

How can you help? Supporting people living with dementia



A guide about dementia, by people living with dementia

Introduction

This guide has been written working alongside people living with dementia who live in our homes or retirement living and members of our community groups. The guide is written in the first person, from the perspective of a person living with dementia. It was created as a starting point to help colleagues and volunteers to understand what it is like to experience dementia and to consider what support they may need.

(All images were taken prior to the COVID-19 pandemic).

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MHA Dementia Lead





What is dementia?

I have dementia, this means that parts of my brain don't work as well as they once did. This is because I have a condition that has caused me to have dementia.

There are lots of different types of dementia, including:

- Alzheimer's disease
- Vascular Dementia
- Lewy Body Dementia
- Fronto-temporal Dementia

Each type affects people differently so you may need to research the different types.

I won't get better as my condition will get worse. Remember my experience is unique to me.

Don't worry you can't catch dementia from me. Having dementia does not mean I am 'crazy' or 'mad'.





“ I didn't want my family knowing, I suppose I wanted to protect them from what was going to happen. I soon realised I had to be open with them. ”

Community group member living with dementia

“ Some of our friends have reacted badly to my diagnosis... It doesn't bother me but I know it has upset my wife. ”

Community group member living with dementia

“ I get irritated when people say stupid things to me like 'my memory is terrible as well' or 'but you don't look ill'. This shows a complete lack of acceptance about my illness. ”

Community group member living with dementia

“ The staff really are super, they are so friendly. You can have a laugh and a joke with them. It makes such a difference. ”

MHA care home resident living with dementia

Some of the difficulties I may have

Because I have dementia it is possible that I may need your support with certain things. The best way you can help me is by supporting me to carry on doing what I want to do. Some of the problems I can have because of my dementia are:

Remembering what's happened recently

My memory is not as good as it used to be. I particularly struggle with remembering what happened recently.

It is likely that you will have to find ways of helping me with my memory problems. This might mean that you have to repeat yourself, show me how to do things more than once or remind me where I have put things. I know this will be frustrating but it is not my intention, it's my dementia.

My long-term memory is still pretty good, this means that you can chat to me about the past. Also, my emotional memory is still good. This means I will remember how other people make me feel, even if I'm not sure who they are.

Thinking clearly

There are times when I find it difficult to think clearly, other times I am fine. Some people describe this like being in a fog, others say it's like being in thick mud not being able to move.

There are times when I can be hesitant and unsure about what to do or what I should be doing.

My actions and behaviour can change

This can be a result of what is going on in my brain, but it is more often about how I am feeling. Because I can't always tell you what is wrong I often will use my behaviour to communicate to you or those around me.

Finding my way

I can sometimes get lost in places that are familiar to me. I can also forget where items are kept or where I have placed things. This can lead to me feeling confused and frustrated. A gentle reminder is often all it takes to get me back on course.

“ My wife is so patient but I can tell from the look on her face that I have asked her already. ”

Community group member
living with dementia

“ When I am chatting with people, I can forget what I want to say... Thankfully my daughter knows when to step in and fill in the gaps. ”

Community group member
living with dementia

How can you help me?

Respect me

Speak to me like an adult, not a child as that can make me feel stupid. I know I can repeat myself, but it isn't helpful to be told that I have already said that.

Another thing I have found from having dementia is that people often correct me. I might get the time wrong or even forget your name but being reminded I've made a mistake doesn't help.

Involve me in conversations

There is nothing worse than being left out of a conversation especially if it is about me or things that matter to me.

Let me do as much as I can for myself

There are still lots of things I can do for myself, but if people take over there is a danger that I won't be able to do these things. So find out what I can still do for myself and what I need you to help me with.

Give me chance to respond

There are times when it takes me a while to respond to what is being asked. Some people jump in and ask me another question, or they finish my sentence for me. This just makes things worse for me. Give me time and I will respond in my own way.

Use humour

I still have a sense of humour so find out what makes me laugh and build on this. Please laugh with me, not at me.

“ It hurts me when people speak to my wife rather than me....but she tells them, 'he can still talk you know'! ”

MHA retirement living resident living with dementia

“ I make my own way to church. I have been going there for over thirty years I'm not giving up on this. It's not just my faith that is important but also being able to see people I know and care for. ”

MHA retirement living resident living with dementia





Help me to keep busy and active

Keeping busy and feeling useful helps a lot. I am not ready to sit and do nothing all day. I can still learn new things if I am given the right support. I know I might not finish things or do them in the 'right order' but this doesn't matter to me. What matters is that I feel useful.

Use my life story

Learn about my life story, talking about my past can help me during difficult days because it gives me something to focus on.

Accept my reality

There may be times when my view of the world is different to you. You might find reminding me helps. If I find this distressing, I need you to be with me in my reality even if it is different to yours.

Making choices

I still have the right to make choices about the way I live my life. Respect the decisions I make for myself, even if you don't always agree with my choices.

There might be times when you feel that these decisions are not safe. At these times it is worth talking to me or those who are close to me.

If I am not able to make a decision, then you might need to make the decision for me.

When you do this you need to think about what is best for me. There is legislation which provides guidance about how you can help me when acting in my best interests. Mental Capacity Act 2005 (England and Wales). Adults with Incapacity Act 2000 (Scotland).

Know my routine

Having a routine can be a lifeline for me and get me through the day. Please learn my routine and let me follow it. Trying to stop or alter this could lead to panic.

“ She is different to the others because she spends time to sit and listen to me – just knowing this makes the world of difference. ”

MHA care home resident living with dementia

“ If you have got any problems you can go and see him and he will open his ears to you. ”

MHA care home resident living with dementia

Find out for what ‘pushes my buttons’

I can get frustrated and there are certain situations or people that can make me feel stressed or agitated. Before I was diagnosed with dementia, these things did not bother me but now I can react before I’ve had chance to think about it. There are times when I don’t know what has upset me or made me angry. If you can find out what or who has ‘pushed my buttons’ then you might be able to find ways of stopping me from becoming distressed. Please don’t just presume I am behaving this way because I have dementia. I am trying to tell you about something.

I can struggle with loud noise or if there are lots of people around me. Help me get away if you can or remove the noise for me. Feeling tired can also affect me. There are days when I feel full of energy and other times I become easily worn out. Watch out for signs that I am starting to struggle and consider how you can help me. Likewise, look out to see if I am in pain because I might not always be able to tell you. Watch my body language and facial expressions to understand what I am trying to tell you.

One of my biggest hates is when other people treat me differently, don’t listen to me or ignore me. Understandably this will upset me and will affect how I act.

Involve my family and friends

These people know me; use them to find out about how you can support me. Many

of them will have shared my experience of dementia with me, learn from them about what works. There may also be times when my family need more support than me.

“ I know my friend is only trying to help but it really irritates me when she smothers me. I think she forgets that I have survived a world war and brought up three children by myself! ”

MHA care home resident living with dementia

“ My family mean the world to me. I don’t know how I would cope without them. ”

Person with dementia living in a MHA retirement living scheme

“ I have always been a proud person and asking for help from others is difficult. ”

Person with dementia living in a MHA retirement living scheme

Help me cope with the changes

Having dementia throws lots of challenges and changes my way. I constantly have to adjust to these changes; this can be exhausting for me and those around me. My relationships with others have changed, some friends avoid me, and they can’t seem to cope with what I am going through. Others have stayed by my side, help me to stay in touch with these friends.

Help me cope with the stigma

I have to live with the stigma associated with dementia. Many people believe that I am no longer a productive member of society and make assumptions about what I can or can’t do. Please don’t assume, ask me or a member of my family.

Help me find support

Help can come from charities such as the Alzheimer's Society, Dementia UK or Alzheimer's Scotland. Such organisations can be a good source of support and help you to support me. Information about these can be found below.

The Alzheimer's Society is a charity that has lots of useful support and information. They also have a National helpline 0300 222 11 22
www.alzheimers.org.uk

Alzheimer's Scotland is another charity with helpful guidance and a 24-hour help line. 0808 808 3000 www.alzscot.org

Dementia UK is a charity that support people living with dementia and their families through specialist nurses called Admiral Nurses. www.dementiauk.org

Communication tips

- If I seem unsure, please speak slowly or write things down
- Tell me your name and remind me of our connection
- Don't interrupt me or I'll lose my place
- Keep sentences short. If your sentences are too long, I might lose track of what you are saying
- If you don't know please say so rather than making it up or saying nothing

Our dementia strategy

MHA has created a dementia strategy. This covers our six commitments to help people living with dementia and their families, live later life well.

1

We will support people living with dementia to engage with their **local community**.



2

We will ensure that our staff and volunteers have the right **attributes, attitudes and knowledge** to support people affected by dementia.



3



We will work in **partnership with families** to help them feel supported and involved.

4

We will work to recognise **behaviour as a form of communication** and take time to respond in a supportive way.



5

We will ensure that people living with dementia live in or visit an **environment** that makes them feel at home, safe and supported.



6

We will assist people living with dementia to access **spiritual support, meaningful music and activities**.





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