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Information Sheet

Alzheimer Scotland
Action on Dementia

Sexuality & dementia

Introduction

Our sexuality, and how we choose to express it, tends to be something we keep private; discussing our needs, desires and feelings can be hard even between partners in long-standing relationships, never mind with health or social care professionals or friends and relatives.

The media tends to portray sex as being the prerogative of the young and beautiful and the notion of older people still having an active sex life as being unusual or a bit of a joke. But people continue to want and enjoy an active sex life at any age. The frequency of sexuality activity may (or may not) change and we may slow down a bit or be unable to be quite as physical as in our youth, but that doesn't mean we lose the need to feel intimate with a partner.

However, dementia does have an impact on all aspects of life and relationships, including sexuality and intimacy.

As dementia progresses, needs change: existing relationships may have to adapt, new relationships may form, desires may fluctuate. What does not change is the right of every adult to be sexually alive should they wish to be so, regardless of age, ability or sexual preference. Sexuality is a basic need which people with dementia and their carers should be able to express without fear of disapproval.

This information sheet considers the situation of a person with dementia living in his or her own home rather than in a formal care setting; however, staff in hospitals and care homes may also find it useful.

Existing relationships

All relationships change with time, but dementia brings increased physical and emotional dependency between partners which can have a massive impact on even the strongest relationship.

Dementia presents and progresses in different ways and at different rates in each individual. As the ability to cope with ordinary life is gradually impaired, changes in personality, presentation and behaviour (including sexual behaviour) may become more obvious.

Loss of memory, declining physical health, inability to concentrate and growing confusion all lead to greater dependency on carers.

Inevitably this impacts on relationships and affects the way in which partners relate to each other, both physically and emotionally.

For some people with dementia, being provided with intimate personal care by a loved one can be a positive emotional experience. For others, it represents a loss of dignity and can have a negative impact on how they feel about a sexual partner and about themselves.

For a carer, the emotional effect of a partner's increased dependency and the need to provide physical care might change their sexual feelings towards their partner. Some carers may simply be too tired for sex or too emotionally drained to give anything towards the sexual aspects of their relationship.

There are no easy solutions to coping with the ongoing changes in relationships. However, understanding that these changes are experienced by many people, and having some insight into their causes, can help.

Seeing beyond dementia

Sometimes, what appear to be personality changes in a person with dementia are caused by sheer boredom, frustration at a misunderstood situation, unfamiliar surroundings or tasks which have become too difficult. Depression can be an underlying cause of personality changes in people with dementia but it can be successfully treated. Carers too can become overwhelmed, frustrated, depressed, anxious and stressed - emotions which their partner may sense and in turn be affected by.

It is important for many couples to have a means of airing emotional issues affecting their relationship. This might be a friend, a support group, a helpline, a confidential internet chat-line, or a counsellor. Supportive family and friends are often vital both to the person with dementia and his or her carer.

Support groups for people with early stage dementia and for carers are an excellent way for some people to exchange feelings, experiences and frustrations. Other coping mechanisms that people have found useful include planning positive time apart to relax and build-up self-esteem. Some people are able to retain their sense of self by channelling energy into creative projects like writing poetry, listening to music, gardening, painting or keeping a journal.

If time apart is difficult to arrange or is not wanted, couples can focus on the positive aspects of their relationship by engaging in activities they still enjoy doing together. For example, putting together albums of photos and souvenirs which prompt positive reflections of past and present events, taking short trips to places and people they like visiting, dancing to favourite music, working together to complete simple household projects like baking or gardening.

Redefining sexual intimacy

Redefining sexual intimacy is an enormous challenge, especially as the needs of both partners must be considered. A person with dementia may experience a loss of sexual manners and appear to be less thoughtful than they once were. A partner can address this by taking a more active role in finding a way to make sex pleasurable for both.

Although a person with dementia may forget how they used to please their partner and themselves during sex, what they will not lose is the need for intimacy and touch.

For both partners, feelings of guilt, despair, resentment, anger, worry and fear for the future can interfere with their ability to sustain a close intimate relationship. Therefore, communication between partners is vital – sharing feelings and thoughts is a far more positive response to stress than nursing anxieties and grievances.

Increased interest in sex

Sometimes a person with dementia forgets that they have just had sex, or tries to initiate more sex than their partner can cope with. If a partner feels unequal to a person with dementia's sexual needs then perhaps they can help them to masturbate in private. Where repeated demands for sex become overwhelming, gentle diversionary tactics may help such as getting involved in an activity together, or avoiding outright refusal by saying "maybe later after I've ....."

Reduced interest in sex

Whilst some people with dementia may lose interest in sex, they are likely to retain their need for physical contact. Gentle stroking and touching may be enough to replace a full sexual relationship and there are several other ways to incorporate touch into a care routine. For example, regular kissing and cuddling or patting and rubbing to allay distress and to communicate reassurance and love. Gentle hand massage using aromatherapy oils is a simple way to enjoy the feeling of shared touch.

For partners who no longer share a bed, it may help the person with dementia to have something to cuddle, such as a soft toy, covered hot water bottle or even a pillow. This may seem a patronising response but should not be dismissed if it is found to be of comfort, especially to someone who has been used to the presence of another warm body beside them in bed for most of their adult life.

Different approaches

Physical ill-health or the side-effects of medication may affect either partner's ability to have intercourse. Mutual masturbation and fondling can provide a less physical substitute but still be a rewarding way in which to express love and desire for each other. You should speak to your doctor if you think the side-effects of medication may be having an adverse effect or if you are worried about problems which may have an underlying physical cause – such as inability to have or to maintain an erection, premature ejaculation, vaginal dryness or loss of libido.

Couples should feel comfortable with whatever works for them within the context of a loving relationship and they should try not to be embarrassed if they need to seek help.

Balancing needs and desires

In some relationships, the partner who is the carer may feel guilty because they still wish to have sex but the person with dementia has become passive and unresponsive. In these circumstances, some carers start to feel that continuing to have sex with their partner is an abuse of the relationship, whilst others see maintaining their sex life as quite normal.

Men in particular may feel that they are taking advantage of a partner who is compliant and unable to signal enjoyment, or indeed consent. It is important to learn to read non-verbal signals and to respect any sign of fear or reluctance from a partner with dementia. For example, does the person with dementia still recognise their partner? Is he or she able to say no or able to express their wishes and views? If the partner with dementia does not want to engage in sexual activity, it is likely to be obvious so the other partner can desist or alter their behaviour accordingly.

If this does becomes a matter of concern, it may help to speak to other carers, a relationship counsellor, or to a psychiatrist.

As with all of us, a person with dementia's sex life is deeply personal. If a person with dementia becomes the subject for discussion with professionals, their confidentiality and right to be treated with dignity and respect should be maintained, as should that of their carer.

Sexual aggression and an excessive interest in sex

Sometimes people with dementia can show an excessive interest in sex. They may appear to be sexually aggressive, demanding repeated sex from partners or they may attempt to have sex with people other than their partner. They may masturbate frequently or try to touch other people inappropriately.

Dementia causes gradual damage to the brain which can change the way a person behaves. As with any behaviour, it is helpful to consider the reasons for any apparently sexual behaviour. Is the person with dementia signalling their need for closeness and reassurance? Are they angry because they no longer feel able to satisfy their partner? Could it be a by-product of medication they have been prescribed? This last is especially important as some drugs, including some anti-depressants, have side-effects which can cause excessive sexual interest and sexual arousal.

In extreme situations, where sexual aggression occurs, it may be difficult to manage. This is especially so when male partners are still physically strong. A carer may have to seek help to keep their partner, themselves and those around them safe in situations where the attentions of the person with dementia are violent or too persistent. It is important for a carer to recognise that their partner's behaviour may be a component of their illness. Domestic violence is a difficult subject to discuss because of the shame associated with it and an added sexual element may make it more embarrassing.

For some couples, the behaviour may be part of a long-learned pattern in a relationship which has been exacerbated by dementia. Although this is a difficult problem to discuss, other carers may provide useful help by sharing their experiences and advice. Day care workers, community psychiatric nurses (CPNs) and psychiatrists should also be a good source of practical support and guidance.

Understanding behaviour which seems sexual

There may be times when a person with dementia behaves in sexually inappropriate ways. For example, undressing at the wrong time, exposing themselves, masturbating in public, making what seem like sexual approaches, using obscene or sexually explicit language. Although this can embarrass a carer, it is vital to remember that dementia affects a person's understanding of social situations and therefore their ability to behave as might be expected.

Realising that apparently sexualised behaviour is the effect of dementia and seldom involves sexual arousal can help to depersonalise it and gives a carer the emotional distance to devise strategies for managing. Rather than "sort" the behaviour, it is helpful to consider the reasons why a person would behave that way.

For example, are they:

- removing clothes because they are too hot, itchy, tight or uncomfortable?
- exposing themselves because they need to go the bathroom?
- bored and frustrated?
- mistaking someone else for their partner?
- expressing a need for touch?
- misinterpreting the behaviour of other people?

How to help

When sexualised behaviour happens in public, it is hard not to be shocked and to over-react. However, it is important to try to remain calm and not to communicate anger or distress to the person with dementia. What is not a good solution is to stop going out in public. Becoming isolated is bad for both carers and people with dementia.

- Try to focus on the reasons why the person with dementia is behaving in a particular way and, if it is causing embarrassment, distract them with something else.
- If necessary, lead the person with dementia away from the situation, calmly and gently. Unless the situation is serious, try to avoid physically restraining the person with dementia, as this may cause them to become more frustrated.
- Speak to family and friends about understanding and dealing with

potentially embarrassing situations.

- Seek practical advice from other carers, and from social workers and healthcare professionals.
- Learn from previous experiences. Try to identify the circumstances in which this behaviour is likeliest to happen. Are there cues? For example – is it when the person with dementia is tired or bored, is restless, starts blushing, or when they start picking at their clothing, or when they are in the company of particular people?
- If you do manage to identify situations and/or triggers you will be more prepared and better-equipped to cope if they happen again. Also, when you need a break from caring, you will be able to pass on practical guidance about how to look after your partner to a substitute carer.

New relationships

Respecting autonomy

People with dementia are usually capable of forming new intimate relationships. Relatives, especially grown-up children, may have difficulty in acknowledging that parents are sexually alive or feel resentment that a new partner appears to be taking the place of a parent who has died. But all adults, regardless of age, have the right to make choices about their relationships and to have a private life. If those closest to a person with dementia are satisfied that their friend or relative is not physically or mentally vulnerable as the result of a relationship, and that no-one else is being harmed, then they should not attempt to interfere.

As long as a person with dementia is able to make decisions about their life these decisions should be respected. Whilst a person with dementia is still capable of understanding what they are doing they may choose to set up a welfare power of attorney. A welfare power of attorney allows a person to make their wishes for the future clear and it only comes into force when the person to whom it applies becomes incapable. For more information see Alzheimer Scotland's booklet Dementia - money and legal matters (available free from the Dementia Helpline on 0808 808 3000).

If protection becomes necessary

If families are still concerned that a relative with dementia is open to physical or emotional abuse in a relationship, there are steps they can take. Initially, they should share their fears with any professionals involved with their relative, such as a GP or social worker. If it becomes necessary to consult others about a person with dementia it is essential to respect their dignity and right to privacy.

Those involved with the support and care of the person with dementia will need to determine a number of things including:

- is that person comfortable with the relationship?
- is that person still able to avoid exploitation?
- is that person's behaviour consistent with their prior beliefs and values?
- is that person capable of saying no?

Sexual abuse of a person with dementia can constitute a criminal offence. It may also be a reason for the local authority to intervene to protect that person. Where an adult is unable to take decisions to protect their own interests, there are procedures to allow a family member to act on their behalf eg as a welfare attorney. It is also possible for a family member or other concerned persons to seek an intervention or guardianship order. For more help with this you can speak to your local authority social work department, a solicitor, or the Mental Welfare Commission (see Further help). Whatever the level of capacity of a person with dementia, their rights must come first.

Safe sex

The risk of sexual infection does not diminish with age. Contraception should still be a consideration for men of all ages and for younger women in heterosexual relationships. Sexually transmitted diseases (STDs), including HIV (human immunodeficiency virus) which causes AIDS (acquired immunodeficiency syndrome) are a potential danger to all those who are sexually active. Although most people in long-term relationships will have addressed the need for safe sex, in new relationships it is important that both partners discuss how they are going to protect themselves. GPs are a good source of advice on both family planning and safe sex.

Further reading

Mental Welfare Commission for Scotland. Consenting adults? Guidance for professionals and carers when considering rights and risks in sexual relationships involving people with a mental disorder. Edinburgh: MWC, 2010.

Alzheimer Scotland. Dementia: money and legal matters. Edinburgh: Alzheimer Scotland, 2010.

White, E. Dementia and sexuality – the rose that never wilts. Hawker Publications, 2011.

International Longevity Centre. The last taboo: a guide to dementia, sexuality, intimacy and sexual behaviour in care homes. Available to download as a pdf from www.ilcuk.org.uk

Further help

Mental Welfare Commission for Scotland.
Thistle House, 91 Haymarket Terrace,
Edinburgh, EH12 5HE.
Service user and carer freephone; 0800 389 6809.
www.mwcscot.org.uk
An independent organisation working to safeguard the rights and welfare of everyone with a mental illness, learning disability or other mental disorder

Relationships Scotland
18 York Place
Edinburgh, EH1 3EP
Tel: 0845 119 2020
www.relationships-scotland.org.uk

Offer confidential relationship counselling and sexual therapy for couples and individuals. These services are provided across Scotland. Contact their national office for visit their website for details of local services.

24 HOUR
Dementia
Helpline

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Action on Dementia

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