Sally Knocker has worked in the field of dementia care for thirty years with a specialist interest in activity and occupation. She has been a lead tutor on Dementia Care Matters University Recognised one-year course ‘Person Centred Dementia Care’ in Cardiff and has project managed Butterfly Projects in Wales, England and Ireland. Sally believes passionately that in an ideal world people working in a care home will be sitting down more and people living with a dementia will be sitting down less. Sally is the author of the latest in the Dementia Care Matters series, published with Hawker Publications, ‘Loving, the Essence of Being a Butterfly in Dementia Care.’

The Fairfield Family

“It’s first class – second to none. When I was down, they were there for me. They are there for everybody. That IS care.”

**Brenda, living at Fairfield**

From the moment you walk through the door at Fairfield Nursing Home in Drimoleague in the West of Ireland, you can feel the love of a real home. There is a genuine sense of people living and working in the home sharing the day and that what matters most is that everybody has moments throughout the day when they feel special.

It was an absolute pleasure and privilege to watch an amazing team creating magic for people and demonstrating all the best elements of the Dementia Care Matters Butterfly Household model in action when I visited in March this year.

In this article we will share what are the key ingredients of success, which Fairfield Nursing Home has put into practice and made a reality in the last two years. There are a number of homes throughout Wales which have also been on a similar journey to join the growing group of Butterfly Households, as well as new projects starting in Australia and Canada.

**Background to Fairfield Nursing Home**

Fairfield Nursing Home is a home for 49 people. Fairfield Nursing home completed a 12 month culture change “Butterfly Project” with Dementia Care Matters in January 2014 and achieved our Butterfly Home award with a ‘Level 2’ outcome in February 2014 which was a significant achievement. A year later, after another day-long observation, they went one step further to gain the highest ‘Level 1’ outcome. They are only the second home in Ireland to achieve this and currently only 5% of homes in the United Kingdom have reached this level.

On the day of the observation, the consultant carrying out the audit spent the whole day (5 ½
hours) in the lounges looking in detail at the lived experience of people living at Fairfield and at the quality of interactions. On this day in March, the majority of people in the communal areas were receiving positive social care or positive personal care experiences for a remarkable 77% of the time. This represents a huge shift from their original observation in January 2013 when only 28% of the time was in positive experiences. The frightening reality in the majority of the observational audits which Dementia Care Matters conducts in the UK and Ireland is that 70% of the day is usually spent in what we describe as ‘neutral care’, where people are bored and sleepy and tasks are being carried out with little or no social interaction.

The Dementia Care Matters approach

Dementia Care Matters works in partnership with a care home during the culture change process with an initial observational baseline audit as the starting point followed by monthly consultancy visits, 8 one-day training workshops for the team and 6 leadership development days. In all our work, there is a central focus on more ‘BEING with’ and less ‘DOING for’ people and this requires a huge shift in approach for many care homes where both nurses and carers are used to being very task focused.

What was life like at Fairfield before the culture change process began?

In January 2013 the observational audit carried out by Dementia Care Matters revealed a very common picture which we see in the majority of homes in the United Kingdom and Ireland; ‘the lived experience of residents observed on the day was characterised by high levels of boredom, lethargy and some isolation. Incidences of “controlling care” were recorded as high with a culture of staff talking over people living here i.e. talking about them rather than to them or including them and also staff talking repeatedly about task, breaks and what they will be doing next.’

The Dementia Care Matters auditor noted that whilst it was evident that staff members were very warm and caring to people living in the home, there were some dominant features in the care culture:

- A strong predominant nursing culture of care. The home looks and feels like a hospital rather than a home.
- Staff are observed to be very task orientated almost passing people by as if they were superfluous to the tasks.
- Long periods of ‘neutral’ care exist – high levels of boredom, lethargy, and staring into space.
- People are engaged with by staff members who have a role of Activity Co-ordinator whilst other staff fade into the background and do not demonstrate that they even notice people who are left for long periods.
- Some attempts have been made to introduce rummage boxes and visual murals in corridors but this is largely ‘wallpaper’ and not part of the staffs repertoire in occupying people.
- All staff are dressed in uniform emphasising ‘us and them’ rather than recreating a home
-like atmosphere.
  • The lounge is empty in atmosphere and comprises of people sitting around the edge disconnected from being involved in ‘living’ in the lounge.

(From Dementia Care Matters qualitative observational audit report January 2013)

It can be very hard for the team to take on board this kind of feedback:

“I remember the hostility from quite a few staff to the Butterfly Project especially when I shared the headlines from the audit with staff. People felt that they were being unfairly criticised and were defensive about facing the truth. It just felt like a massive job at the start, so much boredom, staff stressed and everyone stuck at what to do. The genuine interest of Sean as the owner was crucial. He was always there pushing things along. I remember times when some of the nurses and care staff became tearful as the sheer scale of it all hit them and the frustrations they were having in bringing people along.”

Daren Felgate, Consultant with Dementia Care Matters

The ‘secrets’ of success in transforming the culture of care at Fairfield

• Creating small ‘matched’ households full of love and friendship
• Breaking down ‘us and them’ between people living and working in the home
• Inspired leadership from nurses and House Leaders
• Valuing life stories and identity
• Developing an engaging, cosy and vibrant environment
• A whole team and whole day approach to activity and occupation

Creating small ‘matched’ households

When we first visited Fairfield in 2013, there was a real mix of people living together including some without a dementia who were quite independent, those in the moderate stages of dementia who were still very physically active and often seeking out things to do and those in the later experiences of dementia who were also quite physically frail needing nursing care. It has been the experience of Dementia Care Matters that this ‘mix’ is unhelpful at many levels – it is hard to create an environment that is meaningful for people with such different needs and team members have to adapt their approach and use completely different skills from moment to moment. People who are very frail and much quieter often receive less focused attention and those who are more ‘able’ can be quite unsettled by a person who is calling out or may not understand a person in the later stages of dementia cuddling a doll which they may perceive as childish.

The Fairfield team have worked very hard to develop three distinct houses; Deelish, Dromusta and Rockmount. The three houses all have an appropriate feel, meeting the needs of
people at different points in their journey and there is outstanding consistency across the whole team in terms of demonstrating the importance of connecting with people. Developing separate households can be a difficult process particularly in terms of explaining the benefits to families who might be concerned if they perceive their relative is being labelled in some way or may be spending the day in a different lounge. However, the key to success is creating a sense that each house is special in its own way and that happy households bring out the best in everyone. Creating three teams led by a House Leader means that care staff are able to develop a particularly close relationship with a smaller group of people and also with their colleagues rather than working across the whole home.

Lynda, House Leader of Rockmount, the household for people who don’t have a dementia or are in the early experiences, describes ‘a wonderful buzz and feel. People living here are busy with chores; the smell of baking will fill the air, the joy of gardening, daily sing songs, laughter and lots of TLC. Rockmount has come to life and it is a pleasure to come to work. Our family show and give so much pleasure in return. People have started living life again to the full and have a real sense of belonging.’

The group living approach makes sense to the people living and working here and is providing a specialist approach for people which is appropriate to their experience of dementia and their personality and life experiences. There is laughter, fun and a genuine sense of family together with people living here involved in the everyday life of the home. It is clear that the staff enjoy coming to work and the relaxed ‘go with the flow’ feel to the day appears natural and comfortable for everyone involved.

As Eileen, the House Leader of Deelish House, the household for people who are in the middle ‘stage’ of dementia experiencing different realities, says:

‘The change is incredible, a complete transformation. No longer are people led by a fixed and regimented timetable, people are living ‘their’ day ‘their’ way. We now feel a real sense of family and a deeper understanding of the people we spend our days with. Deelish house has become a relaxed, homely environment full of shared moments and emotional contentment.’

Breaking down ‘them and us’ divide

One of the first and critical components of change is breaking down the ‘them’ and ‘us’ culture between people living and working in a care home. Many care home environments appear to reinforce it as a place of work, rather than a house resembling a family like atmosphere.

It is surprisingly controversial when we ask people to no longer wear uniforms and stop using large trolleys. People working in a care home are quick to point out that some people like staff in uniforms as they can identify them easily. Whilst it is of course possible to be kind and caring in a uniform, it still fundamentally separates people and prevents organisations creating a ‘family home’ like atmosphere. The other key element of staff wearing their own clothes and accessories at work is that sud-
denly they become individuals and people living with a dementia will often notice the colours and varieties of people’s appearance which helps create conversations and connections. The Fairfield team embraced this change after some initial adjustment and it was very quickly evident that they understood the importance of sharing themselves throughout the day.

**Inspired leadership from nurses and house leaders**

Fairfield has a very motivated and passionate leadership team who grasp what dementia care should look, sound and feel like and who have formed/recruited a very genuine, positive caring staff team who have no evidence of ‘controlling care’ or staff who appear to be ‘in charge’ and following a particular regime or routine. Watching the two lead nurse managers and house leaders at work was particularly inspiring during the observations. They truly led by example, rolling their sleeves up in a totally genuine way, spending time sitting and chatting to people, walking with a man who was constantly on the go; demonstrating to their team that they are there alongside them and not locked away in an office. Whilst they were directing their team throughout the day, it was clear that they have created a sense in team members that anyone can be a ‘leader’ to initiate an activity or create a moment with an individual.

Claire, the manager, and Mary, the nursing director, describe what it was like for them; ‘For the 12 months during the butterfly programme, we dreamed of what our home could become. And during this period we saw people come to life, it was truly amazing. Our home became a bright, airy, colourful lively place to work and live. There were days when we thought that ‘it just was not possible;’ change is not easy at the best of times! The whole experience has lifted our spirits and motivated us more than words could possibly describe. We all feel that this is the future of Fairfield now; there is no going back to a ‘task’ run day. We are so proud of the staff’s commitment to improving the quality of peoples’ lives at Fairfield.’

**Valuing life stories and identity**

There are a group of men living in Fairfield who are farmers and it was heartening to see these men still looking the part in their jackets and with caps on as if they were just about to head out to the fields. During my visit a number of these men, some with quite advanced dementia, recognised me as a visitor to the home and greeted me with quiet gentlemanly warmth asking me if I would like a cup of tea and checking I was doing alright.

This is a significant sign that people living at Fairfield really feel that they are ‘at home’ and have sufficient wellbeing themselves to want to look after me; a refreshing reversal when so often people in care homes are always receiving care not giving it!

There is a real sense throughout the home that people’s backgrounds are known about and cherished. Individual life story summary profiles have been put on people’s doors and fuller life story books and memory boxes are read from and looked at during the day. Team members also frequently share stories and photographs from their own families, for example, Mary, the nurse showed a picture of her young daughter in her Irish dancing costume which prompted some lovely banter “She’s better looking than her mother!”

**Developing an engaging, cosy and vibrant environment**

Another key aspect of culture change is creating an environment that is stimulating for peo-
ple living with a dementia. This requires us to look at things in a different way - a tidy lounge may look neat to people visiting but provides no opportunities or invitations for people to be busy. A book which is open on a table is more likely to be read and two piles of towels, one folded and the other lying in a mess, will be an obvious call for action to a person living with a dementia to encourage them to finish the job. Staff may be tempted to tidy things if they are not aware of the new approach and so it needs constant reinforcing with the whole team including the housekeepers.

In Fairfield, there is a great range of pictures, objects and colourful items to stimulate interest including sporting memorabilia linked to some of the men’s interests, farming images, and kitchenettes invite those who are still able to make themselves a drink, do some washing up etc. In Dromusta, the lounge for people in the later experiences of dementia, there is some specialist equipment such as projector with lights and a bubble tube, but some simple bird feeders outside the windows also provide many joyful moments when various birds are spotted feeding.

Vicky and Catherine, House Leaders on Dromusta explain; ‘People are getting the attention and affection they deserve. This is no longer just a job where people are cared for. Our residents are like an extension of our family, staff strive to give love and attention and be in the moment with people. It might be the touch of a hand, a whisper of a song or the smell of flowers. This is what brings a smile to peoples’ faces and makes it all worthwhile.’

A whole day and whole team approach to occupation and activity

It was great to see that attention to people’s individual lives and identities is evident in the choice of things to do with people, rather than just generalised ‘activities’. It is also very clear that the whole team see themselves as activity workers and Lynda, the House Leader who was originally the Activities Coordinator in the home did remark on the benefits of this shift.

There was a remarkable range of opportunities for occupation and activity for individuals and groups throughout the day including:

- Baking cakes
- Hair being done (curlers etc.)
- Foot spa and hand massages
- Knitting
- Life stories being shared
- Hats being decorated for Cheltenham
- Chat about the Wales-Ireland Rugby match
- A fashion parade round the home
- Horse names being put up and for the Sweepstake
- Watching the races
- Brass polishing
- Sweeping floors
- Man blowing bubbles
- Washing up
- Walks to visit other houses and out in the garden
- Folding napkins, sorting cutlery
- Newspapers being read
- Singing
- Ball throwing
- A meditation group run by a woman living in the home
- A visit to the Mobile library to choose books
A few card games which included a visiting husband joining a group of men in the home
• Man (who is a farmer) sorting and fiddling with wool ropes
• Toy farm animals in front of another farmer who is in the later experiences of dementia
• Man lying with feet up listening to own (heavy metal!) music with headsets
• Team sharing stories and photos from home
• Watching birds outside the window
• LOTS OF CHAT – the Irish banter was second to none!

All of these experiences and events were woven into the fabric of the daily life of the home without any sense that they were ‘activities’ in the formal sense of many activity programmes in some care homes.

The team made the most of a topical event like the Cheltenham races, building up expectation throughout the day, talking about a local jockey who had won the day before, preparing supporter banners, decorating hats, doing a fashion parade round the houses and watching the race itself! This was a really clever way of making the day feel a bit different and special and including a wide range of people in different ways.

Conclusion

This article sets out to share in a simple way some of the key elements of transforming a very hospital-like nursing home environment into a real ‘home from home’ experience. It must be emphasised it is no mean feat to achieve this. It takes total dedication and determination from the leadership team as well as financial investment from the owner.

This is driven by the belief that older people living in a care home deserve the very best. When watching a day in the life of people living and working at Fairfield, it becomes evident how rich are the rewards of a whole team who ‘gets it’ and that it really is possible to find a new ‘family’ in a care home when all the right ingredients come together.

In all the homes which go on this journey with Dementia Care Matters, it is noteworthy that the starting point is often one owner or one manager with the vision and the bravery to really ‘go for it’. Sean Collins who is the owner of Fairfield is one of those owners who took that courageous step and describes very movingly in his own words what that process was like;

‘This culture change has been an incredible journey for all the staff and for myself personally. It has absorbed us both physically and emotionally. There were many times over the first year of the transition when we thought we would not make it. We had people in many different stages of dementia with complex conditions and needs. How could we transform their lives? You can’t half do emotional care, you can’t half make people feel like they matter. We had to accept the truth and accept the reality that what we were doing was not the best way and that there must be another way. We needed to change our attitudes, we needed to accept that even though our residents were well looked after physically and that their clinical needs were met, they spent most of their time bored. Our system and culture revolved around getting tasks completed. Our system rewarded task completion. For example meal-times were a task to be completed, a schedule based around staff rather than residents. Now meal-times are a social event enjoyable and relaxing.

We now understand and value what makes people feel alive, we now understand that people must feel like they matter, they must have a purpose. We understand that it is how we make
people feel is what is crucial. It is what we must do everyday. Each and every person in Fairfield has responded incredibly to this challenge. They have given of themselves emotionally. Staff now share personal stories and this resonates with our residents. They have connected with our residents, there is no longer a 'them and us'- it's a family. Our culture, our ethos, our way of living a full life is about recognizing that 'feelings matter most'. People are in our nursing home to continue living.

Dr David Sheard and his team over 12 months of training has changed us all. They have shown us a better way. They have shown us that by our behaviour with people living in the home, and by concentrating on making people feel better, we can ensure that our residents continue to live full and meaningful lives. We have watched people come alive.

For me personally David Sheard changed my attitude to growing old and changed my belief system. He showed me another way. He made me face the truth, he enlightened me to change our culture within Fairfield. He showed me another way, a way based around people's feelings. Moments in Fairfield now are guided by the realization that, 'It is not what you say, It is not what you do, It is how you make people feel. This is what is important.'

Thank you Sean. We couldn’t say it any better than that.

Sally Knocker
Consultant Trainer,
Dementia Care Matters

How the ‘Butterfly’ care homes get their wings

Care homes hoping to achieve the Butterfly Service status undertake a one-year project that will typically include:

- An initial qualitative observational audit and detailed report
- A launch and management strategy day to scope the year's work
- Twelve days consultancy – one day per month
- A nurse and/or house leader modelling project - six days
- A workshop training programme for 15 participants
- An unannounced Kitemark audit

Elements of the whole programme can also be selected depending on the needs of the organisation. For more information about Dementia Care Matters, visit www.dementiacarematters.com or telephone 01273 242335.

Further Reading

- Knocker, S (2015) Loving the Essence of Being a Butterfly in Dementia Care, Hawker Publications