

Dealing with complex emotions

Support for family carers providing personal care for people living with dementia



Crossing the line

Support for family carers providing personal care for people with dementia

The information provided in this booklet is general guidance and not intended to be used as formal advice. Please see your healthcare professional for more personalised advice.

All information was correct at the time of publication. It is recommended to check what is available in your area.

This booklet is one of a series of booklets developed through the 'Crossing the line' research project.

The Crossing the line project was funded by the National Institute for Health and Care Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR202970)

FUNDED BY

NIHR | National Institute for Health and Care Research



UNIVERSITY of WORCESTER

Association for Dementia Studies



GIG NHS
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board



DEMENTIA CARERS COUNT
Supporting Family Carers



NHS
Midlands Partnership
NHS Foundation Trust
A Keele University Health Trust



The giving and receiving of personal care can give rise to a whole range of complex and sometimes unexpected feelings. In this booklet we describe some of the more frequent emotional reactions and offer some advice on working with them.

Acceptance and refusal; coming to terms with change

*“He doesn’t think there is anything wrong with him”
“She refuses any help, saying she can cope on her own”*

Losing the ability to look after oneself in the way which you have been able to do since childhood is a huge issue to come to terms with. Likewise, seeing someone you love struggling to look after themselves can be devastating. Coming to terms with these changes takes time.

People may find it difficult to accept help for many different reasons. Because of the memory loss associated with dementia, the person may not recognise that they are having difficulties, so don’t see a need for you to help. Loss of independence can also bring feelings of fear, shame and embarrassment.

If the person is aware that some things are difficult, they may be feeling anxious about what this means and fearful about the future. It may be that the person wants to hide that they are having difficulties because they are worried.

Top tips for helping someone who refuses help

- Talking about giving and receiving help is a good thing to do early on and can help with acceptance in the future.
- Talk about it gently together, to try and encourage them to accept help. Let the person know that you care about them.
- Try to gently give some specific examples of things you've noticed they are struggling with.
- Listen to their own thoughts and concerns and what ideas they have about getting some support.
- Be respectful of people's right to refuse help, and being open about why you want to help.
- At times, the person may find it difficult to see that they need help, which in turn might lead to refusing it. Try not to get into long discussions of what the person is unable to do.
- Remember that acceptance is easier for a person if they feel respected and listened to.
- Sometimes adopting the approach that you are just helping them out on a temporary basis makes it easier for the person to accept your support.
- By providing a less emotionally charged reason for you helping out today may move things along, such as a dodgy knee or failing eyesight.

Anger

"She gets so angry with me! I'm only trying to help!"

"Suddenly in the middle of me helping him get dressed, he'll fly off the handle for no reason"

"Whenever I try to help them have a wash we just end up in a shouting match"

Anger covers a whole range of emotions from irritation to rage. Different people will express anger in different ways. Knowing the person over many years provides you with a good benchmark for what is an angry reaction for an individual person.

People often react in an angry way when they are confronted with something they cannot do or when they are frightened. This applies to us all, whether we have dementia or not. A person with dementia may be unable to channel or express those emotions in what might be considered a socially acceptable way.

Sometimes personal care activities may trigger feelings of embarrassment or a loss of personal control of their lives. For some people, personal care activities may trigger distressing memories from earlier life. You may find that anger in these situations can be more intense.

What do you think has caused the anger?

- Could the person be in pain? Sometimes movements involved in personal care can trigger pain.
- Have they misinterpreted what you were trying to assist with?
- Was there something in the way in which you spoke to them or physically approached them that triggered the anger?
- Were you rushing or trying to get the person to do something they didn't want to do? If this was the case, how important is it to do it now, can it wait?

Top tips on responding to angry outbursts

- When someone is angry towards us it can prompt us to feel angry ourselves. Try to react as calmly as possible.
- When it happens, try to set aside your own emotions for a few moments. Begin by trying to step into the shoes of the other person, and think about what that person may be feeling.
- Before saying anything, centre yourself and take a deep breath.
- Acknowledge the person's anger by simply saying something like "I'm sorry, I didn't mean to upset you" and ask them "What would make this easier?"
- Try to find out what the person wants or needs from you.
- The anger may be short lived and once you explain kindly that you are just trying to be helpful then the anger may melt away.

Top tips on responding to intense anger

- If the anger continues or intensifies, then taking a breather, changing the subject or activity and trying again later when their mood has improved may help.
- Say something like, “I’m sorry, I’m making you angry, let’s stop, and you can tell me what you need me to do.”
- Be aware that trying to change the subject, distract, or divert attention away from what is being expressed may provide a temporary break from the situation, but the anger may return.

Looking after yourself

- Being on the receiving end of anger is distressing.
- If you have experienced a distressing situation with the person you care for, try to ensure that you talk to someone supportive about it.
- Having a cry or a swear on your own can sometimes help unblock the heavy emotion afterwards, but talking it through may help you to stay strong emotionally.
- Like the person in your care, you also need a trusted listener.
- If the angry reactions are frequent or you cannot understand them, then it is important that you seek help.
- If you feel frightened for your safety then seek professional help. Do not put yourself at risk.

Talk it over with a good friend or phone any of these helplines: Alzheimer's Society 03331 503456; Alzheimer Scotland 0808 8083000; Dementia UK 0800 888 6678; Dementia Carers Count 0800 652 1102. Nothing that you discuss will shock or embarrass people on the other end of the phone.

Apathy

"It's like they've lost their get up and go"

"All he wants to do is sit in the chair all day"

"Sometimes even getting out of the chair to go to the loo seems too much of an effort"

"Whenever, I suggest something she always says she'll do it later"

Apathy often presents as though the person is losing interest in life. It can seem like the person lacks motivation or it takes a long time for them to 'get started' on tasks and activities they would previously have done without any effort. Sometimes people can get into the habit of doing very little because being active exposes them to tasks and situations that they now find too difficult.

In some dementias, the part of the brain that oversees 'starting and stopping' activities can be impaired. Apathy can often affect how the person carries out their personal care, like cleaning their teeth, brushing their hair, etc., and so it may fall to their carer or supporter to take the initiative for them.

Top tips for supporting someone who has lost their get up and go

- If the person you are trying to help does not want to do the personal care task in hand, then it can sometimes help to change tack into a completely different activity such as going for a walk or playing a game.
- The same type of personal care may be tolerated better at different times of day.
- Generally, people's energy levels are better earlier in the day. This varies from person to person.
- Coming back later can sometimes change a person's perspective on the task in hand.
- The person may still manage many aspects of their personal care with prompting and being given more time.
- Try to use prompts and cues, such as putting the toothbrush into the person's hand and guiding them to clean their teeth.
- Depression can impact on motivation and the ability to carry out day to day tasks. If the person is neglecting their personal care for a period of weeks, it is important to consider if the person with dementia could be depressed.



Depression

"I can't stop crying"

"I feel numb and empty"

"She has no appetite"

"Nothing seems to bring him joy anymore"

"I can't stop eating"

"I can't remember the time I last had a good night's sleep"

Feelings of depression are common when you are dealing with a condition such as dementia. This is true both for the person living with dementia and the those caring for them. Feelings of sadness and being fed up are normal reactions to stressful situations, particularly those that go on for many years. Looking after yourself can stop this escalating into depression for many people.

Sometimes, however, the feelings of low mood overwhelm people and become impossible to shake off without help. If a person has been experiencing symptoms of depression for longer than three weeks, then it is important to talk to someone about this. Depression causes people to feel worried, anxious, tearful or hopeless. It also usually impacts on appetite and sleep pattern. It can make it hard to concentrate. In some cases, depression can lead people to have thoughts about suicide or harming themselves.

Depression in the person living with dementia

Depression is common in people with dementia. It sometimes occurs as a reaction to receiving a diagnosis. It also can occur because of the loss of independence that occurs particularly if the person has difficulty depending on others for help. Isolation and loneliness can make this much worse.

Depression can impact on motivation and the ability to carry out day to day tasks. It can affect how well a person can attend to their personal care needs. If the person is neglecting their personal care, it is important to consider if the person with dementia could be depressed.

Top tips for coping with depression in people living with dementia

- Where depression is suspected the person's GP should always be told. The GP should be able to assess for depression.
- They may suggest interventions like talking therapies, depending on the stage of the dementia and the person's ability to engage in them.
- The person's GP will be able to provide advice on whether medications may be helpful or not. Anti-depressant medication is helpful for some people but not for others.
- Try to think about things that the person used to get pleasure from and provide opportunities to enjoy this again. Keep this in small doses initially so that the person does not get overwhelmed.

- Try to ensure that the person is encouraged gently to do as much as they can for themselves. Helping the person to maintain control – even if it’s just a little thing – can make a big difference to depression. Celebrate the small steps.
- Try to encourage some physical activity at a level appropriate for the person.
- Getting outside into nature can often lift people’s spirits.
- Provide opportunities for achievement and enjoyment, little and often, every day.

Depression in those who are caring

Caring for someone with dementia puts them at increased risk of experiencing depression. It is not uncommon for those caring for someone with dementia to experience feelings of depression and low mood. These feelings can be triggered by challenges associated with providing personal care.

Depression can impact on the person’s ability to carry out caring tasks. Where feelings of depression are present, they may make it more difficult to support the person with dementia with their personal care. Depression can make it difficult for someone to make an effort and feel a sense of positivity. Disturbed sleep makes people feel tired all the time, meaning they lack energy to support someone with personal care activities as well as look after themselves. It also may make carers see their caring skills and abilities as not being good enough.

Top tips for coping with depression for carers

- Like the person in your care, you also need a trusted listener.
- If you think you are depressed, then talk to your GP. The GP should be able to assess whether you are depressed.
- They may suggest a course of talking therapies, many of which are now available online as well as face to face.
- Your GP will also be able to advise whether medications may be helpful or not.
- Make your GP aware that you have significant caring responsibilities as they may also be able to put you in contact with extra support services.
- By making your GP and others aware that depression is impacting on your ability to carry out personal care, or that the task of personal care is making you feel depressed, you are opening the way for support to be put in place for both yourself and the person you care for.

Talk it over with a good friend or phone any of these helplines: Alzheimer's Society 03331 503456; Alzheimer Scotland 0808 8083000; Dementia UK 0800 888 6678; Dementia Carers Count 0800 652 1102. Nothing that you discuss will shock or embarrass people on the other end of the phone.

Suicidal thoughts and mental wellbeing

One in four of us will suffer with mental health issues at some point in our lifetime. There is no shame or weakness in reaching out for support. You are not alone. Suicidal thoughts are common. Research suggests approximately 30% of unpaid carers have thought about suicide, with 1 in 10 already attempting suicide.

Evidence suggests there are 5 steps you can take to improve your mental health and wellbeing. Go to www.nhs.uk and search for '5 steps to mental wellbeing'. Trying these things may help you to feel more positive.

Talk to your GP about how you are feeling.

Visit the Talking Therapies website
www.talkingtherapies.hwhct.nhs.uk

If you need urgent mental health support call 111.

The Samaritans charity offers a free telephone helpline on 116 123 and other avenues of help for anyone who feels at the end of their tether
www.samaritans.org



Distress

"She gets so upset whenever I try to help her"

"Sometimes I think that anyone listening would think I was trying to murder him rather than help him change his trousers!"

"Whatever I do, they always end up in tears"

"I feel so awful afterwards, I never know if I am doing more harm than good"

Having help with personal care can make someone have a range of distressing reactions such as tears, anxiety, embarrassment and shame. Personal care is, as the title suggests, personal. It can be one of the most difficult tasks that anyone needs support with.

Someone with dementia may become anxious or agitated when someone tries to help them. They may not want to wash, dress or go to the toilet at the time when care is available and feel it is disruptive to their current plans. Some people may not understand why they are being offered help or what is happening, and this can lead to distress, which in turn can be stressful for you as the caregiver too.

Top tips for understanding the aspect of care that is causing distress

- Try to understand what is causing the distress and explain clearly what you'd like to do and why.
- Taking the time to try and understand what's causing someone's distress may help you to know what the person is trying to communicate. This can help you try to plan to put things in place to minimise it in the future.
- What do you think is triggering the distress?
 - Could it be a problem about the person feeling embarrassed?
 - Could it be about the changing dynamic in the relationship?
 - Could it be triggering unpleasant memories from the person's past?
 - Sometimes the distress may be linked to the person feeling unsafe or in danger.
 - Sometimes a person may be less distressed by having personal care done by someone outside of the family.
 - Reflect on how the person is interpreting the place where they are.
 - Are there any environmental factors that are causing the persons distress? For example, the temperature of the room, or the brightness of the lights, or the reflection they see in the mirror.
 - Think about whether the distress occurs at particular times of day or in particular situations.

- The same type of personal care may be tolerated better at different times of day. Generally, people's energy levels are better earlier in the day. This varies from person to person. Try varying the time of day if distress is repeated.

Top tips for supporting someone who is distressed by care

- Reflect on whether dignity needs are being met. A large warm towel, fleecy blanket or familiar dressing gown can create a feeling of comfort and reassurance as well as maintaining dignity.
- Provide lots of reassurance and reflect on what might feel reassuring or soothing to them.
- Reflect on whether music could help or singing together could help the person relax. The Playlist for Life website may help with this www.playlistforlife.org.uk
- If the person's faith is important to them, they may feel calmer if they can listen to religious music, prayers or recitation of religious text.
- Having a pet to stroke for someone who has always had pets can be very calming for some people. Some people may find it helpful to have a soft ball that they can squeeze, to help relieve anxiety and tension. You could also try a robotic pet, soft toy, fabric, doll, or HUG doll which you can find at www.hug.world
- Humour can also be used to calm distress if you know the person well, but this may not always be appropriate in particular circumstances. Use your own judgement.

Getting help

- If the distress is of sudden onset, it may be being caused by an underlying physical problem. Pain often manifests itself as disturbed behaviour in more advanced dementia. Talk to your GP about a physical health review.
- If the distress does not have a physical cause and is persistent then ask your GP to refer you to your local mental health service or Admiral Nursing service for advice.

Guilt

"I feel guilty whatever I do"

"I feel guilty for doing too much for my mum and not being there for the rest of the family"

"I feel guilty for spending time with my kids and not doing enough for mum"

"I feel guilty if I tell anyone how difficult I find looking after my husband"

"I just wish it would all end but then I feel so guilty for feeling like this"

Guilt is a common feeling in those providing care for a family member or friend with dementia. This emotion can arise for lots of reasons and can be a very uncomfortable feeling to deal with, adding to the often already high emotional strain associated with a caring role.

In relation to personal care, guilt may arise from a feeling of not having been able to perform the care task as well you feel you should, or as well as you think that the person you are caring for would have wanted. It is common that carers may have high expectations of what is possible and may say things like, “He would hate it if he did not have a shave before he came down to breakfast” and so feel guilt at not being able to manage this. Feelings of guilt may also arise when there is a need to have outside support with personal care, such as when having paid carers take over from you for the first time.

Feelings of guilt carry a risk of depression and feelings of burden. These feelings can lead to a downward cycle of then impacting on your ability to provide personal care and be there for yourself and others around you.

Top tips for dealing with guilt

- Try to remind yourself that you are doing your best in a difficult situation.
- It can be helpful to think about what the person you are caring for would say about the care you are giving them if they were able to.
- Often, we are harder on ourselves than others.
- It can be helpful to think about what you would say to a friend who was carrying all the responsibility that you are now. What advice would you give them?
- Looking at things from a different perspective can help you appreciate all you are doing for the person.

- If feelings of guilt become overwhelming, then don't be afraid of seeking help. Certainly, never feel guilty asking for help.

Talk it over with a good friend or phone any of these helplines: Alzheimer's Society 03331 503456; Alzheimer Scotland 0808 8083000; Dementia UK 0800 888 6678; Dementia Carers Count 0800 652 1102. Nothing that you discuss will shock or embarrass people on the other end of the phone.

Humour

"I try to make every task as much fun as possible"

"Many times, we both end up with a fit of the giggles when I'm trying to get her dressed"

"I laugh a lot at my failed attempts to do something"

Humour is a valuable resource as it can defuse situations which could be explosive. It can also be used to help with personal care tasks, to give them an element of fun. If we could bottle laughter, it would be a great medicine! So don't be afraid to laugh as it helps to relieve stress, which is a common emotion while caring.

- Families often have funny stories or sayings. Using these during personal care can help to make the situation more light-hearted.
- If possible, laugh at yourself often.

Relationship changes

"I feel more like his mum than his daughter"

"I feel more like their dad than their husband"

"She was never particularly good at caring for me when I was little, and yet here I am now taking her to the toilet and getting her dressed"



Relationships all vary, and they can change over time. Dementia adds a dynamic to these changes that can be very challenging to manage. Past relationship history and how past conflicts have been resolved will play a part. Even strong or long-established relationships will be affected when a person develops dementia.

Individuals who have hidden aspects of their identity from family may no longer be able to (or want to) do so as their dementia progresses. In some instances, dementia can lead to individuals coming out as LGBTQ+ in later life. This can sometimes be upsetting for families, partners and relatives so support might be required to help.

Top tips for talking about relationship changes early on in dementia

- For some people a dementia diagnosis is catastrophic. For others, after the initial shock, a more positive outlook can develop.
- Using this time to talk together about what the diagnosis means for both of you is very important for the future. These conversations can form the bedrock for decisions that will be made in the future.
- Caring for someone at a distance or caring for someone you live with all the time can create different challenges to the relationship.
- Relationships with the wider circle of friends and family can also be challenging. Some people will need help to manage their reactions and relationships, especially if they struggle with anger and loss.

Changes to your identity

- It can be particularly difficult when the changes in a person due to dementia, affect the love or type of relationship their carer has with them.
- Losing one's identity as a lover and adapting to 'carer' and 'cared for' is a major relationship transition.
- On a practical level, roles may need to change altogether such as a change in who manages finance, cooking, cars, birthdays and home maintenance.

Top tips for looking after yourself and each other

- Setting boundaries around your own time spent caring and having time for yourself is important.
- Building in time for fun and enjoyable activities, both together and apart, will keep the relationship stronger.
- If you are feeling worn down because you are tired, or in pain then it may become harder to maintain positive relationships, and particularly if you are also involved in physical caring.
- Sometimes different people in the family get involved with different aspects of care and support. Knowing who will do what can help with planning support for the person living with dementia.
- Isolation and loneliness are not good for any relationship. Putting effort into maintaining existing friendships and building new social networks for the longer term will help.
- Connect with local support networks. Ask about Dementia Cafés or Dementia Meeting Centres meetingcentres.wordpress.com
- If the relationship is breaking down or you are feeling resentful a lot of the time, don't be afraid to seek help.

Talk it over with a good friend or phone any of these helplines: Alzheimer's Society 03331 503456; Alzheimer Scotland 0808 8083000; Dementia UK 0800 888 6678; Dementia Carers Count 0800 652 1102. Nothing that you discuss will shock or embarrass people on the other end of the phone.

This booklet is part of a series about support for family carers providing personal care for people with dementia:

1. Why does having dementia make personal care difficult?
2. Dealing with complex emotions
3. Common physical issues that impact on personal care
4. Legal and financial issues
5. Changes to the home environment to make personal care easier
6. Strategies that will help make giving personal care easier in the long term
7. Staying strong in the long term
8. Help with continence and using the toilet
9. Help with washing, showering, and bathing
10. Help with teeth and dentures
11. Help with dressing and undressing
12. Help with eating and drinking
13. Help with personal appearance
14. Help with caring for hands and feet
15. Supporting good hearing and vision

All booklets and the information within them can be found online at: caringhelp.on.worc.ac.uk

August 2024 edition

Copyright © Association for Dementia Studies,
University of Worcester

The illustrations in this booklet were created by
Rachael Brazell.



**UNIVERSITY of
WORCESTER**

Association for
Dementia Studies