

Frontotemporal dementia (FTD): Understanding your diagnosis





About this booklet

If you have recently been diagnosed with frontotemporal dementia (FTD) – including Pick’s disease – this booklet is for you. It will help you, and your family and friends, to understand more about the condition and how it can affect you. It covers some of the feelings you might have and suggests ways of staying positive.

In section 2 you can read about what FTD is. This booklet also includes information about different aspects of living with dementia including the treatments, support and services that are available.

You are not alone – in the UK there are at least 16,000 people living with FTD, and around 850,000 people in total living with dementia.

It is possible to live well with FTD. Support is available for you and the people who are important to you.

We produce a number of other resources that can give you more information on particular topics. These are mentioned throughout this booklet. To order any of the resources you can:



[go to \[alzheimers.org.uk/publications\]\(https://www.alzheimers.org.uk/publications\)](https://www.alzheimers.org.uk/publications)



call 0300 303 5933



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Coping with your diagnosis

When you find out you have frontotemporal dementia (FTD), you may feel a range of emotions. Take time to think things through.

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There is no 'right' or 'wrong' way to feel about your diagnosis. However you feel, it is right for you, at this moment. You may be shocked that you have FTD, or find it hard to accept. You may feel that you haven't changed much (or at all). It may also have taken a long time to get a diagnosis of FTD.

Now you have a diagnosis, it is important to give yourself time to think things through. And don't worry if it all seems to be overwhelming at first. There are good and bad times, and with support, many people come to terms with their diagnosis.

Things you should try to think about after a diagnosis include:

- your emotions and relationships
- treatments and ways to stay active and healthy
- financial matters and planning ahead
- your job (if you're working)
- driving
- practical and emotional support – from the NHS, social services, private companies or voluntary organisations.

You won't need to think about all these things straightaway, so take things at your own pace.



Managing your feelings

You may have a number of different feelings after a diagnosis. This is normal and there are ways to cope with them.

- You may have felt (and still feel) a sense of shock, especially if you are middle-aged or younger. You may not have thought of dementia as a condition that affects people of your age. You may be feeling angry that you have dementia.
- You may find it hard to accept that you are having problems or that things have changed – though other people may have noticed changes.
- Many people feel a sense of sadness or loss after their diagnosis. You may feel that you will no longer be able to do the things that you enjoy or that you had planned. It is true that having dementia may mean you need to make changes. But with the right information and support, you should be able to carry on with many regular aspects of your life for some time.

‘When talking to others, let them know early on about your challenges. That way they can help and will understand any difficulties you are having.’

Person living with FTD

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- Fear is another possible reaction. You may be afraid of the future, of losing control or of becoming a burden to your family. Talking about this with others can help. It is important not to feel that you are on your own.
- A few people feel relief after a diagnosis. This may sound strange to some, but it can be better to have a reason for the changes you have been experiencing. This can be especially true if it has taken time to get a diagnosis and you've been worried about what else might have caused these changes. Once you have a diagnosis, you can deal with it and do something about it.

Some people find it helpful to talk about their diagnosis with others. You might not want to, but if you do, speak to close family or friends, other people with dementia or a qualified professional such as a counsellor or psychotherapist (see 'Health and social care professionals' on page 49).

Changes to relationships

Living with FTD is likely to affect your relationships with people. You may have found that some of your relationships have already started to change.

You and the people around you will need to adapt to new challenges. It is important to be aware of this. Changes in your behaviour can be very difficult to adjust to and may affect how others react to you. People may be surprised or even upset by things you say and do.

If you want to, try talking about these changes openly with those people. You may wish to look for professional help, such as relationship counselling or support groups, to help you adjust.



Ask your GP or local Alzheimer's Society about what's available in your area, or search at alzheimers.org.uk/dementiadiirectory

Some people with FTD have less sympathy or empathy – they may seem to have no interest in other people or events, or not care about how others are feeling. It is important that the people who matter to you are aware that this change is caused by FTD and is not directed at them.

As you need more help in daily life, a partner, family member or close friend may take on the role of caring for or supporting you. They will also need information and support.



People who support you may wish to look at factsheet 404, What is frontotemporal dementia (FTD)?

Telling children

If you have young or older children, nieces, nephews or grandchildren, it is important to tell them about your dementia. Try to have this conversation as early as you can.

For around 1 in 8 people with FTD there is a strong pattern of inheritance (where the condition is passed down the generations). Children might become aware of this and worry about it, so it is important for the family to listen to their concerns. How you approach this will depend on different factors, such as your circumstances and the child or children's age. Specialist help is available. For more information see 'Genes and FTD' on page 13.



For more information on how dementia can affect your relationships with others see booklet 1507, Your relationships.



For more help and advice call Dementia Connect support line on **0333 150 3456**





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What causes dementia?

Dementia is not a natural part of ageing. It is the name for a group of symptoms that occur when the brain is affected by a disease.

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Dementia is caused by physical changes in the brain that happen as the result of a disease. Symptoms of dementia may include memory loss and difficulties with thinking, planning, problem-solving, perception or language. They are severe enough to interfere with daily life. Some people also find that their mood or behaviour changes.

The symptoms of FTD are often different from those of most types of dementia. For more information see section 3, 'How does frontotemporal dementia affect people?'

What is frontotemporal dementia (FTD)?

FTD – which includes Pick's disease and is also known as frontal lobe dementia – happens when two parts of the brain are damaged by disease. These are the frontal lobes and the temporal lobes.

When cells in either or both of these parts of the brain die, this leads to the symptoms of frontotemporal dementia.

There are three types of FTD and they lead to different changes:

- behavioural variant FTD – this affects behaviour first
- progressive non-fluent aphasia – this affects language first
- semantic dementia – this also affects language first.

Progressive non-fluent aphasia and semantic dementia are both types of a condition called primary progressive aphasia (PPA). For more information see section 3, 'How does frontotemporal dementia affect people?'



As FTD is a lot less common than other types of dementia like Alzheimer's disease and vascular dementia, many people may not have heard of it (including some healthcare professionals).



It may help to suggest that they read this booklet, or factsheet 404, What is frontotemporal dementia (FTD)?

Genes and FTD

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FTD is much more likely than other forms of dementia to be hereditary (passed down through generations). You may know of close relatives who also have FTD. This hereditary aspect of FTD can cause families a lot of anxiety.

Speak to your GP about any concerns or questions you have. If there is likely to be a genetic cause to your FTD, you should be offered genetic counselling (where you speak to an expert about this) and the option of genetic testing (being tested for certain genes).



For more information see factsheet 405, Genetics of dementia.

'Remember, you are the same person the day after your diagnosis as you were the day before.'

Person living with FTD





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How does frontotemporal dementia affect people?

Frontotemporal dementia (FTD) affects everyone differently. However, some common changes in people with FTD are described in this section. You might recognise some of your experiences here.

Early changes

The early changes in people with FTD are usually different from those in people with the most common types of dementia (Alzheimer's disease and vascular dementia).

There are three main types of FTD. The changes that you experience will depend on which of these you have.

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Behavioural variant FTD

If you have behavioural variant FTD, early changes you may experience include:

- losing motivation or interest in people and things (apathy)
- showing less sympathy or empathy (for example laughing at bad news), or losing your sense of humour
- losing your inhibitions (such as sexual inhibitions) or behaving in ways that are socially inappropriate
- doing impulsive things and taking risks you wouldn't normally take
- saying or doing things repetitively, such as saying the same word over and over or checking the door is closed again and again
- developing obsessions or needing to stick to rigid routines
- craving sweet or fatty foods or carbohydrates.

You may also struggle with planning, judgement and making decisions. You, or others, may have first noticed these kinds of changes when you've been at work or doing complicated things like managing finances.



Unlike someone with Alzheimer's disease, you are less likely to have problems with your day-to-day memory, or with judging relationships and distances between objects (visuospatial skills). However, a few people with FTD still experience these problems.

Progressive non-fluent aphasia

If you have progressive non-fluent aphasia you are likely to have problems with speech. ('Aphasia' means loss of language.) These may include:

- speech being slow or hesitant and taking a lot of effort – this may also include stuttering or mispronouncing words
- making mistakes in grammar – maybe leaving out small link words such as 'to', 'from' or 'the'
- finding it difficult to understand complex sentences.

Semantic dementia

If you have semantic dementia, you will be able to pronounce words as normal but you are likely to struggle with your vocabulary and understanding of what objects are. Early changes may include:

- asking the meaning of familiar words – for example, 'What is a 'fork'?'
- having trouble finding the right word, so using descriptions instead (such as 'the thing for opening tins') or using less precise words (such as 'animal' instead of 'cat')
- difficulty recognising familiar people or common objects.



In the early stages of both progressive non-fluent aphasia and semantic dementia you are much less likely to experience problems with other mental abilities, such as memory, planning and organising. However, a few people do experience these problems.

Other conditions

About 10 to 20% of people with FTD develop another condition called a motor disorder (a problem with movement). In particular they might develop:

- motor neurone disease (MND)
- progressive supranuclear palsy (PSP)
- corticobasal degeneration (CBD).

The symptoms of these conditions are similar and can include:

- twitching
- stiffness
- slow movements
- loss of balance or co-ordination.

Like dementia, these conditions get worse over time. For more information on these conditions, see 'Other useful organisations' on page 57.

Later stages

FTD is progressive. This means your symptoms are likely to become worse over several years and you will need increasing amounts of help. As the condition progresses, the differences between the three types of FTD become much less obvious:

- if you have behavioural variant FTD, you are likely to develop problems with language in the later stages
- if you have progressive non-fluent aphasia or semantic dementia, you are likely to develop changes in behaviour.

Everyone is different, but you may begin to experience other changes, such as:

- having more severe problems with communication
- losing weight and having difficulties with swallowing or eating
- having problems recognising familiar faces
- further changes in behaviour – becoming more restless, agitated or aggressive
- problems with using the toilet or continence.

In the later stages of FTD, someone will generally need full-time care and support. This may be distressing to think about, but it can help to be prepared.







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Treatments

Although there is no cure for frontotemporal dementia (FTD), it is possible to live well with the condition, with the right support.

Treatment for FTD usually involves a number of different health and social care professionals. These might include a:

- GP
- community nurse
- psychiatrist
- clinical psychologist or counsellor
- speech and language therapist
- occupational therapist
- physiotherapist
- homecare worker.

See 'Health and social care professionals' on page 49 for more details on the ways in which these professionals can help.

Non-drug treatments

Most treatment for FTD does not involve drugs. Non-drug methods that may help include:

- support groups – these are for people who are living with FTD to talk to each other
- speech and language therapy – this can help you use the skills you have for communicating, and to develop new ones. In the later stages of dementia, speech and language therapists can also help with any difficulties you have with swallowing

- physiotherapy – this can help you to move around and exercise
- occupational therapy – this can help you to maintain your independence and ability to do day-to-day and leisure activities
- talking therapies – counselling, psychotherapy or cognitive behavioural therapy (CBT).

Ask your GP, memory service or local Alzheimer's Society (if you have one) for details of what groups and activities are available in your local area. You can also search for local services at alzheimers.org.uk/dementiadirectory

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Drug treatments

There are a few drugs that may be offered to a person with FTD. If you have apathy or changes in behaviour, the doctor may offer you an antidepressant. You may be offered an antipsychotic drug (medication usually used to treat mental health conditions such as schizophrenia). The doctor should explain the risks and benefits to you and any carer.

The drugs that are routinely given to people with Alzheimer's disease don't work for FTD and you should not generally be offered these.

'It may be difficult today but tomorrow is another day.'

Person living with FTD





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Living well

Living with dementia is challenging. You may feel angry or frustrated at times. Your plans for the future might change, but dementia doesn't change who you are.

It may take you time to adjust to living with dementia. Your plans for the future might change, but dementia doesn't change who you are – even though it may change aspects of your behaviour and personality.

You might feel like you no longer want to go out or stay involved with the activities you usually do. However, it's important to keep enjoying the things you did before your diagnosis.

To start with, it may be hard to adjust, but you should still be able to continue doing many of the things you do now. Sometimes you will need to make small changes, such as watching shorter programmes rather than full-length films, or asking a family member to help you with tasks – for example, uploading photos from your phone to your computer.

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Above all, keep active and try to remain positive about the future.

Keeping active

Adjustments can be made to help you do certain activities or interests. With support, it should be possible to continue doing the activities you enjoy. Consider new ones too – perhaps crosswords, walking, gardening, cooking, watching videos or playing games online (or on a console). If you enjoy music, you might find listening to music, singing or playing an instrument can help give you a routine. Focus on the things you can and want to do.



Activities that you enjoy or are important to you can help you stay independent and feel engaged in what you're doing. They can also keep you in touch with other people, help you to feel confident, and improve your quality of life. If you are a younger person with FTD, try to find a group of people who are closer to you in age. They are more likely to be doing things that you will enjoy.



**For more information see booklet 1506,
Keeping active and involved.**

Staying healthy

Having frontotemporal dementia doesn't mean you should feel ill. See the doctor if you're feeling unwell, or if someone you trust suggests that you should. If you have other medical conditions (such as diabetes, or heart or breathing problems) it is particularly important to have regular check-ups for these.

Staying healthy is important and can make a big difference to your quality of life. There is a lot you can do to stay healthy (or improve your health) including exercise, eating and drinking well and taking care of your physical health.

It is important to eat enough as if you don't you might be more tired and likely to develop infections. Not drinking enough could lead you to become dehydrated and confused.

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**For more help and advice call Dementia
Connect support line on 0333 150 3456**



You might find the following tips useful:

- Try to eat balanced meals and drink plenty of fluids.
- Take regular physical exercise.
- If you smoke, consider stopping.
- Try to get enough sleep.
- If you find yourself regularly feeling low, anxious or irritable, see your GP.
- If you are in pain, it is important to tell your doctor or carer.
- Have regular check-ups for your eyesight, hearing, teeth and foot care.
- If you enjoy the occasional alcoholic drink, you might want to keep doing this (unless you choose to stop because the alcohol is making you more confused, or your GP advises you to stop).

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Communicating

Many people with dementia find communication becomes more difficult over time. If you have one of the forms of primary progressive aphasia, this will happen earlier on. With behavioural variant FTD, problems with communication are likely to develop later on.



For more help and advice call Dementia
Connect support line on **0333 150 3456**

These problems can be very frustrating and upsetting. They can lead someone with FTD to feel less confident. However, there are things that you or the people supporting you can do to make communication easier:

- Make sure the environment is quiet without lots of distractions (such as the TV on in the background).
- If you're working and find your workplace environment difficult, ask to be moved to a quiet area, or see if you can work from home.
- If you find speaking difficult, find other ways of communicating – for example, writing, typing on a keyboard, drawing or using facial expressions or gestures.
- Let people know how they can help you – for example, talking slowly and giving you more time.
- Ask your GP or consultant for a referral to a speech and language therapist.
- Use technology that can help – for example, a tablet device.

If you have progressive non-fluent aphasia, it may also be helpful to:

- use email, texts or post rather than phone calls to keep in touch
- use cue cards with specific messages, words or pictures
- use devices that have words and phrases stored on them.

If you have semantic dementia, it may also be helpful to:

- communicate with one person at a time rather than in a group
- find other ways of communicating, like drawing, gestures, using technology such as a tablet computer and facial expressions.

Getting involved

Sharing your experiences can help research into the cause, cure, care and prevention of dementia. There are two main ways you can do this:

- **Taking part in research** – this could involve completing questionnaires or interviews about your experiences, or trials for new treatments. You can register your interest in this by contacting Join Dementia Research. This service matches anyone interested in dementia research with studies taking place in their area. For more information see www.joindementiaresearch.nihr.ac.uk or contact Alzheimer's Society on **0333 150 3456**.
- **Planning and designing research** – this gives you an opportunity to influence our research at every stage including identifying topics for research. Involving people with dementia helps to make sure that research focuses on benefits for them now and in the future. To find out more about contributing to research go to alzheimers.org.uk/researchnetwork

Getting involved

Other ways to get involved

There are lots of other ways to get involved in the work of organisations that support people living with dementia:

- Alzheimer's Society is keen to hear from people who are living with or affected by dementia to contribute to our work in different way. These include reviewing information and publications about dementia, and sharing your experience of dementia with the media. For more information visit alzheimers.org.uk/yoursay
- The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. For more information visit www.dementiavoices.org.uk
- The Dementia Action Alliance is a network of organisations across England that aim to transform the lives of people with dementia. For more information visit www.nationaldementiaaction.org.uk







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Planning ahead

As frontotemporal dementia (FTD) progresses, it will become harder for you to make decisions about your health, care and finances. If you are able to, try to think about your future, talk to others and plan ahead as soon as you can.

Health and social care

Advance care planning

You can make decisions now so that your future care is handled in a way that reflects your wishes – known as ‘advance care planning’. It can help you to worry less, knowing that you have some control over future events.

Advance care planning may include setting up:

- a Lasting power of attorney (see page 37)
- an advance statement – where you can state your general wishes for the future (this should be followed but is not legally binding)
- an advance decision to refuse treatment (ADRT) – where you can state your wishes to refuse certain treatments, including cardiopulmonary resuscitation (CPR) if your heart or breathing stops (this is legally binding).

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Talking about care as your needs change and increase – including care at the end of life – can be difficult for you and your family. It is important to have these conversations sooner rather than later, but have them in a way that works for you.



For more information see factsheet 463, Advance decisions and advance statements. In Northern Ireland see factsheet NI467, Financial and legal tips.



Lasting power of attorney

In England and Wales, a Lasting power of attorney is a legal document that gives an adult the authority to make decisions for another adult. Having an LPA will make it possible for someone you choose to make certain decisions for you, should the time come when you are not able to make them for yourself.



For more information see factsheet 472, Lasting power of attorney.

In Northern Ireland someone can make an Enduring power of attorney (EPA) to appoint someone they trust to manage their finances and any property if they are unable to do this in the future.



For more information see factsheet NI472, Enduring power of attorney and controllership.

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‘Sort out the legal aspects like Power of attorney and your will. Having done this, get up, get out and get on with your life.’

Person living with FTD

Employment

Many people with FTD say that their first symptoms appeared at work. You may already find it difficult to plan and organise your work, or to make decisions. However, you don't have to give up work just because you have dementia. Some people work for several years after they receive a diagnosis of FTD.

You will know what's best for you. You may decide that you no longer want to work, or that the type of work you do means it isn't possible to carry on.

This can be a very difficult decision to make and it is important to take the time you need to think this through. Work may be important to you for lots of reasons which are not just financial. It may give you independence and a community, and may be part of your identity.

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It's best to tell your employer about your diagnosis of dementia and let them know whether you want to carry on working. Check your contract as it may state that you are required to tell your employer.

By telling your employer you gain certain legal rights. Your employer cannot discriminate against you on the basis of your diagnosis. You can also ask for 'reasonable adjustments' – changes to your working practice that will enable you to carry on working for longer.



For example, some people may ask to be able to work in a different location, such as an office closer to home, or to work from home. It may be that having more breaks or longer breaks can help.

Reasonable adjustments can also include equipment and adaptations, and there is a lot of assistive technology that can help people with dementia in the workplace. Your employer can only turn down your request for adjustments if they have a business case for doing so.

Some people ask to take a less demanding job or a position with less responsibility. It may help to think carefully about your role and what will be most helpful for you.

Sometimes people with dementia feel that they are able to continue in their current role, while their manager or other colleagues do not agree. If this is the case for you, you may find it helpful to involve someone close to you in a conversation with your employer, to try and understand why they do not feel you are able to continue working. The following tips may be helpful.

- Look at any relevant policy that your employer may have, such as an equality and diversity policy, or a dignity at work policy.
- Involve your human resources (HR) team or department if this is possible and you believe it would be helpful.
- If you are a member of a union, contact them as they may be able to offer support.

In some cases it may help to speak to a solicitor about your legal rights.





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Financial matters

Managing your money

Many people with dementia find some aspects of managing their money more difficult. There are lots of things you can do to make dealing with money easier.

Ways to pay

Find a way to pay that works best for you. This might be using:

- cash
- a Chip and PIN debit card
- a contactless bank card
- direct debit
- cheque.

Bank account

There are things you can do to make managing these easier, including:

- using telephone banking, which allows you to access your account and make payments over the phone
- registering for online banking, which allows you to do many of the things you do in your branch, including:
 - viewing your balance and statements
 - making payments
 - managing standing orders
 - setting up direct debits.



Trusts

If you have property or savings, you might want to set up a trust. This is a legal arrangement that allows someone to hold these things (your assets) on your behalf. It will ensure that your money is managed in the way you want from now on.

Keeping money safe

After a diagnosis of dementia, there are things you can do to make sure your money is safe in the future. People with dementia can be more vulnerable to financial scams and tricks.

Things you can do to keep your money safe include keeping good records of finances, and asking your bank to put a limit on how much money can be taken from your account at any one time. If you are employing a carer or people to support you at home, run background and reference checks through a DBS (Disclosure and Barring Service) check. For more information go to the GOV.UK website.

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For more information on managing finances see booklet 1501, Managing your money.

Benefits

People with dementia and their carers may be entitled to a range of benefits.

- If you are working, you may be entitled to working tax credits or statutory sick pay.
- If you are not working, you may be entitled to employment and support allowance (ESA) or income support.



- Whether or not you are working, you may be entitled to Personal independence payment (PIP), Housing benefit or help with council tax.

Some of these benefits are means-tested so they depend on income or savings. Accessing them can seem complicated but there are people who can advise on what to claim for.

The forms for applying for these benefits can be long and detailed. Try to get help from someone who can complete these forms with you. Help may be available from:

- a social worker
- a local welfare rights service
- Citizens Advice or Age UK
- the GOV.UK website
- the Department for Social Development (in Northern Ireland).

For some benefits, the Department for Work and Pensions (DWP) can arrange for someone to visit you at home.



**For more information see factsheet 413,
Benefits for people affected by dementia.**



Legal matters

Driving

Having a diagnosis of dementia doesn't always mean you have to stop driving straightaway, though you may already have stopped driving or be thinking about giving up soon.

If you have a driving licence, the law says you must:

- inform the Driver and Vehicle Licensing Agency (DVLA) in Great Britain, or Driver and Vehicle Agency (DVA) in Northern Ireland, as soon as possible
- inform your car insurance company.

The DVLA or DVA will ask your doctor for a report. They may also ask you to take a driving assessment. They will use these to decide whether you are still able to drive.

The DVLA or DVA may decide you can no longer drive safely – or you may decide to give up driving voluntarily. This could be for different reasons – for example, if you're feeling less confident, getting more irritated, or if you're getting lost on roads you know well or struggling to judge distances.

If you do need to give up driving, you might find this difficult at first. Sometimes people feel they have lost their independence or freedom. If you have dependent children it can be especially hard, as they may rely on you for lifts.

It can take time to adjust to this. You might find it helpful to think about other ways of getting around. Find out what public transport services are running in your area and when.



Try to focus on the benefits of not driving as well – for example:

- you no longer have to try and find a parking space or remember routes
- you can save money on car insurance, road tax, maintaining your car and petrol
- if you walk more it's a chance to get more exercise.



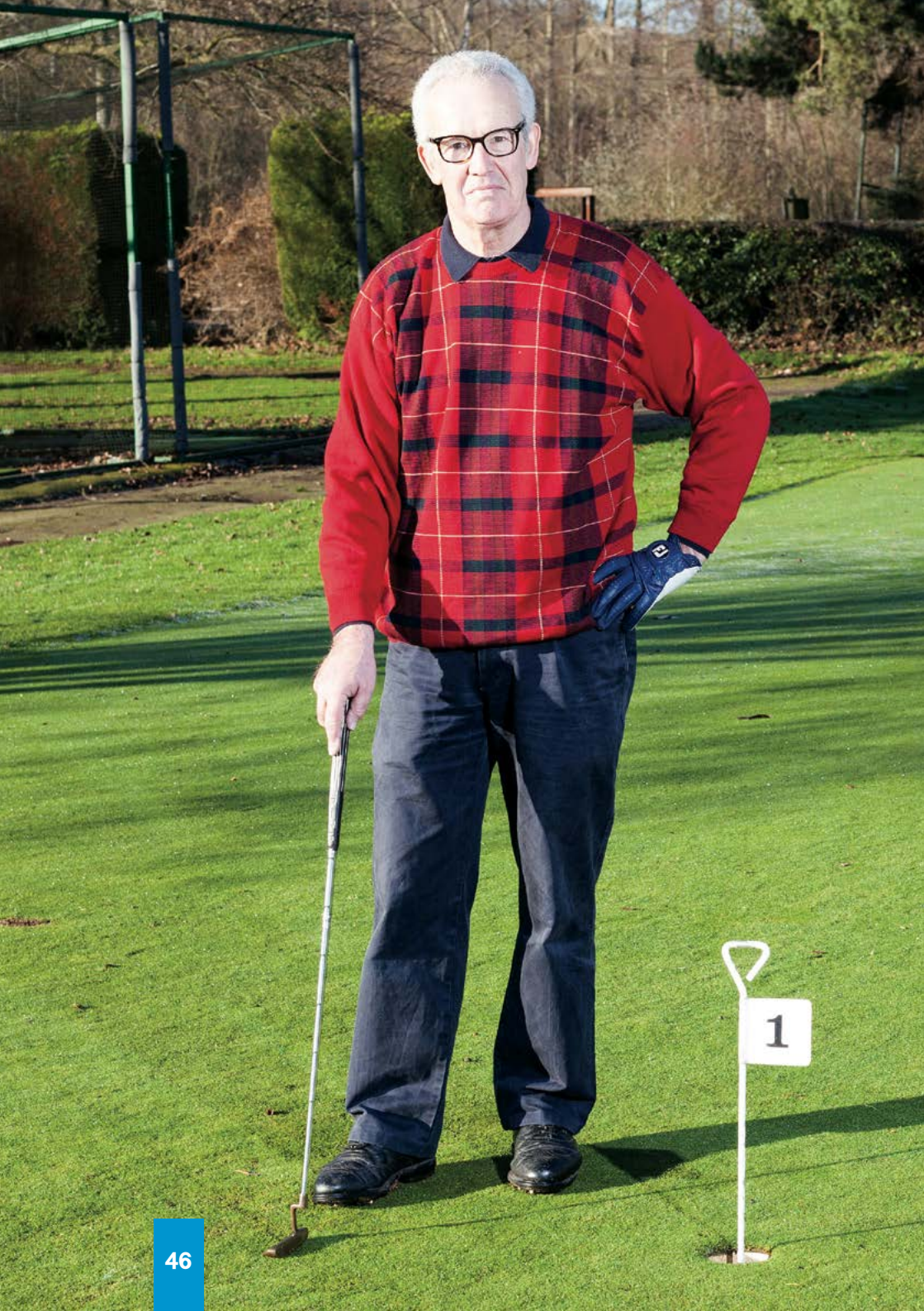
For more information see booklet 1504, Driving.

Making a will

Making a will is an important way of preparing for the future. A will is a legal document that states who your possessions, property or assets should go to when you die. Speak to a solicitor for more information.

‘The best advice is treat each day as it dawns, don’t try and second guess how you think you will be, just be the best you can be on that day!’

Person living with dementia





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Services and support

Asking for help can feel difficult, especially if you've always been independent. You might not feel you need it straightaway, but it can be useful to know that a wide range of information and support is available for you and the people who are important to you.

Some of the support available to you includes:

- **The NHS** – your GP, psychiatrist, neurologist, community nurse, dietitian, occupational therapist or psychologist can help you with a number of health problems.
- **Social services** – a social worker from the local council can work with you to see what care and support is needed. Ask your GP, or look up ‘social services’ in the phone book or online and ask for a needs assessment (also called a ‘community care assessment’ in Wales and Northern Ireland).
- **Charities and not-for-profit organisations** – these can be a good source of local support, advice and information. National organisations include Alzheimer’s Society, Dementia UK and Age UK. Ask about age-appropriate services if you would prefer to spend time with people closer to your own age.
- **Private companies** – these include agencies that can provide care and support services at home and which you may have to pay for. Professional care workers could help you with cooking, dressing, medication or going to work. Ask your local social services or contact the UK Homecare Association to see what is available in your area – see ‘Other useful organisations’ on page 57.



Health and social care professionals

As you come to need more care, many different professionals are likely to be involved. These include doctors, other health professionals, and social care professionals.

Doctors

Your GP can support you in many different ways, including talking to you about your symptoms and medical problems (not just dementia). They can carry out physical examinations, arrange further tests with a consultant or hospital specialist, and review whether your drugs are working.

You may also interact with a number of consultants. These might include a psychiatrist, who can help with dementia and other mental health problems like depression and anxiety, and a neurologist, who specialises in the brain and nervous system.

Other health professionals

Nurses are also likely to care for you, and the people who support you, in a number of ways. These might include community nurses (including community mental health nurses known as CPNs) who can provide support at home, and Admiral Nurses who specialise in dementia care, especially supporting carers.

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For more help and advice call Dementia
Connect support line on **0333 150 3456**

You can get support from other health professionals to help with many different issues:

Issues	Who can help?
communication, eating, drinking and swallowing	speech and language therapist
maintaining skills and independence	occupational therapist
exercising and moving around	physiotherapist
caring for your feet	chiropodist
eyesight	optometrist
hearing	audiologist
behaviours that challenge (such as aggression), anxiety and restlessness	clinical psychologist or a specialist such as a music therapist
relationship and emotional issues	counsellor or clinical psychologist
nutrition	dietitian
toilet problems	continence adviser

Social care professionals

Social workers and social care workers can help you in non-medical ways. Social workers assess your needs and advise on the best support for you. Social care workers help with practical things like washing, dressing and eating.

Support from other people living with dementia

Support from other people living with dementia, especially those who also have FTD, may be important to you. You may be younger than many people with more common types of dementia. You may feel no one else understands your condition.

There are different groups and activities for people living with dementia, though they may not all be available in the area where you live. Different groups and activities include:

- **support groups** – for people with dementia to talk about their experiences and learn from each other. The organisation Rare Dementia Support runs support groups for people with FTD (see ‘Other useful organisations’)
- **activity groups** – for people with dementia to come together regularly and take part in different activities together, such as singing.

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For more help and advice call Dementia
Connect support line on **0333 150 3456**

- **Dementia cafés** – a safe, comfortable and supportive environment for people with dementia and their carers to socialise.
- **Talking Point** – an online community for people living with dementia and for carers.
Go to alzheimers.org.uk/talkingpoint



To find services in your area,
visit alzheimers.org.uk/dementiadirctory

Paying for social care and support

Many people with dementia will reach a stage when they need professional care and support at home to help them live well with the condition. Friends and family who care for a person with dementia may also need support to carry out this role.

Some people with dementia and their carers will be entitled (often called 'eligible') to support with all or some of the costs of this care. They must meet certain criteria to be eligible.

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England

In England, a local authority has a duty to carry out a 'care needs assessment' for anyone with dementia. The assessment is to determine what care needs you have and whether the local authority will contribute towards meeting them.



Wales

In Wales, a local authority has a duty to carry out a 'community care assessment' for anyone with dementia who may require community care. They also have a duty to provide services directly or – more often – make arrangements to meet any needs for which someone is eligible.

Northern Ireland

In Northern Ireland, the local health and social care (HSC) trusts have a duty to carry out a 'community care assessment' for anyone with dementia who may be in need of support.

Carer's assessments are also available so that the person who is caring for you can receive support to help them with their caring role.



For more information see factsheets 418, Assessment for care and support in England, W418, Assessment for care and support in Wales, or NI418, Assessment for care and support in Northern Ireland.

'Seek out the services and support groups. There is tremendous strength and understanding to be gained by mixing with your peers.'

Person living with FTD

Support in the later stages of dementia

Most people with dementia are likely to reach a stage where they need more support. It can be useful to plan ahead for this.

Many people go into a care home or supported living as their dementia progresses. A professional such as a doctor or social worker, your local Alzheimer's Society or another voluntary sector organisation may be able to give advice on housing options, including choosing a care home. At this point, it is likely that someone caring for or supporting you will need to arrange this. It may be helpful to plan ahead for this as early as possible.

Services for people with FTD

You can find out more about FTD and services that are available for people with FTD through Rare Dementia Support: www.raredementiasupport.org/ftd

You can search for local services at alzheimers.org.uk/dementiadiirectory

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Alzheimer's Society support services

Alzheimer's Society's Dementia Connect service provides a range of information, advice and support to anyone affected by dementia in England, Wales and Northern Ireland. You can reach us online, on the phone and face-to-face.

Online

Visit alzheimers.org.uk/get-support for online advice and support whenever you need. Here, you'll find information on any aspect of dementia and the option to download or order what you need from our wide range of publications.

You can also connect to others affected by dementia on our online community Talking Point, and search for services in your area using our dementia directory.

Phone

You can contact our Dementia Connect support line by calling **0333 150 3456** seven days a week. If you speak Welsh, call our Welsh-speaking support line on **03300 947 400**. Our dementia advisers are available to tackle problems, share advice and practical information or simply provide a listening ear. They can send out information that's right for you via email or post and connect you to help in your local area.

Alzheimer's Society offers a Lasting power of attorney digital assistance service to help people with dementia create LPAs online. If you don't have access to the internet, we can help you to create an LPA through a series of telephone appointments. Please note that we do not provide legal advice. Call us on **0333 150 3456**.



For more help and advice call Dementia
Connect support line on **0333 150 3456**

Face-to-face services

Our trained staff and volunteers can connect and signpost you to practical advice, support and information in your local area. This includes face-to-face services when these are available. They can make things easier and help you continue doing things that are important to you.

We also oversee support groups that meet in person and sometimes via video or phone. These include Singing for the Brain®, peer support for people with dementia, and information and support groups for carers.

To find out what support is available in your area, call us on **0333 150 3456** or visit **alzheimers.org.uk/dementiadiirectory**



Other useful organisations

Citizens Advice

0800 144 8848 (for England, 9am–5pm Monday–Friday)

0800 702 2020 (for Wales)

www.citizensadvice.org.uk

Citizens Advice provides free, independent, confidential and impartial advice to everyone on their rights and responsibilities.

Dementia Engagement and Empowerment Project (DEEP)

www.dementiavoices.org.uk

The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia.

Dementia UK

0800 888 6678 (helpline, 9am–9pm Monday–Friday,

9am–5pm Saturday–Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK is a charity providing specialist dementia support for families through its Admiral Nurse service. They also provide support for people with young-onset dementia.

FTD Talk

www.ftdtalk.org

FTD talk provides information and jargon free updates of recent research findings in frontotemporal dementia. Includes a number of factsheets on FTD.



For more help and advice call Dementia
Connect support line on **0333 150 3456**

GOV.UK

www.gov.uk

GOV.UK is the website for the UK government. It covers benefits, driving, housing, money and tax, working and pensions.

Motor Neurone Disease Association (MNDA)

0808 802 6262 (helpline, 9am–5pm and 7pm–10.30pm

Monday–Friday)

mndconnect@mndassociation.org

www.mndassociation.org

The Motor Neurone Disease Association focuses on improving access to care, research and campaigning for people living with or affected by MND in England, Wales and Northern Ireland.

NHS

www.nhs.uk

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NHS.UK is the UK's biggest health website. It provides a comprehensive health information service that aims to put people in control of their healthcare.

Office of the Public Guardian (OPG)

0300 456 0300 (9.30am–5pm Monday, Tuesday, Thursday, Friday, 10am–5pm Wednesday)

customerservices@publicguardian.gov.uk

www.publicguardian.gov.uk

The OPG protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finances. It provides free booklets on Enduring powers of attorney, Lasting powers of attorney and Deputyship.



PSP Association

0300 011 0122

helpline@pspassociation.org.uk

www.pspassociation.org.uk

PSP Association provides support and information to people living with PSP and CBD, while funding research into treatments and ultimately a cure for these conditions.

Rare Dementia Support

contact@raredementiasupport.org

www.raredementiasupport.org

Rare Dementia Support works to support people affected by five rare dementias, including FTD.

United Kingdom Homecare Association (UKHCA)

020 8661 8188

enquiries@ukhca.co.uk

www.ukhca.co.uk

The United Kingdom Homecare Association is the professional association of homecare providers from the independent, voluntary, not-for-profit and statutory sectors.

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For more help and advice call Dementia
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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

To give feedback on this booklet, or for a list of sources, please email [**publications@alzheimers.org.uk**](mailto:publications@alzheimers.org.uk)

This booklet can be downloaded from our website at [**alzheimers.org.uk/publications**](https://alzheimers.org.uk/publications)

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HOLGATE & HOGGET
WILHELM TILKINSON

Polly Langdon's book tells a story and tells personalities

With the death of her mother from typhoid, thirteen-year-old Polly is left to care for the grieving father and teenage brother and sister. When their father, an old man, is in the hospital, she must learn to go to hospital, leaving Polly alone. Charitably she has the support of her neighbour, Bertha Holgate, who has a strong opinion on Polly. According to her, it is not just her own son in the wrong. Let us take down some of the things that Polly will see, be with and love and fight.

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call **Alzheimer's Society** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on **0330 333 0804** or go to **alzheimers.org.uk/donate**



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alzheimers.org.uk

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