St. Cecilia Care
Dorset Ltd

Dementia Care Strategy

Overview

Twenty years ago in Dorset, there was a cohesive strategy for caring for people in the community with dementia. In Poole, there were two consultant psycho-geriatricians based at Alderney Hospital. They were part of a team of OT's, CPN's and Social Workers, who worked together to care for people in Poole with dementia.

There were two wards: Ward 4 was an assessment ward; Ward 3 was a long- stay ward for people whose care needs could not be met in residential or nursing homes.

There were day centres in Poole (Commercial Road) and Ferndown, where people with the early stages of dementia could be cared for several times a week. There was the Haymoor Day Hospital, where people still living at home could be cared for.

Once people were unable to stay at home, either because of a breakdown in family care or because they lived alone, residential care, in what remained of the Part 3 homes, or in private care homes, was the next step. During the pre-admission process and after their admission to a care home, there was always the supervision of a consultant and a team of CPN's, OT's and Social Workers, in case medical intervention was required, or to check on the appropriateness of the placement and the quality of care. Most residents were assessed at Alderney's Ward 4 for at least two weeks to try to find an ideal, minimum medication regime before admission, and sometimes after admission to care. As someone's dementia progressed, a telephone call to Alderney Hospital would bring either a CPN or a consultant. The cases remained open until an individual's life in a care home became stable and comfortable. Even then, a phone call to Alderney would allow the case to be reopened.

This system was as near ideal as could be hoped for in a society which had not planned properly for the care of its growing elderly population. It started to fall apart when day centres divided their days into two halves and only allowed half days for their clients. Instead of increasing medical, OT and Social Work staff to meet the needs of people with dementia, these services were cut. Consultants no longer kept their case-loads open. CPN's reduced their involvement to a maximum of six weeks. Social Workers became obsessed with time-limited intervention, which turned their roles into bed-brokers. The overall cohesion of the system fell apart in the 1990's. Dementia care was no longer the focus of the care professionals. Other political interventions changed the focus of real care into Community Care.

A paper by Challis and Davies (1980) decreed that old people could be looked after more cheaply in their own homes. Pricing and cost issues were the order of the day. Today, there are vast numbers of elderly people with dementia living alone or with an elderly partner, who receive help

in their own homes for discrete periods of time each day, but who are left to their own devices during the night and for lengthy periods during the day.

Residential Care homes now receive residents in advanced stages of dementia. These people are normally disoriented of time and place. They are often doubly incontinent. Their medication has not been assessed by psycho-geriatricians. Some are quietly confused, others are loud and some are aggressive. By the time they have been fished from the community, they are in such an advanced stage of Alzheimer's or multi-infarct dementia that they have very little or no short-term memory capability. They will never find the toilet unaided, they will never know or recognise their rooms. There may be a photograph and room number on the door, but they will not even recognise themselves.

The care home either accepts or rejects potential residents, depending on their overall philosophy of care and on how a resident will integrate with their current clientele. The more confused, aggressive and outspoken a person is, the less likelihood there is that they will be accepted by a care home. For care homes which look after old people without dementia, the chance of acceptance for such clients is nil. For those homes, such as St. Cecilia, which believe they must try to care for people first and their illness second, and who try not to pick and choose residents according to the ease of care they require, the situation is very difficult.

While we understand that caring for people with dementia takes a high calibre of carer, prepared to work hard for minimal pay with people who, through no fault of their own, may be incontinent, aggressive, and even violent, we are surrounded by others who do not understand. Families are often at their wits' end, having had to look after their nearest and dearest with little support and less understanding of the nature of dementia.

Far from working as a team, professionals from outside often feel it is their responsibility to complain and object to their managers, but seldom to us, about smells, strange behaviours, stains, levels of attire and so on. With little or no experience of residential care work with people with dementia, outsiders are at once fascinated, frightened or disgusted by the reality of caring for our residents. Residential care homes are vilified in the press as being uncaring towards their residents, often cruel and frequently of administering too much medication to their already confused residents.

The truth is usually very far from this. Apart from the fact that care homes are among the most inspected sector of society (CQC, Environmental Health, Fire Brigade, Local Authority Quality Improvement Team), medications are administered by care staff, but prescribed by consultants and GPs, not by, or at the request of care home managers. Family, friends and professionals visit at any hour of night or day and are witness to the day-to-day activities within the home.

Most care home owners and managers have been professional carers themselves and have chosen to work in the industry because they care and want to make a difference. Most carers in the care home environment are kindly, tolerant people, who are prepared to face the hard reality of

personal care because they have a vocation for the work, a calling to care for other people and usually a deep feeling of love and compassion for their fellow beings.
The challenge is how to make a residential care home work for its residents and their families, so that staff are fulfilled in their work, and other visiting and inspecting agencies feel able to work with us as team members rather than outsiders.

The answer lies in the following:

- The care home must understand the nature of dementia and the needs of people whose lives have been overtaken by it.
- The home must have a cohesive strategy for working effectively with people who have dementia.
- The home's physical environment must be as appropriate as possible for people who are frail and confused.
- The home must have trained staff of sufficient numbers to care for their residents as individuals.
- The home must work with family members, visiting professionals and the community at large to take its residents outside and bring the community in. Good relationships with the community are essential. Care homes should not be islands.
- There must be openness and transparency in all its dealings with clients and others, so that it not only cares appropriately, but is seen to care appropriately.
- Because of the huge expectations from inspectors and other agencies, not only for good quality care, but also for evidence of good quality care, it is essential that good recording and conforming with external expectations becomes second nature.

St. Cecilia Care Structure

St. Cecilia has been established as a residential care home with special concerns for dementia care since 1988.

The Building

The house was built in 1903 as a residence for Bournemouth professionals. It was originally a large, five bedroomed house. It was first converted as a care home in 1976 and was registered for 9 residents. The owners lived on the second floor.

With an extension in 1998 of four new rooms, and an additional two rooms in 2007 on the second floor, St. Cecilia has grown and is now registered for 15 residents in 14 rooms. We have one double room, which would only be shared by a couple, or at the specific request of residents or their families.

The Garden

The front garden is lawned, with a border of flowers and shrubs. There is parking for at least six cars in the driveway. There are two large red farm gates, which are seldom closed but are mainly for decorative use. They are bright red in colour as an aid to any residents (or their family) who need to recognise us easily.

The rear garden consists of rockeries and sloping ground leading to a sheltered, sunny lawn. There is an area of fruit trees and soft fruit at one end. There is access by a sloping tarmac path to the

garden; there are also brick steps with handrails for those who wish to use them. The side gates which lead into the front garden are closed and inaccessible to residents. For the benefit of those residents who enjoy walking, the side doors to the house are accessible during the day, so that residents may walk through the house, into the garden, around the house (where there are a number of handrails) and round to the entrance on the other side. Some of our residents spend much of the day completing the circuit, with occasional excursions into the garden.

Inside

There is a kitchen for preparing the meals. Food is hand cooked from a menu approved by our dietician and nutritionist, Liz Forsyth. Food is all of a kind enjoyed by our elderly residents. Roasts, casseroles, cottage pie and minced meat recipes are the order of the day. We are experimenting with using more European foods, such as pasta. All our residents or their families are asked about special dietary needs, likes and dislikes. Our cook has lists of individuals' likes and dislikes, as well as of any special diets.

Those residents who are able, sit at our large dining table. Others may sit in their chairs to be given one-to-one feeding supervision. Meals are an important focus for our residents. Not only do they provide nutrition and the pleasure of eating good, well-prepared food, they also help to divide the day into recognisable parts for people whose perception of days and nights may blunt.

The Sitting Room

It is vital for people with dementia to have the opportunity to mix with other residents and carers. Social stimulation is a normal part of a human's day. Without it, people become withdrawn. Many elderly people already have sight or hearing problems, which, in isolation, can exacerbate their mental health state. Sensory deprivation may even cause depression and delusions. Most of our residents spend the day in the sitting room area unless they express a desire for their own company. The sitting room is thus always awash with noise, conversations, singing and shouting, sometimes all at once.

The Conservatory

The conservatory is a glazed area adjacent the sitting room, overlooking the garden, where residents are encouraged to sit if the turmoil in the sitting room is too much for them. It is also available to visitors who do not wish to sit with their family member or friends in the sitting room or in the quiet of their bedroom. (Since this paper was written, the conservatory has become a quiet area for office and meetings.)

Toilets

There are four toilets available at St. Cecilia over three floors, plus 5 ensuite toilets and one staff/visitors toilet.

Toilets are equipped with frames and grab rails. A new toilet has just been installed in the first floor bathroom, in addition to the separate toilet already in situ. This will allow better wheelchair and hoist access for those residents who are less mobile.

Bathrooms

There is a bathroom on each floor: two of them (on the ground and first floor) are now equipped with showers, which are safer for residents and carers than baths. The second floor, because of its position, may only be used by residents who can walk. It was felt appropriate to equip it with a bath when it was refurbished in 2007, for the pleasure of the residents occupying the two adjacent rooms.

Stairs

St. Cecilia has two flights of stairs. These are equipped with stairlifts, installed in 2007, so that those residents who cannot manage stairs are able to go up and down from bedroom to sitting room aided by a carer.

St. Cecilia is one of the few care homes in Dorset to be protected by a Fire Sprinkler System. This covers the area from the front entrance hall up two flights of stairs to and throughout the second floor, and provides a safe exit in the event of a fire. This is an important safety factor for people with dementia, as it will take longer to evacuate them than other people.

Bedrooms

All bedrooms are seen as the home territory of their occupants. They are decorated regularly under our rolling maintenance plan, so that they will all be re-decorated at least every three years. Depending on their condition, some may need to be re-decorated more regularly.

The carpets are especially designed to withstand wear and tear of a care home environment, and are shampooed regularly according to need. (NB For many years we were obliged to provide carpets throughout thanks to government regulations which insisted that a care home should mimic the residents' own homes. Fortunately, common sense now prevails and we have installed vinyl in the bedrooms and wood-effect floors in the sitting areas.)

Bedroom furniture is, for the most part, as our residents would have had in their own homes. They may bring items of furniture from their own homes to personalise their rooms. We have mostly specialised hospital-style beds, as many of our residents who have difficulties with weight-bearing walking or turning themselves during the night. These beds allow carers to use hoists appropriately and to wash and change residents with greater ease and safety.

Dementia Philosophy

In 2008, a book was published which has changed the emphasis of dementia care. 'Contented Dementia' by Oliver James has revolutionised the care of people with dementia. Prior to this, those of us who have worked for may years with dementia, have understood the challenges, but have never been presented with a sensible day to day strategy for giving non-judgemental and non-patronising care to our residents. To understand the nature of an illness is not the same as understanding how to care for its sufferers.

Generally speaking, there was the old school of cleanliness being next to godliness and hospital-style care for the good of our residents, on the one hand, or, on the other, a more user-friendly, laissez-faire care of the individual, which has been the style at St. Cecilia since its inception. This is loosely based on Carl Rogers' *Person-Centred Care*. Person-centred care underpinned social work

in the seventies and eighties, before care became budget-driven. That it has been re-discovered at the end of the noughties by the policy-makers as a catch-all phrase to cover care, is a relief. However, it is descriptive, in so far as it tells us how best to approach our work with elderly people with dementia. It should inform our actions, but it does not go far enough and provide us with a real day in, day out, way of providing in practical terms a way of caring for our residents.

The revolutionary new system uses the person-centred work of Carl Rogers and the Individualisation concept of Tom Kitwood and takes them a step further. The book 'Contented Dementia' is informed by people who care and have cared for those with dementia. It does not come from legislators, inspectors, academics, doctors or old wives' tales, but from the actual work and experiences of Penny Garner, first with her mother and later with thousands of other dementia sufferers at Burford Community Hospital in Oxfordshire. With the support of the Alzheimers society, Penny, through her son-in-law, the writer Oliver James, has produced a way of caring for dementia sufferers which does not challenge them, which gives them a normal feeling in a confused world and which therefore reduces levels of stress and anxiety in the sufferer. This system is known as SPECAL care, which has been described as, "a very impressive demonstration of person-centred care" and " a unique service with a model emphasis on highly individualised, person-centred care" (John J and Pride L, 1997 'SPECAL Project Care Services Review, Care Consortium Alzheimer's Disease Society'). In 1999, its effectiveness was verified and recommended by a Royal College of Nursing Evaluation.

At St. Cecilia, we adopted the SPECAL model of care in Autumn, 2009, so that it now underpins our practice at St. Cecilia. We are contacting the other proponents of this system via the SPECAL website, and are supporting our staff with training and keeping abreast of new developments.

What is SPECAL Care?

SPECAL care offers hope for those who suffer from dementia and those who care for them. Usually, the idea of dementia sends a chill down the spine, like no other ailment (Oliver James, p.1).

Those who know about dementia, know that it is a progressive illness in its various manifestations (Alzheimer's, multi-infarct, Pick's disease, Lewey body and so on) which cannot be halted (except briefly by some drugs, in the case of Alzheimer's), cannot be cured and has no treatment except by hard drugs to alleviate symptoms and behavioural problems.

Dementia's onset is slow and insidious, often exaggerating long-term traits to begin with, so that even family do not always recognise its onset. Sometimes, it seems to happen suddenly, leaving family members bewildered at the changes which have come over their loved ones. Often the personality of the sufferer changes dramatically, so that families grieve the loss of their loved-one long before their death. The illness and its process can, forever, leave their marks on families. Carers may suffer breakdown in their health, families may split apart because of the strain imposed upon them. Those with dementia may find themselves precipitated into care homes through no fault of their own. Admissions to care homes are seldom planned and are usually the result of emergency, such as a fall, an incident arousing public anxiety or the collapse of carer or family.

SPECAL care looks at the needs of the individual and carer in their own home. It advises preparation

for an almost inevitable move into care, at a point when the dementia dictates such a move. It provides a mutual understanding of needs between family and care home when the move takes place. It presents the resident with a mode of care which is unthreatening, which allows the resident to be in charge of their own dementia. It does not attempt to re-orientate the resident, to compel the resident to do quizzes and games, to strengthen the brain (or, more likely, to further confuse them) or to follow a rigorous regime of care and treatment. Instead it follows three basics rules for the carers:

1. Don't ask questions
2. Learn from the residents as the experts on their disability
3. Always agree with everything residents say, never interrupting them

SPECAL care uses the analogy of a photograph album to describe the memory of a person with dementia. Usually, there is a long term series of photos which represent memories of times long ago. As dementia causes short-term memory loss at first, the photographs of more recent occurrences become more and more blank, until all recent photos are blank. This in itself is no problem unless the resident is asked a specific question to which they have no answer (as in the traditional medical test "What is the name of the Queen's consort?, Who is the Prime Minister? Where do you live? What did I ask you to remember five minutes ago?").

Panic may ensue, as our resident realises that they have no idea of what they are being asked, and, even if they have, they have no answer to it. The stress produces what SPECAL calls a 'red blank', which is a blank photograph of the recent past, which has made the resident unhappy, fearful or angry. They can't remember the incident any more, but they still feel angry or emotional. A series of 'red blank photos' through the day keeps the resident angry or fearful. Repeated day in and day out, that emotional state becomes normal for that person. If, on the other hand, the photographs are blank and the resident is not challenged, they remain in a calm and comfortable present, a so-called 'green blank'.

The author uses an analogy which I have myself used many times. For the outsider coming into St. Cecilia it is like walking through Lewis Carroll's 'Looking Glass'. Outside all remains the same. Inside the home, all our values and expectations must change, to be dominated by the needs of our residents. Our residents' needs are paramount.

If someone chooses to wear several layers of clothes, or strange articles of clothing on their head, that is their choice. Apart from a little cajoling from carers, this may remain the mode of attire until a change is desired. People may be walking apparently aimlessly, talking to themselves, or on their way to visit their mother. They may be conversing happily, but apparently nonsensically to their neighbour. This is their world and no-one should judge it by outside norms. Carers are there to watch over people's safety, to help with their personal care, to talk and interact with them, but certainly not to criticise, shout at, correct or try to change or interrupt what a resident is doing. If someone is doing something dangerous or anti-social, there are ways of intervening without causing stress or anger to either carer or resident.

What are these techniques?

SPECAL Care is described as "24 hour wraparound care for lifelong well-being" (p. 61). It has two fundamental goals:

1. To protect our clients from having to share new information. To achieve this, our clients should never be asked or expected to recall anything from the immediate past. The way the caring environment works is to put no emphasis on recent events.
2. To support our clients by referring the present to things in the past which they can understand. It makes a virtue of living in the past. The past and the present become confused, but as the client is comfortable in the past and uncomfortable in the present or recent past, this is a good thing.

In order to achieve a comfortable here-and-now, the three precepts already mentioned come into play:

- Don't ask questions
- Learn from the expert – your client
- Never contradict

The carer develops a system of 'verbal ping-pong', where conversation is initiated by the carer on a topic known to be of interest to the client. It does not have to be an intellectual conversation, quite the opposite. It will wander and be inconsequential – but, at all costs, it never asks questions.

Secondly, the carer spots the most commonly repeated questions of the client and learns to identify acceptable answers to them.

The third technique is to establish 'conversational loops' to get the client from Red to Green, or from frustration and anger to a state of calm.

Every client must be allowed to use old photographs to help them to achieve a more relaxed, comfortable frame of mind. Their carers will establish the client's Primary Theme; something they were good at, interested in or an expert on in their youth. They must also have a Health Theme; some element of their health which can be used by carers to encourage a break or change in the client's behaviour e.g. an old football injury could become the reason why someone needs to rest at bed-time or to sit down for a meal, and so on.

Each client will need explanations for the absence of primary loved figures, long dead, or for main carers when they go off duty.

Finally, the team needs to be trained. Chapter XI of 'Contented Dementia' outlines the training method to be used.

Why follow SPECAL so whole-heartedly?

As prime-mover of St. Cecilia, my reasoning is simple.

In thirty years of caring for dementing people, I have read and studied more than most about the nature of dementia. I know about the tangles and whorls found in the brain, the brain shrinkage in Alzheimer's, the bleeds and starvation of blood in arterio-sclerotic dementia. I have experienced the behaviour of thousands of people with dementia, and the anxiety and guilt of their carers. I have sat in as a professional in hospital ward rounds, where people face a bewildering array of imposing faces. I have read about new break-throughs in gene technology.

'Contented Dementia' is the first sensible book to describe a way to make a dementia sufferer more contented. To me, as a long-term carer, I would prefer to work with people than with theories or descriptions. I would rather be part of a world where Dementia is acknowledged for what it is – a very common condition in our aging population – and be actively involved in improving people's lives rather than waiting for mistakes to happen. You could almost say that it is better to create a miracle for one person now, than to wait for someone else to do it in the remote future. It is, after all, **now** that our families and friends need help for their loved ones.

They cannot wait.

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