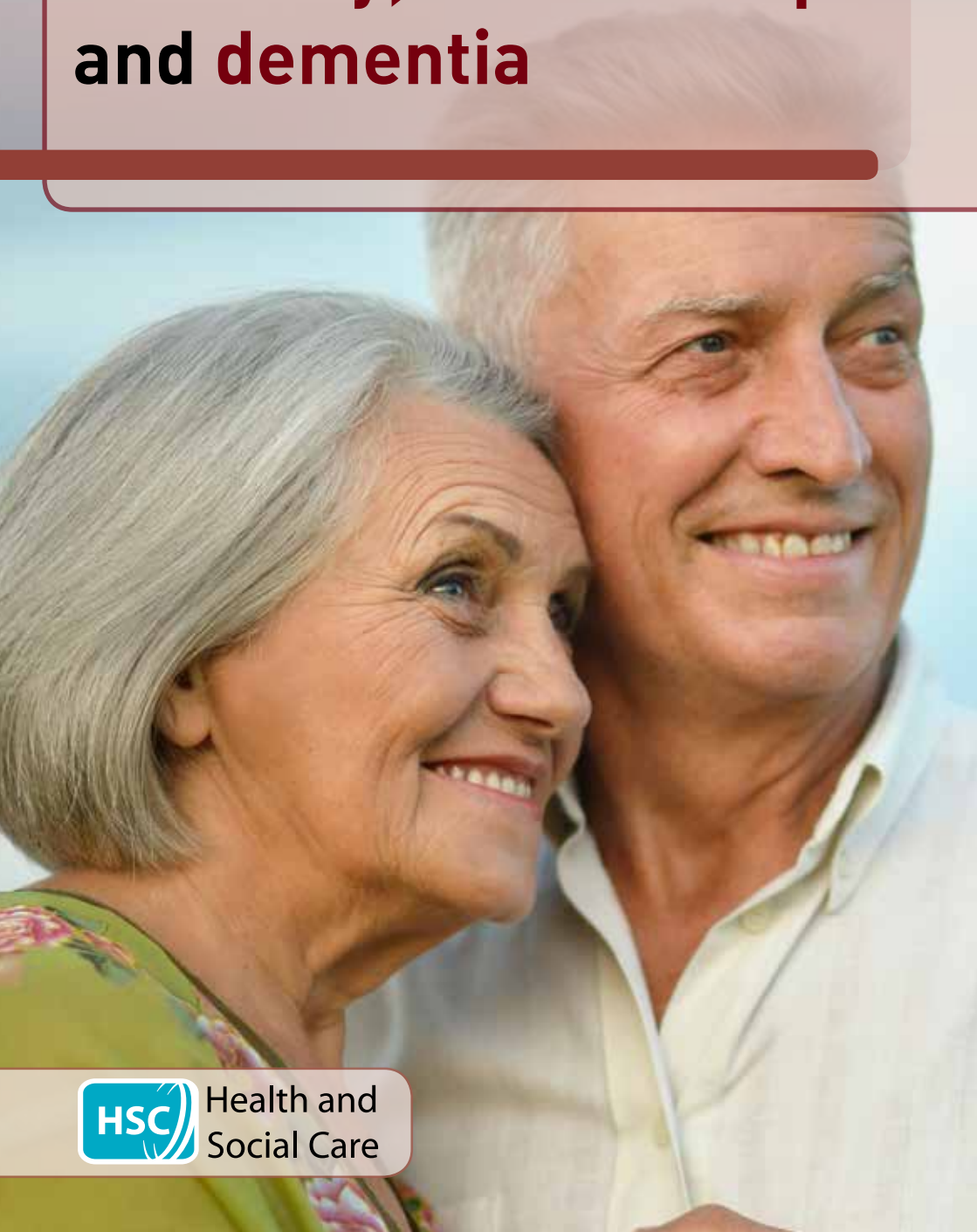


Sexuality, relationships and dementia



Health and
Social Care

***“Nobody ever talked to
us about these changes”***

Couple, one of whom has a dementia



Everyone has the right to love and to be loved. The feeling of being loved and being able to express sexuality in a safe and rewarding way contributes to an individual's overall sense of self-worth and wellbeing.

Developing or maintaining a sexual relationship can be an enriching experience and it is important to remember that a person with a dementia has the same rights and needs as anyone else. However, it is also important to understand that dementia brings about changes to the brain which can result in changes in feelings and behaviours. This may include changes in sexual behaviour and intimate relationships.

In this booklet we refer to 'inappropriate' behaviour but it is important to understand that whether behaviour is inappropriate or not depends on the context, time, person and place.

We also refer to partnerships, but acknowledge that there are many people who are single and for whom sex is important but not with a steady partner or indeed one partner.

This guide is for everyone regardless of their gender or sexual orientation and seeks to endorse the idea that expressing one's sexuality in a safe and legal way is a means of validating one's identity as a human being.

Sexuality, relationships and dementia

All relationships experience change over time and there can be many reasons for this, including poor health or physical incapacity.

Intimate relationships can take many different forms and sex may not be important to everyone. It is important however, to keep an open mind about what sex and intimacy mean to you and your partner and to focus on all the pleasurable aspects of your relationship.

Having a dementia does not mean the end of a healthy sex life and couples can still be close through their sexual relationship even when other means of expression have diminished. Couples may even find new ways of sharing closeness, comfort and intimacy.

Everyone is different and when difficulties do arise, it is important to remember that there is no single way of dealing with this very personal issue. It is a subject that can be difficult to discuss but it might be helpful to talk to someone you trust, maybe a family member or friend or professional. Carers groups can also provide a supportive environment in which to talk as other people will often have the same experiences and be willing to listen and share with you.

Following a diagnosis of dementia, sexual relationships for many couples will carry on as before. This is as it should be.

However, sometimes the person with the dementia can appear cold and detached, they might no longer recognise their partner and reject them or they may forget that they have had sex and become overly demanding. This can be deeply upsetting for partners.

Dementia, the brain and sexuality

Having a dementia can affect how the brain works and sometimes people with dementia will behave in a way that is out of character or socially inappropriate. It is important however, to remember that this behaviour is only inappropriate in the context of when and where the behaviour happens. What consenting adults enjoy or a person alone enjoys is not inappropriate as long as it is safe and legal.

The person with a dementia may not feel the need for affection like they once did or perhaps they will experience an increase in their need for affection. They may even lose the ability to behave in ways that are appropriate to meet this need.

Sometimes a person with a dementia may not recognise their partner or may mistake someone else for their partner. They may mistake receiving help with washing or dressing as a sexual advance and may respond with fear/anxiety or with a kiss/fondle/comment.



Dementia can affect an individual's ability to inhibit their thoughts and behaviour. This may result in the person:

- saying and doing things publically which they would previously have kept private;
- exhibiting more interest, less interest, or even no interest in sex;
- having more, or less, ability to perform sexually;
- appearing less sensitive to others and perhaps being aggressive;
- using sexualised language that others have never heard them use or that seems out of character;
- making unwanted sexual advances towards others or mistaking them for their current or previous partner;
- misinterpreting the intentions of those who are supporting them with personal care tasks.

Some partners and families can adapt to these changes but others will find it upsetting and will experience feelings of loss, anger, embarrassment, anxiety, fear or frustration.

These are perfectly normal reactions and the most important thing to do is to try to remain calm and never be afraid to ask for help. Useful sources of help are listed on page 18 of this booklet.

There may be easily explained reasons for some of this behaviour. The person may feel bored or restless. They may feel too hot or need to use the toilet. Their clothes may be uncomfortable and they want to remove them. They may even have an infection.

It's also possible that the person could be confused about the time of day and may feel ready for bed. They might also be expressing a need for closeness and comfort.

It is important to remember that if the person with a dementia is unable to communicate their feelings verbally, their behaviour is just another form of expression and it may appear sexualised and inappropriate.

How do we respond?

Sometimes, understanding the changes in behaviour can help us and those around us to accept or adjust to them.

Everyone is different and when difficulties arise, it is important to remember that there is no single way of dealing with this very personal issue.

Think about what the person may be trying to tell us

The person with a dementia can have difficulty expressing their needs and feelings and their behaviour can be a sign that their needs are not being met. Asking the following questions can help the person to meet needs which they may be expressing through inappropriate sexual behaviour:

- Does the person have an infection? (Contact GP)
- Are they in pain? (Contact GP)
- Are they too hot/cold?



- Are they uncomfortable? (eg badly fitting clothes/underwear/pad)
- Are they bored? (ensure they are engaged in meaningful activity)
- Do they have privacy? (masturbation is only inappropriate if not done in private)
- Are they lonely? (Does the person need comfort/reassurance?)

Think about how we react

Seeing someone we know and love behaving in a socially inappropriate way can naturally bring up many difficult emotions including shame, embarrassment, anger and fear. It is important to remain calm towards the person with dementia and treat them always with respect and dignity.

Responses to sexualised behaviour can include:

- try to sensitively distract the person and/or encourage them go to a place of privacy eg bathroom, their bedroom;
- using humour respectfully and appropriately can be effective in diffusing a situation;





- telling the person that you are married or in a relationship can be another gentle way to diffuse a situation in a pleasant tone: “well now, my husband/ wife would have something to say about that”;
- try to steer the conversation to something else, such as a funny story from the past “tell me about that time when...”;
- if the person has mistaken you for someone else, gently remind them who you are;
- if the behaviour continues after having tried the suggestions above, it is acceptable to firmly and politely state that you feel uncomfortable and walk away and/or ask for help.

Help the person meet their needs in an appropriate way

We all need to feel that we belong; we all need comfort and reassurance. A person with a dementia can feel lonely and afraid, and need help to make sense of the world around them. Offering help and support can help reduce the risk of inappropriate behaviour.



Things that might help include:

- encourage friends and family to spend time with the person in activities that are suitable for their abilities/interests, such as household tasks, looking through photos/magazines, gardening or rummaging through boxes of interesting items;
- give the person appropriate physical contact when interacting with them eg giving hugs, holding hands, placing a hand on their shoulder/knee, sitting close to them;
- give the person something comforting to hold/touch eg a soft cuddly toy, blanket;
- a hand massage with a scented lotion can be soothing and reassuring.

People with a dementia will still feel the need for ‘self-pleasuring’ or masturbation as a normal response to ‘wellbeing’ as well as a human response to stress and anxiety relief. Living with a dementia can mean that the need and desire for self-pleasuring and/or sexually relating with another person may increase. This may be one aspect of the person’s life over which they still have some control.

“He thought he was with a different person each time which may have been nice for him but I felt awful”

Partner of a man with dementia

Caring for yourself

Dementia affects not only the person with dementia, but also those around them. In order to care for a person with dementia, it is important that we take care of ourselves too.

If you are feeling overwhelmed or upset about how dementia is impacting you, talking to a professional (your GP, social worker or nurse) or someone else you trust is very important.

If you are a carer, plan regular breaks, ask family or friends to help out while you look after yourself. Things that can help:

- Catch up with an old friend
- Go for a nice walk
- Go for a relaxing bath
- Read a book
- Watch a funny movie
- Go shopping (for yourself!)

It is important that both partners have support and time to adjust to the changes that dementia can bring. If you are worried or upset by something, discussing your feelings and concerns with someone who understands can often help.

“Sometimes we would be getting intimate and suddenly he’d turn very aggressive, jumping up and screaming. I get very frightened”

Wife of a person with a dementia



It's good to talk

Talking about our intimate relationships and sexuality and the challenges that they may present can be embarrassing for some people. However, it is not good to allow things to just get bottled up.

If you are worried and need help, contact your GP, consultant or health care professional. Perhaps you have a trusted friend you can talk to and who will listen in a caring and supportive way.

If you think that you or another person is in danger then you should seek help immediately.

Details of who to contact are available on page 18–19 of this booklet.

Tips for a person with a dementia and their partner

- A diagnosis of dementia does not mean the end of an intimate relationship.
- Enjoy your relationship in any way that feels good for you and your partner.
- You don't have to do anything you don't want to.
- Taking up a new hobby, exercise and physical activity can help reduce frustrations.
- There is help available, don't be afraid to ask for it.
- Talk to someone you trust.

Tips for partners

- Gently discourage inappropriate behaviour by redirecting to another activity.
- Is there a reason for the inappropriate behaviours? Does your partner need to go to the toilet, are they feeling some discomfort or are they bored?
- If the person mistakes someone else for their partner approach the situation calmly and take them somewhere private.
- Find ways to include different forms of touch in the everyday routine so that the person gets some physical contact.
- Massage, holding hands, and embracing are ways of continuing to provide loving touch.
- It is important to remember that some behaviours are caused by changed perceptions as a result of dementia.

Care homes

Living in a care home does not signal an end to someone's need for affection nor should it mean an end to their sex life.

People with a dementia who live in a care home may continue to have a sexual relationship with their partner or they may form new sexual relationships with other residents.

However, forming a new relationship can be very difficult for a family to accept, especially if the relationship is not with someone who is the person's recognised partner. In these circumstances, the home manager must ensure that families are fully involved in discussions about how to deal with the situation without causing distress or harm to anyone involved.

If you have a relative with dementia living in a care home and you are concerned about any of this, you should talk to the manager.

All care homes should have a policy on sexuality and relationships which safeguards the rights of all residents, ensures their privacy and promotes the emotional wellbeing and protection of everyone.

The manager and staff of the home should be aware of the policy and trained to respond appropriately to issues around relationships, sexuality and sexual health

For more information on care homes, see the guide at www.pha.site/dementiadocs

***“Sometimes I feel like he doesn’t love me,
he doesn’t even recognise me”***

Partner of a man with a dementia

Forming new relationships

A person with a dementia is still capable of forming new and intimate relationships and as long as they have the mental capacity to make decisions about their life and neither person in the relationship is at risk of harm, then these choices should be respected.

Consent, capacity and protection

It is important to remember that sexual behaviour is only appropriate between consenting adults. If either person does not agree or feels pressured to participate, it becomes inappropriate. Consent should be clear each time people become intimate even if they have been intimate regularly.

Simply having a diagnosis of dementia does not mean that someone lacks the mental capacity to make their own decisions and to understand the implications of those decisions. Furthermore, capacity is always specific to a particular decision at a particular time.

The ability of a person to understand the implications of a decision may also vary on different occasions. It is important to consider whether the person with dementia has the ability to recognise who the other person is, and most importantly, whether they have the ability to say no or to express their wishes in other ways.

Partners should learn to recognise what the person with a dementia may be trying to communicate regarding their consent to intimacy. This may include non-verbal messages.

Sometimes the person with dementia may find it difficult to understand the needs of their partner and to understand that their partner is not consenting to sexual intimacy. It will be important for a partner to respond in a way that is clear, but sensitive so that the person with dementia does not feel rejected or unloved. It may be possible to show affection in other ways that a partner may feel more comfortable with, such as holding hands, hugging and cuddling.

Sexual health

Some health problems and medications can affect sexual pleasure and performance. If either partner has joint pain or arthritis, their local physiotherapy department should be able to suggest ways to make sex more comfortable. If either partner has recently had a serious medical condition, take the consultant's advice before having sex.

Anyone starting a new relationship, or people in a long-term relationship who haven't already done so, should have a discussion about safe sex. Speak to your GP in confidence, or alternatively seek information and advice on safe sex from health centres and websites such as NHS Choices (see details of links on page 18–19 of this booklet).



Useful contacts

If you need help, support or advice in understanding or coming to terms with the changes that a diagnosis of dementia can have on yours or someone else's relationship or sexual wellbeing, there are some useful sources of help.

NIDirect

www.nidirect.gov.uk/dementia

Online information regarding dementia in Northern Ireland

Sexual Health Northern Ireland

www.sexualhealthni.info/

NHS Choices

www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx

Belfast Health and Social Care Trust

info@belfasttrust.hscni.net

www.belfasttrust.hscni.net

Northern Health and Social Care Trust

www.northerntrust.hscni.net

Southern Health and Social Care Trust

www.southerntrust.hscni.net

South Eastern Health and Social Care Trust

www.setrust.hscni.net

Western Health and Social Care Trust

www.westerntrust.hscni.net

Alzheimer's Society

Unit 4

Balmoral Business Park

Boucher Crescent

Belfast

BT12 6HU

Tel: 028 9038 7770

www.alzheimers.org.uk

Age NI

3 Lower Crescent

Belfast

BT7 1NR

Tel: 08088087575

www.ageuk.org.uk/northern-ireland

Carers Northern Ireland

58 Howard Street

Belfast

BT1 6PJ

Tel: 028 9043 9843

Public Health Agency, See Me, Hear Me, Know Me Guidelines

<http://www.publichealth.hscni.net/publications/see-me-hear-me-know-me%E2%80%99-guidelines>

Northern Ireland Health and Social Care Interpreting Service

Business Services Organisation
Franklin Street
Belfast
BT2 8DQ
Tel 028 9536 3777

Dementia NI

54 Elmwood Avenue
Belfast
BT9 6AZ
Tel: 02890 68 67 68
Email: info@dementiani.org
www.dementiani.org

CAUSE

Building 2,
Lesley Office Park,
393 Holywood Road,
Belfast,
BT4 2LS
Helpline – 08456030291
www.cause.org.uk

The Rainbow Project

23-31 Waring St,
Belfast
BT1 2DX
02890319030
www.rainbow-project.org

Relate

3rd & 4th Floors,
3 Glengall Street,
Belfast,
BT12 5AB,
Tel: 028 9032 3454
Email: office@relateni.org
www.relateni.org/contact



Public Health Agency
12-22 Linenhall Street, Belfast BT2 8BS.
Tel: 0300 555 0114 (local rate).
www.publichealth.hscni.net

