



The last taboo

A guide to dementia, sexuality, intimacy
and sexual behaviour in care homes

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Foreword

Dementia is one of the great health and social care challenges of this century. In the UK, it affects some 750,000 people directly but, as the strain on carers and families can be immense, the number of people it touches is much larger. The costs to society are enormous, estimated to be £20 billion in the UK and, internationally, some \$600 billion, or 1% of Gross Domestic Product (GDP). As dementia, and in particular its commonest cause Alzheimer's disease, is a deteriorating condition, people need more support as the illness progresses. We know that a high proportion of residents in care homes suffer from dementia and securing best quality of care for this vulnerable group is one of the Coalition Government's priorities.

The Last Taboo is devoted to the very important area of sexuality, intimacy and sexual behaviour in people with dementia resident in care homes. It is an immensely valuable document which deals with this most sensitive of issues in a clear and open way. It shines a light on this hitherto hidden aspect of dementia care, underscoring the needs of people with dementia in this most personal of areas. It represents an important endorsement of the need for personhood and dignity in people with dementia and the individual expression of sexuality is a core part of that individual. By discussing the subject openly the opportunity is there to promote good care, underscored by empathy. The case histories bring together some key aspects of sexuality and it is helpful in the summary to be reminded that intimacy is a need and improves wellbeing, that capacity needs to be assessed and its lack not assumed, that it is fundamental to allow free expression and that our own pre-determined perceptions may need to be addressed.

Respecting a person's individuality and preserving their dignity are the cornerstones of person-centred care. The expression

of sexuality and intimacy is fundamental to an individual, the understanding and appreciation of which are helped by the publication of this booklet.

Alistair Burns

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About this guide

This guide focuses on dementia and sexuality, intimacy and sexual behaviour in care homes – a subject which remains one of the last taboos of long-term care. The onset of old age or a cognitive impairment does not erase the need for affection, intimacy and/or relationships and yet this aspect of ageing has often been ignored and sidelined in policy and practice.

While the issues involved can be complex, controversial and sensitive and may challenge our own beliefs and value system, it is essential that we understand more about them to foster a more person-centred approach to dementia care. Care home residents with dementia often have complex care needs and trying to understand and respond to the more intimate and sexual aspects of a resident's personality can be challenging.

Aimed at care home workers and managers, this guide not only provides essential information on this aspect of dementia care but offers practical advice to support current work-based practices. Set out in an accessible and easy-to-read format, this guide includes case studies, questions, suggestions and a self-assessment quiz to promote easy learning. It also provides a possible pathway for care home managers to develop a guiding policy on sexual expression in dementia.

There are no set rules on dementia care in this area and there are certainly no set answers. As you know, each situation and resident is unique. It is possible, though to improve levels of understanding and education and help you balance what may appear to be competing demands of resident safety and protection, human rights and dignity with the overall protection of other residents and their families.

This guide will also aim to challenge negative attitudes and misconceptions about older people with dementia and their sexuality. This has been highlighted as a key factor that influences care patterns and responses.

We hope that this guide will help you learn more about this subject and about your own attitudes, beliefs and values concerning older people with dementia. Your willingness and ability to recognise and understand this aspect of dementia care, will not only be helpful to your everyday work, but could have a positive impact on the quality of life for residents and their families in the care home.

The information included in this guide comes from a comprehensive review of the literature, best practice examples from the UK and abroad and interviews with stakeholders involved in dementia care, policy and practice. At the back of this guide a resource pack provides further links to relevant literature, policies and guidelines.



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An introduction to dementia, sexuality, intimacy and sexual behaviour

What do we mean by sexuality, intimacy and sexual behaviour?

Intimacy and sexuality are basic human needs that are intrinsic to people's sense of self and wellbeing. Regardless of age, individuals require companionship, intimacy and love and yet for older people this intrinsic right is often denied, ignored or stigmatised. For older people with dementia the problem is even worse: they face the 'double jeopardy' of being old and cognitively impaired.

While intimacy can be defined in many ways, the evidence suggests that 'light forms' of expression such as holding hands, stroking, or kissing by people with dementia is widely considered acceptable in care homes. However, any further form of sexual expression is met with concern at best and outrage and shock at worst. Clearly there are a range of issues involved in terms of autonomy, dignity, mental capacity and safeguarding, which come into play. Nevertheless most people are not even willing to consider or contemplate that people with dementia may have intimate or sexual needs.

'Sometimes our problem as individuals to understand and respond to the sexuality or sexual needs of older people with dementia links directly to our own misconceptions, preconceptions and prejudice.'

What is the best model of care for people with dementia and how does this affect care responses to sexual expression and behaviour?

Medical Model changing to Social Model of Care

- | | |
|---|---|
| • 'Old culture' focuses on disease, disability and old age. | • Allows for the construction of dementia as a disability (Kitwood). |
| • Individual's identity defined by dementia. | • Emphasis on 'person centred care' – emphasis on the self. |
| • Can lead to an over-emphasis on protection and paternalism. | • Take into account resident's personal history, health status previous response to stress and personality (Kitwood). |
| • Tendency for residents to be disempowered and infantilised (Kitwood). | • Social and environmental factors are considered. |
| • Social and environmental factors in care sometimes ignored. | • Has led to a more liberal model of understanding of sexual expression and in teaching (Archibald). |
| • Lead to difficulties for care staff when considering sexual expression. | • Though defining dementia as a disability is potentially problematic when it comes to sexual expression (Bartlett). |
| • Individuals seen as passive and receivers of care. | • The resident's family, care staff and fellow residents may also need to be considered. |

But, is there a third way? The biopsychosocial model

Biopsychosocial model (Cohen-Mansfield) – how we view dementia is linked to?

1. **Initial predisposing factors** – linked to genetic/biological/medical, psychosocial and environmental influences.
2. **Lifelong events factors** – linked to genetic/biological/medical, psychosocial and environmental influences.
3. **Current condition factors** – linked to genetic/biological/medical, psychosocial and environmental influences.

By looking at dementia in a more holistic way and considering a range of factors, a more thorough understanding of people with dementia and the development of management responses and interventions can be achieved.

Based on article by Carole Archibald, 'Sexuality and Dementia: The role dementia plays when sexual expression becomes a component of residential care work', 2003.

These needs may manifest themselves in very different ways. Residents with dementia may simply wish to express their sexuality in the form of cuddling or kissing, or in the form of some or all of the activities linked to a relationship. This relationship may be a pre-existing or new relationship. Residents may also wish to continue personalised acts of sexual behaviour such as masturbation. While it may not be immediately apparent, how we consider and respond to this form of behaviour, it links to how we view care for older people with dementia more generally (see page 7).

How we view care for people with dementia will affect how we respond to the intimate and sexual needs of people with dementia. We also need to confront our own views and possible prejudices, sometimes unknowingly towards older people and older people with dementia. It is not uncommon to hear one or more of the following comments regarding sexual expression:

'I have always thought of older people as being sexless.'

'Touching and cuddling is ok, but I am not sure about anything else.'

'How do we know this is really what they want?'

'Sex is for younger people.'

'I just want to protect the residents and look after them. They are defenceless. How can they be expected to fend off the advances of some of the other residents?'

'If we do let older people with dementia have an intimate relationship, what would other people or their families in the care home think?'

'I did not realise until now, but my reaction to men and women is quite different. When I see an older man with dementia touching an older women I do tend to get quite angry, whereas towards the older women with dementia I feel quite protective and maternal towards them.'

We all need to ask ourselves to what extent we may agree or disagree with these comments and what may have led us to form such conclusions. There are lot of myths regarding older people, people with dementia and their sensual or sexual needs which need to be challenged.

Fact not fiction

- The need for human intimacy for most people lasts until the end of their life (Kuhn, 2002).
- Many people with dementia, particularly in the later stages, may become less interested in sexual activity. This, however, may not diminish their need for human affection, touch and warmth (Bouman, 2002).
- The benefits of sexual expression and intimacy for older people with dementia are often overlooked – evidence suggests they enhance general health and wellbeing (Kuhn, 2002).
- 'Very few care plans address the sexual needs of individual clients, despite the potential benefits to person-centred care of this aspect of care planning' (Wallace, 2003).

Did you know?

A brief guide to dementia

Background on dementia

In order to tackle the subject of dementia, sexuality, intimacy and sexual behaviour in care homes it is important to have an understanding and working knowledge of dementia more generally.

The number of people with dementia in the UK is rising. There are 750,000 living people with dementia in the UK and it is estimated that this will soar to over one million by 2025 (Alzheimer's Society, 2007).

Dementia represents a huge challenge not only for individuals and families, but also for our health and social care system and its workforce. More than one-third of people with dementia live in care homes and dementia is the strongest determinant for entry into residential care for people over 65. At least two-thirds of all people living in care homes have a form of dementia (Alzheimer's Society, 2007).

Care homes are now 'front-line' dementia providers, particularly during the severe stages of the disease. People with dementia who live in care homes have among the most complex health and social care needs of any group in UK society (Heath and Sturdy, 2009).

A report from the Alzheimer's Society in 2007, entitled *Home from Home*, highlighted that while some care homes are providing good-quality care to people living with dementia, many homes are still not providing the level of person-centred care people with dementia deserve. As only 60% of the people with dementia

in care homes are in dementia-registered beds, standards of dementia care need to improve across the board to ensure the needs of all residents are met.

The National Dementia Strategy launched in February 2009 set out an ambitious plan to improve the experience of people with dementia in care home settings. This is an area which is considered by many to be one of the most challenging aspects of the Strategy (for more information on the Strategy, see Policy Framework section).

A quick guide

Dementia is a descriptive term for a collection of symptoms that affect the brain.

Early stage, middle stage and late stage dementia are the three phases identified with the disease progression.

Memory loss and decline in multiple areas of function such as communication are some of the most common symptoms.

Early diagnosis of dementia is essential to ensure the best support for the individual and their family.

No cures or treatment have been proven to prevent the development of dementia.

Tangles and plaques develop in the brain during Alzheimer's disease, leading to the death of brain cells.

Ignorance, fear and misconceptions surrounding dementia can affect quality of care and outcomes.

Alzheimer's disease is the most common cause of dementia.

What is dementia?

- Dementia is characterised by loss of or decline in memory and other cognitive abilities. It is caused by various diseases and conditions that result in damaged brain cells.
- Dementia is a progressive condition. This means that the symptoms become more severe over time.
- The symptoms of different types of dementia also overlap and can be further complicated by co-existing medical conditions.
- Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia.
- Dementia can affect people of any age, but is most common in older people.
- Alzheimer's disease is the most common form of dementia.
- Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with increasing difficulty in remembering new information. As damage spreads, individuals also experience confusion, disorganised thinking, impaired judgement, trouble expressing themselves and disorientation to time, space and location, which may lead to unsafe walking and behaviour that challenges us.
- In advanced Alzheimer's disease, people need help with bathing, dressing, using the bathroom, eating and other daily activities. Those in the final stages of the disease lose their ability to communicate, often fail to recognise loved ones, become bed-bound and reliant on 24/7 care. Alzheimer's disease is ultimately fatal.

Type of dementia	Description
Alzheimer's disease	Most common type of dementia. It accounts for 60 – 80 per cent of cases. Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgement, disorientation, confusion, behaviour changes, trouble speaking, swallowing and walking.
Vascular dementia	Considered the second most common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterised by the presence of the hallmark abnormalities of Alzheimer's disease and another type of dementia, most commonly vascular dementia, but also other types, such as dementia with Lewy bodies.
Dementia with Lewy body	Shares characteristics with both Alzheimer's and Parkinson's diseases. It accounts for around four per cent of all cases of dementia in older people. The symptoms that indicate this specific type of dementia are mental decline, recurrent visual hallucinations or depression, increasing problems handling the tasks of daily living, repeated falls and sleep disturbances and fluctuations in autonomic processes.
Dementia in Parkinson's disease	Many people who have Parkinson's disease develop dementia in the later stages of the disease.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language.

Source: *Dementia and the Eight Types of Dementia*, Bob De Marco, 2011.

Dementia, relationships and sexuality in care homes

Relationships

This section explores how care homes can facilitate existing or possibly new relationships in care homes for people with dementia.

While the onset of dementia may change the expression, form and nature of a sexual relationship, we should not assume older people with dementia no longer have any desires of a sexual or intimate nature. Each situation and individual is unique, so we know there is no set response. However, with some practical tips and case studies of best practice provided by care homes, we hope to show you how to respond to and meet the sexual needs of residents with dementia.

Pre-existing relationships

As the previous section on dementia and sexuality explored, sexuality and intimacy are important to a considerable number of older people in residential care. Many couples may wish to maintain a sexual relationship, experiencing sexual intimacy as a source of comfort, reassurance and mutual support (Bouman, 2007). It may be the case that they have entered the care home as a couple both with dementia, or with dementia affecting only one of them. Perhaps more common will be the scenario of one partner with dementia in the care home and the partner without dementia remaining in their own home. When one individual or both have

dementia the nature of the sexual relationship may change. This can prove to be difficult in different ways for both individuals.

Possible changes to a relationship when an individual has dementia

- Awkward sequencing of sexual activity
- Requests for activities not normally performed
- Lack of regard or consideration for the sexual satisfaction or feelings of the healthy partner

Also maybe additional problems of

- Loss of sexual interest
- Increased sexual demands
- Inadequate sexual advances by the individual with dementia
- Concerns over mental capacity

Source: *Sexuality and Dementia*, Dr Walter Pierre Bouman, May 2007.

To the outside world it may seem uncomfortable or odd at first sight for a sexual or intimate relationship to continue when one partner has dementia. However, many couples do wish to maintain some level of intimacy and any problems, such as those highlighted above, can be handled and successfully navigated within the relationship.

‘There are few reports of behaviours being characterised as bizarre or inappropriate expressed outside the marital relationship.’ (Bouman, 2007)

When partnerships have formed before entry to a care home, family and friends are often (though not always) supportive and expect the relationship to continue in some way. Nevertheless some care workers and relatives may be uncomfortable and reluctant to acknowledge or support the sexual aspect of their relationship. The relationship will also need to be monitored carefully to ensure the resident with dementia has the mental

capacity to consent to intimacy of a sexual nature. If this is not the case, then a range of factors including autonomy, capacity, competence and protection will need to be considered (see next section).

What is the role of the care home in supporting pre-existing relationships?

- Acceptance and acknowledgment that older people with dementia have a need for intimacy, love and sexual expression.
- Promoting a culture of acceptance, dignity and privacy for all residents and remembering not all relationships will be heterosexual.
- Education and awareness-raising for all care workers on the sexual and intimate needs of residents.
- Care home workers and managers should try to include, if possible and if volunteered, the social and sexual history of residents in care plans.
- Facilitating relationships by allowing regular visits either within the care home setting or outside.
- Promoting privacy for residents and space so couples can be together: a simple 'do not disturb' sign can help.
- Providing sexual advice, information and support for residents.
- Continued monitoring and assessment in terms of the resident's dementia and their mental capacity.
- Communication with the resident's partner and possibly their close family or friends.

Case studies

Sheila and Bill's story

Sheila lives in a care home and was diagnosed with dementia with Lewy bodies. Bill, her partner of 18 years, visits Sheila on a daily basis. The couple choose to spend time together in Sheila's room and were often disturbed unintentionally by staff, specifically housekeepers carrying out cleaning duties and delivering laundry. Staff wanted to ensure the couple were afforded undisturbed privacy and suggested a 'do not disturb' sign on Sheila's door. This was welcomed by Sheila and Bill, who now enjoy undisturbed quality time together.

The simple 'do not disturb' sign has since been adopted in many areas of the home and is proving to be very effective.

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Patricia and Elaine's story

Elaine and Patricia are partners who lived together as a couple for several years. Patricia, however, was diagnosed with Alzheimer's disease. Elaine managed to support Patricia at home for over a year, but when she suffered a stroke she felt she could no longer cope with the physical demands of her care. It was agreed by Patricia and Elaine that Patricia needed additional care and support and Patricia moved into a local care home.

Elaine visits Patricia on a regular basis. Patricia looks forward to spending time with Elaine when she visits; this is the time when Patricia appears most content. Patricia and Elaine sit and hold hands and spend time together in Patricia's room. However, Patricia's family are opposed to her relationship with Elaine and asked staff not to 'allow' Elaine to visit Patricia. The staff, as a result of their dementia training, were aware and supportive of the relationship and were very concerned about the attitude and response of the family.

The Manager talked to the family and then used the legal framework of the Mental Capacity Act to ensure Patricia had the capacity to make her own decisions. Taking into consideration Patricia's past history and with the input of staff in ensuring Patricia showed no signs of distress during visits, and speaking with Patricia, it was decided that Patricia was able to make the decision to continue in her loving relationship with Elaine. Following discussions and support from the dementia key contact the family choose not to visit at the same time as Elaine. Patricia and Elaine continue to have a loving, safe relationship.

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Norman and Marie's story

Norman was diagnosed with vascular dementia following a stroke. Marie had been Norman's constant support for four years prior to Norman moving into a care home. They had a very close, loving relationship and Norman would constantly ask when Marie was coming to visit, Norman appeared quite anxious when Marie was not around and this was often communicated through his behaviour. He would open doors 'looking' for Marie and approach female residents for a hug or try to hold their hand. Marie visited on a regular basis and Norman was always overjoyed to see her. They spent lots of time hugging each other and always held hands.

Norman's physical health began to deteriorate and Marie spent as much time with him as possible. She spoke with staff and said she would ideally like to spend a night with Norman. Staff spent time with Norman to ensure he would be happy for Marie to spend a night with him. He clearly communicated through body language and facial expression that he wanted Marie with him.

Staff organised for Marie to spend the night with Norman in their guest room. A small dining table was placed in the room to enable the couple to have a meal together; flowers were put in the room and music played to create a nice atmosphere. Norman was

taken to the guest room prior to Marie's arrival to see if he was happy with the situation; he pushed the two single beds together, sat at the dining table and refused to move until Marie arrived. Norman and Marie spent the night together and staff served breakfast to them both as agreed in 'their' room the following morning.

Two weeks later Norman died. At his funeral Marie said she would never forget the Manager and staff's kindness in enabling her and her husband to spend that precious night together.

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Forming new relationships

One of the developments which can cause most concern for care staff and often families and friends is when a new relationship forms in a care home. This may take the form of a relationship when there is one resident with dementia and one without dementia or two residents with differing degrees of dementia. Added to this, the resident with dementia may already have a partner who does not live in the care home.

When such a situation arises, it is important to remember that there is often no right response and each case must be assessed on an individual basis. Responses will also be determined to a large extent by the nature of the relationship. Cuddling and holding hands, for example, does not often provoke concern or a strong reaction from family members or care staff. However, when relationships appear to be more intimate and of a sexual nature, several issues emerge which may have to be addressed. These include autonomy, preservation of dignity, competence related to informed consent, privacy and protection from harm (Gordon, 2004).

Perhaps one of the hardest aspects when considering how to respond to residents with dementia and their involvement in a relationship is to understand how our own judgements and opinions may affect the decision-making process. It is important to

remember that people with dementia are capable of forming new intimate relationships. As long as the person with dementia is able to make decisions about their life, then their decisions should be respected. If the resident is not physically or mentally vulnerable as a result of the relationship, then ways to facilitate and support the relationship should be considered.

'It is often difficult to assess to what extent a resident has full mental capacity, partial capacity or limited capacity, thus it can be difficult to reach a consensus on an appropriate response.' (Kuhn, 2002)

'A resident may perform poorly on a mental status test but his or her preference for a special friend or lover may be quite evident.' (Kuhn, 2002)

So, as Kuhn rightly points out, there cannot be an 'all or nothing' approach to the resident's capacity to participate in sexually intimate relationships. While it is still necessary to consider the sexual needs of the resident, these needs must be balanced against a range of other factors and the potential risks involved. In the box opposite are some suggestions on how to consider and balance these competing demands.

Matters become complicated, however, when one or both of the residents with dementia may not have the 'mental capacity' to consent to sexual relations. Residents with dementia are open to abuse and in these instances it is essential to assess the 'mental capacity' of the individual, according to the legal definition of the Mental Capacity Act 2005 (see Policy Framework section for more details). If the resident is deemed not to have the capacity to consent to the sexual activity, the Mental Capacity Act does not provide any mechanism to allow people to make advance decisions or have decisions made on their behalf about sexual matters. Depending on the circumstances, therefore, the relationship and individual involved, could be in breach of the Sexual Offences Act 2003, which prohibits sexual activity with

someone with a mental disorder if they are unable to refuse or communicate their refusal. (for more details see, Bartlett, 2010). There is also a duty imposed on carers and/or staff to ensure that vulnerable people are safe in their care.

How to determine the capacity and risk to the individual

- To what extent are the residents involved capable of making their own decisions?
- Does the resident with dementia have the ability to recognise the person with whom they are having the relationship? Could he/she have mistaken, for example, said individual for their original partner?
- Is the resident with dementia capable of expressing their views and wishes within the relationship through either verbal or non-verbal communication?
- Can the residents involved understand what it means to be physically intimate?
- What is the resident's ability to avoid exploitation?
- What is the resident's ability to understand future risks?
- How may the resident be affected if they are ignored, rejected after intimacy or the relationship ends?

Questions based on the work of Lichtenberg (1997) and Lichtenberg and Strzepek (1990).

Wider considerations and ethics

- Is the behaviour in keeping with their past values, beliefs and/or religious views?
- If the behaviour is not in keeping, but the resident appears content and happy, to what extent should this matter (Kuhn, 2002)?
- To what extent do care providers have the 'right' to intervene in the sexual lives of people with dementia and what rights are denied when such interventions occur (Ward et al 2005)?
- To what extent should others be allowed to make decisions about the relationship of residents (Kuhn, 2002)?
- How do you balance the safety of the residents while also empowering them to live their lives?

Family matters

- Are family and friends aware of the new relationship?
- If there is a partner living outside of the care home, are they aware of the relationship and do you know how will this will make them feel?
- Does the family or partner feel comfortable in expressing their views about the relationship?
- To what extent should the views of family or friends be taken into consideration if they are unhappy with the relationship?

If there is any concern that the resident with dementia has been subject to sexual abuse, then immediate action needs to be taken. The resident must receive protection and support. Care workers should consult the care manager on duty at the time, remove the individual from any potential risk and liaise with the appropriate safeguarding or vulnerable adults team and authorities.

Remember, the very nature of the situation may raise some complicated ethical and legal issues and some personal confusion as to your own beliefs and values. Each situation must be considered on a case by case basis and will need to be monitored over time, given the progressive nature of dementia and the impact it has on cognitive function.

Case studies

Andrew and Jane's story

Andrew lived at the care home for three years. Jane came to the home two years ago. During this time Jane and Andrew developed a close relationship. Andrew had some symptoms of dementia although not diagnosed and Jane had been diagnosed with Alzheimer's disease about a year previously. As the relationship developed, the staff were aware that Jane and

Andrew talked about getting engaged and making it an extra-special occasion. They set a date and decided to get engaged on Valentine's Day. Unfortunately, Jane's family were very unhappy and did not support the decision. They told the staff at the home that the engagement should not be allowed to happen under any circumstances.

The manager at the home was aware of the Mental Capacity Act, sought additional advice from the dementia specialist key contact and they had many discussions with Andrew, Jane and the family. The manager with the dementia specialist key contact then used the legal framework to ensure that Andrew and Jane had the capacity to make this decision. The manager spoke to Jane on several occasions and at different times of the day. This was to make sure Jane wanted to continue the relationship with Andrew and to see if Jane understood the commitment she was making.

The manager and other professionals who were involved in Jane's care all agreed that Jane did have the capacity to make this decision. Jane and Andrew were engaged on Valentine's Day 2010.

Frank and Maggie's story

Frank had a diagnosis of vascular dementia and had been living in the care home for two years when Maggie arrived. Maggie had been diagnosed with Alzheimer's disease and after several years of living at home, supported by her family, it was decided she needed greater levels of care and support. Frank and Maggie started spending increasing amounts of time together at the home and it soon became clear to the staff and their families that they had formed a relationship of a sexual nature.

Both Frank's and Maggie's family objected to this relationship. Both individuals were widowed and it was felt by family members that the relationship was inappropriate. As a result, it was decided to assess Frank and Maggie according to the Mental Capacity

Act and It was agreed that they both had the capacity to make this decision for themselves and the relationship was a positive one. While both families were still unsure about it, they did accept Frank and Maggie's close relationship.

However, over the next year, Maggie's health declined. She had a serious fall and numerous other health problems. Frank's dementia had also become more severe and he lacked the capacity to understand just how ill Maggie was and wanted to continue the relationship as before. Maggie could not continue the relationship and was spending a lot of time in bed in her room, which unfortunately confused Frank further, as he kept trying to get into bed with her.

As both Maggie's and Frank's mental capacity was being closely monitored, it was decided that, according to the Mental Capacity Act, the sexual relationship should end. It was not in the best interests of Maggie for the relationship to continue and it was becoming clear that Frank was not sufficiently able to relate to Maggie's feelings or needs. To help ease this transition, as Maggie and Frank were still close, Frank was allowed to see Maggie when accompanied by a female member of staff.

Maggie died several months later and Frank would continue to visit her room despite her not being there. It was decided that Frank should attend the funeral and Frank was given extra support by the care staff to help him overcome this loss.

George, Anne and Veronica's story

George had a diagnosis of vascular dementia. Anne, his 35-year-old daughter, had supported him in the community for the past 15 years, since his wife died. Anne eventually, and reluctantly, saw that she could no longer cope with caring for her father in this way. George had the capacity to agree that it would be better if he lived in a care home. But everyone involved felt worried that the move to a group living situation would be a difficult transition, as

George was very much in control in his own home.

But within a month of moving into the care home George had struck up a non-sexual but close, caring relationship with Veronica, who had also been diagnosed with dementia. They clearly enjoyed each other's company sat together at mealtimes, and in the lounge, and sometimes held hands. George's depression lifted, his outlook brightened, and his behaviour changed. He was well liked by staff and residents.

At first, George and Veronica's close friendship was difficult for Anne to accept. She told a member of staff and felt she had given many years of her life to caring for her grieving and sick father. Now, in a very short time, it seemed to Anne that he had cast the memory of her mother aside and was happier than he had been for many years. Initially she felt confused and betrayed, but she talked with staff who had attended an advanced dementia training course. They encouraged her to see that both George and Veronica had the capacity to choose to have a close relationship, and that this was making them happy.

By talking to staff who from their dementia training and support felt confident in providing advice and spending time at the care home, Anne also came to see how she could now move on with her own life without feeling guilty about her father. Anne now attends a family-and-friends rolling programme of dementia education and support sessions.

Sinita and Dorothy's story

Sinita and Dorothy had lived at the home for over four years and during this time they had become very good friends. Both of them were diagnosed with vascular dementia and although there was evidence of deterioration they were managing by helping each other.

One day, Sinita was observed in the lounge by staff and visitors touching Dorothy's breasts in a sexual manner. Dorothy was

smiling at Sinita. Staff had attended dementia training that incorporated the Mental Capacity Act and therefore understood the importance of supporting the individual, assessing their capacity and acting within their best interests.

Staff approached the situation with care and caution, as they assessed the relationship over a period of time to make sure both women understood and consented to the new sexual aspect of their relationship. Staff also liaised with their families and friends to try to determine whether this new relationship was compatible with their previous sexual history and preferences. It was decided, after much consideration and liaison with the dementia specialist key contact, that the relationship was consensual and arrangements were made in the home to ensure Dorothy and Sinita could have some privacy.

However, some staff continued to find this relationship difficult. Additional training in sexuality and intimacy was offered to all the staff within the home. This helped the staff who had reservations about the relationship to understand their own feelings and enable them to be supportive of the relationship.

Jack's story

Jack came to live in the care home six months ago. Before then he had lived at home supported by his wife Sue. Jack settled quickly into his new home and staff were understanding and supportive of his needs. Sue maintained daily visits to Jack, but found it increasingly difficult when Jack developed a friendship with another female resident, Dorothy (who also had dementia). Jack would often spend time sitting with Dorothy holding hands, talking in the garden or lounge area. Sue found this very difficult to understand and cope with. Jack's closeness to Dorothy upset her and she felt unwanted. Consequently Sue reduced the frequency of her visits to Jack to just twice a week.

The care home manager noticed the reduced frequency of Sue's



Posed by models (www.istockphotos.com)

visits and asked her how she was feeling about the situation. Sue was visibly upset and expressed her feelings of rejection. She was distressed by Jack's growing affection for Dorothy and how he no longer seemed to recognise her or be interested in her visits. The care manager spent time with Sue listening to her concerns. She reassured Sue and suggested she speak to the dementia specialist key contact. Sue found this one-to-one support extremely helpful. Sue was keen to learn more about Jack's condition and was invited to attend the family-and-friends rolling programme of education and support sessions delivered at the home. Subsequently Sue started to feel more relaxed about Jack's friendship with Dorothy and has since increased the frequency of her visits to the care home.

Individual sexual behaviour and expression

This section will try to classify different types of sexual behaviour to aid our understanding, present suggestions on how to respond when challenging situations arise and provide some good-practice case studies.

As discussed, sexual expression for some people with dementia remains important. For some residents this may take the form of physical acts, such as masturbation or fondling, or it may be expressed in a simple desire to feel close to people in terms of wanting a hug or a kiss. However, sometimes a resident with dementia may exhibit their desires or feelings in the wrong place. This could take the form of masturbating in the lounge, for example, or trying to touch other residents or care staff in an inappropriate way against their wishes. As always, each case will be unique and certain types of sexual behaviour can be challenging to respond to.

What does the research say?

- Inappropriate sexual behaviour is not particularly common in people with dementia (Higgins et al, 2004).
- It is more likely to occur in the moderate to severe stages of most forms of dementia, though it is sometimes evident in residents with mild cognitive impairment (Alagiakrishnan, 2004).
- The reasons for sexual disinhibition or inappropriate behaviour in people with dementia remain unclear, but may include disease-related factors, social factors, psychological factors and certain drugs and alcohol (Series 2005).

- Research suggests that staff, residents and family often disagree on what is meant by appropriate or inappropriate behaviour (Gibson et al, 1999).
- Large variation in reported levels of sexual disinhibition both in the community and residential care ranging from 2 to 17 per cent (Series et al, 2005).
- Some studies have suggested there is equal frequency in inappropriate behaviour in men (8%) and women (7%) (Burns et al, 1990). Several other studies suggest much higher frequency in men, but this may be linked to subjective definitions and over-reporting of men to women.

How do we categorise sexual behaviour and how do we decide what is and what is not appropriate?

There are no hard and fast rules when it comes to assessing sexual behaviour and responses and there is no particular definition as to when behaviour becomes abnormal (Manchip and Menon, 2007).

What do we mean by behaviour of a sexual nature and how do we categorise it?

Verbal

- Sexualised comments to staff may include swearing.
- Sexualised comments to other residents; may include swearing.

Physical linked to self

- Masturbating in private.
- Masturbating in communal areas.
- Touching in private.
- Touching in communal areas.
- Undressing or disrobing/ exposing genital areas.
- Defecation or urination.

Physical linked to others

- Prolonged kissing and hugging that exceeds normal affection.
- Touching or grabbing personal parts of a member of staff's body.
- Touching or grabbing personal parts of a resident's body.
- Attempting intercourse or oral sex with member of staff.
- Attempting intercourse or oral sex with resident.
- Attempting sexual acts with objects.

Source: Framework based on Manchip and Menon (2007), content Manchip and Menon, Burns et al (1990), Devanand et al (1992), Miller et al (1995), Archibald (1998) Mayers (1995).

From the categories in the box, it does become easier to determine what may or may not constitute abnormal sexual behaviour. This is also sometimes referred to as 'sexual disinhibition', 'inappropriate behaviour', 'improper behaviour' or 'hypersexuality'. Such terms, though, are not always helpful, as what is inappropriate to one person may not be to another. Often the judgement made will be subjective and be based on our own attitudes, beliefs and values (Higgins et al, 2004). Responses will also be determined by the culture and ethos promoted within the care home and the individual circumstances involved. The frequency and location of the behaviour will also be important. As one care manager noted:

'One older gentleman with dementia often started masturbating in the lounge, admittedly shocking some of the other residents and staff. The thing is, you could not really call his behaviour inappropriate as he was doing what felt nice to him. The problem was [that] the location was completely inappropriate.'

Let's consider, for a moment, responses in care homes to older men with dementia who exhibit sexual behaviour, compared to women. Several studies have reported that this sort of behaviour exhibited by men is often reported as 'challenging' or

'inappropriate'. So at first sight it may appear that men are more predisposed towards this type of behaviour than women, or rather, is it the case that we are just more likely to notice it and then judge it to be inappropriate? In contrast, sexual expression by female residents is often overlooked or prompts a more protective response by care workers and families (see Ward et al, 2005). We also need to bear in mind the higher number of women both as residents and as care workers, both of which could have an impact on sexually based interactions (Ward et al, 2005).

Another reason why this is a problematic area for many is linked to the nature of dementia as a condition. Trying to form an assessment as to what extent an individual is aware or cognisant of his or her own behaviour can be extremely challenging (though this should not necessarily make a difference in terms of deciding how to respond to the situation).

There are no set guidelines on how to respond to situations of this nature in care homes at present in the UK. The suggestions below promote a person-centred, behavioural management approach, but will not be appropriate in all situations. A clear assessment of the resident's behaviour is needed. This could also be explored through dementia care mapping (see Kitwood and Bredin, 1992).

Behaviour of this nature is often best managed by non-pharmacological means. Currently there is no drug licensed in the UK for the treatment of sexual disinhibition (Series and Degano, 2005).

How should you respond at the time to behaviour of a sexual nature which you consider inappropriate in some way?

- Try to remain calm, try not to feel embarrassed or show shock.
- Remember to be respectful to the resident and try to preserve their dignity.
- Try to reassure other residents or families present that the resident means no harm.

- Try to remember that the resident with dementia may have no awareness that their behaviour is inappropriate or shocking in any way.
- Depending on the situation, if the behaviour is taking place in a communal area try to distract the resident and lead them away.
- Jokes, witty replies and humour can sometimes be used to respond to some forms of sexual behaviour (Bauer and Geront, 1999).
- If the resident is touching you in a way you do not like, it is acceptable to identify the behaviour and point out that it is unacceptable and you feel uncomfortable.
- Remind the resident who you are.

What should you consider after the event?

1. What form does the behaviour take?

- In what context?
- How frequently does it take place?
- Review the resident's behavioural history and current routine.
- Consider speaking to the resident's family, friends or partner to gain a greater understanding of their social and sexual history.

2. What factors may contribute to this? Could there be a social, environmental, medical or psychological cause?

- Has there been a change to the resident's routine or environment? For example, sometimes a lack of privacy can force patients to express sexual behaviour in an overt fashion (Manchip et al, 2007).
- Is it possible that the resident is misinterpreting the actions of, for example, the care worker or believes them to be someone else they know well or intimately?

- Have you checked the resident has no underlying medical condition which may be contributing to this behaviour? Or that their medication has been changed? For example, urinary or vulva/vaginal problems may lead to increased touching.
- Have you assessed the resident's mental wellbeing? Could they be depressed, manic or simply feeling lonely and looking for reassurance, comfort or touch?
- If the resident is trying to take their clothes off, is it because they are wearing an item of clothing that is irritating them?

3. Reflect on how you define and classify inappropriate behaviour

- Consider how you have formed this judgement and try to work out if the behaviour offends your attitudes, cultural beliefs or values. Or do you find the behaviour inappropriate because you feel it would be judged so by other staff members, residents or maybe the residents family?

4. Consider what risks are involved

- Does the resident pose a risk to other residents? A risk to themselves? Or to the wider residential community?
- Try to assess the awareness and understanding the resident has of their behaviour.
- Continue ongoing assessment of the resident's mental capacity.

5. Looking after yourself

- It is understandable that you may feel upset and/or angry and/or emotional if you have been subject to aggressive or inappropriate behaviour.
- Seek support and reassurance from your colleagues.
- Make sure you report and record any behaviour that may be inappropriate.

(Source: Series and Degano, 2005)

Case studies

Bill's story

Bill has dementia and has lived in the care home for three years. Staff have increasingly found the need to support and assist Bill with his personal care, such as washing and dressing. However, in recent months Bill's language and behaviour towards them have become overtly sexual and explicit. Such to the point he was reaching out and trying to grab hold of female staff when they tried to assist him.

The care manager was concerned that members of staff were becoming reluctant to support Bill and often scared to enter his room. There was not always a male member of staff available to support Bill. The care manager asked the dementia specialist key contact for help. She did not just want to assume that the home could no longer support Bill and was keen to understand what was behind his changed behaviour.

The dementia specialist spent time with staff and held discussion groups to help staff to identify possible reasons for Bill's responses and behaviour towards them. Staff spent time looking into Bill's life story and talking to his family to understand more about his background. They focused on their own approach to Bill and considered strategies that could help them support Bill, without aggravating his feelings and responses towards them. They also looked at ways to support Bill to feel occupied and involved him socially with other residents.

Bill is still living in the care home, with ongoing support from the dementia specialist and the care manager; staff are feeling more confident and better able to support Bill. Bill appears more content and is engaging with staff and residents. The dementia specialist continues to support the staff.

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Paula and David's story

Paula and David had been looking forward to enjoying their retirement together.

Then Paula was diagnosed with Alzheimer's disease. As her dementia progressed, she was admitted to a hospital ward before going to live in a care home. At first David visited her every day, then once a week, and then less often. It was clear that he found the changes in his wife difficult to cope with, despite support from staff. He said he had lost the woman he fell in love with. Paula found verbal communication very difficult and would approach all men in a sexual manner.

Paula would smile, hold hands, kiss and rub herself against any man who was near or approached her. Staff had attended dementia training but sought further advice from the dementia specialist key contact. Following visits, observations and discussion groups, the staff were encouraged to promote appropriate physical contact for Paula. An aromatherapist was booked to give Paula regular gentle hand and foot massages every week. Paula was also supported to become involved in a full program of activity that was meaningful and pleasurable for her. For life story work, it was identified that Paula enjoyed clay modelling, as she had been interested in pottery. She also enjoyed looking at fashion magazines and trying out make-up, as she had a keen fashion sense. She also enjoyed going out for long walks.

All these activities alleviated the situation. Paula was much happier and no longer seemed to need explicitly sexual contact when she was meaningfully occupied, and receiving the regular massage. The massage provided an alternative, appropriate, and pleasurable means of touch. But for David the situation remained difficult as he no longer found his wife desirable. He found it helpful to have the support of staff on his visits, and following support from the home he asked his GP to be referred for bereavement counselling to help him come to terms with the personal loss he felt.

Older people from the LGBT community

The onset of dementia means that private matters may suddenly become public. As this guide aims to explore the expression of sexuality in care homes, we need to remember that not all older people are the same and in future years there will be an increasing number of lesbian, gay, bisexual and transgender older people living in residential care.

The transition from living in their home to moving into residential care may be particularly challenging for this group of older people. Why? Because some older people from the LGBT community, may have spent a lifetime not disclosing their sexuality and have kept this aspect of their life private. Suddenly finding themselves in a more public setting, they may be uncertain and afraid of 'coming out' either for the first time or yet again. It could also be the case that while some residents may be perceived to be heterosexual and may have hidden their homosexual tendencies throughout or for periods of their life, as social controls weaken as a result of dementia, their homosexual feelings may emerge. So it is worth remembering that while understanding the sexuality of residents based on previous life practice is important, it is also wise to observe the sexuality people exhibit as they age.

Despite some good practice in the field, we know older people from the LGBT community are fearful of the attitudes and potential prejudice of staff, other residents and their family. Sometimes any sexual deviation from what is considered the 'norm' gives rise to concern in dementia care home settings (Archibald, 1998). As a result, some of these older people choose not to disclose

their sexual identity and assume heterosexual behaviour within the home, having a detrimental effect on their wellbeing and quality of life. Some older people from the LGBT community are so fearful of residential care they turn to other social care provision, for example choosing to stay in their own home or using direct payments, thereby avoiding any potential embarrassment, ignorance or prejudice (Commission from Social Care Inspection, 2008).

'There was one lady in the care home who did not have a partner, but we could tell she preferred women to men. Sometimes the care staff did find her trying to touch other women, which for some reason either provoked complete outrage or extreme amusement amongst the staff. Neither response was appropriate and it just served to remind me how much work we still needed to do on this issue.'

Care home manager

We need our care homes to be accepting of the growing diversity within our ageing population and respond accordingly. What do we need to know?

- The need for intimacy by lesbian, gay, bisexual and transgender older people must be acknowledged and supported in residential care (Ward, Vass, Aggarwal, Garfield and Cybyk, 2005).
- On entry to a residential care home, this group may need particular support and reassurance. This group is more likely to have lived alone and so decisions regarding finances, for example, may bring staff immediately into contact with their partners.
- An understanding and acknowledgement that some residents, their families and some members of staff may

be embarrassed, ignorant, nervous or prejudiced against older people from the LGBT community. This could be linked, for example, to cultural norms or religious beliefs. Awareness-raising and education are essential to prevent possible discrimination or prejudice and challenge stereotypes.

- There needs to be equality training for all care home managers and senior staff to familiarise themselves with the experiences and possible problems facing older people from the LGBT community. They should then review policies, procedures and forms to ensure an inclusive and open environment for the full spectrum of sexualities (Commission for Social Care Inspection, 2008).

Safe sex

When we talk about safe sex, we frequently think about younger people or adults and rarely do we consider older people. Age is not a barrier to sexually transmitted diseases, including HIV (human immunodeficiency virus) that can lead to AIDS (acquired immunodeficiency syndrome). Older people who are sexually active and are embarking on a new relationship are at risk and need to practise safe sex.

Prevention is the key and it is important within the care home that advice, support and resources are made available to older people, who are wishing or are involved in a sexual relationship. Awareness among certain groups of older people about the need for safe sex may be low, so it is crucial that older people have access to GPs and/or nurses to discuss or share any concerns.

Good hygiene is also imperative to avoid the risk of infection for both partners. Older people with dementia may need additional support in this area.

How to develop good practice and policy on dementia, sexual expression, behaviour and intimacy

The care home environment

- Encourage residents to cultivate friendships and interact with each other, while continuing to monitor in order to ensure that this is in the best interests of those involved.
- Promote opportunities for residents to spend time together, if the relationship is considered to be in the best interests of both parties.
- Promote privacy and dignity within the home.
- Provide an environment where residents have things to touch or stroke: this could include pet therapy or providing cuddly animals. Such devices have been shown to relax some residents and foster wellbeing.
- Encourage residents to feel good about themselves and maintain their sexual identity. This could be through providing services such as hairdressing and beauty treatment or by making sure residents wear clothes they like and feel comfortable in.
- Promote a safe and secure environment, in terms of safe sex.

Support and training for the care workforce

Have your care workforce and other members of staff received training in dementia awareness and care?

- Has this training involved working on strategies and tips to respond, and also awareness training and exploration of attitudes, cultural values and beliefs?
- Have you considered the types of support your care workers may need and how to foster an environment that encourages staff to share their problems and receive support?
- How do you address the anxieties and embarrassment of your care staff in this respect?

Policies and practice

- Have you reviewed your risk assessment policy with particular reference to the Mental Capacity Act 2005?
 - What guidance or policies are in place with regard to responding to the intimate and sexual needs of residents with dementia?
 - Were or have these been drawn up in consultation with the staff?
 - Have you considered creating working definitions of key concepts in terms of (see Christie et al, 2002):
 - sexual intimacy and sexual behaviour
 - sexual behaviours to be interpreted as normal
 - sexual behaviours requiring assessment
 - sexual behaviour of concern/risk (Sloane 1993)
- Source: *Intimacy, Sexuality and Sexual Behaviour in Dementia*, Christie et al.
- Have you looked at good practice or policies of other care homes?
 - Do you feel fully confident as a care home manager and are you aware of the key issues involved?

- Do you consider a person's social and sexual history?
- How do you record and monitor situations of a sexual or intimate nature? Is there an adequate paper trail which you use to record the decisions made as well as the outcomes?
- What are the values you promote in your care home? Do you advocate a person-centred approach to dementia care?
- How do you assess and monitor the changing physical, mental and spiritual needs of your resident?
- What forum of support do you provide for your staff so they can discuss any problems or issues?
- Evaluate and monitor.

For care workers

- Confront your own attitudes and behaviour towards older people and sex generally.
- Talk to colleagues.
- Look after yourself.
- Remember there are no set answers.



Posed by models (www.istockphoto.com)

Top ten key points

- 1 Some residents with dementia will have sexual or sensual needs
- 2 Affection and intimacy contribute to overall health and wellbeing for residents
- 3 Some residents with dementia will have the capacity to make decisions about their needs
- 4 If an individual in care is not competent to decide, the home has a duty of care towards the individual to ensure they are protected from harm
- 5 There are no hard and fast rules. Assess each situation on an individual basis
- 6 Remember not everyone with dementia is heterosexual
- 7 Inappropriate sexual behaviour is not particularly common in dementia
- 8 Confront your own attitudes and behaviour towards older people and sex generally
- 9 Communicate – look at how you can improve communication with your colleagues, managers, residents and carers on this subject
- 10 Look after yourself and remember your own needs as a care professional

Test yourself – a quick quiz

Look at the questions below and note down if you **agree strongly, agree, disagree, disagree strongly, do not know** or have **no opinion**, on the following questions.

We suggest you respond to these questions individually and then open up and discuss some of the answers in a group environment. Remember there are no right or wrong answers.

1. Do you think the expression of sexuality is important for older people?
 st.agree agree disagree st.disagree do not know no opinion
2. Do you believe there are positive links between health, wellbeing and sexual expression for older people?
 st.agree agree disagree st.disagree do not know no opinion
3. Would you agree with the statement that most people as they age become less interested in sex or sexual expression?
 st.agree agree disagree st.disagree do not know no opinion
4. Do you think residents should be allowed to express their sexual needs in care homes?
 st.agree agree disagree st.disagree do not know no opinion
5. Do you feel residents with dementia, compared to a resident who has full cognitive capacity, should not be encouraged or facilitated to have a sexual relationship?
 st.agree agree disagree st.disagree do not know no opinion
6. As far as you are concerned, should care homes play a role in allowing residents to express their sexuality?
 st.agree agree disagree st.disagree do not know no opinion

7. Do you feel your role as a care worker is more about looking after the residents than encouraging or facilitating their sexual needs or desires?
 st.agree agree disagree st.disagree do not know no opinion
8. Do you feel confident in applying the Mental Capacity Act and 'best-interest' decision-making as it relates to sexual expression for residents?
 st.agree agree disagree st.disagree do not know no opinion
9. Do you see sexual expression as important for people with dementia, but lack the time in your day-to-day working routine to respond?
 st.agree agree disagree st.disagree do not know no opinion
10. Do you see sexual expression as important for people with dementia, but lack the confidence or support in responding to situations of a sexual nature when they arise?
 st.agree agree disagree st.disagree do not know no opinion
11. Do you see sexual expression as important for people with dementia, but feel it contradicts or conflicts with your own social, cultural or religious beliefs, values or norms?
 st.agree agree disagree st.disagree do not know no opinion
12. Do you see sexual expression as important for people with dementia, but are worried about the response of the partners or relatives of residents?
 st.agree agree disagree st.disagree do not know no opinion

It is hoped that by exploring your responses as individuals and as a group you will learn more about yourself as care professionals and be able to identify areas in which you may need more support or training.

Policy framework for dementia, sexuality, intimacy and sexual behaviour in care homes

Department of Health, Living Well With Dementia: A National Dementia Strategy (2009)

The first ever National Dementia Strategy set out a five-year strategic framework to improve the lives of people with dementia, their carers and families. The aim was to improve dementia services in three key areas: improved awareness, earlier diagnosis and intervention and a higher quality of care.

Objective 11: *'Living well with dementia in care homes. Improved quality of care for people with dementia in care homes through the development of explicit leadership for dementia care within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and thorough inspection regimes.'*

Objective 13: *'An informed and effective workforce for people with dementia.'*

To find out more about the key objectives of the Strategy and the implementation plan, visit:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

The Health and Social Care Act (2008) (Regulated Activities) Regulations (2010)

The essential standards of quality and safety for care homes consist of 28 regulations (and associated outcomes) that are set out in two pieces of legislation: the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009.

There are identified outcomes in six key areas: user involvement and information, personalised care, safeguarding, staff suitability, quality and management, and management suitability.

The care home must make suitable arrangements to ensure the dignity, privacy and independence of service users; and that service users are enabled to make, or participate in making, decisions relating to their care or treatment. (17, 1a & b) and encourage service users, or those acting on their behalf, to understand the care or treatment choices available to the service user, and discuss with an appropriate health care professional, or other appropriate person, the balance of risks and benefits involved in any particular course of care or treatment, and express their views as to what is important to them in relation to the care or treatment. (17, 2 c)

The care home must also must make suitable arrangements to ensure that service users are safeguarded against the risk of abuse, this includes sexual abuse. (11,1)

To find our more, visit: <http://www.legislation.gov.uk/ukdsi/2010/9780111491942/contents>

National Institute for Clinical Excellence/Social Care Institute for Excellence Clinical Guidance on Dementia, Developed by the National Collaborating Centre for Mental Health (2007)

These comprehensive guidelines were devised to offer advice on supporting people with dementia and their carers in health

and social care. Person-centred care, non-pharmacological and pharmacological interventions, risk, abuse, neglect and a section on the impact of dementia on sexual relations (Chapter 3.7.2) are all included.

To find out more about the NICE/SCIE guidelines, visit: <http://www.nice.org.uk/nicemedia/pdf/CG42Dementiafinal.pdf>

Mental Capacity Act 2005/Code of Practice

The Mental Capacity Act applies to all decisions taken on behalf of people who permanently or temporarily lack capacity, including decisions relating to medical treatment. The Act is designed to protect and restore power to vulnerable people who may lack capacity and therefore are unable to make all or some decisions for themselves. The Act applies to England and Wales.

There is also a code which explains how the Mental Capacity act works on a day-to-day basis and provides guidance to those working on the front line with people who may lack capacity.

A person is defined according to the Act, as being unable to make decisions for themselves if they are not able to undertake at least one of the following: understand information given to them, retain that information long enough to be able to make a decision, weigh up the information available to make a decision, communicate their decision by any possible means (Alzheimer's Society, 2010).

The Act encompasses five main principles:

- Adults must be assumed to have capacity to make decisions for themselves unless proved otherwise.
- Individuals must be given all available support before it is concluded that they cannot make decisions for themselves.
- Individuals must retain the right to make what might be seen as eccentric or unusual decisions.
- Anything done for or on behalf of individuals without

capacity must be in their best interests.

- Anything done for or on behalf of individuals without capacity should restrict their rights and basic freedoms as little as possible. (NICE Clinical Guidance, 2006)

The Mental Capacity Act 2005 created a new type of power of attorney known as a lasting power of attorney (LPA). LPAs replaced enduring power of attorney (EPA) in 2007, when the Mental Capacity Act came into force.

To find out more about the Mental Capacity Act and the Code of Practice, visit:

<http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>

http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1

To find some useful summaries go to:

NICE Guidance: <http://www.nice.org.uk/nicemedia/pdf/CG042quickrefguide.pdf>

SCIE Guidance: <http://www.scie.org.uk/publications/guides/guide03/process/capacity.asp>

Alzheimer's Society: http://alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200137&documentID=354&pageNumber=1

Department of Health, National Service Framework for Older People (2001)

Chapter 2, Standard 7, looks at the mental health of older people and includes a section on dementia. It includes a recommendation that the NHS and local councils should review arrangements for health promotion, early detection and diagnosis, assessment, care and treatment-planning and access to specialist services for people with dementia.

To find out more about the Framework and dementia, visit:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4901983

Department of Health, No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse (March 2000)

This gives guidance to local agencies who have a responsibility to investigate and take action when a vulnerable adult is believed to be suffering abuse. It offers a structure and content for the development of local inter-agency policies, procedures and joint protocols which will draw on good practice nationally and locally.

Section 3.7: '*Residential care homes are required under the Registered Homes Act 1984 (as amended in 1991) "to notify the Registration Authority not later than 24 hours from the time of its occurrence...of any event in the home which affects the well-being of any resident" and specifically of any serious injury to any person residing in the home (Regulation 14(1)(b)) and any event in the home which affects the well-being of any resident (Regulation (1)(d)).*'

Section 6.10: '*The communication needs of victims including people with sensory impairments, learning disabilities, dementia and whose first language is not English must be taken into account.*'

Section 7.5: '*Provider agencies will produce for their staff a set of internal guidelines which relate clearly to the multi-agency policy and which set out the responsibilities of all staff to operate within it. This will include guidance on identifying vulnerable adults who are particularly at risk, recognising risks from different sources and in different situations and*

recognising abusive behaviour from other service users, colleagues and family members, routes for making a referral and channels of communications within and beyond the agency, assurances of protection for whistle blowers, working with best practice as specified in contracts, working within and co-operating with regulatory mechanisms and working within agreed operational guidelines to maintain best practice in relation to challenging behaviour, personal and intimate care, control and restraint, sexuality, medication, handling of user's money and risk assessment and management.'

To find out more about the guidance, visit:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4074540.pdf

Department of Health, The Use of Antipsychotic Medication for People with Dementia: Time for Action. A Report for the Minister of State for Care Services by Professor Sube Banerjee (November 2009)

This independent clinical review examines the use of anti-psychotic drugs for people with dementia in recognition of widespread concern about the over-prescription of anti-psychotic drugs and as part of the priority being given to improving care for people with dementia.

Recommendation 7: 'There is a need to develop a curriculum for the development of appropriate skills for care home staff in the non-pharmacological treatment of behavioural disorder in dementia, including the deployment of specific therapies with positive impact. Senior staff in care homes should have these skills and the ability to transfer them to other staff members in care homes. A national vocational qualification in dementia care should be developed for those working with people with dementia.'

To find out more about the review, visit:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf

Department of Health, End of Life Care Strategy (July 2008)

This report from the Department of Health aims to provide people approaching the end of life with more choice about where they would like to live and die.

To find out more about the review, visit:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

Department of Health, Working to Put People First: The Strategy for the Adult Social Care Workforce in England (April 2009)

This report from the Department of Health outlines the workforce implications of the Putting People First programme and provides a high-level framework to support the transformation of the adult social care workforce.

To find out more about the review, visit:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098494.pdf

Resources and references

Academic articles on dementia and sexuality

Archibald C (1994) Never too late to fall in love. *Journal of Dementia Care*. 2, 5, 20–21.

Archibald C (1998) Sexuality, dementia and residential care: managers' report and response.

Health and Social Care in the Community. 6, 95–101.

Archibald C (2002) Sexuality and dementia in residential care – whose responsibility? *Sexual and Relationship Therapy*. 17, 3, 301–309.

Bartlett, P (2010) Sex, Dementia, Capacity and Care Homes. *Liverpool Law Rev*. 31:137–154.

Bauer M and Geront M (1999) The use of humour in addressing the sexuality of elderly nursing home residents. *Sexuality and Disability*. 17, 2, 147–55.

Bouman WP (2007) Sexuality and Dementia. *Geriatric Medicine*. 35, 5, 35–41.

Burns A, Jacoby R and Levy R (1990) Psychiatric phenomena in Alzheimer's disease. I: Disorders of thought content. *British Journal of Psychiatry*. 157, 72–6.

Devanand DP, Brockington CD, Moody BJ, Brown RP, Mayeux R, Endicott J and Sakeim H (1992) Behavioral syndromes in Alzheimer's disease. *International Psychogeriatrics*. 4, 161–84.

Gibson M, Bol N, Woodbury M, Beaton C, Corey J (1999) Comparison of caregivers', residents', and community-dwelling spouses' opinions about expressing sexuality in an institutional setting. *Journal of Gerontological Nursing*. 25, 4, 30–39.

Gordon M, Sokolowski M (2004) Sexuality in long-term care. *Annals of Long-term Care*. 11, 2, 53–9.

Hellen CR (1995) Intimacy: nursing home resident issues and staff training. *American Journal of Alzheimer's Disease*, 11, 2, 53–9.

Heymanson C (2003) Sexuality and intimacy in care homes. *Journal of Dementia Care*. 11, 5, 10–11.

Janes E, Shirley L (2008) Acknowledging the man, not the behaviour. *Journal of Dementia Care*. 16, 1, 20–24.

Kitwood T and Bredin K (1992) Towards a theory of dementia care: personhood and well-being. *Ageing and Society*. 12, 269–87.

Kuhn D (2002) Intimacy, sexuality and residents with dementia. *Alzheimer's Care Quarterly*. 3, 2, 165–76.

De Medeiros K, Rosenberg PB, Baker AS, Onyike CH (2008) Improper sexual behaviors in elders with dementia living in residential care. *Dementia and Geriatric Cognitive Disorders*. 24, 4, 370–77.

Kamel HK, Hajjar RR (2003) Sexuality in the nursing home, Part 1: Attitudes and barriers to sexual expression, *Journal of the American Medical Directors*. 5, 2, 42–7.

Kamel HK, Hajjar RR (2003) Sexuality in the nursing home, Part 2: Managing abnormal behavior – legal and ethical issues. *Journal of the American Medical Directors*, 4,4, 203–6.

Mayers KS (1998) Sexuality and the demented patient. *Sexuality and Disability*. 16, 3, 219–25.

Rheume C, Mitty E (2008) Sexuality and intimacy in older adults. *Geriatric Nursing*. 29, 5, 342–9.

Sloane PD (1993) Sexual behaviour in residents with dementia. *Contemporary Long-term Care*. 16, 10, 66–8.

Walker B, Harrington D (2002) Effects of staff training on staff knowledge and attitudes about sexuality. *Educational*

Gerontology. 28, 8, 639–54.

Wallace M (2003) Sexuality and Ageing in Long-term Care. *Annals of Long-term Care*. 11, 2, 53–9.

Ward R, Vass A, Aggarwal, Gartfield C, Cybyk B (2005) A kiss is still a kiss? *The Construction of Sexuality in Dementia Care*. *Dementia*. 4, 1, 49–72.

Legal and ethical considerations of cognitive impairment and sexual expression in the long-term care setting (2001). *Canadian Nursing Home*, 12, 3, 13–14.

Academic articles focused on sexual behaviour

Alagiakrishnan K, Lim D, Brahim A et al. (2005) Sexually inappropriate behaviour in demented elderly people. *Postgraduate Medical Journal*. 81, 957, 463–6.

Black B, Muralee S, Tampi R (2005) Inappropriate sexual behaviors in dementia. *Journal of Geriatric Psychiatry and Neurology*. 18, 3, 155–62.

Higgins A, Barker P, Begley C (2004) Hypersexuality and dementia: dealing with inappropriate sexual expression. *British Journal of Nursing*. 13, 22, 1330–34.

Ketti P (2008) Inappropriate sexual behaviour in long-term

care. *Annals of Long-term Care*. 16, 12, 29–35.

Manchip S, Menon VB (2007) Sexual disinhibition in Alzheimer's disease. *Geriatric Medicine*. 37, 9, 51–6.

Nagaratnam N, Gayagay G Jr (2002) Hypersexuality in nursing care facilities – a descriptive study. *Archives of Gerontology and Geriatrics*. 35, 3, 195–203.

Prakash R, Pathak A, Munda S, Bagati D (2009) Quetiapine effective in treatment of inappropriate sexual behavior of Lewy body disease with predominant frontal lobe signs. *American Journal of Alzheimer's Disease and Other Dementias*. 24, 2, 136–40.

Series H, Degano P (2005) Hypersexuality in dementia. *Advances in Psychiatric Treatment*. 11, 6, 424–31.

Stokes, G (2000) *Challenging behaviour in dementia. A person-centred approach*. Speechmark, Bicester. 112 – 114, 190 – 193.

Stokes, G (2008) *Still the Music Plays: Stories of People with Dementia*. Hawker Publications, London. Chapters 6 and 22 .

Tsai SJ, Hwang JP, Yang CH, Liu KM, Lirng JF (1999) Inappropriate sexual behaviors in dementia: a preliminary report. *Alzheimer Disease and Associate*

Disorders. 13, 1, 60–62.

Wallace M, Safer M (2009) Hypersexuality among cognitively impaired older adults. *Geriatric Nursing*. 30, 4, 230–37.

Wallace M, Safer M (2009) Hypersexuality among cognitively impaired older adults. *Geriatric Nursing*. 30, 4, 230–37.

Reports

Department of Health (2003) *Care Homes for Older People: National Minimum Standards and the Care Homes Regulations* (3rd edition). The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4135403.pdf

Department of Health (2008) *End-of-life Care Strategy*. The Stationery Office, London. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Department of Health (2009) *Living Well with Dementia: a National Dementia Strategy*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf

Department of Health (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf

Department of Health (2001) *National Service Framework for Older People*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4071283.pdf

Department of Health (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4074540.pdf

Department of Health (2009) *The Use of Antipsychotic Medication for People with Dementia: time for action. A report for the Minister of State for Care Services by Professor Sube Banerjee*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf

Department of Health (2009) *Working to Put People First: the Strategy for the Adult Social Care Workforce in England*. The Stationery Office, London. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098494.pdf

Mental Capacity Act 2005, The National Archives, <http://www.legislation.gov.uk/ukpga/2005/9/contents>

Publications

Alzheimer's Society (2007) *Home from Home: a report highlighting opportunities for improving standards of dementia care in care homes*. AS, London. http://alzheimers.org.uk/site/scripts/download_info.php?fileID=270

Commission for Social Care Inspection (2008) *See Me, Not Just the Dementia: understanding people's experiences of leaving in a care home*. CSCI, London. http://www.cqc.org.uk/_db/_documents/Dementia%20Report-web.pdf

Committee of Public Accounts (2008) *Improving Services and Support for People with Dementia*. The Stationery Office, London. <http://www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/228.pdf>

Crown Prosecution Service Guidance (2003) *Sexual Offences*

Act. <http://www.legislation.gov.uk/ukpga/2003/42/contents>
Accessed 6th June 2011

Heath H, Sturdy D (2009) *Living Well with Dementia in a Care Home: a guide to implementing the National Dementia Strategy*. RCN Publishing Ltd. Published with Nursing Older People, *Mental Health Nursing*, *Caring Times* and *Journal of Dementia Care*.

Help the Aged (2007) *My Home Life: quality of life in care homes*. Help the Aged, London. http://myhomelifemovement.org/downloads/mhl_report.pdf

National Audit Office (2007) *Improving Services and Support for People with Dementia*. NAO, London. http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx

National Council for Palliative Care (2007) *Building on Firm Foundations: improving end-of-life in care homes. Examples of good practice*. National Council for Palliative Care, London. <http://www.ncpc.org.uk/download/publications/BuildingOnFirmFoundations.pdf>

National Institute for Clinical Excellence/Social Care Institute for Excellence (2007) *Clinical*

Guidance on Dementia. Developed by the National Collaborating Centre for Mental Health

<http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf>

Stokes, G (2000) *Challenging Behaviour in Dementia: a person-centred approach*. Speechmark, Bicester. 112–14, 190–93

Stokes, G (2008) *And Still the Music Plays: stories of people with dementia*. Hawker Publications, London. Chapters 6 and 22.

Websites

DeMarco, B, 2011. *Alzheimer's Reading Room*. [online] Available at: < <http://www.alzheimersreadingroom.com/2009/09/dementia-and-eight-types-of-dementia.html> > [Accessed 1st June 2011].