



an information guide for people
with long-term illnesses

Your health, Your way ... dementia

This booklet is aimed at helping people with dementia, their carers, families and friends.

While there is no cure, dementia can be managed so that it doesn't dominate and control your life and there is plenty that can be done to control the condition and improve your quality of life.

Living with a long-term condition such as dementia can sometimes be difficult to manage day to day. So it's important you get the right information and the right help at the right time.

If you understand your condition and its treatment, you'll feel more confident. You'll be able to take better care of yourself and manage your condition; you'll be better equipped to make informed choices and decisions about your care.

So it's important to have good, reliable information about the local services available to you.

This booklet is aimed to help you, the people around you, including family and friends, in these difficult times. It will guide you in the right direction - show you where you can get local help, support, services and information. It won't give you the answers to all your questions, but it will show you where and how to get those answers.

It is designed to point you in the right direction to find out more about your condition, your treatment, how to live with it and manage it, how to get involved with local support groups if you want to; who to turn to when you need help and support, and who to talk to if you want to discuss things with people who know what you are going through.

Your condition ... what is dementia?

The term 'dementia' is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. Dementia is a progressive illness, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual. Each person is unique and will experience dementia in their own way. However, people who have dementia can also have a good quality of life with the appropriate care and support.

Even if you've suspected for a while that you, or someone you love, might have dementia, the diagnosis still may come as a shock.

People with dementia should try to remain as independent as possible and continue to enjoy their usual activities. The progression depends on the personality and general health of the person with dementia, and on the type of dementia. Over time, people with dementia will need help to cope at home and are eventually likely to need residential care in a nursing home.

It's natural to feel worried about the future. But remember that you're not alone. Whether you're a person with dementia or a carer, the NHS, social services and voluntary organisations can provide advice and support to help you and your family.

Your treatment

There is no clinical cure for dementia, which usually gets worse slowly, often over many years, and may mean that the person affected can no longer live independently. However, drugs and other treatments can improve the effects in some people, and you and your family can get the help and support you need to live with dementia.

A person with dementia will receive care from many different people across the NHS and social care. Providing services ranging from chiropody and dentistry to physiotherapy.

People who have been diagnosed with dementia, or who are worried that they may develop dementia in the future, are often worried about how decisions regarding their medical treatment might be made if they lose the ability to decide for themselves.

The Mental Capacity Act 2005 gives people in England and Wales a statutory right to refuse treatment through the use of an 'advance decision'. An advance decision allows a person to state what forms of treatment they would or would not like should they become unable to decide for themselves in the future.

Living with dementia

Dementia affects the whole life of the person who has it, as well as their family and friends. But there is advice and support available to help you, whether you've been diagnosed or are caring for someone with dementia.

It is important for a person with dementia to organise their financial and legal affairs while they are still able to do so. This ensures that their affairs will be organised in the future in a way that they have chosen. A person with dementia may want a friend or family member to help them with this. To get guidance on this option, talk to The Alzheimer's Society (see contact details on next page) or Citizens Advice.

The Mental Capacity Act 2005 made provision for people to choose someone to manage not only their finances and property should they become incapable, but also to make health and welfare decisions on their behalf. They will be able to do this through a lasting power of attorney for personal welfare.

Many people are happier if they can remain independent and in their own homes as long as possible. To achieve this, it may be necessary to make some adaptations to their homes or to use equipment that has been designed to enable people with dementia to remain independent for longer or make it easier for others to give support.

If they wish to continue driving, a person with dementia must fulfil certain legal requirements. When the person's condition deteriorates to the point where they are unsafe on the roads, they must stop driving.

If you are working, you may be having problems at work as a result of your dementia. When you feel ready, speak to your employer about your diagnosis. It will be easier if they are involved from the beginning.

Where can I find out more?

Leicestershire Partnership NHS Trust, tel: 0116 225 6647, are local providers of specialist mental health care. For more information, see their website at **www.leicspt.nhs.uk**

Alzheimer's Society: Is the national charity for people with dementia and their carers and offers a wide range of services including carer support, advocacy, monthly support groups, befriending, information and advice and training.

The Leicestershire and Rutland branch is at The Lodge, 46 Humberstone Gate, Leicester LE1 3PJ, **tel: 0116 251 0366** or email at **leicscityoffice@btconnect.com** The charity's website for more information is **www.alzheimers.org.uk** and the helpline is **0845 300 0336**.

West Leicestershire Mind: Mind is the national charity for mental health and offers a wide range of advice and support, including counselling. You can contact Mind at 4 Druid Street, Hinckley, Leicestershire LE10 1QH, **tel: 01455 890168**, or at their website **www.mind.org.uk**, or contact them by email at **wlmind@btconnect.com**

Rethink: support services and information for people with severe mental illness and their carers. For advice, contact the **National Advice Service** on **020 7840 3188** or email **advice@rethink.org**.

LAMP, the Leicestershire Action for Mental Health Project at 65 Regent Road, Leicester LE1 6YF, **tel: 0116 255 6286** or email **lamp@lampdirect.org.uk**, is an independent voluntary sector mental health organisation working for all the people of Leicester, Leicestershire and Rutland to promote good mental health and to challenge the stigma and social exclusion often associated with evident mental distress. For more information see Lamp's website at **lampdirect.org.uk**

Leicestershire Focusline: 0800 027 2127: Focusline is a free telephone helpline for people experiencing mental distress and their carers. This service is open every day from 5pm to 1am.

Savera: provides services for Asian people with mental health problems and their carers, and is based at 125 Loughborough Road, Leicester. **tel: 0116 2612837.**

Akwaaba Ayeh offers advice, support and information to African, African-Caribbean and Asian peoples who experience mental ill health difficulties and their carers. 40 Chandos Street, Leicester, LE2 1BL. **tel: 0116 2471525.**

Depression Alliance: tel: 020 7633 0557

Out of hours support: In an emergency, it is possible to visit the Accident and Emergency unit at Leicester Royal Infirmary and ask to see the duty psychiatrist. **NHS Direct - tel: 0845 46 47** can also provide you with medical advice around the clock.

Samaritans: 08457 909090 provide 24-hour emotional support.

Saneline: 0845 767 8000 can provide information and crisis support. Available 1pm to 11pm every day.

Leicestershire Focusline: tel: 0800 027 2127: Focusline is a free telephone helpline for people experiencing mental distress and their carers. This service is open every day from 5pm to 1am.

YOUR care plan

If your doctor has just told you that you are suffering from dementia, it can both daunting and frightening. But you are not on your own. As well as your health teams, there are charities, support groups, and even internet blogs and meetings where you can talk to people in the same situation as you.

Your health teams are there to give you support, help and treatment. However, you can make choices and decisions that affect your condition and it's important that you develop your own personal care plan to help you manage it. Your health team will help you with this, but there are certain things you might want to do as well.

Your feelings: Most people feel overwhelmed when they are told that they have a long term illness. People experience many different emotions, which can cause confusion and frequent mood swings. These emotions are part of the process that many people go through in dealing with their illness. You may find it helpful to talk to your GP, a counsellor or a member of your medical team, who can help you.

Lifestyle: Changing your lifestyle can help manage and control your condition. Local help is available to support you:-

Giving up smoking: Both NHS Leicester city and NHS Leicestershire County and Rutland have dedicated teams to help you give up smoking through one-to-one advice, clinics, personal advice and nicotine patches and replacements. The City **STOP!** Team can be contacted on **0116 295 4141**, and the County and Rutland team on **0845 045 2828**.

Healthy Weight, Healthy Life: maintaining a healthy weight can have a major impact on your health. Being overweight can increase your risk of raised blood pressure, diabetes and heart disease while being significantly underweight can impact on your immune system.

The **Leicestershire Nutrition and Dietetic service** has a team of dietitians who work in a variety of clinical specialties and can help you make informed choices about the food you eat. You can access general healthy eating advice and condition specific advice via their website at **www.lnds.nhs.uk**. If appropriate your GP or practice nurse can refer you to a dietician working within your local area.

Keeping Active: Regular physical activity can help and also reduces the risk of other serious conditions, such as heart disease and stroke. Leicester, Leicestershire and Rutland has a wide range of activities available such as gentle aerobics, cycling, salsa, walking and yoga. Every level of fitness is catered for, with help and advice readily available. Each district or borough has its own physical co-ordinator who provides advice on what's available in your area. Whether you are new exerciser; returning after a long time off; or a regular exerciser, all different abilities are catered for.

For more details, go to the Leicester-Shire and Rutland Sport website, **www.lrsport.org.uk** or telephone your local co-ordinator on:

Hinckley and Bosworth **tel: 01455 255875**

North West Leicestershire **tel: 01530 454830**

Charnwood **tel: 01509 634836**

Melton **tel: 01664 502389**

Harborough **tel: 01858 821284**

Blaby **tel: 0116 272 7704**

Oadby and Wigston **tel: 0116 257 2672**

Rutland **tel: 01572 720936**

Leicester **tel: 0116 252 7350**

Fit and Active Buddies (FAB) Project – personal trainers and cut price gym sessions to help people lose weight in Braunstone, Beaumont Leys, New Parks and Belgrave. **tel: 0778 538 5911**

Walking: www.leicester.gov.uk/walking

City Sport: www.leicester.gov.uk/sports for a variety of sport and leisure activities to suit all.

Talking to others: Meeting and talking with other people who are, or have been, in a similar situation can be both reassuring and helpful. Details of local and national support and help groups can be found on the websites detailed in this directory.

Support groups are also listed on the Leicestershire **'Infolinx'** website, a community information website run by the nine county and local councils, detailing more than 5,000 clubs, societies, organisations and self help groups based in the region. It can be reached at infolinx.leics.gov.uk.

Getting the most from your medicines

Around half of patients with a long-term condition do not take their medicines as prescribed. However, for patients to take real control of their conditions, they need fast and convenient access to medicines, involvement in decisions about those medicines, advice about how to take them and information on any side effects which they may suffer.

Pharmacists have an increasing role as a source of advice for patients and their carers. There are more than 200 pharmacists throughout Leicester city, Leicestershire and Rutland who are available to help with advice and information.

Refer to the NHS Choices website at www.nhs.uk, or talk to **NHS Direct** on **0845 46 47** for details of your nearest pharmacist.

Benefits and financial help

Many people find that facing a long term illness effects their finances and can cause money problems. Several local organisations offer information and advice about benefits, grants and loans you may be able to obtain.

Another useful source of information is the Government citizens' information website, **www.direct.gov.uk**

Benefit Enquiry Line: Confidential advice and information for people with disabilities, their carers and families about social security benefits, **tel: 0800 882200**

Leicester Money Advice: Free debt service which provides money advice and counselling for people who live in the city, **tel: 0116 242 1120**

Welfare Rights Advice Line. Telephone advice about benefits to people with a mental health problem and their carers, **tel: 0116 225 62 22**

African-Caribbean Support Service: Service provided by Foundation Housing Association for adults from the African Caribbean community with mental health difficulties who live in independent accommodation, **tel: 01165 254 42 30**

Age Concern: Offers practical help, advice and information about services for older people. Age Concern Leicester has its own Welfare Rights Officer on **tel: 0116 222 0555**. Other officers can be contacted at:

Leicester, Leicester-Shire and Rutland - **tel: 0116 299 2233**

Lutterworth - **tel: 01455 557116**

Oadby and Wigston - **tel: 0116 288 5203**

Hinckley and Bosworth - **tel: 01455 619519**

It's worth checking that you're claiming everything that you are entitled to: www.entitledto.co.uk or [www.direct.gov.uk/en/MoneyTaxAndBenefits/ BenefitsTaxCreditsAndOtherSupport](http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport)

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Need help or advice?

The **Patient Advice and Liaison Service (PALS)** is a free, confidential and individual service where you or your carers can be advised about the NHS, or voice your concerns about either your own or a relative's treatment. It aims to help solve any problems, concerns or questions you have when using health services in the area - a customer care service for your local NHS. PALS:

- Provides advice and support to patients, their families and carers
- Provides information on NHS services and local support groups
- Listens to your concerns, suggestions, queries or compliments
- Gives advice on how to make a complaint
- Helps sort out health concerns on your behalf
- Provides information on how you can get more involved in developing NHS services

You can contact a member of the PALS team in person, by telephone, email or letter. Patients and members of the public can meet PALS staff by arrangement.

NHS Leicester City PALS tel: 0116 295 7011 (Monday to Friday, 9am to 5pm. Outside hours please leave a message and PALS will call you). **email: pals@leicestercity.nhs.uk**

NHS Leicestershire County and Rutland PALS tel: 01455 441971
or **01509 564444**. **email: pals@lcr.nhs.uk**

University Hospitals of Leicester PALS tel: 0116 258 3100.
email: pals@uhl-tr.nhs.uk

Leicestershire Partnership NHS Trust PALS tel: 0116 225 6647.
email: pals@leicspart.nhs.uk

Other organisations that could help:

LEEAP (Leicestershire Ethnic Elderly Advocacy Project) 30 Chandos Street, Leicester **tel: 0116 275 5515**

For city services and support groups: visit
www.leicester.gov.uk/socialcare or **www.leicester.gov.uk/health**

The right equipment and social care

You might need special equipment to help you live at home, for example stair rails, jar openers, stair lifts, bath rails or even tap turners. If you are experiencing some form of disability as a result of your condition or its treatment, you may be entitled to help. If you are a hospital inpatient you may be seen by occupational therapists (OT) before you are discharged. The OT will assess you to find out if you need any special equipment or living aids to help you maintain your independence or improve your quality of life. If you are not an inpatient, you can ask your local social care services department for a care assessment to assess your needs.

The social care services offices are:

Blaby, Oadby and Wigston - **tel: 0116 278 7111**

Market Harborough - **tel: 01858 465331**

Charnwood - **tel: 01509 266641**

Melton Mowbray - **tel: 01664 564698**

Hinckley and Bosworth - **tel: 01455 636964**

North West Leicestershire - **tel: 01530 275200**

Rutland County Council - **tel: 01572 722577**

Leicester - **tel: 0116 253 1191**

British Red Cross Disabled Living Centre: The Disabled Living Centre at Aquis House, 211 Belgrave Gate, Leicester, LE1 3HT has a permanent display of daily living aids and equipment to promote independence. They offer free, impartial advice, information and assessment to people with disabilities, the elderly, carers and health professionals.

A referral is not required. Assessment is by appointment only. Monday – Friday, 9.00 am – 4.15 pm on **0845 373 0217** or **dlcinfo@redcross.org.uk**

British Red Cross Independent Living Products Shop at 113 Clarendon Park Road, Leicester, LE2 3AH stocks extensive range of equipment to improve the quality of life for elderly and disabled people on **0116 244 9049**. Monday – Friday: 9.00am – 5.00pm, Saturday: 9.00am – 4.30pm.

British Red Cross also provides a dial-a-wheelchair service providing manual wheelchairs on short-term loan (up to two months). This service is available from 244 London Road, Leicester, LE2 1RN **tel: 0116 270 0210**. Monday: 10.00am – 4.00pm

The Disabled Living Foundation – **www.dlf.org.uk** is a national charity that provides free, impartial advice about all types of daily living equipment for disabled adults and children, older people, their carers and families on **0845 130 9177**.

Carers

A carer is someone who, without payment, provides help and support to a relative, friend or neighbour who, because of frailty, illness or disability is unable to manage without help.

CLASP, the carers centre, provides a wide range of support services for carers in Leicester, Leicestershire and Rutland. **CLASP** is located on the Fourth Floor, Matrix House, Unit 19, Constitution Hill, Leicester LE11PL, www.claspthecarerscentre.org.uk or **tel: 0116 251 0999**.

email: enquiries@claspthecarerscentre.org.uk

Crossroads Mental Health Outreach Support Team provides emotional and practical support to carers of adults with mental health problems living in the city. Please contact the team on **0116 254 6464** or

email leicestermentalhealthproject@crossroads.org.uk.

The team is based at The Old Exchange, 449 Hinckley Road, Leicester, LE3 0WD and runs coffee mornings and carer support groups regularly.

Leicestershire has its own **carers project** which aims to provide carers with a local contact who can supply information, advice and support. The project also runs quarterly forums every year bringing carers together to enjoy each other's company and meet organisations and individuals providing support.

Carers development workers are located around the county and each team offers a variety of practical help, support, information and advice. Contact your local office for further details of the services and help available.

Voluntary Action Blaby District: Sandra Stocks **tel: 0116 272 7669**
email: carers@vabd.org.uk

Voluntary Action Charnwood: Nita Patel **tel: 01509 631783**
email: nita.patel@voluntaryactioncharnwood.org.uk

Voluntary Action Melton: Helen Brocklehurst **tel: 01664 485304**
email: Helenb@voluntaryactionmelton.org.uk

Voluntary Action Rutland: Gill Huddleston **tel: 01572 720052**
email: gill@claspthecarerscentre.org.uk

North West Leicestershire CVS: Sarah Hault-Ellingworth
tel: 01530 510515 email: sarahhe@nwlcvs.org.uk

Oadby and Wigston Community Action: Sarah Lambrianou
tel: 0116 281 0026 ext.28 email: ksmith@vaow.org.uk

Voluntary Action South Leicestershire runs a carers telephone befriending Service, where carers enjoy a weekly call from a volunteer befriender giving them time to talk to someone confidentially outside the family. If you care for someone and would like more information to help you in your caring role, contact either Jacqui Mowson on **01858 439263** or Diane Claridge on **01858 439262**. The carers project is based at Voluntary Action South Leicestershire, The Settling Rooms, St, Mary' Place, Market Harborough, Leicestershire LE16 7DR. **email: jmowson@vasl.org.uk**

Advice

Citizens Advice Bureau: www.citizensadvice.org.uk gives advice on debt, benefits, housing, employment and other legal rights.

Leicester - **tel: 0116 285 2801**

North West Leicestershire - **tel: 01530 454751**

South Leicestershire (Blaby, Lutterworth, Market Harborough) and outreach venues - **0844 848 9009** Debtline - **tel: 0844 248 0040**

Melton - **tel: 01664 484050**

Charnwood (Loughborough) - **tel: 01509 267376**

Hinckley - **tel: 0844 826 9710**

Shepshed - **tel: 01509 506663**

Rutland - **tel: 0845 120 3705**

Mosaic, Shaping Disability Service (Leicester) - tel: 0116 251 5565 Helpline: 0116 262 6900 textdirect: 18001 0116 251 5565.

Voluntary Action Leicester Shire provides information and support for voluntary and community groups and volunteers in Leicester city and various venues across Leicestershire. See their website, **www.valonline.org.uk** for more information or email **helpline@valonline.org.uk** or telephone the helpline on **0116 257 5050**.

Voluntary Action Blaby District - **tel: 0116 272 7669**

Voluntary Action Oadby and Wigston - **tel: 0116 281 0026**

Voluntary Action South Leicestershire - **tel: 01858 432014**

NW Leicestershire CVS - **tel: 01530 510515**

Voluntary Action Charnwood - **tel: 01509 631750**

Voluntary Action Melton - **tel: 01664 483043**

Voluntary Action Hinckley and Bosworth - **tel: 01455 633002**

Shopping

Shopping can be difficult if you find it hard to get around because of your condition. But there are local shopmobility schemes that provide or loan disability equipment to help, such as mobility scooters.

Leicester Shopmobility operates from two locations in the heart of the city:

Highcross Shopping Centre - **tel: 0116 253 2596**;

Haymarket Shopping Centre - **tel: 0116 253 7125**

Further information can be found at **www.leicester.gov.uk/shopmobility** or for details and contacts of other Shopmobility schemes, visit **www.shopmobility.org**

Melton Mowbray - **tel: 01664 480677**

Market Harborough - **tel: 01858 410864**

Hinckley - **tel: 07982 302 780**

Fosse Park - **tel: 0116 263 0600**

Coalville - **tel: 07982 706 285**

Loughborough - **tel: 01536 412 886**

NHS Choices

A wide range of information and advice about your condition and how to your choices about your care and treatment is available on the NHS website, '**NHS Choices**', or from the NHS telephone helpline, '**NHS Direct**'.

'**NHS Choices**' on **www.nhs.uk** is a wide ranging comprehensive guide and directory that gives:

- Medical advice about most conditions
- Services from GPs to gyms, doctors to dentists, midwives to memory problems
- 'All you need to know' guides covering 750 conditions and treatments
- Carers help and advice
- Blogs to talk to the experts and other patients
- Feedback from other patients
- Up to date medical news and views on treatment and research
- Tips and help on keeping you healthy
- Benefits advice
- Links to other medical, charity and support websites
- Comparisons between hospitals to help YOU chose where YOU want to be treated

For those without internet facilities, the same information and more is available from 'NHS Direct' – the 24 hours a day every day of the year helpline.

Trained staff are available round the clock to give advice and information on all aspects of health - from instant help with immediate symptoms or problems and where to get treatment; to details of walk in centres, clinics, local organisations, support and help on **0845 46 47**.

This publication has been jointly produced by the four NHS organisations in Leicester, Leicestershire County and Rutland. Printed copies are available by contacting any of the organisations:

- **NHS Leicestershire County and Rutland**

Lakeside House, 4 Smith Way, Grove Park, Enderby,
Leicestershire, LE19 1SS

tel: 0116 295 7689

or **email: communications@lcr.nhs.uk**

- **NHS Leicester City**

St John's House, 30 East Street, Leicester, LE1 6NB

tel: 0116 295 1100/1400

or **email: enquiries@leicestercity.nhs.uk**

- **Leicestershire Partnership NHS Trust**

George Hine House, Gipsy Lane, Leicester, LE5 0TD

tel: 0116 225 6485

or **email: feedback@leicspt.nhs.uk**

- **University Hospitals of Leicester NHS Trust**

University Hospitals of Leicester NHS Trust Headquarters,
Gwendolen House, Gwendolen Road, Leicester LE5 4QF

tel: 0116 258 8963

or **email: communications@uhl-tr.nhs.uk**

For further information or comments, or if you would like to contribute to the production of this document or further publications, please contact any of the above trusts.

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The NHS trusts listed above cannot be held responsible for any information provided by non-NHS organisations detailed in this document