



Bolton Dementia Guide

Information, advice and support for people with dementia and memory problems, and their carers

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About this booklet

The Bolton Dementia Guide explains about dementia, the support and treatment available and how to live as full a life as possible with the illness. It provides important contacts for local services and highlights other sources of more detailed information.

The guide has hints and tips for people with memory problems and dementia, as well as those who are caring for them, including information to help people to plan for the future.

This booklet has been produced in conjunction with Bolton's Dementia Partnership. The information in the guide has been put together with the help of many local organisations that are working with people with dementia and their carers.

Introduction

Memory problems

Memory problems are common, however, they can be an early sign of a medical condition such as dementia.

Many people notice that their memory becomes less reliable as they get older, and tiredness, stress, anxiety, depression, some physical illnesses and the side effects of medications may also be factors.

You should seek help if your memory is not as good as it used to be, especially if:

- You struggle to remember recent events, although you can easily recall things that happened in the past
- You forget the names of friends or everyday objects
- You lose the thread of what you are saying
- You feel confused even when you are in a familiar environment.

Are you starting to feel anxious or depressed about your memory loss, or are other people starting to comment on it?

If you are worried about your memory, go and see your family doctor, who will address your concerns and may arrange for further investigation.

What is dementia?

Dementia is not a single illness but a group of symptoms caused by damage to the brain. The symptoms include loss of memory, mood changes and confusion.

Dementia is caused by a number of diseases of the brain. The main types of dementia are:

- **Alzheimer's disease:** small clumps of protein, known as plaques, begin to develop around brain cells. This disrupts the normal workings of the brain.
- **Vascular dementia:** problems with blood circulation result in parts of the brain not receiving enough blood and oxygen.
- **Dementia with Lewy bodies:** abnormal structures, known as Lewy bodies, develop inside the brain.
- **Fronto-temporal dementia:** the frontal and temporal lobes of the brain begin to shrink. Unlike other types of dementia, fronto-temporal dementia develops most often in people under the age of 65.

Some people have mixed dementia – more than one of the four types.

It is important that these conditions are identified as early as possible, yet less than half of people who have dementia have been diagnosed.

Dementia mainly affects people who are older, and the numbers of people with dementia is forecast to grow as people live longer, but younger people can sometimes have dementia - this is referred to as **early onset dementia**.

Who can get dementia?

Anyone can develop dementia – it is not restricted to sex, age, gender, ethnicity or background.

However, some groups are statistically more likely to develop it. For example, women are more likely to develop it than men.

People with learning disabilities may carry a higher genetic risk of developing it. Also, people from black and minority ethnic populations have higher rates of early onset dementia than other groups.

How common is dementia?

In England, 800,000 people currently live with dementia. The older the age, the more common it is.

Around one-in-14 people aged 65 or over has a form of dementia, and one-in-six people aged 80 or over.

So the great majority of people with dementia are more than 75 years old, but it does occur among younger people.

What affects the development of dementia?

Anyone can develop dementia, but some factors appear to contribute to whether we develop the disease:

- **Age:** you are more likely to develop dementia when you get older, especially if you have high blood pressure or have a higher risk of other genetic diseases such as heart attacks and strokes.
- **Genetics:** genetics are known to play some role in the development of dementia, but the specific effects vary considerably.
- **Medical history:** having current conditions or having experienced certain conditions in the past may make us more likely to develop dementia – such as multiple sclerosis, Down's syndrome, diabetes, HIV and metabolic syndrome.
- **General lifestyle:** a poor diet, a lack of exercise and excessive alcohol or drug consumption can all increase the chances of developing the disease.

People with Parkinson's disease have a higher-than-average risk of developing dementia, although most people are unaffected.

Further information

The **Alzheimer's Society** national dementia helpline has trained advisers ready to discuss your concerns from 9am to 5pm from Monday to Friday and 10am to 4pm at the weekend.

T: 0800 222 11 22

W: www.alzheimers.org.uk/memoryworry

The **Open Dementia** e-learning programme is for anyone who comes into contact with someone with dementia and provides an introduction to the disease and living with dementia.

W: www.scie.org.uk/publications/elearning/dementia/index.asp

There are **Alzheimer's Society** factsheets on a wide range of topics related to information about dementia.

W: <http://alzheimers.org.uk/factsheets>

Diagnosis and treatment

Getting a diagnosis

If you suspect that you or someone you care about is showing symptoms of dementia or memory loss, you should contact your family doctor as soon as possible.

A diagnosis will usually be made depending on how you are affected, your family history and psychological changes. It is often useful to bring someone with you when you see your family doctor who can help answer questions.

The earlier a diagnosis is made, the more effective treatment can be. For example, prompt use of medication may help delay symptoms, as well as improving those which already exist.

A diagnosis is important to rule out other possible causes of confusion, such as poor sight or hearing; emotional changes and upsets, such as bereavement; or the side-effects of certain drugs or combinations of drugs.

Getting a diagnosis will also ensure timely access to advice and information and allow you and your carers to plan and make arrangements for the future.

Whether a diagnosis of dementia comes as a shock or confirms your suspicions, you could experience a range of emotions – you may feel numb, frightened, angry, worried, sad, guilty or frustrated.

However, you may also feel relieved to find there is a medical reason for your memory problems.

Although there is currently no cure for dementia, with treatment and support many people who have the condition lead active, fulfilling lives.

What tests are involved?

Tests to help diagnose dementia can include:

- Memory tests.
- Questions relating to language and mathematical skills.
- A physical examination and laboratory investigation (eg blood and urine tests).
- A computerised tomography (CT) scan or a magnetic resonance imaging (MRI) scan.
- A referral to a memory assessment service for a specialist diagnosis.

Treatment for dementia

As drugs for treating different conditions become available, it is becoming increasingly important to identify which type of dementia the person has.

For example, drugs are already available to treat some people with Alzheimer's disease and some people with dementia with Lewy Bodies.

Although there is no cure, medication can stabilise the condition for a while.

Medication should be reviewed regularly and continued so long as the drug benefits outweigh any side-effects.

At present, there are no treatments that can reverse the progress of dementia once it has developed.

However, there are drugs that may alleviate some of the symptoms of Alzheimer's disease, for a limited period of time.

These drugs (Aricept, Exilon and Reminyl) are known as cholinesterase inhibitors and they prevent enzymes related to Alzheimer's Disease breaking down in the brain.

Medication can provide some people with improvements in confidence, daily activities, memory and thinking. In some cases, it can also temporarily slow down the progression of symptoms.

However, they don't work for everyone and the medication can cause a number of side effects (the most common side effects are loss of appetite, nausea, vomiting and diarrhoea).

Treatment for vascular dementia

People with vascular dementia will be treated for their vascular disease to try to prevent it from worsening. This may involve taking drugs to lower blood pressure and making lifestyle changes.

People will especially benefit from a healthier lifestyle by stopping smoking, taking regular exercise, eating healthily, and drinking alcohol only in moderation.

Complementary and alternative medicine

For those who wish to consider the help that complementary and alternative therapies may offer, an Alzheimer's Society factsheet outlines several therapies and describes how to access them.

Therapies for which there is some evidence of effectiveness include aromatherapy, music therapy, acupuncture, light therapy, massage, and herbal therapy.

Looking after yourself

Those who are prescribed medication should always take it regularly.

It is also important to consider other things that may improve the quality of life for people with dementia.

This may include:

- Eating a well-balanced, healthy diet.
- Reducing smoking or alcohol intake.
- Staying mentally and physically active as far as possible. Try to continue any interests, such as walking, gardening, music and sport.
- Staying physically active as far as possible.
- Talking about concerns and symptoms with family or specialist services.
- Keeping in touch with and raising any concerns with your family doctor.

For further information

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Living with dementia

People with dementia should remain as independent and active as possible and continue as many of their usual pastimes for as long as they can.

While a person with dementia can prepare food, or can put the groceries away, these tasks should not be taken over. Those people who enjoy going on walks, trips and holidays should continue to do so.

Continuing to meet friends and relatives is particularly important. Maintaining your social life makes an important contribution to your continuing wellbeing.

It may be that new social opportunities need to be sought as dementia develops – this could include joining a group such as the **Dementia Support Group**. It can be very helpful to meet others who are in a similar situation, for those with dementia and for their carers.

Safety in the home

It is important to minimise the potential for accidents and make your home as safe as possible. Avoid trips and falls by dealing with any worn carpets and potential trips over rugs. Declutter your home so there is less to trip over. Think about whether you may need hand rails on stairs, on outdoor steps and next to the bath. These needs may arise over time.

Adapt or simply reorganise your kitchen so that sharp or dangerous objects are less easy to reach. Ensure your house is well lit, and consider using (electric) night lights or leaving a light on for safety when moving around at night. Install gas and smoke detectors around the home.

A free Home Fire Safety Check is available from **Greater Manchester Fire Service**. If you can, stop using electric

blankets as they can be a fire hazard. If you smoke, get help to stop smoking – this is a major cause of fire for people with dementia.

Crime prevention

Take sensible precautions:

- Don't leave windows and doors open or unlocked.
- Take care of keys – keep them somewhere safe.
- Always ask doorstep callers for photo ID. Never pay for work by cash.

Helping with your memory

When your memory starts to fade, there are some measures you can try to make you feel safe and secure around the home and help your memory.

It may be helpful to keep a diary or calendar, and make a list about important things you need to do in your day-to-day routine and keep it to hand to refer to. Consider using a notice board to pin appointment cards and information leaflets to.

Try to keep things in their place so they are easier to find. To make sure to take your correct medication, buy a special dispenser for your medication so your dosage is correct.

It may be a good idea to put together a collage of photos of those who are important to you with their names on.

Getting out and about

A person with dementia's memory problems may eventually mean that most activities outside the home have to be accompanied, but short walks independently in well-known areas should not be ruled out.

Going to a local shop should be possible, and it helps if the shop owner and assistants are made aware of your condition, and know who to contact if there is a problem. Encouraging people in the neighbourhood to be 'dementia friendly' will also help others.

Driving

Once you have been diagnosed with dementia, by law you have to let the DVLA know, as well as your insurance company. The DVLA may decide to assess you, and may issue you with a limited license. You can appeal against any decision made.

You may decide to have your driving assessed. This can be done via a driving assessment test. As dementia progresses it is important that you are reassessed – it is possible that at some point you will need to stop driving.

The DVLA can be called on 0300 790 6806, or you can find more information at www.gov.uk/dementia-and-driving.

Keeping active

If you are able, keeping active is a good way for a person with dementia and anyone who cares for them to enjoy spending time together. Being active burns up the adrenalin produced by stress and frustration and produces endorphins, which can promote feelings of happiness.

This will help you to relax and increase your sense of well-being. Being active also helps you develop a healthy appetite, can increase your energy levels and can help you get a better night's sleep.

As dementia progresses, it may become more difficult to take part in physical activities. However, keeping active can play a big part in your overall wellbeing and happiness

as well as providing many physical benefits. You should continue doing activities you enjoy for as long as you feel comfortable doing so.

Find a hobby or activity that you enjoy – it can make difficult times seem easier to cope with.

Activities that remind you of the past may help to retain your memory – for example, listening to music, watching old films, looking at photographs, talking about the past, and visiting your favourite places can all help.

Privacy

Everyone has the right to privacy – and your privacy should always be respected by people who are supporting you. This includes things like knocking on your door before they enter and locking the door if they are attending to your personal hygiene.

Further information

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Planning for the future

People who have dementia and their carers worry about what will happen in the future. Concerns may include who will care for you as the dementia gets worse, whether you will be able to stay in your own home, how you can be sure that your money and other assets will be looked after as you wish, and what practical and medical help you can get.

Consider discussing plans for the future with the people closest to you. Making plans in good time, or at least considering the issues involved in potential care arrangements, medical treatments and finances can bring peace of mind.

Finances

Dementia might affect your ability to look after financial affairs. It is important to take some early decisions. Make sure that all the important papers are in order, such as your mortgage, insurance, tax details and bank and building society statements. If you can, go through them with someone you trust.

Making a will

The earlier on you make your will, the more confident you can be that it will reflect your wishes. It can be a relief to know that your financial affairs are in order and that the will can be filed away. Further down the road, it may not be possible for you to be actively involved in making a will.

Living wills

You may want to consider making a 'living will'. This sets out your wishes in the event of you being unable to make your own decisions later. It can include instructions about nursing home care, types of treatment, whether you wish

to be resuscitated and who you wish to make decisions on your behalf. Give a copy of a will or living will to everyone who is affected by your instructions so they can discuss it with you if they need to and are prepared.

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a legal document available to help you plan ahead for a time when you may not be able to make decisions about your finance and welfare. It allows you to appoint someone you trust to make decisions on your behalf.

You may want to make sure you have done all you can to prepare you and your loved ones for the future. You may have specific wishes about what medical treatment you may wish to receive or what care you would like in the future.

You will also be reassured that someone will manage your financial affairs if you can't do this for yourself. There are two types of LPAs:

- Property and Affairs – this is about your finance, the selling of property and paying of bills.
- Personal welfare - this could be about making decisions about where you live and the kind of care you may need, and consent to receive medical treatment

If you want to find out more about a Lasting Power of Attorney you can talk to a solicitor or visit www.directgov.uk and search for 'mental capacity and the law'.

Planning for your future care

At the right time you may want to take the opportunity to think about how you want to live and how you want to be cared for if you become unable to make or communicate decisions for yourself in the future. You may wish to record

your preferences and wishes for future care and treatment and one way of doing this is by a process of advance care planning.

A booklet explaining how you can explore different options, record your wishes and who to involve is available from the Dying Matters website.

W: www.dyingmatters.org/page/planningyour-future-care

Residential care

At some point, you will need to decide whether to remain in your own home, or whether you would prefer to move into sheltered housing or a care home.

If you want to stay in your own home there are options available to help you. It is important not to rush into a decision.

Looking for suitable care accommodation for you, a relative or friend can be difficult. You can find out more about Bolton residential and nursing homes and current vacancies on the Bolton Council web site (search for 'residential care') or by calling 01204 338027

You can also call the national charity Independent Age advice line Lines are open Monday to Friday from 10am - 4pm.

T: 0845 262 1863

E: advice@independentage.org

The later stages of dementia

Dementia is a progressive illness and the symptoms will unfortunately get worse. This can happen over a period of months but it is likely to be a number of years.

Changes in behaviour, incontinence, communication problems, changes in appetite and more severe memory loss are potential symptoms that may worsen.

It may be helpful to read more about how dementia may progress but no information can predict just how the disease may progress, as each person is an individual.

Living arrangements

As dementia progresses it may become increasingly difficult to continue living at home – your care needs may increase and be more around the clock. You may need to receive specialist care for your own safety. You may develop illnesses related to dementia that make this a necessity.

You may, however, be able to move into a care home (either a nursing care home or a residential care home) where your family can visit frequently.

End of life care

At the final stages of the illness it may be appropriate to move into a hospice or receive palliative care at home to help reduce the physical and psychological distress and provide the additional support to your family.

Further information

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Caring for someone

Who is a carer?

Carers give a large amount of their own time to support the person with dementia. A carer may be a spouse, family member, friend or neighbour but it is important to acknowledge the role of being a carer. A carer can then get access to information and support. Over time the recognition of the caring role will become increasingly important.

Carers carry out a large variety of tasks including personal care, cooking meals, dressing, helping the person move around, jobs around the house, shopping, picking up medication and generally spending time with the person they care for and keeping them company.

It is often a big commitment that can bring feelings of resentment, fatigue, frustration and despair. It can also bring a big sense of achievement and feeling of satisfaction of being able to help their loved one in such a big way and play such an important role in their life.

Letting people know you are a carer

With the permission of the person you are caring for, it is worthwhile to ask your GP for your name to be added to that person's medical records as their carer. As dementia progresses, it may be increasingly necessary to discuss confidential matters with the GP about that person and help make decisions.

If you continue to work, it is worth letting your employer know that you have an extra, important commitment. This way they will be more supportive when you need time off work and they will be more understanding when you are feeling tired. They may also provide a more flexible working pattern for you.

Your own well-being

It is vital to look after yourself so that you can continue to care successfully.

Here are some tips for looking after yourself:

- Set aside some time for yourself – if possible, every day. Even if it's just a quick walk, or reading the paper – it's very important that you get time to relax and clear your mind.
- Socialise – meet friends and family, go for a meal or meet up with local support groups. And remember to talk about you – because you are important too.
- Remember to do enjoyable things with the person you care for.

The pressures of caring for someone

If you are close to someone with dementia, there may be times when you are faced with behaviour that can be confusing, irritating or difficult to deal with.

This might include repetition, wandering, shadowing, night-time waking, restlessness, aggression, shouting and screaming, sexual inhibition, suspicion, and general agitation. This can be very distressing and may make you feel exhausted.

There are some tips which can help in dealing with difficult behaviours and coping with these pressures:

- Don't take the behaviour personally
- Work out what triggers the behaviour
- Take time to deal with your own feelings & seek support.

It is important to think about your communication – tell the person you are caring for what you are going to do, reassure them that they are safe and loved.

Some carers of people with dementia have found it particularly helpful to share experiences with other carers on an online forum such as the [Alzheimer's Society's Talking Point](#) forum.

The [Alzheimer's Society](#) has several factsheets about unusual behaviour and dealing with aggressive behaviour and other topics ranging from incontinence to sexual behaviour and walking and wandering.

Carers' Assessments

You can ask for a carer's assessment from adult social care. They will be able to point you towards extra resources and support to help you in your carer's role.

You will need a carer's assessment which will identify what level of support, if any, you will be entitled to.

An assessment can be an opportunity to discuss exactly what kind of help your loved one needs both now and what support they are likely to need in the future as the dementia develops.

Before you have your assessment, it is a good idea to write down your thoughts on paper – you need to make it clear what the state of your own health is, your own mobility, what relationships are affected by the diagnosis of dementia and what information and help you will need as a carer.

Please see the previous chapter, 'Services and Support', for contact information for services for carers.

Further information

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W: <http://alzheimers.org.uk/factsheets>

Services and support

Age UK Bolton

Age UK Bolton is the major local charity for older people. It provides a range of information, advice and support services and healthy lifestyle activities.

T: 01204 382411

E: postmaster@ageukbolton.org.uk

W: www.ageuk.org.uk/bolton

Benefits

Having dementia can have a big impact on all areas of your life, but particularly on your finances. Now or in the future there may be benefits you could claim. Advisers at Bolton Council can give you advice and information about social security benefits and how to claim them and can signpost you to other organisations which might be able to offer the particular help or information you need.

The welfare rights team can assist customers with complex cases, appeals and tribunal representation. If you need this type of assistance you will be referred to the specialist team who will contact you with further advice.

T: Welfare Rights 01204 333820

T: Citizens Advice AdviceLine: 0844 826 9707

Bolton Care and Repair

Bolton Care and Repair aims to help people maintain their independence and remain living in the comfort of their own home. The scheme provides repairs and adaptations around the house. Services can be adapted depending on your individual needs and circumstances.

T: 01204 335679

Bolton Carers Support

Bolton Carers Support is the borough-wide carers' organisation, providing advice and information, trips out, courses and a wide range of support for carers. They will guide you towards a wide range of sources of help and advice.

You can contact Bolton Carers Support to register with them so you will receive a regular newsletter for them keeping you up to date, telling you about activities and linking you with other carers.

T: 01204 363056

W: www.boltoncarerssupport.org.uk

Bolton Council – needs assessment

If you are an adult aged over 18, and need support because of illness or disability, or if you are caring for someone and need help with your caring role, you can contact Bolton Council.

They can give you:

- Options for people who feel that they are struggling to continue living at home.
- Information about getting help at home, such as Community Meals or Home Support.
- Information about support for carers.
- Specialist help.
- Adaptations or equipment to make it easier for you or your carer.
- Advice if you have problems with your sight or hearing.
- Information about social activities.
- Information about short breaks or long-term residential care.

If required, you will be redirected to other organisations. For general enquiries, call Access Bolton on 01204 338027.

The short-term assessment and reablement team can be contacted on 01204 333410 for the north of Bolton (postcodes BL1, BL2, BL6 and BL7), and 01204 337000 for the south (BL3, BL4, BL5 and M).

Bolton Council – local directory

You can search the council's local directory for a wide range of local services, activities and events.

W: www.localdirectory.bolton.gov.uk

Bolton Council – website information

For up to date local and national information, and links to related issues and services visit the council's webpage.

W: www.bolton.gov.uk/dementia.

Bolton libraries

Books and information on dementia are available from the library service. There is also free internet access to online resources and websites including those mentioned in this guide.

T: 01204 332853

W: www.bolton.gov.uk/libraries

Careline and telecare equipment

Personal alarms and monitoring equipment is available to enable people to remain safe and independent in their own home.

T: Careline: 01204 335733

T: Telecare: 01204 337534

Carers database

If you are a carer of someone with dementia you can ask Greater Manchester West Mental Health NHS Foundation Trust to add you to its carers' database. This will ensure that you are kept informed of training and events.

T: 01204 390 390 (extension 3503)

W: www.gmw.nhs.uk/about_GMW/serviceusersandcarers.html

Crossroads Care

Crossroads Care provides tailored support packages for people with dementia and their carers. Trained support workers can provide replacement care in the home, including overnight, enabling short breaks or respite care.

T: 01204 365025

E: admin@gmcrossroads.co.uk

W: gmcrossroads.co.uk/contact-us/Bolton

Dementia Support Group

The Dementia Support Group is a voluntary organisation which supports people with dementia and those who care for them by providing weekly support groups for carers with parallel guided activity sessions for people living with dementia.

There are, regular memory cafés, weekly activity afternoons using traditional games, and a wide variety of outings.

T: 01204 386696

W: allcommunity.co.uk/dementiasupportgroup

Memory Assessment Service

This new service delivers early diagnosis and intervention for people living with mild to moderate dementia.

Run by Greater Manchester West Mental Health NHS Foundation Trust, it is hoped that the service will help to reduce crisis later in the illness and enable people to be cared at home for as long as possible.

The service promotes early identification of dementia by encouraging people to attend assessment. Where there turns out to be a diagnosis of dementia this will be communicated sensitively, and people with dementia and their carers will be given information to help them to manage their care.

The service involves a consultant psychiatrist, a clinical psychologist and two assistant psychologists. Mental health nurses, occupational therapists, support time recovery workers, carer support workers and a dementia advisor are also on hand to help.

If you need to attend the service, you will be referred by your GP.

T: 01204 336152.

Supported housing

If you are worried about managing in your current home, you may wish to consider moving into sheltered housing or extra-care housing to access support and care.

Sheltered housing is designed to help older people to live independently in their own tenancies, with a little extra support.

Schemes provide greater security, good accessibility for those with mobility issues, emergency alarm systems and a manager on-site to help resolve issues and provide information, advice and support.

The communal facilities in many schemes also offer opportunities to meet other people and take part in social activities.

Extra-care housing is similar to sheltered housing in that properties consist of self-contained flats and provide good communal facilities. The schemes also provide an on-site care team who are able to provide care services, or alternatively help support carers to meet an individual's need.

All schemes have a 24-hour response service in place and some schemes also provide midday meals. The majority of extra care properties in Bolton are available for rent, but there are a few available to part buy.

For more information, contact the Housing Advice Service.

T: 01204 335900

Young Onset Group

The Young Onset Group meets regularly and is for people aged under 65 diagnosed with Dementia.

T: 01204 397403

Further information

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Factsheets from the Alzheimer's Society

Alzheimer's Society factsheets cover a wide range of dementia-related topics and provide more details than this local guide can do.

Bear in mind that the factsheets provide national information. The online factsheets can be saved as a PDF, printed as seen on screen or emailed to a friend.

The most popular factsheets are available in audio on CD and tape. The publishing team can also print out some factsheets in larger text if needed.

For printed copies of any of the factsheets, phone 01628 529240 or email alzheimers@xcalibrefs.co.uk. Up to six sheets are free; further copies cost 20p each.

Causes of dementia, progression and treatments

What is dementia? (Factsheet number 400)

What is Alzheimer's disease? (401)

What is vascular dementia? (402)

What is dementia with Lewy bodies (DLB)? (403)

What is fronto-temporal dementia (inc. Pick's disease)? (404)

Genetics and dementia (405)

Aluminium and Alzheimer's disease (406)

Drug treatments for Alzheimer's disease (407)

Drugs used to relieve behavioural and psychological symptoms in dementia (408)

The later stages of dementia (417)

Learning disabilities and dementia (430)

Complementary and alternative therapies (434)

What is Korsakoff's syndrome? (438)

Younger people with dementia (440)
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This leaflet is produced by the Bolton Dementia Partnership, which includes: Age UK Bolton; the Asian Elders Resource Centre; the Alzheimer's Society; Bolton Carers Support; Bolton Clinical Commissioning Group; Bolton Council; Bolton LINK; Bolton NHS Foundation Trust; the Dementia Support Group; Greater Manchester West Mental Health NHS Foundation Trust; and the Young Onset Group.