Phase 2 report

Dementia care study confirms dramatic reduction in requirement for antipsychotic medication with improvement in wellbeing

References:

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Dementia care study confirms dramatic reduction in requirement for antipsychotic medication with improvement in wellbeing

A new study of residents in specialised dementia care homes has confirmed a dramatic reduction, averaging 48%, in the requirement for antipsychotic medication, together with a corresponding improvement in the wellbeing of participants.

Analysis of data from 16 homes in this second study of the outcomes from the PEARL specialised dementia care programme developed by Four Seasons Health Care, supports the findings of its initial study at eight other homes published in 2010.

A full list of key study findings is detailed overleaf.
**Summary of key study findings**

Antipsychotic medication reduced on average by 48% across the homes involved in the most recent study, with the highest reduction being 84% in one home. The average is in line with an average reduction of 50% across the earlier study involving residents of a different group of eight of the company’s homes. The slight variance between the two groups of homes may be accounted for by the fact that some of the homes in the second phase study had already started putting the PEARL specialised dementia care principles into practice when the study began and so had already begun to experience a reduction in the need for antipsychotic medication.

Wellbeing increased among 46% of residents. Wellbeing can be profiled against a set of smaller sample of 14 homes that measured wellbeing. However the findings are consistent with the earlier study.

Reduced requirement for Anxiolytic medication to alleviate anxiety, on average by 40%.

Depression score reduced in 30% of residents. Also use of anti-depressant medication reduced on average by 19% as wellbeing improved. Depression is often undetected in people with dementia who are routinely prescribed antipsychotics.

Reduced requirement for hypnotic medication to induce sleep, on average by 44%.

Weight gain among an average of 42% of residents in the participating homes, against the tendency for people with dementia to lose weight.

Falls reduced by 32% on average. Fall reduction may be attributed to increased alertness as a result of a reduction of antipsychotics and hypnotics as well as improved wellbeing.

Pain relief medication use increased 10% on average while 17% of residents had a reduced pain score with appropriate pain relief medication.

As the use of antipsychotic medication has decreased, the use of analgesics increased, following assessment utilising the Abbey Pain Scale*, a tool which assists in assessment of non verbal cues from people with dementia who may be unable to articulate their experience of pain. This suggests pain is under-recognised in dementia care. Typically, on nursing units, 40% of residents are taking analgesic medication. By contrast on typical dementia units, with a similar population profile, 0–10% of residents are taking analgesics.

Far too many people with dementia are robbed of their wellbeing and effectively part of their lives because they are over-prescribed antipsychotic medication. Reducing use of these drugs is a national priority. The consistent outcomes of the two studies in our PEARL specialised dementia care homes, carried out two years apart, provide confirmation that with better understanding of how to care for people with dementia we can reduce the need for medication and at the same time improve the residents’ wellbeing.\(^*\)

Caroline Baker  
Head of Quality & Dementia Care  
for Four Seasons Health Care

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We should never lose sight of the reality of what it means in human terms to be someone living with dementia, or to care for someone with dementia. We must look beyond the symptoms to see the person within.

A new case of dementia occurs about every three minutes in England and Wales and this rate is forecast to increase as the population ages. There are approximately 820,000 people in the UK with a form of dementia. It affects one in 14 people over 65 years of age and one in six people over 80 years.

Dementia is a group of related symptoms associated with an ongoing decline of brain functions. It affects peoples reasoning, language, memory, understanding and judgement. Those symptoms in turn alter behaviour and personality. But we should never lose sight of the reality of what it means in human terms to be someone living with those symptoms, or to care for someone with dementia.

We must look beyond the symptoms to see the person within.

If you have dementia, you may experience a combination of some of these conditions or all of them. Memory loss that is becoming progressively worse and you find yourself unable to remember recent events. You may fail to recognise your partner or other family members; have trouble thinking clearly and difficulty to find the right words to say what you mean. You may experience disorientation and confusion. You may find yourself struggling to do things that you used to do easily. As a result you may lose your self confidence, feel anxious or depressed and become withdrawn, or frustrations at your condition may spill over into temper with yourself and those around you. It is not surprising then that dementia impacts upon even the closest relationships.

“...”

“My husband was diagnosed with dementia. We were on holiday in Cyprus when it happened. We were out for dinner and we’d had a perfect day. We were holding hands across the table and he said to me, where do I know you from?!”

Wife of a resident in a PEARL unit

The progressive nature of dementia is also associated with significant changes in daily living activities, behaviour, appetite and eating habits. These may put people living with dementia at an increased risk of physical health problems and mean they become increasingly dependent on health and social care services.

The ethos of our dementia care service is to appreciate the person as an individual and support them to continue to live their lives as closely as possible to the way that they always have. ‘Person centred’ care plans are drawn up with the resident together with relatives, friends, community clinicians and GPs. The home is designed with consideration of the impact of light, colour, contrast, texture, aroma and sound to assist the overall orientation of residents and create a balanced sensory stimulating environment. The programme uses a range of therapies in daily care including sensory rooms, music therapy and reminiscence therapy to communicate with residents. Importantly, because staff have learned something about the person’s life, they are able to engage in a more meaningful way. Staff are selected for their aptitude to be trained in the skill sets they need for this demanding but fulfilling role. For a home to achieve accreditation as one of our specialist dementia care centres it may take as long as a year.

As we have come to understand more, we have re-defined some of the language of dementia care. For example, we introduced the term ‘distressed reaction’ recognising it as more appropriate to re-define what many health care organisations used to describe as challenging behaviour (the term is still used in many care environments). Just two words, but this recognition and the associated cultural shift is fundamental.

We now have data from a second study which confirms that our specialised dementia care programme is having a positive effect, with dramatically reduced need for antipsychotic medication; indicators of enhanced wellbeing and, although not as scientifically measured, every bit as compelling, the remarks by the families of people in our care who have seen the benefit to their loved one.

Dr. Pete Calveley Chief Executive Officer

“...”

“My husband had been in bed for 16 months. In a matter of weeks at the home he was up and about. On the next visit we sat in the lounge eating breakfast together and he is much more aware and alert. The only medication he is on now is blood pressure tablets. It is remarkable”

Wife of resident at Ashcroft Care Home
Four Seasons Health Care

Four Seasons Health Care is the largest independent provider in the health and social care sector in the UK. It operates 445 care homes in the UK, Isle of Man and Jersey. Its specialised services division, The Huntercombe Group, operates 61 hospitals and care centres. It is a leading provider in the areas of adult and child and adolescent mental health, acquired brain injury, neurodisability, eating disorder, addictions and children with special needs. Four Seasons employs more than 30,000 staff caring for more than 20,000 residents.

The origins of the PEARL specialised dementia care programme

Over a third of the people with dementia live in a care home and it is estimated that over 80% of people living in care homes have a form of dementia.

A former GP and Primary Care Trust Director and Executive Chairman, the Chief Executive Officer of Four Seasons Health Care, Dr. Pete Calvey was dissatisfied with what he saw happening as then accepted practice in dementia care and in particular, the routine use of antipsychotic medication to keep patients quiet and compliant. He believed there was a better way and wanted to challenge the status quo. In 2007, he assembled a team and with them developed his concept of creating a specialised approach to dementia care. That was the beginning of the pioneering PEARL dementia programme.

After two years in development, the pilot of the PEARL specialised dementia programme was launched early in 2008. The name is an acronym for the programme mission – Positively Enriching And Enhancing Residents’ Lives. It is also derived from the concept of the ‘hidden pearl within’ described in the book ‘Dancing with Dementia’ and is a tribute to its author Christine Bryden, who was diagnosed with dementia when only 46. [Dancing with Dementia: My Story of Living Positively with Dementia, by Christine Bryden, published by Jessica Kingsley Publishers 2005]

Today, Four Seasons Health Care has 56 homes that are accredited as PEARL specialist dementia care centres with another 70 undertaking the demanding pathway to accreditation. The programme was recognised for its market-leading excellence by being awarded the prestigious 2009 Guy Rotherham Care Home Award by The Improvement Foundation. It has been highly commended in the Nursing Times Awards 2012 and was runner up in the Guardian newspaper’s Public Service Awards 2012 for Evidence Based Policymaking. The awards set out to showcase innovation and best practice across national and local government and the NHS so the placing is significant for a dementia care programme developed by an independent operator. PEARL is now studied by health and social care providers internationally.

“…”

We have all gained a better awareness of what we need to be looking for with each resident. Dementia Care Mapping has made a real difference in individualising care plans.

The unit now seems calmer and more relaxed since the start of the project.

PEARL unit Manager
Care begins with knowing the person rather than just seeing the symptoms

Person centred care begins by engaging with the person with dementia, their family and friends, social worker and GP to build a picture of their life story. From this, an individual medical and social care plan can be drawn up that takes account of the person’s individual needs, recognising what is important to them, their beliefs, their likes and dislikes, their fears and comforts and their life routines.

It requires the care provider to recognise and value the person and treat them as an individual rather than merely seeing the symptoms of dementia and creating an environment in which they can live as closely as possible to the way they always have and experience relative wellbeing.

Four Seasons Health Care has worked closely with Professor Dawn Brooker, Director of the University of Worcester Association for Dementia Studies to develop and incorporate her thinking on person centred care into the PEARL programme. Professor Brooker describes what has become known as the VIPS* [Brooker 2007] model:

• Valuing people with dementia and those who care for them
• Treating people as Individuals
• Looking at the world from the Perspective of the person with dementia
• A positive Social environment in which the person living with dementia can experience relative wellbeing.

Putting person centred care into practice can be as simple as addressing people by their name rather than ‘dear’ or ‘pet’ to knowing which toiletries they like to use and what side their hair is normally parted. A story board based on their life history outside their room helps provide staff with talking points and a focus for communication and engagement with the resident. Staff are trained to recognise each person’s “reality” and to focus their communication on helping each resident through a time of distress or confusion and gradually enabling that resident to recognise where they are and what they are doing.

If a person with dementia is distressed about wanting to collect her children from school, rather than simply shocking that person into the reality that her children are already adults, staff are trained to talk to the resident about her children, recognising her ‘reality’ and gradually helping her to acknowledge to herself that her children are grown up.

References


“We have a resident who used to be a station master who tells us to all walk one way around the corridors and organises certain things for us – like which way the chairs are facing. Another resident used to be a head teacher and from time to time will communicate with authority and tell everyone to sit down and listen. We understand their behaviour and respect this is their reality.”

Lynda Hodgkinson
Home Manager, Ashcroft Care Home.
Dementia Care Mapping - seeing care from the perspective of the person with dementia

Dementia Care Mapping is a tool designed to evaluate quality of care from the perspective of the person with dementia. Dementia Care Mapping is a practice recommended by the National Institute for Health and Clinical Excellence, the Social Care Institute for Excellence, the Audit Commission and the Commission for Health Improvement as a method for improving care practice for people with dementia.

It involves observing a number of residents over a period of time and recording information about their experience of care, including what they are doing (for example walking or talking), how they are responding to the experience, and any interaction they receive. This information is then analysed and interpreted, before being fed back to the staff and used to put together an action plan for change and improvements. Dementia Care Mapping is also used as a focus for staff training and development. Four Seasons currently has 300 staff trained in the use of Dementia Care Mapping with a further 100 planned for 2013.

Staff training challenges traditional thinking about dementia

Staff are selected for their aptitude for specialist dementia care. Training includes the principles and practice of Person Centred Care and Dementia Care Mapping. It helps trainees to identify the malignant social psychology of a mindset that sees someone with dementia as dysfunctional. It re-defines what the care industry has tended to term ‘challenging behaviour’ and recognises that this often is a distressed reaction. Trainees are taught the skills to communicate with someone with dementia and to recognise their reality. Life story work enables them to build a picture of the life of each resident prior to entering the home and to understand how this may impact on their care, as well as providing a basis on which to communicate.

Four Seasons Health Care developed ‘Resident Experience Training’ [Caroline Baker 2008*]. The fundamentals of the training are founded in the concept of experiential learning and in particular ideas discussed in Introducing the Experiential Taxonomy-Steinaker & Bell, 1979. The purpose is to enable care home staff to gain greater understanding of and empathy for the needs of people with dementia by experiencing something of what it is like not to be treated as a unique person.

“The unit looks more homely, the corridors are well decorated with pictures and themed to enhance orientation. There is signage that helps residents find their way. There are rest stops and good lighting in the corridors.”

Manager, Maple Lodge

This training session takes a full day, broken into two distinct sections. In the morning, trainees who have agreed to take part experience aspects of sensory deprivation, in which their vision is impaired by wearing glasses smeared with Vaseline and their hearing is impaired by ear plugs. One arm is immobilised. They wear a wet continence pad. Throughout the morning they are not addressed directly or referred to by name. They are given no choice of food and are fed a little too quickly. They have no chance to express an opinion or select a favoured activity. They are given beverages not to their taste, such as sugar in their tea when they don’t normally take it, have ‘tablets’ administered without warning, and have their hair brushed in a way they would not normally wear it. They are moved without warning and taken to a bedroom to sit in a chair with the door closed without any explanation and left there until lunchtime. During the afternoon participants are treated in a person-centred way. They are recognised as individuals with thoughts and feelings and they are given choices. Staff then carry out a reflective discussion with the trainer following the exercise to enable them to identify, internalise and disseminate the lessons learned. This is a powerful way of teaching them always to remember the person inside the symptoms and take on board all the other training they have received.

References

An environment that balances stimulation and helps residents orientate

The home environment is important to the quality of life of people living with dementia and in our dementia care homes we set out to create an environment which balances stimulation, considers the impact of light, colour, contrast, texture, aroma and sound and assists in the identification of environmental features and the overall orientation of residents. The environment also maximises the opportunities for residents to sustain their optimal levels of independent living.

Sensory rooms, present in some of Four Seasons’ care homes, are designed to allow people to engage themselves in working with tactile materials. Activities can range from enjoying a hand massage to a complete sensory experience in a room with visual, tactile, olfactory and aural stimuli.

Several care homes have been equipped with a sneezelen room, which is a specially equipped space where residents can receive therapy. The concept of the room is proven to provide relaxation and a sensory experience that promotes comfort to people with dementia. The therapy room benefits the residents, by not only having a calming influence but also improving mood levels and decreasing agitation.

Many homes provide a sensory garden with wind chimes, windmills, hedgehogs, herb gardens, lavender, butterflies, water features and raised garden beds so residents can sit and take part in gardening activities.

Themed corridors have been introduced in the majority of PEARL care homes to help residents to orientate and provide further sensory stimulation.

The themes in each care home are decided through a collaborative process that includes residents and relatives along with the staff and have some relevance to the residents. The theme might be interpreted through pictures and familiar items. For instance, a gardening theme created with pictures of garden scenes together with real pot plants and gardening implements. Some homes on the coast have created images of seaside promenades or the local docks on their walls.

Colour plays a crucial role in facilitating the everyday lives of people with dementia. Care homes have doors to rooms that are not for resident use – such as storage rooms. These doors are now painted in a colour that blends in with the corridor to avoid resident confusion or attempted access, whereas rooms for residents’ use are clearly accessible in a different colour and marked with visual signage.
Activities & alternative therapies

The PEARL dementia programme features a range of activities and therapies to engage residents and although there is little high quality research into such therapies, there is now a mass of anecdotal evidence of their beneficial effect.

Music therapy is used as a means of communication and as a catalyst to help residents discuss their emotions or reminisce. The degree of familiarity, how much the resident likes that particular music and the memories associated with the music or the significance that the music holds for the individual are certain factors which define the extent of positive impact or beneficial effects of the music therapy. Staff are encouraged to play music that has been identified in the life story work.

Reminiscence therapy is intended to engage people by encouraging them to talk about their past. Many people with dementia also have short term memory loss whilst their long term memory remains intact for a longer period of time. Considerable knowledge of the person with dementia is required for this therapy in order not to cause distress. Staff are trained to not make assumptions, but rather try to establish stories that residents like to relate about a happy time in their life.

Rummage & memory boxes are generic terms encompassing any container holding items of a tactile nature that may evoke memories. Rummage boxes tend to sit in communal areas of the care home, accessible to all, whereas memory boxes are more easily portable and are kept in a resident’s room. Both residents and their families contribute to the contents of each box, which may help evoke memories for that person as well as a sensory experience. Life story books and photo albums or DVDs of old movies always evoke a positive response.

Doll therapy is helpful, particularly for those experiencing loss or attachment issues. These do not necessarily have to revolve around a partner, but can relate to a relative, friend, or a pet. Doll therapy is not patronising, but a method by which residents are encouraged to communicate and interact and is successful with both men and women – and in particular those that have become very withdrawn. It can be challenging for people to understand the beneficial impact of interacting with a doll and carers tend to be cynical about the benefits of doll therapy initially until they witness its effect directly. The concept of doll therapy was introduced many years ago, but is only recently that doll therapy has been adopted more universally. There is now a wealth of publications within health care journals surrounding the benefits of doll therapy.

Animal assisted therapy has a visibly positive impact on residents and provides companionship, sensory stimulation and is another method of engaging. Pet therapy with animals such as dogs, cats, rabbits, guinea pigs, even chickens, is popular with residents and more importantly it is beneficial. Like any other type of therapeutic intervention, pet therapy takes the patient’s likes and dislikes into account and is only used when carers are confident residents can benefit and be comfortable with an animal.

Accreditation of PEARL specialist dementia care homes

It may take a year for staff in a care home to achieve accreditation as a PEARL specialist dementia care centre. The assessment is based on 158 criteria and involves an unannounced validation inspection by the company’s central specialist dementia care group. The criteria were initially developed by Caroline Baker, Four Seasons Health Care’s Head of Quality & Dementia Care, drawing on her experiences within a PCT and working with Bradford Dementia Group. In her previous role within the PCT, Caroline Baker and her colleagues had developed a Benchmark for Person Centred Care to align with the Essence of Care Benchmarks (Baker et al*) but this would not serve to measure the other crucial factors that contribute to Person Centred Care. Experience of working with Bradford Dementia Group and the initial criteria of the National Dementia strategy incorporating AGE concern standards and the NICE guidelines were all factored into the evolution of the PEARL accreditation criteria.

Resident experience training gave staff great insight and made them really think about the way they cared for residents and how the quality of the residents’ experiences can be improved.

Reference
Positively Enriching And enhancing Residents Lives