

**Booklets in the Living with dementia series**



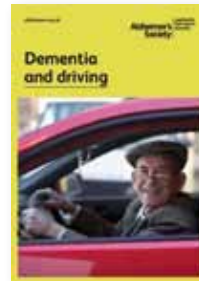
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Reviewed in 2008 by members of the Alzheimer's Society Living with Dementia programme and revised 2010. This series of booklets has been made possible through the generous support of Francelle Bradford.  
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Registered charity no. 296645 A company limited by guarantee and registered in England no. 2115499  
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# What your diagnosis means for you



You have just found out that you have a diagnosis of dementia. This can be a frightening time, and you may feel low and dispirited. This publication looks at how you may be feeling, and suggests ways of coping. It is important to remember that everyone is different: there is no 'right' or 'wrong' way to feel. Whatever you feel is right for you, at this moment.

This booklet looks at what dementia means, how it may progress, how many people feel and how to cope. Further publications in this series look at some of these aspects in more detail.

## What is dementia?

Dementia is a physical illness that causes problems with memory, thinking, speaking and doing. Physical changes in the structure of the brain cause dementia. These changes can be seen on brain scans, which can help in diagnosing dementia. You are not mentally ill, and you are not going mad.

Several different conditions can cause dementia – Alzheimer's disease, vascular dementia, fronto-temporal dementia (including Pick's disease), dementia with Lewy bodies, and others.

**Alzheimer's disease** is the most common cause of dementia. During the course of the disease, 'plaques' or 'tangles' develop in the structure of the brain. These change the structure of the brain, and lead to the death of brain cells. The brain also needs certain neurotransmitters (chemicals that help messages travel through the brain) to function properly. People with Alzheimer's disease have a shortage of some of these neurotransmitters.

| 'If only I could clear my brain  
and stop the confusion.'

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**Vascular dementia** is caused by damage to blood vessels in the brain, which leads to the death of brain cells. Several conditions can cause this – high blood pressure, strokes, heart problems, diabetes and high cholesterol.

**Fronto-temporal dementia** covers a range of conditions, including Pick's disease, frontal lobe degeneration and dementia associated with motor neurone disease. All are caused by damage to the frontal lobe or the temporal parts of the brain. These areas are responsible for behaviour, emotional responses and language skills.

**Dementia with Lewy bodies** is a type of dementia that shares characteristics with Alzheimer's and Parkinson's diseases. Small protein bodies develop in the brain, and cause the death of brain cells.



## How will dementia affect you?

The various forms of dementia affect people differently, and your experience of dementia will be unique to you. Your physical make up, your emotional resilience and the support you have will all have an effect. You are also likely to feel different at different times. Don't worry if sometimes it all seems to be overwhelming. The bad times do pass.

### Some signs of dementia include the following:

- Finding it easier to remember things that happened a long time ago than things that happened recently.
- Forgetting things you've just said.
- Finding it harder to grasp new ideas; feeling more comfortable with ideas you are familiar with.
- Feeling uneasy in new surroundings.

**'I begin to think I can manage something. Then all of a sudden it goes.'**

# Feelings

## Shock, disbelief, denial

- Shock, leading to disbelief or denial is a very common reaction. Sometimes denial can be a good thing, and can help you cope with the reality of your disease at your own pace.

## Fear

- Often, the biggest fear is of a loss of control – over the future, and over one's own life. Not knowing can be very frightening indeed.
- Common fears include becoming a burden to one's family, becoming demanding and difficult, and generally being a nuisance.
- You may be frightened of passing your condition on to your children.
- Many fears are of physical indignities, such as becoming incontinent and dribbling.

‘Am I to blame for any of this?  
I can't move on until I know.’

## Guilt

- Guilt is a very common reaction. You may think that you have done something wrong, or not tried hard enough to prevent the disease. You may even feel you're to blame. Be assured: this is an organic disease, whatever the type of dementia. It is not your fault.

## Sense of loss

- You may feel sad that perhaps you will not be able to do some of the things you'd planned.

## Relief

- This may seem strange to some, but you may feel relieved that you finally have a diagnosis. There may even be a sense of euphoria – now that you have a concrete diagnosis, you can do something about it.

## Acceptance

- You may never accept your illness. This is OK. You will find a way of living with it.

## How to cope with the feelings

- Talking with other people can help. You may find that you only want to talk to your husband or wife, or close family. Or it may be difficult talking to those closest to you. Think about joining a support group. Many people with dementia find it helpful to talk to other people in the same situation. Your local branch of the Alzheimer's Society will be able to help you. The number will be in the local phone book, or you can call the helpline on 0845 3000 336.
- Think about what you may need in times ahead. Talk to your family about it. The Alzheimer's Society publishes Fact sheet 471 After a diagnosis, that prompts you to prepare for your future health and finances. Call the helpline to request a copy. You need

to think about these things now. It can take the fear away, knowing that you have control over future events. Or if not control, knowing that you have a say in what happens.

- Discuss your treatment with your doctor. Several types of treatment can make your dementia easier to live with. These include drugs, counselling, group support, occupational therapy and complementary therapies. Again, it helps to feel in control if you know what your treatment will be, and have a say in what you do. You may also find support is available from social services and other voluntary organisations, such as MIND, Age Concern, the Samaritans, as well as the Alzheimer's Society.

**'Being encouraged to do as much as possible keeps me going. It stops me feeling unwanted and builds my confidence.'**

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- Stay active: exercise will make you feel better. Carry on seeing your friends and doing the things you enjoy doing.
- Sometimes writing down your feelings can help. It can help to have a record of the bad times as well as the good. The bad times will pass.
- Many people say that keeping a sense of humour makes everything easier to bear.



## Conclusion

There are ways of living with dementia. It can be painful to think about it, and it isn't always easy to ask for help. It needs courage, and the way can be hard, but there are people who will be with you on your journey.

**‘Support is the key to leading as normal a life as possible. People knowing and treating me as the person I still am. Giving me room to live.’**

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