

Dementia and end of life care: implications for people with sensory loss

Report from a half-day seminar on 7 February 2012,
organised by the Social Care Institute for Excellence
(SCIE), ARUP and the Thomas Pocklington Trust

ARUP

 Thomas Pocklington Trust
Housing and support for
people with sight loss

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Key messages

- People with dementia often suffer from a range of sensory losses – especially of sight and hearing – which can be mistakenly ascribed to their dementia. If these losses are identified and addressed by those caring for them, the quality of life of people with both dementia and sensory loss can be significantly improved.
- People with dementia at the end of life will often be unable to communicate their wishes. This makes it especially important to diagnose dementia early and to produce advance care plans – although everyone has the right to refuse to make these plans.
- It is difficult to identify when someone with dementia is approaching the end of their life. However, there are some clinical signs that indicate that someone is entering the final phase of life.
- Care home staff often lack the training and confidence needed to support people with dementia at the end of life. Experiential learning to help them see the world from the resident's perspective can be valuable.
- When a relative is dying, it is a difficult and stressful time for carers. They need support to make the difficult decisions they face.
- It is vital that staff provide individual, person-centred care that is integrated with external services such as general practitioners (GPs), out-of-hours services and secondary care.
- As well as other health care services, care home residents are not always getting access to the specialist palliative care services they need. This is unacceptable.
- Good design of the environment can play a big part in helping people overcome some of their sensory and cognitive problems, such as poor sight, forgetfulness and limited attention span.
- A guiding principle in designing living environments should be to favour the domestic and familiar wherever possible. For instance, mono-functional rooms are preferable to multi-functional rooms.
- Everybody – including staff, residents and carers – should be involved in environmental design. This is not something to be left solely to architects and building designers.

Introduction

Dementia is a major and growing issue. An estimated 820,000 people have dementia in the UK and the figure is set to double in the next 40 years (Knapp, 2007, Luengo-Fernandez, 2010). Many of these people will also have some degree of sensory loss. Both dementia and serious sensory loss are often triggers for admission to a care home.

A quarter of all hospital beds are occupied by older people with dementia and around a third of people with dementia live in care homes. As more people are surviving into older age, the incidence of dual sensory loss is growing. More than two thirds of people over the age of 70 have some form of hearing loss, while 42 per cent of those over the age of 75 have cataracts and almost 50 per cent have some symptoms of age-related macular degeneration (Age UK, 2011). Half of those with sight problems also have some form of hearing loss (Action on Hearing Loss, 2011).

But how confident are carers and staff about supporting and meeting the complex needs of people with dementia and sensory loss? When someone is approaching the end of life, what are the main challenges that staff face? How can good environmental design support best practice and care?

These are some of the questions that SCIE, Arup and the Thomas Pocklington Trust explored at a half-day seminar on 7 February 2012. These organisations are committed to sharing information across sectors and to breaking down the 'silos' that sometimes prevent best practice. They want to foster links between research, building design and sensory loss and facilitate discussion of what can be done to improve the care of people with dementia and sensory loss as they reach the end of their lives.

The format of the event comprised presentations from three leading researchers followed work in small groups. Each group was asked to explore one of the presentations in more detail and identify themes and ideas for further action.

The event was introduced by Baroness Sally Greengross, chief executive of the International Longevity Centre – UK, who said that poor eyesight can lead to falls, depression and malnutrition, severely affecting someone's quality of life.

Hearing loss is a less visible disability but the effects are equally serious. People are very intolerant of deafness – the result is that people with hearing loss are all too often ignored and socially isolated.

'We know that there are already big challenges about communicating if you have got dementia,' Baroness Greengross told her audience. 'It is not easy for the person with dementia and it is not easy for the people who are caring for them. But the result is that it is easy to lapse into poor care.'

An underlying problem, she said, is that many older people have not one but multiple conditions and staff do not always recognise this. Dementia is one condition and not the explanation for all behaviours. 'People with dementia are people who may have arthritis, a hearing condition or poor sight or poor sensory awareness.'

There are examples of good care but many people suffer from poor-quality care. This is a systemic rather than individual problem and needs to be addressed as a priority.

At heart this is a human rights issue, said Baroness Greengross. It comes down to people's values – the values of the person with dementia, their family and the staff who care for them. 'We are talking about vulnerable people here. Basically, it is the feeling for another person that counts.'

Presentations and workshop themes

1 Social care evidence about people with dementia in care homes at the end of life

Caring for people with dementia at the end of life presents particular challenges, said Jo Moriarty, from King's College London, drawing from a Research Briefing she has recently completed on caring for people with dementia at the end of life in care homes, commissioned by SCIE.

The nature of dementia means that people at the end of life might well be unable to communicate their wishes, she said. And because the decline is slow, it is difficult for staff to identify exactly when the end of life is approaching.

She identified three areas where improvements were needed:

- **Advance care planning**

Earlier diagnosis gives time for the person with dementia to state their wishes for future care. However, we do not know how many people with dementia do make advance care plans and not everybody will want to make them.

Studies show that people at the later stages of dementia can still talk about death and dying and some have strong views. Sometimes staff appear reluctant to talk about this.

- **Training**

Care home staff often lack the training and confidence needed to deal with end of life care. In particular, they say that they are not confident about: recognising and managing pain; helping people who have problems eating; and managing ethical dilemmas.

Training makes a big difference, but the end of life is connected to many different and difficult issues. Staff may not share the same cultural or religious

views as the people they are caring for and may have different ideas about what a 'good death' involves.

- **The carer's role**

It is important to recognise the effects that the end of life may have on family carers. They may not receive the support they need to make difficult decisions or deal with the stress they experience. It is easier for carers to make decisions about the end of life when they know what their relative wanted. But often that is not the case. And communications with staff may be poor. Moreover, because of the individual's gradual decline, carers and staff may not realise that the end of life is near.

Carers are very upset if standards of basic care are not met. 'If people at the end of life have not had their hair washed or combed, this can be very distressing.'

There are big gaps in the research on this subject. For example, little is known about different ethnic and cultural preferences for end of life care. And the cost-effectiveness of good carer support, for instance, is unknown.

In the workshop on this presentation, participants raised the issue of pain management and poor recognition by staff of pain among people with dementia. And, unlike many other areas, it was felt that people with dementia tended to be under-medicated for their pain.

One participant pointed out that people with dementia experience pain in the same way as everyone else, but may process it differently and may not be able to communicate their feelings. 'It's important to look for other non-verbal signs of someone's distress.'

Action points from the workshop

- People have the right to refuse to plan for their care. It is important that this is documented.
- It is vital to have clear systems and procedures in place for the end of life so that care can be coordinated between paramedics, GPs, out-of-hours staff and care home staff.
- Care home staff can sometimes be 'driven' by the home's policies to override individual preferences.
- Staff may also be inclined to call 999 in an emergency in order to avoid prosecution or blame.
- Although it is difficult to pinpoint when someone is approaching the end of life, there are some clinical indicators in people with advanced dementia. These include a combination of infections, swallowing problems, weight loss and increasing immobility. Increasing the awareness of these among carers and staff is important.

2 Sensory loss in people with dementia

People with advanced dementia will often have sensory losses as a result of age-related eye conditions and/or damage within the brain due to the condition, said Pam Turpin, senior consultant with Arup.

Hearing problems include central auditory processing problems, which are associated with competing noises, and tinnitus, which is associated with auditory hallucinations. Meanwhile, sight loss can lead to misperceptions, misidentifications as well as illusions and hallucinations.

People who have no cognitive impairments may learn to adapt to sensory loss. But when they have dementia this may affect their perception of the world.

As a result, people may make visual and auditory mistakes, which can lead to illusions and misperceptions. For instance, a shadow may be seen as an animal or hallucinations may be felt to be real.

As Jones and colleagues (2006) have commented: 'Persons with advanced dementia may be behaving relatively normally in a perceptually abnormal world versus the more common notion [of them] behaving abnormally in a normally perceived world.'

Among people with advanced dementia, normal age-related visual changes may be exacerbated by visual pathology associated with dementia, the visual side-effects of medication and cognitive confusion. All of this will have a predictable, negative impact on activities of daily living.

This is why it is so important that care home staff know about people's sensory disabilities, and how these (rather than dementia) may be the cause of a problem. For instance, macular degeneration¹ could explain why someone experiences hallucinations.

It has been argued that in the later stages of dementia, people retreat into a bubble where everything is perceived in a muffled and distorted fashion. It is important to try to break through this bubble 'to ensure that individuals have a good death with dignity and respect,' said Turpin.

Turpin highlighted three fundamental changes that are needed to ensure better care at the end of life:

- individual, person-centred care, including regular holistic needs assessments, advance care planning and an understanding of an individual's sensory difficulties

¹ Age-related macular degeneration is a medical condition that usually affects older adults and results in a loss of vision in the centre of the visual field (the macula) because of damage to the retina.

- an understanding among commissioners that the majority of older people at the end of life have multiple conditions and that therefore care and support must be integrated
- all staff working with people at the end of life having core competencies, including an understanding of sensory losses.

A delegate suggested that some care needs are very basic: 'People don't know how to clean out a hearing aid and put in a battery or even where to get batteries,' she pointed out.

A carer in the audience said that her experience with her father underlined the time and patience needed to 'burst the bubble': 'When you talk very clearly, eyeball to eyeball, there is real communication. But it's very focused and it's a matter of giving him lots of space and time, and that's such a challenge for care homes.'

Meanwhile, a community psychiatric nurse who works with people over the age of 65 felt that she had been living in her own bubble: 'I have a client who has just been diagnosed with macular degeneration but it didn't even occur to me it could cause hallucinations. The problem is that when someone has dementia everything gets blamed on dementia.'

Staff should try to see the world as the person with dementia sees it, via experiential learning where staff wear dark glasses, ear plugs or gloves to simulate particular impairments, which can help them to understand a person's difficulties.

Action points from the workshop

- Good care is a human rights issue.
- All environments must be appropriate for residents at the end of life and this requires that staff have the skills to deliver good end of life care.
- Do not over-complicate the messages to frontline staff. Avoid clinical jargon.
- Care home residents with dementia may not have access to the specialist palliative care services that they need.
- An effective interface between health and social care is vital to prevent inappropriate hospital admissions and ensure that people are discharged to die where they want. Often there is only a small window of opportunity to ensure that someone who is dying gets home. If that moment is not seized, the chance is lost.
- Good work will be wasted if commissioners fail to commission settings in which good practice can be delivered.

3 Better care homes for people with dementia and sight loss

Care homes are often seen as the antithesis of a home, said Gregor Timlin, a design researcher at the Royal College of Art, who has been examining how environmental design can improve the quality of life of older people in care.

When he talked to older people as part of his research, he found that they associated the word 'home' with choice, control, protection and security. Some care homes, on the other hand, were felt to undermine those values.

The findings have been used in a new web-based tool that aims to support care homes in reintroducing these domestic values. 'People's aspirations of what they want from their home and from their lives do not change because of age,' Timlin said. 'But what does change is that residents in care homes can be disabled to the point where they can no longer carry out actions to fulfil their aspirations.'

The principal aims of the research were to define environments that support independence and in the process free up staff to spend more time in meaningful activity with residents.

The Better Care Homes website (www.bettercarehomes.org) – which showcases the outputs of a one-year collaboration project between the Helen Hamlyn Centre for Design and Bupa – seeks to demonstrate how good environmental design can mitigate the effects of things like short-term memory and forgetfulness, attention control, long-term memory strength, recognising objects, way finding, language and communication and late stage dementia and palliative care.

A core element of the website is encouragement to move away from multi-functional day rooms, which can cause problems associated with high levels of stimulation, and replace them with smaller mono-functional rooms, which promote each person's ability to focus on the task in hand.

An example of this is the virtual 48-bed care home developed by the project. This is divided into four units, each of which is seen as a household. At the centre of the home is a 'village cluster' of communal spaces such as a hall, hairdressing salons, cafes and a playground where families can bring children to play and engage with their grandparents.

The website promotes individual bedroom spaces that allow each resident to introduce their own furniture, decoration and other mementos that can help reassert their identity.

Open and well-designed links between the different parts of a building can help people with cognitive difficulties to find their way around and reduce wandering. Techniques include open double doors that allow the sounds of the living room to escape, glass doors leading to the garden and ensuring that all walking paths travel through areas of activity, which can help residents to orientate themselves.

Environmental design suggestions that can support people who have sight loss include higher colour contrasts, improved lighting and reduced glare when someone moves from indoors to outside, which can also help with balance. Potential hazards should be minimised by locating obstacles away from the main thoroughfares.

Action points from the workshop

- It is important to involve everybody in care home design. This is not something that can simply be left to the designer. Staff need to be encouraged to think differently – and creatively.
- Consider creating a care home on the model of the small household. Integrate the relationship between resident, care staff and people visiting. Design an environment that supports people's remaining abilities to do what they want to do.
- Staff need to be valued. Staff who are valued equals happy staff and that equals happy residents.
- In the workshop, questions were raised about how existing care homes can be adapted. Many care homes are small – 'little old Victorian houses that have been knocked together,' said one participant. 'It is hard for these sorts of care homes to have access to the resources and training to know about the real changes they could make.'
- For many participants, the big question was: how will this be financed?

Next steps

When planning this event, SCIE, Arup and the Thomas Pocklington Trust agreed that the work should not stop with one event and a report. They have agreed to meet to consider how to build on the work, feed into existing initiatives, such as the Dementia Action Alliance, and influence best practice. It is hoped that a continued dialogue on emerging issues will continue with those who attended the event and other practitioners.

Resources

Arup is an independent firm of designers, planners, engineers, consultants and technical specialists offering a broad range of professional services (www.arup.com).

Thomas Pocklington Trust is a leading provider of housing, care and support services for people with sight loss (www.pocklington-trust.org.uk).

www.bettercarehomes.org

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