

Living Well



with

Dementia

Dementia Self Care Pack



Name	
(please state the name you prefer to be known as)	
Date of Birth	
NHS Number	
Emergency Contact/ Carer's Details	
If found, please return th	nis pack to:

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We have tried to include as much information as possible in the pack. As everyone's situation is different, you may find that there is information in this pack that doesn't apply to you.

You may also use it to make notes, store appointments, and add letters, leaflets and anything else you may find useful.



... and what does it mean for me?

Looking after yourself in a healthy way, whether it's brushing your teeth, taking medicine when you have a cold, or doing some exercise, is really important to help to keep yourself as well as possible.

If you have a long-term condition, there are extra things you may need to consider, such as making changes to your diet, different types of exercise or different types of medication you may need to take.

It is important to stay active and do things that are important to you, such as gardening, seeing friends and family, going on holiday, or continuing to work where possible. Self care involves looking at what you can do and want to do, rather than what you can't do.

Living a healthy lifestyle is an important part of self care for everyone. You can take responsibility for your own health and wellbeing, with support from the people involved in your care.

When you talk to your doctor or nurse about your condition, you may want to discuss some of the things you need to do to stay well. Some of these will be things that you do yourself, such as eating healthily, exercising, or taking your medicines at the right time.

NHS Choices

There's lots of useful information about keeping well and healthy living. Look out for the Live Well section of the NHS Choices website. If you're living with a long-term condition, Your health, your way has advice on self care and taking control of your health.



www.nhs.uk

Self Care is committed to working in collaboration across Bradford CBMDC, Bradford City CCG, Bradford Districts CCG and Airedale, Wharfedale and Craven.

What is dementia?

Dementia is an umbrella term for a set of symptoms that may include:

- Memory loss
- Difficulties with processing information
- Difficulties with problem solving
- Difficulties with speech and language

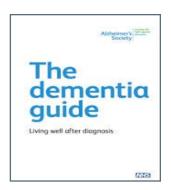
Dementia is caused by damage to the brain by diseases such as Alzheimer's or a series of strokes.

Dementia is progressive which means that it will gradually get worse over time.

A diagnosis of dementia can be scary and confusing. However it is possible to live well with the illness.

There are organisations that can give information and support about services available and how to cope and live well with dementia.

There are also a number activity and peer support groups that you can access. As with any condition it is important to plan for the future and look after all aspects of your health and wellbeing.



A really useful source of information for people living with dementia, their families and friends is 'The dementia guide.'

To receive a free copy delivered to your home contact:



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464



www.alzheimers.org.uk

Memory

Being given a diagnosis of dementia can be worrying, upsetting and confusing. It can also be hard for those around you but there is much you can do to make life easier and more enjoyable both now and in the future.

Problems to do with your memory can have different causes. You can discuss these with your doctor.



There is a very useful booklet called the 'Memory handbook' - a practical guide to living with memory problems.

To receive a free copy delivered to your home contact:



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464



www.alzheimers.org.uk

If you find it hard to remember things, you may find it useful to follow these tips:

- Don't be afraid to ask questions
- Don't be afraid to say that you have not understood
- Don't be afraid to say that you have forgotten what has been said.

Remember, it is not your fault if you can't remember as well as you used to.

Alzheimer's Society produces free helpcards that help to explain your condition to anyone you might encounter in daily life.

Memory

Some things that might help you with your memory

Use a medication reminder box. Your pharmacist should be able to help you to get one and put your medication in the right compartments for you

- Using a diary or calendar
- Using a memo board or whiteboard
- Using sticky notes and reminders
- Stick notes on the inside of doors reminding you to take your keys
- Make lists and tick off tasks you complete
- Labelling cupboard doors and room doors to remind you where things are
- Using stronger light bulbs or task lamps to improve lighting
- Using coloured drinking glasses, placemats and coasters to improve contrast
- Keep things in the same place, especially things you use all the time such as keys or glasses, and have a routine
- Keep helpful phone numbers by the telephone where you can see them
- Displaying a timetable of your usual routine—one is included in the pack, on pages 18, 19, 20 and 21
- Breaking information into smaller chunks can help you remember more easily.
 For example it might be easier to remember phone numbers like this, as it's always easier to do once someone has shown you how
- Rhymes can be useful. For example, Richard of York Gained Battle In Vain can be used to remember Red Orange Yellow Green Indigo and Violet
- Using pictures to help remember. Photos can be used as prompts
- If you lose something imagine yourself putting it down
- If you can't remember why you went upstairs, picture yourself where you
 were when you decided to go upstairs. Retracing your footsteps mentally or
 physically can help retrace your train of thought
- If you can't remember a recipe try picturing yourself cooking it and adding all the ingredients
- Smells, tastes and music can all prompt memories



You might also find it helpful to:

Join a group/Dementia Cafe – stay active and occupied

Joining a group or attending a dementia café can be a good way to find something meaningful to do, meeting other people and receiving support. There are also groups for families and friends. To find a group that suits you and or those who support you, contact The Alzheimer's Society:



01274 586008 / 01756 799971 / 01423 813464

Talk to a support worker

A support worker can help you talk through some of the difficulties you might be having and help you to better understand your illness. They can also help you to make contact with others in a similar situation and point you in the right direction for other sources of help.

You can speak to a support worker on:



01274 586008 / 01756 799971 / 01423 813464

If you want 24 hours support and you use a computer, give the online forum a try:



www.alzheimer's.org.uk/forum.php

Dementia Friendly Communities



People with dementia and their carers talk about the everyday challenges they face in living well with dementia. This can include difficulty using technology, getting appropriate service in shops, banks and post offices and in using transport, going on holiday, maintaining social contact and hobbies. Although help from health and care services is vitally important, making it possible for people affected by dementia to live well will require help from people and organisations across society.

Dementia friendly communities

The dementia friendly communities programme focuses on improving the inclusion and quality of life of people with dementia. We want to make Bradford district a dementia friendly community.

In order to do this we are working to make sure people in the community and services are aware of and understand more about dementia so people with dementia and their carers will feel included in their community, be more independent and have more choice and control over their lives.

Initiatives are taking place across the district creating awareness about making communities easy to access and more accepting. Working with shops, businesses and services, work is being planned in training staff about dementia, support that customers may need and that the environment is improved, for example, by clearer signs and lighting.

Look out for the 'Dementia Friendly' symbol in shops and services near you to identify which ones are working to be dementia friendly, this is an ongoing process so keep looking as more places will display this sign over time.

If you or your local shops and services want to know more about this work please contact the Alzheimer's Society.



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464



Looking after your health



It is important to take good care of your health.

Having dementia should not mean that you feel ill, so always check with your doctor if you feel unwell.

This is important because any illness can make you feel more confused and forgetful.

- Try to eat balanced meals
- Try to take regular exercise
- Enjoy the odd alcoholic drink if you want but avoid too much alcohol, as it may make you more disoriented
- If you are on medication, ask your doctor to check whether it is essential, as it can sometimes increase confusion
- Poor vision and poor hearing can make you more confused, so it is important to have regular eye and hearing checks
- Painful teeth, gums or dentures can also make life more difficult. Make sure that you have regular dental check-ups
- If you want help to stop smoking or have trouble sleeping ask your doctor for advice
- Notice the signs you are feeling stressed and do something you enjoy
- Keeping your mind stimulated can also support physical health, such as reading, jigsaws, games and chess
- Smiling actually does improve your mood

Factsheets are available from the Alzheimer's Society:

- Dental care and dementia Factsheet 448
- Eating and drinking Factsheet 511
- Staying healthy Factsheet 522

NHS Choices

NHS Choices is the UK's biggest health website. It provides lots of information to help put you in control of your health and help you make choices about your health - from decisions about your lifestyle, such as smoking, drinking and exercise, to finding and using NHS services.



www.nhs.uk/Pages/HomePage



Keeping well

Dementia can affect the whole family. It is important for you (and your carer) if you have one, to look after your health and wellbeing.

You might want to:

- Have a flu jab
- Have regular health checks
- Ensure you are receiving any benefits you are entitled to



Carers' Resource 01274 449660 / 01756 700888



Carers' Connection 01274 323323

Health Trainer Service



If you would like free and confidential one to one support to:

- Eat healthier
- Get fit
- Manage your weight
- Feel happier
- Reduce stress
- Access new groups
- Make any lifestyle or behaviour changes to improve your health and wellbeing

You can refer yourself to a local NHS trained Health Trainer, or ask your doctor to make a referral.



Health Trainer Service 01274 777527



healthtrainers@bdct.nhs.uk

Keeping socially active

Dementia can sometimes be a very isolating illness. Reducing isolation helps improve and maintain your mood.

Doing activities that you enjoy and keeping as active as possible can help you cope better with the effects of dementia.

Enjoying life

Some of your previous interests may seem too stressful or demanding. But there will be many activities that will still give you satisfaction.

- Try to find things that you still enjoy doing such as listening to music, knitting, playing a game, exercising or talking to a friend
- Caring for a pet can be very satisfying and reassuring. Taking a dog for a walk is a good way of getting regular exercise
- Conversation between large groups of people can be hard to follow, so you
 may prefer friends or family to visit one or two at a time
- Try to concentrate on what you can still do, rather than worrying about what you can't
- Consider starting a life history book. Use a simple scrapbook or photo album to record details of your past and present life that will be helpful for anyone who may be supporting you. This is something your family and friends can help you with, and it is a great opportunity to share your history, memories and thoughts with those close to you

Relationships

Dementia can affect the whole family. It is important to have a good support network of supportive people that you trust. You may need a carer or support from relatives, families or friends. Having any long term condition can put a strain on relationships.

Things that might help include:

Talking things over

You will need to discuss plans for the future with those who are closest to you and with certain professionals.

If your family and friends do not already know about your diagnosis, try to tell them as soon as possible. At first, they may not want to believe you if they are very upset by the news. Try to discuss matters in a calm way.

- It will help if you can talk about your own wishes for the future, but try not to ask people to make promises now that may be difficult for them to keep later.
 You may find it helpful to write your wishes down
- It may help if you can talk about your feelings to someone you trust outside the family

Relationship Advice

If dementia is putting a strain on family relationships, you might want to talk to someone from Relate. They offer advice, consultations, sex therapy, relationship counselling, workshops and support face-to-face and by phone. Counsellors are experienced relationship experts and are specially trained to work with families to help people resolve their problems.



Relate Bradford 01274 726096
Relate Keighley & Craven 01535 605047

Support for Carers

If you have a carer and they need help or advice, please contact:



Carers' Resource 01274 449660 / 01756 700888



Carers' Connection 01274 323323



Taking care of yourself

Tips on taking care of yourself:

- Keep any inserts from repeat prescriptions with this pack so that you remember which medication is important to take
- Regularly check with your pharmacist or doctor to ensure you are taking the right medication
- It is important to have a health check each year. Remind your doctor if it has been longer than a year or you feel your health has changed
- The free annual flu jab can reduce the risk of getting seriously ill in winter months and is available to over 65 year-olds and those with serious medical conditions. Ask your doctor for details
- You should also contact your doctor if you haven't had the pneumococcal vaccine, routinely offered to over 65s, and the shingles vaccine, currently given to those aged 70 and 79 year olds
- If you have had a fall or are at risk of falling in the future, you can be assessed for support in your own home. Contact your doctor or District Nurse to get a Falls Assessment. These are carried out by individual practices or District Nursing teams

Everyone has the right to continence where achievable. With proper assessment and care, incontinence may be cured, improved or made easier to live with



Bradford & District Continence Service 01274 322171

Taking care of yourself

Appointments

It is important to pay attention to any changes in your health, and to stay up to date with your health checks.

Filling in this page and sharing it with people who support you can help.

	Date of last check up	Appointments	Notes
General Health check			
Flu jab			
Dentist			
Hearing checks			
Other checks			

It is important to let your health or social care provider know if you have dementia so that they can offer any extra support you may need.



Taking care of yourself

Eyes

Having an eye examination is really important for you because symptoms of dementia may cover up the symptoms of sight loss.

With dementia, additional sight loss may also increase your risk of falls or sense of disorientation.

RNIB (Royal National Institute of Blind People) recommends that you have regular eye examinations to check your vision as well as your eye health. Biannual sight tests are free if you are over the age of 60. If you are over the age of 70 they are free annually.

Alternative tests and approaches are available to help you, with some practitioners having particular experience of working with people who have dementia. Some opticians will even come to your home or make arrangements to see you at a time most suited to you. Speak to your local optician to see what support they can offer or contact RNIB for further advice.



RNIB 0303 123 9999

You can list your eye appointments here.

Date	Time	Comments

Feet

Regular check ups for your feet can identify and solve issues with walking, mobility or pain. Speak to your doctor to refer you to a podiatrist.



You can list your appointments here.

Date	Time	Comments

Everyday routines

Managing your routine

You may find it helpful to maintain your previous routine as much as possible:

- As your dementia develops, you may find it increasingly reassuring to do things at the same time each day or each week
- Nevertheless, try to keep on making the occasional one-off visit or trip, to keep life interesting and enjoyable
- Keep up things you like doing for as long as possible if you find this difficult, try to take things at a slower pace
- It may help other people, including family and friends, if you keep a record of your usual routine so they are aware of your timetable and can work together to support you (there is a chart on pages 18–21 to help you do this)





You can use these pages to help you keep track of weekly routines, groups, clubs, visits, and appointments eg: nursing support, hairdresser, shopping, etc.

Monday

Activity	
Time	
Transport	
Cost	
Contact person	
Number	
Notes:	
Tuesday	
Activity	
Time	
Transport	
Cost	
Contact person	
Contact person Number	
Number	
Number	

9

You can use these pages to help you keep track of weekly routines, groups, clubs, visits, and appointments eg: nursing support, hairdresser, shopping, etc.

Wednesday

Activity	
Time	
Transport	
Cost	
Contact person	
Number	
Notes:	
Thursday	
Activity	
Time	
Transport	
Cost	
Contact person	
Number	
Notes:	



You can use these pages to help you keep track of weekly routines, groups, clubs, visits, and appointments eg: nursing support, hairdresser, shopping, etc.

Friday

Activity
Time
Transport
Cost
Contact person
Number
Notes:
Saturday
Activity
Time
Transport
Cost
Contact person
Number
Notes:



You can use these pages to help you keep track of weekly routines, groups, clubs, visits, and appointments eg: nursing support, hairdresser, shopping, etc.

Sunday
Activity
Time
Transport
Cost
Contact person
Number
Notes:
Additional notes

Work

If you are still at work and are finding it stressful there may be an opportunity to switch to a less demanding job or to reduce your hours.

Seek expert advice on your pension rights if an occupational pension is due to you. It may be possible to negotiate a lump sum.

Before leaving work, check whether there are benefits that you or your family may be entitled to. If necessary, your personnel department or manager should be able to help you make enquiries.

Driving

If you drive, you may have to give up doing so either now or in the near future.

- Anyone who drives and has a medical condition that may affect their ability to drive, such as dementia, must inform the Driver and Vehicle Licensing Authority (DVLA) who will assess every case individually
- It is a criminal offence not to inform the DVLA of your diagnosis
- Check with your insurance company to make sure you are still covered following your diagnosis

Factsheets available from the Alzheimer's Society:

- Benefits Factsheet 413
- Driving and dementia Factsheet 439



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464



www.alzheimers.org.uk

End of life care

You may want to talk about your wishes for your end of life care, which may be difficult for you and your family to discuss. Reassure your family that you are not being morbid but want to share your thoughts around what you would like to happen to make it easier for them when the time comes.



Benefit checks

Many people don't claim the benefits they are entitled to.

Some people who have been given a diagnosis of dementia and/or those who care for them, may be entitled to certain benefits or concessions such as:

- Personal Independence Payment (PIP)
- Attendance Allowance
- Council Tax Disregard
- Blue Badge (parking permit)
- Carers Allowance
- Concessionary travel permits
- Cinema Pass
- Radar key (access to disabled toilets)

You are entitled to a benefits check to ensure you are receiving the right amount. The organisations listed below can help you with this:



Disability Advice Bradford 01274 609895



Bradford and Airedale Citizens Advice Bureau 0844 245 1282



Department of Work & Pensions 0845 60 60 265





Putting your affairs in order

Now is the time to make sure that any important documents are in order and can easily be found.

These include details of your mortgage or tenancy agreement, insurance policies, bank statements or building society books.

Go through all the details with a member of your family, partner or trusted friend.

- Sort out any recent bills, guarantees and regular payments. It might be a good idea to arrange to pay your regular household bills by direct debit, if you are not already doing so. Details of how to do this are given on each bill
- Look again at your Will and make sure that it expresses your wishes, or consult a solicitor about making a new one
- Consider making an advance decision. An advance decision allows a person to state what forms of medical treatment they would or would not like should they become unable to decide for themselves in the future
- Grant lasting powers of attorney, if you have not already done so. This
 enables you to appoint someone to manage your legal, financial and health
 affairs and make decisions on your behalf should you become unable to do
 this for yourself

Factsheets are available from the Alzheimer's Society:

- Advance decision Factsheet 463
- Enduring Power of Attorney and Lasting Powers of Attorney Factsheet 472
- Financial and legal affairs Factsheet 467



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464 www.alzheimers.org.uk

Notes:			

Lasting Power of Attorney



When planning for the future, it is a good idea to think about a Lasting Power of Attorney (LPA).

An LPA is a legal tool that enables you to appoint someone to make certain decisions on your behalf. The person you choose can manage your finances for you in the future if you reach a point where you are no longer able to make decisions for yourself.

There are two types of LPA:

- Property and Affairs
- Health and Welfare

For more information on LPA's or how to apply or any of the benefits listed above contact:



National Dementia Helpline 0300 222 1122



Notoc:

helpline@alzheimers.org.uk

Notes.		



Support in hospitals

In Bradford District and Airedale, Wharfedale & Craven, the main hospitals including, Bradford Royal Infirmary, St Luke's Hospital and Airedale Hospital have schemes to ensure people with dementia are properly supported during their stay. This means that all people involved in your care will be made aware of your needs, and that all staff are given formal training about dementia and how to support you.

If you need to go into hospital in for any reason, it would be advisable to inform staff in advance or on admission, that you have a diagnosis of dementia and should receive sensitive and appropriate support.

You can also get a copy of the 'This is me' leaflet, for you to use, to tell staff about your needs, preferences, likes, dislikes and interests.



This can be ordered or collected through the Alzheimer's Society.



Alzheimer's Society 01274 586008 / 01756 799971 / 01423 813464



www.alzheimers.org.uk



Services

Look at what services may be available to you. Even if you don't need them now, they may be useful in the future.

By using the services that you are entitled to you can ensure that those closest to you don't have to take on all the responsibility for helping you.

- Find out what services can be arranged through your doctor or consultant
- Find out what kinds of services and support are provided by local voluntary organisations, such as the Alzheimer's Society and Carer's Resource. Your local Citizens Advice Bureau, or Social Services will be able to advise you
- Connect to Support Bradford District is a website to help people seeking social care or support, with everything you need to help you, from local to national products and services, information, advice and more



www.connecttosupport.org/bradford



Support for diverse communities

Bradford District has a wide range of communities with people speaking many different languages, from different cultures with different needs and specific support available to them. The area has a range of specialist organisations that aim to meet the information and support needs of Black and Minority Ethnic communities.



Meri Yaadain Dementia Team is one such organisation that has been raising the awareness of dementia amongst the BME communities (especially South Asian) to help people with dementia and their families or carers to understand the dementia and the impact it has on people's lives. The Meri Yaadain Dementia Team are able to take referrals from health, social care and VCS organisations or directly from individuals. They help to meet information needs, help through a support group and limited advocacy. Information is available in a number of community languages as well as a DVD in Urdu with English subtitles.

For more information or a referral either ring the team on



01274 431308



akhlak.rauf@bradford.gov.uk



www.meriyaadain.co.uk

There are also many other organisations offering community based support for older people, with trained staff, who are able to provide culturally appropriate general support. You can find out more, in Connect to Support Bradford District, under 'local groups and activities.'

Contact your local social services department for details of services that they
can arrange. Find out about getting a community care assessment to assess
your needs. Social Services departments are listed in the phone book under
the name of the local authority

A factsheet is available from the Alzheimer's Society:

Community Care Assessment - Factsheet 419

Important contacts

Use this page to list people whose numbers you may need to keep handy, for example: doctor, social worker, podiatrist, etc.

Name	Contact Number	Details



Other useful contacts

A list of contact detalis which are often useful.

Name	Contact Number	Details
Emergency Services	999	To call in case of fire, medical emergency or if you urgently need the Police.
111	111	NHS 111 is a fast and easy way to get the right help, 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.
Alzheimer's Society	01274 586008 01756 799 971 01423 813 464	Alzheimer's Society offers information and support to people with dementia and their carers.
	www.alzheimers.org.uk	
Meri Yaadain	01274 431308	Working with South Asian people with dementia.
First Contact Self Care	www.carersresource.org/ first-contact/	First Contact connects you to support for your health and wellbeing needs
Health Trainers	01274 777527 Service covers Bradford District and inner city parts of AWC	Health Trainers can support you to make lifestyle changes and improve your health.
Age UK	01274 395144 01535 610100 www.ageuk.org.uk	Support for people aged 50.
Relate	01274 726096 01535 605047 www.relatebradford.org.uk www.relate-keighley.co.uk/	Relate offers advice, relationship counselling, and support face-to-face and by 'phone.

Other useful contacts

A list of contact detalis which are often useful.

Name	Contact Number	Details
Carers' Resource	01274 449660 01756 700 888 www.carersresource.org	The Carers' Resource provides support for carers, no matter what their age, race, religion or needs.
Carers' Connection	01274 323323	Carers' Connection offer an advice and support service to carers on any matter of interest to them, such as: health and social care, residential care, holidays, equipment, leisure and wellbeing.
Adult Safeguarding	01274 431077	If something does not feel right, or you feel uncomfortable that you are being harmed - or at risk of harm - please contact the Adult Safeguarding team.
Fire Safety Checks	0800 5874536 www.westyorksfire.gov.uk/ contact#safety-check	Firefighters can visit you to inform and give practical, common sense advice to eliminate or reduce the risk of fire happening in your home.
Connect to Support Bradford District	www.connecttosupport.org/ bradford	A website to help people seeking social care or support in the Bradford District.



Airedale, Wharfedale and Craven Bradford Districts Bradford City





Produced by:





Based on the RNIB Living Well with Diabetes Folder developed by Elaine Appelbee in collaboration with local communities and health service providers.

Special thanks to the Alzheimer's Society Bradford, for their contribution to the Dementia Self Care Pack.

The wording in this publication can be made available in large print or Braille. Please call 01274 437963.