

# The expression of sexuality in dementia

People with dementia, just like other people, often have sexual needs. Sexuality contributes to a person's identity, and helping people to hold onto a sense of their own identity is fundamental to person-centred dementia care. For many people with dementia, maintaining or developing a sexual relationship can enhance wellbeing.

There is sometimes a fine line between appropriate and inappropriate sexual behaviour, which often depends on the values of the staff and relatives of the patient concerned.

## **Walter Bouman (2008)**

But problems can arise in relation to sexual expression and behaviour. If this is the case, identifying the nature of the problem – and indeed establishing whether there really is a problem at all – is the important starting point in deciding what to do for the best.

## What is the problem?

Sometimes, problems with the sexual expression of a person with dementia relate to other people's prejudices, preconceptions or misunderstandings. We need to be careful that we are not imposing our own assumptions onto the person with dementia. For example, many younger people believe that older people no longer have sexual needs, and therefore they assume that sexual expression by an older person is abnormal. This is not the case. Many older people are sexually active, and if an older person doesn't have an active sex life, it's more likely to be because of the lack of a partner or physical health problems than simply old age.

It is also important that we do not judge the appropriateness of a person's behaviour according to our personal preferences or standards. For example, our own religious view may be that homosexuality is 'wrong', but we cannot let this personal viewpoint lead us into condemning a person's natural sexual preferences as 'inappropriate'. Sadly, many older lesbians and gay men have had experiences of their closest relationships being ignored or even denied, so it is particularly important that we are open-minded and inclusive (see Knocker, 2006).

Sometimes a person with dementia will have genuine problems with sexual expression, caused by the dementia. For example, the person may have lost their ability to judge what is appropriate and what isn't, and as a result they may act on their sexual desires without regard for where they are or who they are with.

## How staff can help

Staff need to respond with sensitivity and empathy to the sexual behaviour of people with dementia, respecting people's feelings and their dignity. For example, if someone wishes to fulfil their own sexual needs by masturbating, it is very important to give them privacy.

Staff may have a key role to play in assisting people with dementia to express their sexuality. In particular, staff should be aware that they need to compensate for difficulties that have arisen due to symptoms of the dementia.

For example: if a person exposes themselves or begins to masturbate in the lounge of their care home, a staff member should discreetly advise the person to go to their bedroom, and guide them there if necessary. If a person mistakes another member of their day centre for their spouse, staff need to gently remind them who the person is and let them know when they will be seeing their husband or wife. If a person has misunderstood the situation when a home carer is helping them with intimate personal care, and believes that they are having a sexual encounter, the home carer needs to calmly explain the situation to the person and be aware that this person may need frequent reminders during personal care of exactly what's happening.

## Could there be other reasons for sexual behaviour?

Sexual expression from a person with dementia may be a straightforward expression of sexual needs, but there are many other possible reasons for behaviour that seems sexual. For example:

- a person might be expressing a need for closeness and comfort
- a person might be indicating that they feel bored or physically restless
- a person who seems to be exposing themselves might be indicating a need to go to the toilet or that they are too hot.

Identifying needs that the person is communicating through apparently sexual behaviour is very important, because we may be able to meet many of these needs – for example by helping a restless person get some physical exercise or by providing the comfort that the person is missing and needs.

## Capacity and consent in a sexual relationship

Sometimes when a person with dementia is sexually active, there are concerns about whether the person has the mental capacity to consent. This may be a concern both in existing relationships and in new relationships. All health and social care staff have a vital role to play in protecting vulnerable people from abuse and exploitation.

However, it is essential to be aware that the first statutory principle of the Mental Capacity Act 2005 is that 'a person must be assumed to have capacity unless it is established that he lacks capacity'. A diagnosis of dementia alone does not automatically mean that a person lacks capacity to consent to sex.

The Mental Capacity Act also tells us that a person must be given help with decision-making. This could involve developing some awareness, if possible, of a person's past sexual preferences and habits and reminding them of wishes they have communicated previously. It also needs to be recognised that consent to sex will often be communicated non-verbally rather than verbally. For more on this, see the **Dementia and decision-making** section.

If somebody does have the capacity to consent to engage in a sexual relationship with another consenting adult, then they have the right to do so regardless of whether other people approve and their privacy must be respected.

## Talking about sex

It is important to be open and willing to talk to people with dementia and/or their spouses or partners about sexual matters, particularly if they have concerns they wish to share. Talking to someone who is prepared to listen and be non-judgemental can be of great help.

Sometimes, if we have concerns about a person's sexual behaviour or their ability to avoid exploitation, we may need to engage in a multidisciplinary discussion with other professionals and carers who are involved in the person's welfare. But it is also important to be very mindful of confidentiality, and ensure that information about a person's sexual behaviour is shared strictly on a need-to-know basis.

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