



Sexuality & dementia

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“Sex and sensuality encompass a kaleidoscope of feelings and activities; from the deepest longings for mutual affection to the simple enjoyment of the company of a loved one. Sexuality also covers a gamut of behaviours – touching, kissing, caressing and cuddling, genital intercourse with mutual orgasm and feelings of closeness and being wanted and valued as a human being.”¹

This information sheet is for people with dementia, their carers and their families.

It looks at sexuality and intimacy when someone with dementia is living at home.

Introduction

According to the World Health Organisation “sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed.

¹ Sherman, Barbara (1998) *Sex, Intimacy and Aged Care*. Jessica Kingsley Publishers.

Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors."²

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.

Existing relationships

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

People with dementia experience its progression in different ways and at different rates. As the ability to cope with ordinary life is gradually impaired, alterations in personality, presentation and behaviour (including sexual behaviour) may become more obvious. Loss of memory, declining physical health, inability to concentrate and growing confusion lead to greater dependency on carers. Inevitably this will impact on relationships and affect the way in which partners relate to each other both physically and emotionally. Being provided with intimate personal care by a loved one can be a positive emotional experience for some people with dementia. For others it represents a loss of dignity and can have negative impact on how they feel about a sexual partner and about themselves.

Similarly for carers, the emotional effect of a partner's increased dependency and need for physical care might change their sexual feelings towards them. Some carers may simply be too tired for sex or too emotionally overwhelmed to expend precious energy on 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 safe place (this might be a friend, a support group, a helpline, a confidential internet chat-line, a counsellor) in which to air emotional issues affecting their relationship. 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 then couples can focus on the positive aspects of their relationship by engaging in

² World Health Organization. Sexual health: working definitions; 2003. Available at: http://www.who.int/reproductive-health/gender/sexual_health.html. Accessed November 6th, 2003.

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. (See Alzheimer Scotland's *Activities* booklet for more ideas.)

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. However, 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 then 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. The positive benefit of gentle hand massage using aromatherapy oils has been reported³ and is another 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 vigorous 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. (See Alzheimer Scotland's booklet – *Getting help from your doctor*.) 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.

³ Kilstoff K, Chenoweth L, *International Journal of Nursing Practice* 1998 Jun;4(2):70-83 Faculty of Nursing, University of Technology, Sydney, Australia.

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. If this does become a matter of concern, it may help to speak to other carers, a relationship counsellor, or to a psychiatrist (see section headed "Further help"). Those involved with the support and care of the person with dementia will need to determine a number of things including:

- is your partner still able to recognise you?
- is your partner able to say no or able to show an ability to express their wishes and views?

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. However, all of these kinds of behaviour are fairly rare.⁴

⁴ Redinbaugh EM, Zeiss AM, Davies HD, Tinklenberg JR (1997), Sexual behavior in men with dementing illness. *Clinical Geriatrics* 5(13):45-50.

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 the apparently sexual behaviour has occurred. 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, any person – not just a person with dementia, 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 to 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 (see above) and, if it is causing embarrassment, to 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

Older people with dementia are faced with society's reluctance to accept that sex is not the sole preserve of the young. Whilst younger people with dementia are less likely to have their sexual needs questioned they too may find that relatives worry on their behalf.

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 then 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: A Guide*.

If protection becomes necessary

If families are still concerned that a relative with dementia is open to physical or emotional abuse in a relationship, then there are steps they can take. Initially they should share their fears with any professionals involved with their relative, such as GPs and social workers. 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. For example, the person with dementia may have granted a welfare power of 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, the [Public Guardian](#) or the Mental Welfare Commission (see Further help). For more information see Alzheimer Scotland's booklet *Dementia - Money and Legal Matters: A Guide*. 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.

Key points:

- People with dementia have lived with their sexuality for much longer than they have lived with dementia.
- Not everyone with dementia is old – in Scotland there are approximately 1600 people with early onset dementia (under 65).
- Not everyone with dementia is heterosexual.
- Not everyone chooses to exercise their right to be a sexual being.
- Couples who work on their relationships can keep them stronger for longer.
- Maintaining a healthy sex-life can improve overall quality of life for carers and people with dementia
- Carers need to consider their own needs alongside those of people with dementia.

Further help

For carers and people with dementia

Alzheimer Scotland Dementia Helpline

The 24 hour **Dementia Helpline, 0808 808 3000** is for:

- people with dementia
- carers
- relatives
- and anyone concerned about dementia.

DASN – Dementia Advocacy and Support Network

A worldwide organisation run by and for those with dementia working together to improve their quality of life. As well as information about dementia, this website has links to chat rooms where people can meet on-line and to their e-mail community.

Web: www.dasninternational.org

Relationship counselling

GP - some surgeries now have NHS counselling services available.

Person Centred Therapy Scotland have a downloadable leaflet called *Finding a counsellor in Scotland*, and a directory of counsellors.

Tel: 0870 7650871

E-mail: info@pctscotland.co.uk

Website: www.pctscotland.co.uk

Couple Counselling Scotland, 40 North Castle Street, Edinburgh. EH2 3BN

Tel: 0131 225 5006

E-mail: enquiries@couplecounselling.org

Website: www.couplecounselling.org

Offers couples and individuals an opportunity to explore their intimate personal relationships in a safe and comfortable setting.

SPOD (Association to Aid the Sexual and Personal Relationships of People With a Disability), 286 Camden Road, London. N7 OBJ

Helpline: 020 7607 8851. Tuesday 11.00am - 2.00 pm, Thursday 11.00am - 2.00pm

E-mail: info@spod-uk.org

Offers advice on sex, sexuality and personal relationships tailored to the needs of disabled people.

The British Association for Counselling, BACP House, 35-37 Albert Street, Rugby. CV21 2SG.

Tel: 0870 443 5252 (calls charged at national rate)

E-mail: information@bacp.co.uk

Website: www.bacp.co.uk

Has a searchable database of therapists and holds a list of trained counsellors and psychotherapy organisations.

Lesbian, gay, bisexual and transgender support

Gay and Lesbian Carers Network

Alzheimer's Society, Gordon House, 10 Greencoat Place, London. SW1P 1PH

E-mail: gaycarers@alzheimers.org.uk

Lesbian women and gay men caring for a partner, relative or friend with dementia face many challenges. The Network has trained and skilled volunteers able to offer a listening ear.

Tel: Roger - 01843 220932, Arthur - 01273 628047, Bruce - 01865 847471, Sally - 020 8675 0660

Scottish lesbian and gay switchboards

Provide telephone counselling and support on: sexuality, relationships and 'coming out'; safer sex and sexual health and information on social life, support groups, housing, legal issues and employment. The service is completely confidential.

Ayrshire 01292 619 000

Borders Gay Switchboard Thursdays

7:30pm - 10 pm, Tel: 01896 756 611

Dumfries & Galloway Lesbian & Gay

Phoneline Thursdays 7:30pm - 9:30pm, Tel: 01387 261 818

Dundee LGB Switchboard Mondays 7pm - 10 pm, Tel: 01382 202 620

Fife Friend Fridays Fridays 7:30pm - 10pm, Tel: 01592 266 688

Grampian LGB Switchboard Wednesdays and Fridays 7pm - 10pm, *Tel: 01224 633 500*

Lothian Gay & Lesbian Switchboard

Nightly 7:30pm - 10pm, *Tel: 0131 556 4049*

Lothian Lesbian Line Mondays and

Thursdays. 7:30pm - 10pm, *Tel: 0131 557 0751*

Moray LGB Switchboard Men: Fridays. 7pm - 10pm, *Tel: 01343 541 188*, **Women:** Thursdays 7pm – 10pm

Strathclyde G&L Switchboard Nightly 7pm - 10pm, *Tel: 0141 332 8372*

Strathclyde Lesbian Line Wednesdays 7:30pm - 10pm, *Tel: 0141 354 0400*

Help with intervention or guardianship orders

Mental Welfare Commission for Scotland,

Argyle House, 3 Lady Lawson Street, Edinburgh. EH3 9SH
Tel: 0131 222 6111

E-mail: enquiries@mwscot.org.uk

Website: www.mwscot.org.uk

Safeguards the rights and welfare of people with mental illness and learning disability both in hospital and living in the community.

Public Guardian

Office of the Public Guardian, Hadrian House, Callander Business Park, Callander Road, Falkirk. FK1 1XR

Tel: 01324 678300, Fax: 01324 678301

E-mail: opg@scotcourts.gov.uk

Website: www.publicguardian-scotland.gov.uk

The Public Guardian registers continuing and welfare powers of attorney, authorisations to access funds, guardianship orders and intervention orders pronounced in terms of the Act.

Further reading

Sex, Intimacy and Aged Care by Barbara Sherman. Jessica Kingsley Publishers Ltd, London 1999. £13.95. This book challenges us to examine our own attitudes. Stories of the experiences of caregivers, families of people affected by dementia illustrate the difficulties encountered by sexual partners, as

well as the complexity of the situations confronting professional careworkers.

Sexuality and Dementia Video and Training Handbook by Carole Archibald, University of Stirling, 1994. Training handbook and supporting video focusing on the expression of sexuality by people with dementia and the subsequent difficulties experienced by care staff.

It costs £40 to buy the full training pack, or £9.00 for the carers' video but both can be borrowed from the Dementia Services Development Centre (details below). They also have, available for loan only, an American video about heterosexual couples where one partner has dementia, called *A Thousand Tomorrows*. For more information contact Dementia Services Development Centre, University of Stirling, Stirling. FK9 4LA
Tel: 01786 467740

Activities – a guide for people worried about their memory, people with dementia and their carers, Alzheimer Scotland. £1.50 (post and packing free within the UK) – single copies free to carers and people with dementia in Scotland via the 24 hour **Dementia Helpline 0808 808 3000**. For carers who look after someone who has moderate to severe dementia and need help with planning daily activities. Keeping someone with dementia busy and engaged will become more difficult as the dementia progresses. However by focusing on what he or she can do, even when the illness is quite advanced, you can both enjoy a range of stimulating activities and outings together.

Getting help from your doctor – a guide for people worried about their memory, people with dementia and their carers, Alzheimer Scotland. £1.50 (post and packing free within the UK) - single copies free to carers and people with dementia in Scotland via the 24 hour **Dementia Helpline 0808 808 3000**. It will help you to find out how doctors and other health workers can help you. The information in this booklet will also help relatives or carers

of people with dementia, and there is a section especially for them.

Don't make the journey alone, Alzheimer Scotland. £1.50 (post and packing free within the UK) - single copies free to carers and people with dementia in Scotland via the 24 hour **Dementia Helpline 0808 808 3000**. Clearly presented information about dementia written by people with dementia for people with dementia.

Dementia – Money and Legal Matters: A Guide, Alzheimer Scotland. £3.50 (post and packing free within the UK) - single copies free to carers and people with dementia in Scotland via the 24 hour **Dementia Helpline 0808 808 800**. A 52 page booklet. This information is for people with early stage dementia and for people helping or caring for someone with dementia.

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Feedback

Alzheimer Scotland actively seeks the views of people with dementia and their carers. If you have any comments or suggestions about this information sheet please send them to:

Information Department
Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh EH3 7RN
E-mail: alzheimerscot@alzscot.org

This information can be found on-line at www.alzscot.org/info/sexuality.html

It is also available in portable document format (pdf) and as a large-print version.
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