we need to ensure we are continually listening, learning and acting on the information so that their one-page profile grows and evolves with them and stays truly reflective. As the information gathered by both the working/not working person-centred thinking tool and the one-page profile process are regularly updated, they are a fantastic resource to use when action planning.

One-page profiles are fundamental to the care planning process. They become our job description and help us to be aware of what needs to be present on a daily basis. It ensures that people are consistently supported in a way that makes sense to them, truly enhancing their choice and control because those supporting them follow their one-page profile. Knowing what is important to people and knowing how best to support them from their perspective also means that truly personal and achievable outcomes for the person can be created.

Ultimately, one-page profiles are about supporting a person to have as much of a normal way of life as possible. Ensuring this happens moves service providers away from those care plan boxes that often focus only on a person’s physical needs, without paying good attention to what matters to people.

Conclusion

Our quality of life is determined by the presence or the absence of those things which are important to us and so we have to take this into account when providing support.

Personalisation and the process of implementing one-page profiles has taught us that we need to stop reflecting on what we have achieved in dementia care today and begin to run towards what we can achieve in the future. Better still, in the words of Christine Bryden (2005) “let’s dance” our way there.

More information about one-page profiles and person-centred thinking tools is available at: www.helensandersonassociates.co.uk

References


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In the lead-up to his Australian speaking tour in June, David Sheard outlines the Butterfly Household Approach to achieving real culture change in dementia care homes, based on a model of emotional intelligence as the primary competency.

The adventure begins

In 1995 I left the UK National Health Service where I was general manager of dementia care services, vowing “I won’t run factories in dementia care anymore,” and embarked on the biggest adventure of my life. That year I founded Dementia Care Matters, now a global dementia care culture change and training organisation, and developed the Butterfly Household Model of Care.

The first Butterfly Household began in 1995 with a care home of 36 people living with dementia at Menenval House in Atherstone, Warwickshire, UK. The model of care, not previously tried, was based on some simple, fundamental beliefs that people living with a dementia can thrive well in a nurturing environment where those living and working together know how to be person-centred with one another.

There was no ‘them and us’ distinction between people living and working together. Instead the focus was on the importance of people’s emotional memory, helping them to be who they were and through knowing the person’s life history, understanding that at times they will be experiencing and living defining emotional moments from their past. Rooms were filled with the stuff of life – domestic items, work-related objects, things relating to the locality, family events and the mess from the past. This helped people living with a dementia to be who they were by validating their reality, supported by an approach which emphasises being loving and a real sharing of each other’s lives.

The Butterfly Household Model

The essence of the Butterfly Household Model of Care rests on four key beliefs – first, that it is possible to restore people’s positive emotions and identity on the inside, enabling people with a dementia to come alive again.

Secondly, that this requires a whole new approach to recruitment, training and appraisal of staff which focuses on the development of people’s emotional intelligence as the primary competency in dementia care.

Thirdly, that this requires, at a strategic level, an organisation to first show it knows how to become a person-centred organisation itself, before trying to foster person-centred care in others.

Fourthly, that to achieve the above, residential aged care homes need to be physically divided into recognisable self-sufficient domestic houses.

We use the symbol of a butterfly formed by two hearts to represent people living and working in a residential aged care home coming together to create, like a butterfly, moments of connection, colour and transformation in each other’s lives.

Since these early beginnings, over the past 20 years the Butterfly Household Model of Care has grown across the UK and Ireland, more recently moving into Canada. Care homes are supported to undergo a one-year culture change program known as a Butterfly Project, incorporating three elements – leadership consultancy, house leader/nurse coaching and the ‘Being A Star’ staff program.

Currently there are 65 Butterfly Projects and hundreds of care services across the UK adopting the approach.

Real culture change: the Butterfly Care Homes experience
Introducing the model in Australia

We are now looking to expand the model into Australia and are seeking expressions of interest from Australian residential aged care providers to become demonstration homes for the first phase of the Butterfly Household Approach in this country.

My adventure in trying to move the care sector from an institutionalised ‘them and us’ culture to a true Household Model of Care over the past 20 years has been like jumping off a cliff into the unknown. Therefore, this significant leap of faith should not be underestimated by anyone embarking on this culture change journey.

The power of malignancy

Professor Tom Kitwood (1997) introduced the four key concepts of personhood: well-being and ill-being, malignant social psychology and an enriched model. This offered an alternative path for the care sector to follow in radically changing cultures of care and focusing on the lived experience of people.

Yet 18 years later, the health and social care sector within the UK is still swathed in Department of Health inquiries into the failings of care services. Despite Kitwood’s vivid description of the malignant social psychology he saw as the cause of institutionalised care, and the inspiring vision he offered of transformation within care services, the UK is still learning the lesson that there are care services only ‘talking the talk’ of person-centred care, whilst ignoring evidence that the power of malignancy in care cultures lives on within their own care service.

The search for loveliness

Unfortunately, even with the commissioning, regulation and inspection of dementia care services, visitors to care homes in the UK are faced with stark images of people ‘parked’ in lounges, staring into space and experiencing stupefying levels of boredom and lethargy.

The ‘herd’ of people en masse into large-scale dining rooms, the focus on task orientation, the presence of high levels of controlling care and the clear dehumanisation of staff in care homes is not uncommon. Despite dementia-specific design features being heavily prioritised, long-hospital-like corridors still prevail in care homes. Even those in the UK that have spent up to $A28 million on a new build have done so without any associated change to their model of care.

Worse of all, professional disharmony continues as competing camps within care cultures fight to hold on to, or dismantle, the ‘them and us’ features such as staff uniforms, the removal of drug trolleys from the middle of lounges, the use of nursing stations within people’s ‘home’ and the nonsense of so-called ‘legitimate’ reasons for staff not eating with those living in the home.

Recently, I entered the lounge of a care home where about 30 people sat in silence in strange configurations of chairs, all facing into the room, with no view and no meaningful occupation. As I approached the first woman, knelt down and held her hand, her words to me were: “I just sitting”. Similarly, as I held the hand of another woman, she said: “I want to thank you for looking so lovely and bringing loveliness into my day”. Her search for loveliness in her life was dearly a desperate one.

This woman’s search mirrors, at times, the desperation I feel at stepping into this overwhelming picture. My journey in wanting to transform people’s lives by radically voicing the current unacceptability of ‘care’ can be a lonely one too.

Confusion in models of care

Yet despite all this, I do not believe that care staff and nurses come to work each day, often on a minimum wage, wanting to create this type of malignancy. People come to work to do their best, often despite the organisation and its management culture. Staff often know that there is an over-reliance on systems, processes and audits which do little to improve the lived experience of the people living and working together.

Care cultures have become increasingly confused by layering a new language of person-centred care onto outdated organisational cultures and leadership. Engaging the personal commitment of staff in compassion relies, fundamentally, on a radical transformation of senior management’s beliefs in care models. Failures in compassion directly correlate with restrictive models of care. Achieving a national culture of compassion, in the UK at least, would require a complete unravelling of senior managers’ current confusion about what good care looks, sounds and feels like and the real methods to achieve this.

Dementia Care Matters has analysed care home cultures and identified important features of an organisation’s model of care. This analysis of four
models (see above) – the clinical service, the confused service, the creative service and the congruent service – enables an organisation to measure itself. It maps how far the organisation is prepared to travel in its adventure to transform into a truly person-centred organisation where results can be seen in people’s daily lives.

The pace of change

The Butterfly Household Approach to changing a care home’s culture is not to everyone’s liking. The degree and pace of culture change has even been called ‘brutal’, however, this is set alongside people’s amazement at the quality of life that Butterfly Care Homes achieve.

A recent care home providers signing up to a Butterfly Care Home Project and having done his own detective work on Dementia Care Matters, noted he had been told “it’s David Sheard’s way or no way”.

My response is that this singularity ‘of the way’ is about achieving pace and momentum, requiring an organisation to show significant emotional depth, with a total focus on the lived experience of people working and living together.

The Butterfly Household culture change model is certainly well defined, with an array of pilots and rigorous practice tools, and it proceeds at a vigorous pace of change. Through the use of emotional intelligence training and person-centred appraisals, staff at all levels of the organisation are assessed as being either ‘naturals’ in the Butterfly approach, ‘learners’ prepared to develop, or ‘fighters’ who instigate and defend the malignancy. Staff are given time to reflect and develop, but clear expectations are also set on staff being open to change within themselves. Many ‘fighters’, once they see the power of a new culture of care, realise they no longer fit and make their own decisions to seek alternative employment.

However, in relation to the ‘brutal’ change, we were reassured when a Butterfly Care Home, Dan-Y-Mynydd House in Wales, completed its transformation and care staff admitted that although they had found the change very hard at first, now “it doesn’t feel like going to work and we would never want to go back to how it was”.

‘Feelings Matter Most’: the core approach

Dementia Care Matters’ model of care is outlined in the Feelings Matter Most series of 10 publications and eight DVDs. These focus on the following essential core elements of the model, known as BEING ALIVE:

Dementia Care Matters’ culture change model

Dementia Care Matters’ approach to culture change is based on the premise that if you focus primarily on changing the beliefs, culture and leadership within a senior team then you will create a person-centred organisation which is able to do what works through the senior team ‘being’ person-centred with one another.

Dementia Care Matters has recently audited its range of practice and development tools (150 in total). However, no amount of such tools will work until the board-level members of an organisation grasp the shift in beliefs, culture and leadership required. Once these are adopted, staff can then be enabled to flourish in creating a person-centred culture of care and providing more positive daily life experiences for people.

The Dementia Care Matters’ model is based on the following principles:

Key beliefs

- Person-centred is not primarily about care services but first must be adopted as a life philosophy.
- Being person-centred must be practiced at a senior level within an organisation before expecting staff to ‘be’ this.
- The demonstration of attached leadership and not detached management is the bedrock of transformation.
- Facing the truth of people’s daily lives must be owned at senior level rather than being consumed by an organisation’s internal processes.
- People living with a dementia can’t wait years for this to happen, therefore a ‘brutality of direction’ and pace is needed.
- These beliefs, not outdated processes, are the way to achieve regulatory compliance and quality of life outcomes.

Culture

- Person-centred beliefs need to lead the service, not nursing-led, hospital-type practices.
- Services need to be emotionally driven not process driven.
- Expert nursing care is compatible with a household model.
- Household cultures, not nursing home cultures, must be central to the organisation.
- Staff need to feel attached to small houses which provide, on a homely scale, people’s care, meals and domestic cleaning, rather than these being provided through institutionalised central services.
- No ‘them and us’ features can be tolerated; the lives of staff and those they support must be shared together.
- ‘Rights to life’ rather than ‘protection from life’ is fundamental.
- Person-centred and relationship-focused support must drive the household with clinical risks secondary to this.
- Qualitative observation becomes the key movement of quality of life, not mechanistic audits.

Leadership

“The culture we are creating does not need managing, it needs inspirational leadership. The leadership style needs to be heartfelt, it has to come from within you – people have to feel it is who you are. This cannot be achieved from sitting in an office; you need to model this approach in the houses.”

– Eve Carder, deputy CEO, Dementia Care Matters

To be a new culture leader in dementia care takes vision, stamina and dogged determination. New culture leaders know, and are wedded to, the following principles:

- The model of care drives environmental design – not the other way around.
- Dementia-specific environments must suit people’s dementia-specific needs, rather than professionals’ view of what a home should look like.
- The unorthodox and disorder in an organisation are valued to enable creativity, thereby mirroring the lives of people living with dementia.
- Teaching regulators the new culture of dementia care and how they can be pivotal influencers in care services, rather than reverting back to ‘old cultures’.
- Cohesion in a senior management team and not protection of ‘old culture’ and professional egos.
- Support of emotional labour is the organisation’s core strategy.
- Emotional intelligence is the main investment in learning and is always prioritised before skills competencies.
- Zero tolerance for controlling and neutral care.
BEING person-centred involves helping staff to shift their focus from doing tasks to ‘being’ emotionally intelligent (Sheard 2007).

ENABLING quality of life begins with measuring people’s lived experience and as a ‘butterfly’ changing the moment (Sheard 2008).

INSPIRING leadership involves guiding people to be an attached person – joining up the personal and professional and not acting like a detached professional (Sheard 2009).

NURTURING staff’s emotions in dementia care requires an emotional labour strategy that practises being person-centred with staff first, before expecting staff to be this with others (Sheard 2009).

GROWING training that works means focusing on the development of people’s emotional intelligence as the primary competency by sharing emotional memories through reflection, modelling and coaching (Sheard 2008).

ACHIEVING real outcomes is not about focusing first on policies, procedures and systems, but knowing how to externally achieve quality of service indicators whilst internally ensuring the main focus is on quality of life (Sheard 2011).

LOVING the real essence of being a ‘butterfly’ in dementia care involves developing intuitive ways to connect and reach people through a mixture of 20 essences – the intrinsic qualities of really good dementia care. Mattering, Identity, Usefulness, Being “at home inside oneself” (Knocker 2015).

INVESTING in the transformation of dementia care nurses from bureaucracy to compassionate care (Carder 2015, to be published).

VALUING the contribution of migrant workers in dementia care and ensuring their life histories are validated and at the heart of workforce development (Sheard 2015, to be published).

ENGAGING in the shift from restrictive task-orientated contact with people in dementia care to the restoring power of expressive touch (Tanner 2015, to be published).

Soft skills that matter. Most as a philosopher, and the Butterfly Household Model of Care are robust, rather than ‘soft and fluffy’, save lives and multiple service costs. The collected data looks at 24 baseline and ongoing monitored culture change measures including pain reduction, reduced use of neuroleptic medication, reduced incidence of ‘expressive behaviour’ and increases in people’s weight, well-being and quality of life.

Recently, one Butterfly Project care home reported that over a six-month period the number of people who gained weight increased from six to 23, the use of painkillers was reduced from 200 occasions to 37 and administering of neuroleptic drugs as reduced from 70 occasions at the beginning of the period to just one at the end of the period.

As one manager/owner who has transformed her care home commented: “The Butterfly Project is about injecting humanness and compassion. It focuses on nurses and care workers back to this from task allocation, targets and efficiencies and creates a culture conducive to person-centred care. Its greatest impact is in creating households and Butterfly skills for everyone to connect. It shifts the balance of power, by removing controlling care, enabling staff to become care partners. In addition, it achieves a dramatic reduction in displays of behaviour, falls and staff sickness—creating a home where people want to be together.” (Arun Aslde, MBE, managing director, Wren Hall, Nottinghamshire, UK).

The adventure continues

Twenty years on in our adventure, Dementia Care Matters has some final messages. The old culture of care is always waiting in the wings to return, its power stronger than any transformatonal care culture change program. For all the methodologies and practice development tools, their success still usually rests on the existence of one inspiring manager/leader within an organisation. This person is a leader who acts like an emotional magnet within the care home, recruiting and appraising staff completely on heart, who is comfortable with not always knowing what will work next, but who constantly pushes the boundaries.

The sadness is that sustainability is hard and when that person leaves, the deck of cards is at enormous risk of falling down. This is not a model set in concrete and a one-size-fits-all approach does not work. A whole variety of Butterfly Care Homes exist within the UK and Ireland – different in size, design and service configuration – but all have the following key features in common: domestic households; intuitive house leaders; and the essence that really great dementia care is only as good as the loving, warm, heartfelt, emotional care given by people who know that feelings matter most in life.

Later this year, a British TV series will show a Butterfly Care Home at its very best – as Dementia Care Matters celebrates its 20th anniversary. It has been, and still is, quite an adventure.

Dr David Sheard and Dementia Care Matters Director/senior consultant Peter Priednies will be in Australia from 2-19 June, presenting a series of talks about how to achieve real culture change in residential aged care. Events include:

- Friday 5 June, Melbourne and Friday 12 June, Sydney – one–day public workshops in association with Improvement Matters;
- Tuesday 9 June, Brisbane – public lecture in association with Alzheimer’s Australia (Qld);
- Thursday 11 June, Adelaide – one–day public workshop in association with Alzheimer’s Australia (SA).

Dr Sheard is also presenting at the Dementia Behaviour Management Advisory Service (DBMAS) Symposium in Perth on 18-19 June.

For event details, bookings and information about the Butterfly Household Approach, visit: www.dementiacarematters.com

References


Tanner L (2015) Engaging: in the shift from task orientated contact to expressive touch (awaiting publication).