

Dementia: Essential Facts

What is dementia?

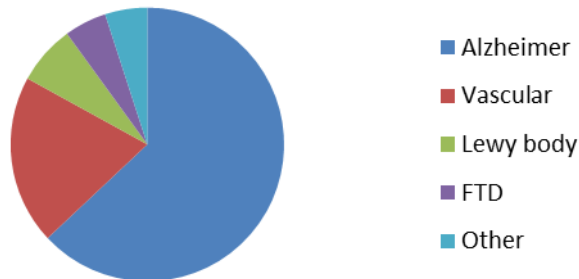


'Dementia' refers to a change in a person's thinking and memory abilities that is disabling; the changes go beyond mild slips of memory to create difficulties in performing the activities of daily life.

What causes dementia?

There are many different diseases and conditions that can cause dementia. Alzheimer's disease is the most common cause but only accounts for about 60 – 65% of all cases. Other common causes are vascular dementia (20 – 25% of all cases), Lewy body dementia (5 – 10% of all cases) and frontotemporal dementia (3 - 5% of all cases).

Causes



'Other' is very wide and includes over 50 different conditions that can affect the brain, including the late stages of other neurological diseases (e.g. Parkinson's), the late stages of physical diseases (e.g. AIDS or syphilis) and abuse of alcohol or other drugs

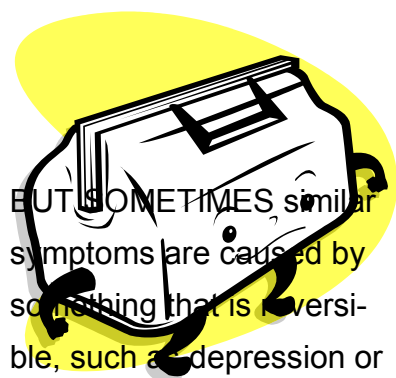
Dementia and age

Dementia is not a normal part of growing old but is caused by the onset of one of the brain diseases listed above. Risk of these diseases increases with age, but they are not inevitable:

Age	Risk level
Less than 60	Less the 1 in 1000 BUT do not forget younger people can get dementia
60 – 70	1 in 100
70 – 80	1 in 25
80 +	1 in 5

It is very difficult to tell the difference between the early signs of brain disease and the normal slowing of the memory, but the table on the next page gives some guidance. In essence, the normal signs of ageing result from the brain slowing down but there is no structural damage (i.e. brain cells are slower but still alive). Dementia, by contrast, is caused by progressive structural damage to the brain (i.e. brain cells die in significant numbers). The symptoms of dementia, therefore, are more severe; access to information and thinking skills is not merely slowed down and less reliable, chunks of information start to go missing and thinking skills are irreversibly lost. If you would like further information contact the Alzheimer's Society or make an appointment to see your GP

Can dementia be cured?



BUT SOMETIMES similar symptoms are caused by something that is reversible, such as depression or vitamin B deficiency. **This is why it is important to**

NO. The causes of dementia listed above are irreversible and progressive. Most people with dementia and their families are living with the very difficult knowledge that their impairments are going to get worse over time. **This is why it is so important that we include, value and support people who are affected by dementia within our communities.**

visit the doctor if you are worried. AND even though there are no cures, a diagnosis of dementia is the gateway into essential networks of support and help. **‘No**

cure' does not mean 'nothing can be done'.

Normal signs of old age – the brain is slowing down but is not damaged structurally:

- You get to the top of the stairs and wonder what you came up for
- You find it is harder to learn new information, to work a new gadget or adapt to a new environment
- You forget people's names and other details more than you used to
- You are experiencing a little bit of word finding difficulty in conversation
- Your brain gets tired more easily
- BUT although you forget details you do not forget whole events or conversations
- Although it is harder to learn, you can still learn
- When you forget something a little 'jog of the memory' usually brings it back
- Or it comes back several hours later when you are doing something completely different

Early signs of a dementing condition – the brain is not merely slower (although it will be), there are also signs of structural damage:

- You forget entire episodes or conversations rather than just names and details, even when people try to 'jog your memory'
- You start to forget a lot of appointments and get confused by time
- People tell you that you are repeating yourself but you can't remember saying it before
- Lost information and words do not come back later
- You find it difficult to hold the threads of thought together in order to achieve complex tasks (e.g. doing personal finances)
- Even though you make great efforts to pay attention and improve your memory, you still forget things
- You get lost within a familiar environment

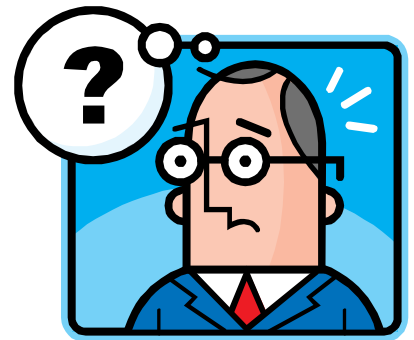
Common symptoms of dementia

If a person has dementia they will:

1. Have a very poor short term memory
2. Get confused easily in busy or complex situations

They might also:

1. Be repetitive in conversation
2. Have problems with concentration and attention
3. Struggle to understand what others are saying to them
4. Get lost, even in a very familiar environment
5. Experience problems with their visual perception, causing them to drop things, bump into things or be anxious about moving around
6. Experience problems with everyday tasks (washing, preparing meals, handling money, using a knife and fork)
7. Become very anxious and worry obsessively about certain things
8. Experience paranoid or delusional thoughts about family and neighbours (e.g. people stealing from them, eavesdropping, tapping into their electricity, moving the boundaries of their property etc)
9. Become confused by the television or telephone (e.g. think there are real people inside the television, think television presenters are their personal friends, be confused as to how a voice can come out of the telephone)
10. No longer follow the 'rules' of appropriate social behaviour
11. Lose their inhibitions (e.g. tactless comments, swearing)
12. Believe that the present is the past – many people with dementia start to interpret the present in terms of their past life (they may believe they are at work, looking after a family, they need to get back to an earlier home etc)



Long term memory

In the early stages long-term memory usually holds up whilst short-term memory is badly affected. This is why many people believe they are living in a time several decades earlier. They still see the present environment, but because only old memories are left, these old memories are used to interpret what is happening now. For example, in the early evening it is common for people to get restless because they feel they ought to be going home from work or collecting children from school. Many apparently strange behaviours reflect habits from the person's past life (e.g. people who worked as security guards repeatedly checking doors, a hospital ward making someone believe they are in an army barracks). **It is not easy to find solutions to calm behaviours being driven by confusions between past and present, but it is important to start from where the person is rather than where we are. We must acknowledge and work with their mis-placed beliefs, and especially the feelings and anxieties they create. Don't reject their beliefs and challenge them with the facts of our reality; we have to accept that our current reality is now beyond the reach of the person.**

When the person no longer knows who they are

By the mid to late stages of a dementia many people will have lost their language skills and know very little about who they are and their life history. **This is very hard for friends and family and it is tempting to think visiting is pointless. But the person is still alive and needs social contact; that need is never lost.** Friends and family do remember who the person is and their life history; it is very painful but there is a call to remember and hold this knowledge within ourselves when we go to visit so that our love for who the person was in the past can be turned into love for the person in the present; diminished but still alive.

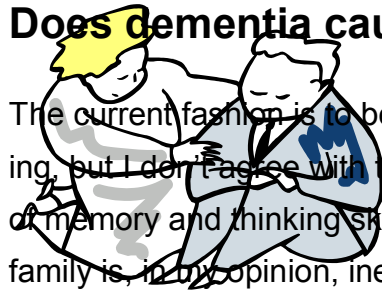
HOWEVER, most people on the outside under-estimate just how painful it is to see someone you have loved for a long time so diminished. **Many people cannot bear to visit; it is just too painful.**

- **If this is you**, don't feel guilty and don't force yourself to visit. Forcing yourself to visit can deny and repress the pain, causing more damage in the long run. Make some space for yourself so you can be alone with your pain: offer your pain up to God and pray for strength to work through it. If you face up to

the pain in this way you are more likely to be able to work through it into a place of acceptance which makes visiting possible and easier.

- **If this is someone else** – don't judge.

Does dementia cause suffering?



The current fashion is to believe that dementia does not necessarily produce suffering, but I don't agree with this. When faced with a devastating and progressive loss of memory and thinking skills then deep grief for the person and their friends and family is, in my opinion, inevitable. The losses also make the ongoing need to keep going with daily life difficult, frustrating and exhausting for everyone.

HOWEVER, people with dementia consistently report that it is **not the symptoms** themselves that cause them the most suffering, but the **attitude of other people** towards their symptoms. And it is true that, with the right help and support, people with dementia can experience a good quality of life. We cannot do anything about the losses, but we can do something about our attitude. This will not eliminate the suffering but it will make a big difference in terms of alleviating it and reassuring people that we are not leaving them to suffer alone.

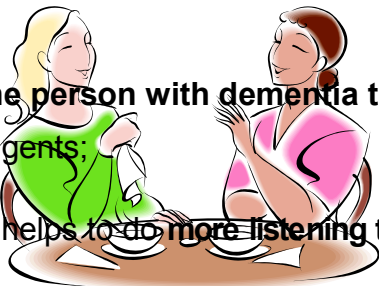
People with dementia need to feel:

- That they are still valuable and loved even though their mental skills are now diminished
- That they are listened to and still have some degree of control over their lives
- That they are still recognized and treated as a person (rather than an object of care)

DO NOT confront people with their mistakes and confusions. Try to help people without drawing attention to their confusions. Try not to be continually correcting the person. Don't speak to the person as if they were a child. Be sensitive to the person's feelings and needs and make sure these are taken into account when making decisions, but also remember that the main carer has feelings and limitations too. Carers should not feel that every decision must be made for the person's benefit and not their own. Sometimes the carer's needs need to come first (e.g. attending day care against the person's wishes).

Keeping people included

- Find opportunities to talk, or share without talking, in **quiet places**;
- The person with dementia needs the **full attention** of those who are talking with them;
- **Give the person with dementia the lead**; learn to be tolerant of repetition and tangents;
- It often helps to do **more listening than talking**;
- Find ways of **acknowledging** (regular eye contact and a smile is good) and **involving** people (e.g. by 'buddying') in group situations where they may get overshadowed and overwhelmed;
- **Slow down** and **repeat** things (without any tone or signs of frustration);
- Let go of the informational level and **work at an emotional level**; often repetitions and tangents are covering something that is emotionally important to the person;
- If you cannot understand what the person is trying to tell you treat this as puzzle that you can try to solve together – **be patient** and give the person time and space to show you what they mean;
- If you cannot work out what it is the person is trying to tell you **don't worry**; the process of trying to understand makes people feel acknowledged and this is more important than being understood;



Communication without words

Don't give up on someone because they have lost their words. **The loss of social connection hurts much more deeply than the loss of words.** When words have gone the challenge is to find **ways of spending time together that do not involve words.**



- **Simple pleasures** are a good source of inspiration. What music does the person like? Can you listen together? Or does the person like to sit outside in the sun and listen to the birds?
- **Let them show you the way** and learn to 'go with the flow". What are they interested in at this moment? What is capturing their attention? It may well be something apparently random or meaningless but can you watch them and try to see what it is that is engaging their attention so you can share in it?
- Don't get anxious (may need practice!). People with dementia are very sensitive to the emotions of others. If you are putting yourself under pressure 'to get it right' they will pick up on this and become anxious themselves. On the other hand, if you are relaxed and allow yourself to enjoy the moment, then they will relax and be able to share the moment with you.
- **Familiar hymns, psalms and prayers** are comforting to many people; it is now well established that **singing holds up well** in dementia and brings joy to most people
- **Touch** is the most direct sense for communication, but **you must have a person's trust and permission**. Will the person allow you to hold their hand so that they know you are there? Maybe the person will start tapping your hand? What if you tap back? Can you have a 'tapping' conversation in which no words are exchanged but you both know the other is present and connected?
- **Don't equate mistakes and bad times with failure**

Sometimes your time together will be successful, other times it will not.

Sometimes people with dementia are tired or upset and it is impossible to get a good connection. It is unreasonable to expect anyone to be calm and happy all the time; this applies just as much and maybe even more so if a person has dementia. We need to be flexible; learn to value the good times and share the bad times in as far as they want this. We have to accept that sometimes our presence is an irritation and not a balm and know when is the right time to leave and come back later.