

Understanding dementia

people with learning disabilities finding out and raising awareness together



About this booklet



This booklet will tell you about dementia. It will also help you to understand what happens to people when they have dementia.

Dan Herron from Keele University worked with members of a self advocacy group in Staffordshire called Reach.



This booklet was made using the ideas, thoughts and experiences from our work.

There is space for you to write and draw your thoughts and ideas.



We made up the stories in this booklet to help you think about how the person with dementia and their carers are affected.

Understanding dementia



Dementia is an illness which stops parts of the brain from working properly. It is not a normal part of getting older.

Dementia occurs more in older people, but some younger people can have it.



There are different types of dementia, the most common is Alzheimer's disease. Each type can affect the person differently.

What happens to people when they get dementia?

Dementia starts slowly and can be there without us knowing.

People start to change as the dementia gets worse.





Someone with dementia may start to act differently, getting easily upset and shouting more.

Someone with dementia may forget about safety, leaving the cooker on or the door unlocked.

Someone with dementia will forget things, and may not remember family or friends.



What should I do if I think someone has dementia?

If you think someone has dementia, you should speak to their family or carer.

If you think you have dementia, staff or family members may ask healthcare professionals to speak to you.



Healthcare professionals may want to ask questions or do medical tests. They want to help and find out what the problem is.

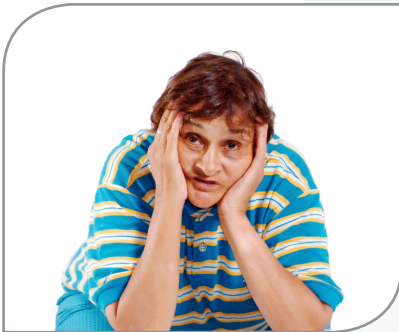
If it is dementia, how does it affect people?



People with dementia may not like doing things they use to like.

People will need extra help, which will increase as the dementia gets worse.

Eventually, the person's brain and body will stop working, and they will die.



These changes aren't always dementia

Changes can be caused by different things not just the dementia.



People may be feeling sad, or they may not be able to see or hear properly.

Doctors and other healthcare professionals can help to make some of these things better.

People with dementia still feel pain



When someone has dementia, they may struggle to tell others about their pain and where it is.

Someone with dementia may start to act differently if the pain is not treated.

Communication changes with dementia



As the dementia gets worse, people may find it harder to communicate.

Someone with dementia may not be able to find the right words, and become unable to speak.



They may forget other ways of communicating, such as sign language, or makaton.

Eating and drinking will change



As the dementia gets worse, people struggle to eat and to drink.

Someone with dementia may forget about meal times or how to use a knife and fork. They will need help.



Sleeping may change

Night time sleep may change when someone has dementia.

People may sleep more through the day.



Someone with dementia may stay awake and walk around at night, instead of sleeping.

They need people around them to be understanding.

What can help?



People can't get better with dementia. At the moment nothing can stop it.

People can help though.



Doctors can give people medicine and treatments which helps to slow down dementia.

Having patient people around the person with dementia will help.



It is important to remember that the person with dementia is still a unique, valuable person.

Everyone should be treated with respect.

How dementia can affect carers



Caring for someone with dementia can affect carers in different ways.

Carers need support too.

Carers may get upset when someone they know has dementia.



Carers may spend more time caring and helping someone with dementia.

Carers may have less time for themselves.



As the dementia gets worse, carers may need extra help and support too.

It is important that carers speak to someone if they need help. This may be their friend, doctor or someone they trust.

“ Sometimes people don't see me, they only see the dementia ”



Sarah's Story



Sarah is 65 and shares a house. Sarah's house mates started to notice that she had changed.

Sarah started to ask them repeatedly "What's the time?", even when people told her.



Sarah started to shout at them, and she got upset a lot more. Sarah didn't understand what was happening to her.



Sarah kept on forgetting where she had put things.

After some tests, Sarah was eventually diagnosed with dementia.

You can write notes or draw pictures about this story.



How does dementia affect Sarah?



How do you think Sarah feels?



What could help Sarah?

What could help Sarah?

Please tick the 'yes' or 'no' box to show what could help Sarah.

Staff and house mates knowing she has dementia, and that she needs extra support

Yes

No

Treating Sarah as a person, with respect

Yes

No

Giving Sarah short pieces of information, and giving her attention until the conversation is over

Yes

No

Having information about good support and care

Yes

No

Being patient, understanding and giving Sarah time

Yes

No

Understanding Sarah's actions are not always deliberate or on purpose

Yes

No

People getting annoyed because Sarah has forgotten something

Yes

No



“I know that I have changed but my family and carers still treat me the same”

Steve's Story



Steve was told he had dementia five years ago. He needs 24 hour care from carers.

Steve kept forgetting that he had left the cooker on.



Now Steve is struggling to speak and needs help from carers to get dressed, to stay clean, to eat and drink.



Steve hardly goes out now but enjoys spending time with his family and friends.

This still makes Steve smile and he feels happy.

You can write notes or draw pictures about this story.



How does dementia affect Steve?



How do you think Steve feels?



Who could help Steve?

What could help Steve?

Please tick the 'yes' or 'no' box to show what could help Steve.

Doing things he still enjoys, like spending time going out

Yes

No

People spending time to understand Steve him instead of judging him

Yes

No

Having trained carers, who can support people with dementia

Yes

No

Having his family and friends coming to visit Steve

Yes

No

People seeing the person not just the dementia

Yes

No

People ignoring Steve's forgetfulness as they are scared of upsetting him

Yes

No

Being patient and understanding that Steve needs more support

Yes

No

“Things are harder since James got dementia. I have less time for myself, but we still help each other”

Karen's Story



Karen is 75 and looks after her husband, James, who has dementia.



James is now unable to help around the house, and Karen is finding it difficult to do everything alone.

“Sometimes I feel alone, and have no one but James to speak to” says Karen.



Karen now spends most of her time caring for James.

She never sees her friends anymore.

You can write notes or draw pictures about this story.



How does James's dementia affect Karen?



How do you think Karen feels?



Who could help Karen?

What could help Karen?

Please tick the 'yes' or 'no' box to show what could help Karen.

Providing support for Karen	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
Having someone to talk to that Karen can trust and turn to	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
Knowing where and how to get help	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
Information about dementia, and how it will affect James and Karen	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
A support group nearby	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
Karen having some time to relax and do things she enjoys	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<hr/>		
Having no support or people to talk to when Karen feels sad or lonely	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Think about what could help if you or someone you know has dementia.



What do you want to find out?



Who could you get support from?



What could you do to help?

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Some of the information in this booklet is from:

www.learningdisabilities.org.uk

www.learningdisabilityanddementia.org

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