



Belfast Health  
and Social Care Trust

Your relative has been diagnosed  
with dementia. What now?



Information for  
relatives and carers

Community Mental Health Team for Older People

## After your appointment...

You accompanied your relative to their appointment today with a doctor who specialises in conditions, such as dementia, that can affect memory or other thinking processes.

Your relative received a diagnosis of dementia at this appointment and it is important that you, as family member or carer, have the supports and information you may need at this time.



## Thinking about your appointment.....

Attending a doctor's appointment can be worrying. Sometimes people have questions that they either didn't get the chance to ask, or didn't know if it was ok to ask, or maybe didn't want to ask in front of their relative. This is the same for many people; it is ok to have questions that you wished you had asked and to come up with more questions after the appointment.

You may also have concerns or worries around your relative being diagnosed with a long term condition such as dementia, again, most people will have worries along the way, either about how they can do their best for their relative or how they are managing or coping themselves.

Your relative's Doctor will have asked if you would like a member of the Community Mental Health Team for Older People to contact you in the next few weeks and you can ask any questions then, or if you want to contact us before then, please telephone 02895040346.

If you had felt a phone call may not be useful, you can ask your GP any questions you may have. Or, if you now decide it may be useful you can change your mind and contact us on 02895040346, your call will be very welcome.

In the meantime, this leaflet lets you know what other people whose relative has been given a diagnosis of dementia have found useful to think about.

## Common reactions after diagnosis

**Your** feelings may have had to be put ‘on hold’ initially because you were with your relative and were responding to their needs. At this time you, like many people, may find it takes a while to get your thoughts together, work out how you feel about this news and what you might want to do now.

Perhaps it has taken you a long time to get to this stage, you have maybe spent many weeks or months trying to persuade your relative to go to their GP, or, you may have attended many appointments prior to your relative being diagnosed—you may already feel emotionally drained. On the other hand, you might not have considered a diagnosis of dementia and may now be feeling quite shocked.



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People react in different ways and there is no right or wrong way to feel, it is quite normal to feel and think one, more, or all of the following:

**Fear:** What now? How will I manage? What will other people think?

**Guilt:** Should I have done something sooner? If I'd known I would have...

**Sadness/Disappointment:** What about all our/my plans for the future?

**Relief:** I knew there was something wrong. Now we know we can...  
My mother had dementia and she lived well and happily.

**Numb:** I can't take all of this in

**Anger/Frustration:** Why is this happening?

**Denial:** There's been a mistake...nothing is wrong

## So how do you feel...

It's all very well knowing how other people have felt, but what about how you are feeling? As with any life event, taking the time to find out how you feel about the diagnosis and any changes you think this may bring can help you adjust and figure out how you will deal with it.

Thinking about how you feel may be something you do a lot, however, most of us are just not that used to thinking about how we feel, or what we think. It might help to ask yourself the following questions:

- How do you feel? What do you think about it?
- How did you feel when the diagnosis was given?
- Do you still feel the same way?
- How have you coped since the diagnosis was given?
- What do you know already and what do you need to know?
- What are your concerns/fears/worries?

Feelings are emotions and neither right nor wrong, good or bad. Be assured that the feelings you have about the diagnosis and the impact this may have on future plans does not reflect how you feel about your relative. Feeling angry is common, as is feeling numb or refusing to believe the diagnosis - many people cope this way until they are ready to deal with the situation.



When you are ready you may find it good to talk about how you feel with friends and/or health professionals, people tell us this helps them more than bottling everything up inside. You can also access support groups (we have details of some local groups at the back).

Whatever you decide to do it is important to know that others have very likely felt the same as you and that feelings can change over time; what you feel today will not be exactly the same as what you feel tomorrow, next week or next year.

## Talking to each other...

You and your relative may have talked about the changes that lead to attending the doctor, if so, it may be natural to continue talking to each other about what you both feel and need now. This can be both sad and reassuring for both of you.

Maybe like others have found, your relative has had difficulty recognising there has been anything different at all, or maybe they become upset if you talk about memory, other thinking difficulties, or differences in behaviour you have noticed.

Either way, when you know changes in your relatives thinking and behaviours are because of dementia, you will likely want them to feel as little upset or distress as possible.

Many other people in your position tell us it is helpful to avoid using statements that remind the person of their difficulties and have given us some examples of what they found may distress their relative with dementia, and what can be more reassuring.





Try to avoid saying:

- You've just asked me that
- You don't go to work anymore
- Can't you think of something to do
- You have forgotten again
- I've already told you
- Wait a minute
- Stop doing that

Instead, try using:

- You seem worried/ anxious
- I can never remember either
- You seem to miss your...
- It can be hard to think of things
- Let's do this together
- Can you help me do this instead
- I'm feeling a bit lost too
- Isn't it frustrating when you can't remember.....

## Telling Family & Friends.....

Maybe your family and friends knew you were going with your relative to the Doctors and they knew why, or, maybe you have not spoken to anyone at all about why you were going to the Doctors.

Whatever your situation, telling others that your relative has dementia can be difficult; indeed, it might be tempting to say nothing at all. Dementia is nothing to be ashamed about, it is an illness and is nobody's fault.

You are likely to feel and cope much better if you do not keep it to yourself, and your family/friends are likely to feel and cope much better if they are able to talk with you and support you.



## What can make it difficult to talk about?

- You might worry about worrying your family and friends, but it is likely they will worry more if they don't know what's going on for you both.
- You might worry about what other people will think about your relative's diagnosis. Some people may be surprised (perhaps as you were), but talking can help all of you to support each other.
- You might worry that friends or family might treat your relative, and maybe also you, differently. Some people can take a bit of time to get used to the news, however, mostly friends or family want to do what's best for you both and you can help them do this.
- You might worry that friends or family will ask you questions that you don't have the answer to. It's ok not to know the answers, you can say 'I don't know' and you can get them to write their questions down. You can then decide later whether or not it's something you would like to know more about.

## What might make it easier to talk to others?

When talking to others about your relative's diagnosis or about how you are coping and managing with the news, it can be hard to know where or how to start. Here are a few ideas that others have found helpful:

- Consider whether your relative can be involved for all or some of the discussion. Think about whether your relative will find discussing dementia and any difficulties they have confusing or overly distressing. It may be that you have some discussions with your relative present and some when they are not there.
- Meet somewhere where you will be comfortable talking. This might be in your own home, or the other person's home.
- Try to make sure you have enough time to say what you want to say, don't pick a time when you or the person you will be speaking to are busy doing other things as this will make it more difficult for both of you.



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- Some people have told us that they found it useful to write down a few notes before they meet to talk. This gave them time to think about what they needed to say, and what might help at this time or in the future.
- It is usually a good idea to talk to family and friends in small numbers—face to face and one on one is probably best but if you decide to speak to a number of people keep the groups small. Otherwise it can be hard to keep track of what everyone wants to discuss.
- Your friends and family will feel useful if they can be involved. Have a think about how you might want others to assist you and your relative and let them know: for example going to appointments, setting up a calendar, spending some time with your relative, or maybe giving you some time to talk.
- Perhaps you and your relative do not need any assistance at the moment, but it can be good to let people know that this might change in the future.

## Where do I go from here?

At your relative's appointment you may have agreed that someone from the Community Mental Health Team for Older People will phone you in the next few weeks.

If you had felt a phone call may not be useful and now feel it may be, you can change your mind and contact us on 02895 040346, your call will be very welcome.

This is an opportunity for you to ask any questions or talk about worries you may have. We will be able to give you useful information, or, be able to direct you to the right people if needed. It might be a good idea to write down any questions, worries or comments that you have in a notebook. Keep this close at hand so that you can write in it whenever you need.



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## Some books people tell us they found helpful

As well as organisations, there are a number of books written about caring by carers. Some of these are listed below but you will find others in a book shop, library or on the internet:

Keeping Mum: Caring for Someone with Dementia  
by Marianne Talbot

The Essential carer's guide to dementia  
by Mary Jordan

Chicken Soup for the Soul: Living with Alzheimers & Other Dementias:  
101 Stories of Caregiving, Coping, and Compassion  
by Amy Newmark & Angela Timashenka Geiger

Knickers in the fridge  
by Jane Grierson

Telling Tales about Dementia: Experiences of Caring  
by Lucy Whitman

Can I tell you about Dementia?: A guide for family, friends and carers  
by Jude Welton

## 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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