



Belfast Health
and Social Care Trust

You have been diagnosed with
dementia. What now?



Information for patients

Community Mental Health Team for Older People

After your appointment...

The appointment you attended today was with a Doctor who specialises in conditions, such as dementia, that can affect memory or other thinking processes. You have been given a diagnosis of dementia which can be a shock for some people.

Here, we let you know what other people have found useful to think about in the time just following their appointment and diagnosis.



Thinking about your appointment...

Attending a doctors appointment can be worrying in itself, and receiving a diagnosis of a long term condition such as dementia can be a lot to take on board.

Following their appointment, people tell us that they may have had 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 family. 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. If you think of anything, write it down so you can ask when you next talk with your GP or a member of our team.

Your 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, you may find the following information useful.

Common reactions after diagnosis

Having just received a diagnosis of dementia, you, like many people, may find it takes a while to get your thoughts together, to 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 may have attended many appointments prior to being diagnosed, and now know the answer to your questions, or, you might not have considered a diagnosis of dementia and may now be feeling quite shocked.



We are all different, therefore react in different ways and can feel many different emotions. There is no right or wrong way to feel or react, many people feel and think one, more, or all of the following:

- **Fear:** What now? What about the future? What will other people think?
- **Guilt:** Is this something I brought on myself? Should I have done something sooner?

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- **Anger/frustration:** Why is this happening to me?
- **Sadness:** What about all my plans? What if they have to change?
- **Relief:** I knew there was something wrong. My mother had dementia and she lived well and happily.
- **Numb:** I don't feel anything. I can't feel anything just now.

So how do you feel about your diagnosis?

It's all very well knowing how other people who have been told that they have dementia have reacted, but what about how you are feeling? As with any new life event, taking the time to find out how you feel about it can help you adjust to it 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.

How do you feel? What do you think about it?

It might help to ask yourself the following questions:

- How did you feel when you were given your diagnosis?
- Do you still feel the same way?
- How have you coped since?
- What did you think about your diagnosis?



You don't have to share your answers with anyone if you don't want to, however, most people say they found it useful to talk to others, and having answered the questions for yourself means it is easier for you to help family, friends and others understand what it is like for you.

Emotions are neither good nor bad, they are how we feel, and just as you would like to be there for your family and friends when they could use support, they are likely to want to be there for you. Talking with them, and sharing how you feel, can be a good thing.

Telling Family & Friends.....

Maybe your family and friends knew you were going to the Doctors, maybe they knew why and you have already been talking to them.

Maybe you have only spoken to the relative who went with you.

Maybe you have not spoken to anyone at all about why you were going to the Doctors.

Whatever your situation, telling others that you have dementia can be difficult; indeed it might be tempting to say nothing at all. However, 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 to others:

- 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.
- You might worry about what other people will think about your 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 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?

If you have made the decision to talk to others about your diagnosis, it can be hard to know where or how to start. Here are a few ideas that others have found helpful:

- Meet somewhere where you will be comfortable talking. This might be in your own home, or the other person's home.
- Make enough time to say what you want to say, don't pick a time when you or the person you will be talking to are busy or doing other things as this will make it more difficult for both of you to talk.
- It can be useful to write down a few notes before talking to others. This can give you time to think about what you need to say, and notes can be used to remind you of what you want to say during the conversation.



- 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 at once then 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 them to assist you and let them know: for example going to appointments, setting up a calendar or maybe even giving you some time to talk.
- Perhaps you 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 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 02895040346, 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.



Community Mental Health Team for Older People



We hope that you will find us very easy to talk to, but just in case you don't you can give your questions to a family member or a friend so that they can ask for you. We will also be able to give you some ideas about what other people in your situation have found helpful.

If you want to talk to us before we phone you, contact us on:
02895 040346.

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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