



Belfast Health
and Social Care Trust

Dementia and Behaviour: Affection, Intimacy and Sex



Information for relatives

Community Mental Health Team for Older People

We hope this information helps you understand changes in your relative's behaviour due to dementia, and that you find some tips that work well for you both.

Share the tips that worked with family, friends and others who spend time with your relative, it will reassure them that they are doing all they can for both of you - give them this booklet to read or go through it together.

We have booklets on many other changes in behaviour that may occur due to dementia and would be very happy to share them with you.

Please call us on: 02895040346

Community Mental Health Team for Older People



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Physical Touch

Throughout our lifetime we may touch or be touched by others for many reasons:

To help with a physical task such as washing or dressing.

The need for help with physical tasks can come and go throughout our lifetime, we need a lot of help when we are very young, we may also need help if we are ill, and we may need quite a lot of help if our ability to complete tasks for ourselves changes, for instance due to a physical injury, stroke or dementia.

To show affection and caring towards others.

Giving and receiving affection is an important human need. We may do this when talking with each other, and we may also do so through touch - a hug, kiss on the cheek, a squeeze on the shoulder are some ways we show others we care. Physical affection can be a very individual thing; for some it can be a very important part of giving and receiving affection, however, others may not give or receive affection in this way and may find hugs and kisses quite uncomfortable.

As part of an intimate or sexual relationship

We may be more intimate with certain people; a husband and wife may share kisses and cuddles throughout their lifetime. Physical touch is also part of any sexual relationship we may have. It is important to remember that the need for an intimate and sexual relationship can last throughout our lives, while for some our need for a sexual relation may lessen in later years, we are unlikely to completely lose the need for human warmth and affection at any age.

Dementia affects how the brain works and because of this, you may notice changes in how your relative behaves, including how they use and receive physical touch. Sometimes these changes can be because of direct impact of dementia to the brain; a particular part no longer works as well as it once did. Or, sometimes changes can be more to do with the brain no longer being able to put all the information together to make good sense of a situation; the person may get things mixed up and behave in a way that seems strange to others.

Some changes can be easily adapted to and cause no difficulties in everyday life, however, other changes can be more challenging and may cause embarrassment or be distressing for all involved.

This booklet will look at some of the most common ways using and receiving physical touch may change, including intimate and sexual touch, and give some tips that others who care for someone with dementia have found useful.



Changes in Behaviour

A change in behaviour can sometimes be understood as a direct impact - the link between the brain and a behaviour can be likened to a switch or dial in the brain being turned up or down.



The dial being turned **down** means a **decrease** in the need to behave in a certain way.

The dial being turned **up** means an **increase** in the need to behave in a certain way.

Because of this, you may see your relative's behaviour change in one or more ways:

- You may notice your relative's need for affection change. For some people the dial may be turned down and they don't feel as strong a need to give or receive affection as they once did, for some the dial is turned up and this need becomes stronger. As touching, hugging etc. are ways of showing affection, you may notice your relative's need for this increases, or perhaps decreases.

- It may be that you see a change in your relative's need for intimate or sexual relationships; the dial may be turned up or turned down and they may seek more or less intimate or sexual contact than they used to.

Sometimes the link is not quite as direct:

- It may be that a change in your relative's ability to communicate by talking (either with expressing themselves or with understanding what others are saying), means they show you affection in a more physical way - squeezing your hand, giving you a hug or kiss etc. They may also need to understand your affection for them in the same way, particularly if they are upset, distressed or need to be reassured and comforted.
- A decrease in showing affection with hugs etc. can be due to a change in your relatives ability to initiate, or start behaviours or actions. Indeed, if your relative is very happy to receive affection, hugs, a kiss or hold your hand, it is likely that they still need and enjoy this. You can help by gently prompting and encouraging your relative and by frequently giving hugs, kisses etc to continue feeling close and connected.



Sometimes changes in behaviour can be more complicated:

The way your relative makes sense of a situation, how they understand why others may be touching them, or when it is ok to touch other people, can be changed because of dementia. They may no longer be able to put all the information together to make sense of a situation the way they once did. Your relative may get people, places or what is happening mixed up and behave in a way that seems strange to you and others. This can mean your relative may misinterpret receiving help with washing or dressing with a more intimate or sexual relationship and respond in that way, perhaps with a kiss or fondle.

Understanding why such changes have happened for your relative may be enough to help you and others accept and adjust to them. Indeed you, along with other family members, may enjoy feeling close to your relative through hugs etc and an increase in their need for affection can bring you closer together. Adjusting how gently or strongly you hug or touch your relative can be a simple way of adapting to changes in how they receive touch from others.

However, sometimes such changes can bring difficulties which can be harder for you and your relative to adjust to and manage. Indeed, some of the ways your relative's behaviour can change may cause embarrassment, and perhaps be a shock, for everyone involved.

Affectionate Behaviour

Physical contact and touch can be an important way of showing affection for many of us. Along with voicing our feelings, hugs, a kiss on the cheek or a squeeze of a hand can help many of us to feel we belong and that we are wanted. It can also be a way for us to let others know they are dear to us. Dementia can change a person's affectionate behaviour in certain ways.

Your relative does not seem to need as much affection

If your relative's need for affection lessens (the dial has been turned down), you may notice they not only give less hugs etc., they also do not seem as keen to receive them. While your relative may seem to accept this change well, it can be very difficult for you or other family members as you may feel they no longer care for you and that an important part of your relationship has been lost.

What can help

- It can be very helpful to share these feelings of loss with others, perhaps you could talk with a family member or close friend, or join a Carers Group where you will find other who have also experienced similar changes.
- Spending time with your relative in a different way, indeed, away from the hustle and bustle of physical tasks that caring for a person with dementia can bring, can also bring closeness and affection.
 - ♦ Going for a walk around the garden when you can share closeness by talking about the flowers and birds, or perhaps doing household tasks together such as folding laundry or preparing food.

- ♦ A life-story book can provide hours of enjoyment for both of you. The book can contain family photographs with a few lines written about the pictures such as who is in them and where they were taken. You can also include holiday pictures, poems, tickets from concerts, and the words of songs.



You may notice your relative does not hug or give you a peck on the cheek as often as they would have yet they are more than happy for you to show you care in this way. It may be that they need your help to **show** affection rather than that their need for affection has reduced.

What can help

- Helping your relative show and receive affection by frequently giving them hugs, squeeze their hand etc. can help you both feel close to each other.
- You may find other physical touch helps you and your relative stay emotionally close. Your relative may find having their hair brushed soothing.
- Massage can help you both feel connected, and can also prevent or reduce any feelings of loneliness, upset, anxiety or distress your relative may experience:
 - ♦ Hand massage - a simple hand massage using cream can help your relative and you feel emotionally connected. Perhaps use a cream or oil with a calming aroma.
 - ♦ A scalp or shoulder massage can relieve tension or anxiety for your relative while also being a way to communicate affection.

If you would like more information on Carers Groups, or creating a life story book please contact the Community Mental Health Team for Older People.

Community Mental Health Team for Older People

Your relative seems to need more physical affection

Your relative's need for affection may increase; the dial may be turned up. They may become more physically affectionate when previously you would both have been comfortable with less physical displays.

Or, it may be that your relative now struggles with conversation and talking (either with finding their words or with understanding what others are saying), you may see them increasingly show you how they feel in a more physical way - squeezing your hand, giving you a hug or kiss etc. They may also need to understand your affection for them in the same way, particularly if they are upset, distressed or need to be reassured and comforted.

These changes can take some getting used to, particularly if you are more used to conversation than physical touch to express emotions, and especially when there are other people around.



What can help

- You may need to remind yourself that many people express how they feel through touch. Getting more comfortable with this is likely to help your relative, you, and perhaps other family and friends continue to feel emotionally close to each other. It can take some practice!
 - ♦ Practice giving or receiving a hug, holding hands, giving a reassuring squeeze of the hand or shoulder etc.
 - ♦ Let other people such as family, friends and social groups you may attend know; other people knowing that these changes have happened can make you feel more comfortable. Just as you would be understanding for them, others will be for you.
- If your relative seems anxious and in need of your affectionate comfort, you may find giving them something to touch or hold while sitting close to them helps. This can be particularly helpful where hugging, giving a peck on the cheek etc. may feel more uncomfortable for you, perhaps when in a public place with people who don't know you both.

Intimate and Sexual behaviour

We don't usually spend a lot of time talking about intimacy or sex, indeed, it might be a bit embarrassing for some of us. However, wanting to feel attractive to others and keep an intimate or sexual relationship alive (sexual intercourse between two agreeing adults or masturbation) is normal and continues throughout life for many people.

Sex can be both physically and emotionally satisfying; relieving tension and providing feelings of security, belonging and love. Many couples, quite naturally, continue to enjoy a sexual relationship after one of them has been diagnosed with dementia. Where there is no willing partner masturbation in private may continue.

Dementia can change a person's sexual behaviour in several ways:

- For some people with dementia, the need for intimate or sexual behaviour may change; the dial may be turned up or turned down. If this is part of your relative's dementia, they may approach you more, or less, frequently for intimate and sexual contact. You may be happy with this, however, if you were happy with how things had previously been, you may find such changes in your relationship more difficult.
- Your relative's ability to think as well as they once could may have changed due to dementia. Previously, while they may have had an impulse or need to do something, they may have been able to think about it and not act on that impulse. However, if their ability to hold back is reduced (the dial has been turned down) your relative may act on impulse without being able to judge whether it is a good

time or place to do so. This might mean your relative may be more clumsy, less subtle, in their approach to intimate or sexual behaviour, and this can understandably change how you may respond to them.

- Dementia can also affect the brain's ability to gather and put together all the bits of information that are necessary to make sense of a situation and to then behave in a way that makes sense to others. Therefore your relative may get people, places or what is happening mixed up, they may behave sexually with people or in places where they previously would not have done so.

It is important to remember that sexual behaviour is only appropriate between two agreeing adults. If either do not agree or feel pressured to participate, it becomes inappropriate. Sometimes changes in the brain due to dementia can mean your relative's sexual behaviour is inappropriate and you will find more examples of inappropriate sexual behaviour and what may help further on in this booklet.



Your relative's interest in intimacy or sex decreases or stops

An intimate or sexual relationship that lessens or stops due to a decrease in your relative's desire can be a loss for you. It may mean you feel less attractive, you may also miss the physical satisfaction and emotional closeness such a relationship can bring.

What can help

- It is important to understand that this change is due to your relative's dementia, it is not personal and your relative is not behaving this way intentionally. Remembering this means you can be more assured about how you feel about yourself and your relationship.
- Continue to look after your appearance, have your hair cut or styled regularly, go to the barbers for a hot towel shave, or to the beauticians for a beauty treatment.
- Share other activities with your partner to ensure you both continue to feel emotionally close and cared for. Go for a walk when you can share closeness by talking about what you see, or perhaps doing household tasks together such as folding laundry or preparing food.

Your relative's interest in intimacy or sex increases or re-emerges

Your relative approaching you for intimate or sexual contact more frequently, or when it may not have been part of your relationship for some time can be difficult. You may have been content with how things were and feel uncomfortable or shocked with this change. You may feel unable to say that you would prefer not to, or you might wonder if you would be taking advantage of your relative because the situation has arose when they have dementia.

What can help

- Try to be gentle in your reaction, appearing shocked or annoyed may be embarrassing for your relative.
- Notice when your relative may be becoming interested in intimate or sexual contact with you, for example if an affectionate hug begins to turn into a fondle, you can gently disengage and encourage your relative to another activity. Or if you notice signs suggesting your relative may want to masturbate you can give them the privacy to do so.
- Sometimes a new behaviour, or an insistent behaviour can be due to an infection or something else that may need medical treatment. Or it may be a review with a psychogeriatrician is needed to assess the behaviour and provide appropriate treatment and advice. Be assured that your GP or a member of the Community Mental Health Team for Older People will be familiar with behaviours to do with dementia, so talk to them if:
 - ♦ Your relative becomes insistent in their need to engage you in intimate or sexual activity
 - ♦ Your relative frequently become distressed when you do not engage, or you are distressed by their response to you.
 - ♦ You are unsure about what you should do.

Inappropriate Sexual Behaviour

There can be times when sexual behaviour becomes challenging to deal with, for example when it is not appropriate for the other person or for the setting they occur in. This can be a difficult situation for both you, your relative and other people if they are involved. It can be both embarrassing and distressing.

It can sometimes be difficult to decide whether something said or done is an inappropriate sexual behaviour. If the behaviour is directed towards or involves another person who has not agreed to participate (perhaps care staff), or if it occurs in a place where others who would not wish to hear or see it (perhaps when you have friends round), it becomes an inappropriate sexual behaviour.

Some examples include:

- Comments such as ‘She’s got lovely breasts’ or ‘I want to take you to bed’
- Touching themselves, undressing, or masturbating in public
- Touching others; rubbing up against someone else, touching their breasts or groin, lifting skirts.

Why inappropriate sexual behaviour may happen

Dementia is a long term condition and changes in behaviour can emerge over time. As part of this, your relative may behave in ways that don't make sense to others, or in ways that are not appropriate to the situation they are in.

Indeed this is not uncommon, along with aggressive behaviour people find inappropriate sexual behaviour very hard to understand and to talk about. However, family and carers who have talked with professionals (such as members of the Community Mental Health Team for Older People) have found this really helpful – remember, you don't have to manage alone.

Having a good understanding of why your relative may behave in this way can be very helpful, you can then respond in the best way for them and encourage others to do the same. This can be very important for your relative's, and your, emotional wellbeing.

As mentioned earlier, we can understand how this behaviour can happen in several ways:

- Your relative's ability to hold back an impulse may be reduced (the dial has been turned down) and they may act on impulse without being able to judge whether the behaviour is appropriate to others or the situation.
- ♦ This can mean that when your relative has a sexual thought, they may not be as subtle in their approach as they once were or they may be more physically or verbally explicit in their attitude.

- Your relative may have a reduced ability to put all the bits of information together to make sense of a situation and to then behave in a way that makes sense to others. They may get situations, people, places or what they, or others, are doing mixed up and behave in a way that is not appropriate for that person or situation.
 - ♦ This could mean that your relative's mistakes you or someone else as a possible sexual partner, perhaps they then flirt, make comments, or touch inappropriately.
 - ♦ It may be that in making sense of where they are, they mistakingly think they are in their own house, privately with you and behave in a sexual way in a public place.
 - ♦ Your relative may get mixed up about how other people are behaving. If they are being helped with physical care, perhaps are undressed and being helped with getting washed, they may get mixed up and make sense of the situation in a more intimate way, they may then respond with an intimate or sexual comment or behaviour.
- Your relative may be bored or feel they need comfort and masturbating may be their way of coping with this. This is not an inappropriate sexual behaviour, but it becomes so if your relative struggles to understand that they are not in a private place.

- Being tired or having an infection can make it even more difficult for your relative to stop themselves from acting on an impulse or for them to interpret where they are, who they are with and what is happening correctly.
 - ♦ You may see the effects of tiredness, infection, or other physical illness as an increase in how often or how explicit your relative behaves in sexual, or indeed other ways.
 - ♦ Your relative's physical wellbeing is important and they may depend on you or others to notice when they are unwell.

What can help

Remember your relative's behaviour is due to dementia, they don't realise that they are being inappropriate and they are not intending to annoy or embarrass themselves, you or others.

- Try not to react with shock, anger or disgust, treat your relative as you would like to be treated yourself.

If you think your relative's sexual behaviour is in response to a need for comfort or security or perhaps because they are bored, try to meet that need in a different way:

- Encourage family, friends etc to spend time with your relative, perhaps also doing an activity with them.
- Include your relative in household tasks, or activities that they enjoy.

If your relative is undressing or masturbating in public you can try to protect their dignity by:

- Clothing which may be more difficult to remove can be selected when going to public places - giving you time to notice behaviours at an early stage and help your relative to a more private place.
- Otherwise, cover your relative up and help them to go somewhere private such as their bedroom or bathroom.

If your relative is misunderstanding your (or other's) intentions while being helped with a physical task such as getting washed try to:

- Encourage your relative to do as much as possible for themselves. For example give them the soap to hold when washing.
- Give your relative the wash cloth to wash their lower half themselves.
- Use towels to cover up parts of the body that are not being washed.
- Talk them through the task, or talk to them about something that interests them - distract your relative from their misunderstanding.

If your relative is likely to misunderstand a social situation (perhaps getting mixed up and thinking they are at a dance or other place where they socialised in their youth), they may respond by becoming flirty or inappropriate. If your relative misinterprets an affectionate physical touch as an intimate touch and respond with a sexual comment or behaviour, you and others can try these tips:

- Noticing the early stages of such misinterpretations can mean you, and other people, can gently re-direct conversation or gently disengage from an affectionate hug etc.

- If your relative becomes flirty, sometimes it is enough to say ‘Oh, I’m married’, or ‘well now, my husband might have something to say about that’ keeping a pleasant tone and then re-direct by asking your relative to tell them about the time when..... or talking about a favourite activity
- If your relative reaches out to touch others in different situations or misinterprets a touch, again, try to disengage gently, move to ensure there is enough space to discourage further attempts to touch until your relative is engaged in a different activity. Provide an alternative activity for your relative.

If your relative’s inappropriate sexual behaviour has suddenly become apparent, or becomes very frequent or insistent, or if it causes emotional or physical distress, speak with your GP. As mentioned earlier, sometimes a new behaviour, or an insistent behaviour can be due to an infection or something else that may need medical treatment. Or it may be that a review with a psychogeriatrician is needed to assess the behaviour and provide appropriate treatment and advice.

USEFUL CONTACTS

Age NI Advice Line

0808 808 7575
www.ageuk.org.uk

Alzheimer’s Society

(028) 9066 4100
www.alzheimers.org.uk/northernireland

CAUSE

(families, partners, friends caring for mental health)
 0845 6030 291
www.cause.org.uk

Lifeline

0808 808 8000
www.lifelinehelpline.info

MindWise

(028) 9040 2323
www.mindwisenv.org

Caring for yourself

All of the information in this booklet may make caring for your relative easier, but your well-being is just as important. You will find it easier to look after your relative the way you want to if you can get regular breaks. Ask friends and family to keep your relative company whilst you look after yourself, they will want to help.

If you have been caring for a while it might be hard to think of what you would do if you had a break!

What can help

- Catch up with some friends
- Go shopping for yourself
- Go for a walk
- Go for a relaxing bath



How to contact us:



Community Mental Health Team for Older People Tel: (028) 9504 0346

operates from Monday to Friday
9am to 5pm

We also offer an extended telephone advice
and support service for people living with
DEMENTIA and their carers operating:
Monday to Friday until 8pm
Saturday to Sunday 10am to 2pm

If you need to speak to someone
outside these hours please contact:
Regional Emergency Social Work Service
(028) 9504 9999

[www.belfasttrust.hscni.net/services/
CommunityMentalHealthTeams](http://www.belfasttrust.hscni.net/services/CommunityMentalHealthTeams)

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