.

The Butterfly Household Model's central belief is that the primary competency needed to achieve quality of life in dementia care is the development of emotional competency, because 'feelings matter most'. The core action required in this model of care is the implementation of an emotional labour strategy where being person-centred is practised as an organisational philosophy. There is no 'them' and 'us' distinction between management and care staff nor between people living and working together while in the care home. It is an emotional journey for all involved, where feelings, beliefs and care approaches are turned upside down, before the organisation settles into a new way of people 'being' with one another.

Inspiring action

Our goal in speaking at conferences across Australia in 2015 was not only to inspire people to believe that dementia care could be so different, but to also test the level of real culture change being achieved in dementia care homes in Australia. Conference participants were asked to



Sharing the stuff of life at a Butterfly Care Home in the UK

assess the residential aged care homes where they worked using Dementia Care Matters' *Inspiring action 50-point checklist*.

This checklist is a compilation of the 50 elements of the current Butterfly Household Approach. I designed it in 2008 and it was originally published by the UK's Alzheimer's Society in the third book in Dementia Care Matters' *Feelings matter most* series titled *Inspiring: leadership matters in dementia care*.

The checklist acts as a self-assessment for care homes to evaluate their progress in moving towards a new culture of dementia care. It requires participants to indicate whether they have implemented each element 'fully', 'partly' or 'not at all' by answering 'yes', 'no' or 'partly' against each one. The elements are listed under the following 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 50 elements are listed in order of

importance, with number one as the first priority for achieving culture change. Underpinning this is a pivotal challenge to dementia care homes to focus first on removing institutional barriers, providing core emotional care and recognising the importance of people's emotional identity, rather than the quick fix of creating a dementia-specific designed environment and doing nothing else to really change the quality of interactions between people living and working together in the home.

Australia's results

Across six cities in Australia, 264 *Inspiring action* checklists were completed. Whilst residential aged care homes were able to keep their results anonymous, the overall findings are a core indicator of the state of culture change in Australia now.

The majority of respondents (112 out of 264) indicated that their organisation had fully implemented only 0-5 of the 50 elements. A total of 67 participants said their organisation had implemented 5-10 of the 50 elements; 57 had implemented 11-20 elements; 24 had implemented 21-30 elements; and 14 had implemented 31-plus of the 50 elements.

Interestingly, across all 264 completed checklists, the elements that participants had the most difficulty in answering 'yes'



Butterfly Care Homes are full of colour and activity

to in terms of achieving full implementation were the most important elements: 1-8 – ‘Removal of Them and Us Barriers Leading to Culture Change’, as follows:

1. Uniforms have been removed and staff look like ‘best friends’ and not like nurses in charge.
2. All toilets are communal and there are no separate staff toilets.
3. Staff do sit to eat meals with people with a dementia.
4. All use of trolleys has been stopped – medication is given out individually from locked cupboards in people’s own rooms. Drinks and meals are served individually.
5. There is a relaxed ‘go with the flow’ feel to the day with no sense of the routines that occur in hospital.
6. Evidence can be seen of managers modelling person-centred care in the living areas daily.
7. Staff see management as feelings-based leaders towards them and use words which describe this when talking about managers.
8. Labelling language in care plans has been removed, ie, words such as ‘wanderer’, ‘challenging’, ‘aggressive’, are banned and staff do not use this language nor ‘talk about’ people in communal areas in front of people.

This finding is no different to those in other countries where the movement to achieve culture change in dementia care seems to place the cart before the horse – focusing on improving environments and initiating practice development initiatives around activities and meaningful occupation, without first grasping that real culture change only becomes embedded when the core foundations of an institutional model of care are removed. This begins with the removal of a ‘them’

and ‘us’ culture.

As in the UK, where thousands of these checklists have been completed over the past nine years, the impact of this self-evaluation process for Australian participants was salutary. Comments included:

“I found today was the first day I’ve learned anything about dementia as I was stuck after 20 years in the thought process of behaviour management, not feelings first.”

“This has shown me how desperate residential aged care is. The focus in Australia is dollars and regulation – not the people. Their emotional and spiritual needs and those of the staff are blatantly ignored.”

“This makes the point of how change is required urgently – while I only scored four ‘yesses’ on the 50-point checklist, I am feeling completely excited and re-energised. This is what I’ve been looking for and is why I originally entered aged care.”

What the results indicate

As we visited care homes in Australia and I began to see the results of the checklists come in, our nervousness about bringing the Butterfly Household Approach to Australia diminished, as the care homes and the checklist findings were very similar to those in the UK, Ireland and Canada where this approach has already been implemented.

What do the Australian results indicate? As with the other countries, they demonstrate, as one participant said of the huge challenge facing their organisation: *“I feel like this offers so many opportunities but feel overwhelmed by the task ahead – we have a long way to go but it is possible. Person-centred care begins with care homes affording this on staff first. Only then can they bestow this on older people – we need to create houses,*

where casual dress, creating stimulating décor, undertaking person-centred appraisals of staff and moving on staff that don’t ‘get it’ are all possible.”

In Dementia Care Matters’ experience, care homes that initially achieve only 0-10 ‘yes’ answers are obviously at the very early stages of this journey. However, it does not mean that all these care homes are stuck in a malignant social psychology of care. Many with this current score will have already begun, with passion and enthusiasm, to improve people’s quality of life.

Care homes that are currently achieving 11-20 ‘yes’ responses probably have been working very hard in the past two to three years to get to this stage of culture change.

Care homes achieving a rating of 21-30 ‘yesses’ will already be care homes which look, sound and feel like the beginnings of a Butterfly Household Model of Care – in other words, very different to the hospital/hotel model of care which will eventually come to be viewed as anachronistic in all countries.

Very few care homes around the world achieve a rating of 30-plus ‘yesses’, and if they do, they will already be like a Butterfly Care Home (in the UK Butterfly Care Homes with a rating of 30-plus ‘yesses’ are likely to receive a Butterfly Quality of Life Kitemark Award if the unannounced qualitative audit evidence backs this up).

Fully implementing all the elements of the 50-point checklist, even for Butterfly Care Homes, is generally an ongoing journey. When people ask ‘how long’ I often reply, “another 20 years”.

Saving time in Australia

We hope that the following key lessons learned from implementing the Butterfly Household Model in the UK over the past 20 years will make the journey easier for those Australian aged care homes wishing to introduce culture change in dementia care:

- We have learned that culture change must be addressed as a government- and board-level strategic priority, rather than the focus being only on practice development for nurses and care staff.
- It must be prioritised as the driver in regulation rather than an add-on to current exhaustive compliance measures.
- Evidence of quality-of-life outcomes must be given equal importance to quality-of-service outcomes.
- It must be valued financially as having cost benefits across the entire organisation’s core business.
- It must be invested in as a leadership requirement, to demonstrate that

emotional intelligence is a priority competency.

- It requires the focus to shift from dementia awareness training to mentoring culture change in action.

The quest for evidence

Whilst the qualitative evidence and need for culture change in dementia care is incontrovertible, the quest to gain commitment at a government or care home organisational level has shown the need for solid quantitative evidence too.

Dementia Care Matters has undertaken over 700 qualitative observational audits of care homes in the UK where we found people with dementia were spending 70% of their time in neutral care – sitting, doing very little, with tasks being done to and for them, with little or no meaningful interaction. However, years of presenting this evidence has not been sufficient to speed up the pace of real culture change in care homes.

Our advice to Australian organisations is, as well as collating the qualitative evidence and wanting to win the hearts, minds and values argument about why this has to be part of the future of dementia care, it is also imperative to collate vast quantities of quantitative evidence.

Dementia Care Matters wasted many years thinking the culture change argument would be won through qualitative audits, and this has not worked. In 2014/15 our organisation shifted its argument and believes the quantitative evidence it is now collating is of even more importance to governments and care home boards. The following statistics show some of the quantitative evidence we have collected from Butterfly Care Homes:

- Falls – 43% reduction in incidents.
- Expressions of behaviour – 58% reduction in incidents.
- Weight gain – 15-18% increase.
- Positive interactions – 81% increase.
- Use of PRN medication – 100% decrease.
- Use of PRN pain relief – 100% decrease.
- Sustainability – 90% achievement.

The journey continues

Dementia Care Matters has received over 45 inquiries from residential aged care organisations in Australia interested in becoming Butterfly Dementia Care Homes. The zest for culture change in dementia care in Australia is strong and will flourish. The opportunity Australia has to fast-forward some of the steps in this journey is significant.

The learning from other countries is that, whatever the method in achieving

this change, be it the Butterfly Household Approach, The Eden Alternative, The Green House Project or Montessori for Dementia, our belief is that practice development initiatives on their own will have frustratingly reduced effect over time. The focus on nursing and care home staff in changing people's daily lives in residential aged care will have limited impact too, without the solid foundation of organisational support at a strategic level for a totally new culture and new model of care.

The frustrations voiced by those attending Dementia Care Matters' Australian events were as high as any we have experienced in 20 years in the UK. The majority of participants despaired that Australia would truly embrace what is required to achieve culture change, and yet they remained emotional and passionate in their commitment that this had to occur. Comments included:

"Although we would be able to implement some aspects of person-centred care, the whole aged care framework and funding model will need to be changed in order to roll this out effectively nationally – more government lobbying will be required – it is going to be a long journey."

"Accreditation regulators will need to be involved in how these changes will be looked at during accreditation."

"Where were the directors at these events? The whole focus needs to be towards facility owners and directors as, at the end of the day, they are the ones that can change the culture entirely."

Dementia Care Matters is in discussions with a number of aged care home owners and directors in Australia and hopes to create the first three Butterfly Household Demonstration Projects here in 2016. We also intend to introduce our one-year course *An emotional journey: merging person-centred care and culture change* to Australia in 2016 for 50 participants initially, thereby creating the beginnings of a network of people committed to creating Butterflies in Dementia Care within Australia.

As one Australian conference participant said: "Culture change sometimes needs a catalytic moment." Australia will need many catalytic moments along this journey and we hope Dementia Care Matters can contribute some of these along the way. ■

To download a copy of the *Inspiring action 50-point checklist*, visit: www.dementiacarematters.com (under the section 'What we offer/Butterfly Care

Homes/Butterfly Household Approach). A revised updated version of the checklist will be published in 2016.

For event details, bookings and information about the Butterfly Household Approach, becoming a Butterfly Household Demonstration Project or attending the one-year culture change course in Australia, visit the Australia page at www.dementiacarematters.com

UK Channel 4 TV recently screened a series about Dementia Care Matters' work, titled *Dementiaville*, focusing on Poppy Lodge care home in the UK, where the Butterfly Household Model operates. Details at: www.channel4.com/programmes/dementiaville

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Bibliography

- Sheard DM (2008) *Growing: training that works in dementia care*. London: Alzheimer's Society.
- Knocker S (2015) *Loving: the essence of being a butterfly*. London: Hawker Publications.
- Budd H (2015) Dementia innovator sees key role for LPNs. *Care* 29(3) 6-7.
- Gaelick K (2015) Peace of mind: model of dementia care accepts and embraces people's reality. *Alberta RN* 71(3) 23-25.
- Sheard DM (2015) Safeguarding emotions really matters in dementia care. *Journal of Dementia Care* 23(4) 22-25.
- Sheard DM (2015) Real culture change: the Butterfly Care Homes experience. *Australian Journal of Dementia Care* 4(2) 29-32.
- Sheard DM (2015) Good dementia care: it all comes down to mattering. *Listening to dementia* 4 17-21, University of Chichester.
- DeSantis B (2015) The 'Butterfly' approach as it applies to culture change and person-centred care. *Canadian Nursing Home* 26(1) 26-28.
- Sheard DM (2014) Achieving culture change: a whole organisation approach. *NRC (Nursing and Residential Care)* 16(6) 2-5.
- Sheard DM (2013) Accepting that homes have front doors while institutions have 'units'. In: *Not another care handbook ... Pearls of wisdom for care staff*. London: Hawker Publications.
- Sheard DM (2013) Implementing person-centred theories in dementia care: exploring the Butterfly approach. *The Modern Registered Manager* 1(3) 9-12.
- Sheard DM (2013) The feeling of mattering: the positioning of emotions in dementia care. *Journal of Dementia Care* 21(2) 23-27.
- Sheard DM (2008) *Inspiring: leadership matters in dementia care (Feelings matter most series)*. London: Alzheimer's Society.
- Channel 4 (2015) *Dementiaville* (three-part series). UK: Open University.