KNOWLEDGE IS POWER England

Making life easier after a diagnosis of dementia

"Dementia is life changing, but it's not life ending. Take advantage of every opportunity offered to you. Try to learn to ask for help, because nobody should be going through this on their own."

This booklet was written by people living with dementia, for people living with dementia.

It includes information and advice that we hope you will find useful.

"You don't know what you don't know – we hope this will help you know more."

COMMUNITY FUND

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iD Innovations in Dementia

A message to you from the editors

You may have been diagnosed with dementia, or you might think you could have it. Alzheimer's disease is the most common kind of dementia, but there are many different kinds and causes. Different tyes of dementia will also affect us all in different ways.

This booklet is written for you and for those people who are close to you. A diagnosis does not automatically turn the people you are close to into carers and you into a patient. We use the term carers, as this will be most commonly used to find what you need to find.

The editors of this booklet, Maxine, Lorraine and Pete, have been through a diagnosis of dementia, and we are all at different places in this new stage of our lives.

Nobody wants to have dementia, but there is hope. You can do so much to make the very best of your life; many people we know go on for many years contributing to, and being a part of their community.

In slowing down, many of us become more creative. We can learn new skills, meet new people and discover new interests.

There are losses, of course, and fears. There will be times when we feel low, and times when we feel frustrated, struggling to do things we used to find easy.

Dementia doesn't make us any less of a human being. But some of the stigmas and stories we see and hear can make us feel less than we are.

We've written this booklet to give a different picture. We're moving past a medical diagnosis, and saying something about what helps us to live well with dementia, and what supports us to do that for as long as we can.

We hope we might support you at a challenging time.

With all good wishes

Maxine, Lorraine, Peter and Rachel

Members of the DEEP Network October 2023

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deep

The UK Network of Dementia Voices

Some dementia myths… that aren't true!

You only get dementia when you're old

Almost anybody can get dementia. It shows up in different ways. We're all different, and our dementia will be too.

Everyone forgets things as they get older

Dementia is a condition which is different from ordinary ageing, although there can be similarities in what happens.

Once you've got dementia, that's the end of your life

After a diagnosis, you can usually go on living your life. You might need some new strategies, or some help. But the more you do, the better you'll feel.

There's only one kind of dementia

There are around two hundred kinds of dementia. Alzheimer's is the most common. It is important to know which type of dementia you have because every type of dementia is different.

Not everyone loses memories

Dementia can affect everything including your senses and perception. This is why it is important to know and understand what type of dementia you have.

Dementia is genetic

Some forms of dementia are genetic, some are a mix, and some aren't.

Dementia is all about the end of life

There can be many years to do almost everything you want to. And when you know what to expect, you can plan ahead. Then you'll still have some control.

Nobody wants to know about dementia

If you find out some of the ways dementia can affect you, you'll be well prepared. You can work out ways to deal with it, and set up the support you may need.

There's nothing you can do about dementia

Nobody knows how to cure dementia yet. Some medications can help, and there's research into more.

There are people who know a lot about living with dementia, and there are people who can support us.

Keep doing what you have always done as much as you can. You might need to change the way you do things, and how much you can do.

We can't talk about dementia

It might be hard at the start, but talking about dementia helps everyone.

We can talk through our feelings and our worries with the people around us.

We can make decisions and plans.

We can help other people understand more about dementia.

Talking about dementia with other people who have dementia can be great. You're not alone, there are lots of us. Many of us have a good laugh about things that happen to us.

We can go on with our lives, do what helps, and enjoy every day as much as we can.

You can see when somebody has dementia.

We often hear people being told "you don't look like you have dementia." You might want to come up with a response that sits comfortably with you. We might ask what someone with dementia should look like. We know someone who smiles and answers: "you don't look like you're stupid."

There's nothing to be ashamed of. Every time you don't fit the image people have been given of people with dementia, you do something to help change people's minds and attitudes.

Our editors

Maxine Linnell from Leicestershire

I am a writer and was a psychotherapist for many years. I am a mother and grandmother. I was diagnosed with Alzheimer's in September 2022. I'd thought about what I might want to do if this happened, and because the diagnosis came early, I've been able to set up some things which matter to me now–like an Advance Decision and an Advance Statement, a RESPECT form, and Lasting Powers of Attorney. That's helped me to feel less anxious, and now I'm gradually adapting to this new life, with the help of the DEEP Network and others who have dementia. They've given me hope. I am setting up a DEEP group in my area.

www.maxinelinnell.com

Peter Middleton from Northampton

I was diagnosed with Alzheimer's disease in January 2019. A lot of water has gone under the bridge. I have been actively engaged with the Alzheimer's Society who have given me the opportunity to be involved in public speaking and even appear in a TV documentary on Channel 4. I have my ups and downs, but I want anyone who is newly diagnosed to know that you can live well with dementia.

Lorraine Dunn from Darlington

I am known as the “wee fiery Scot” and I have taken dementia and life like a bull by the horns. I have a background in social care and have set up my own DEEP group in Darlington. As a member of a virtual DEEP group, I have worked with and supported my friends to fight for and understand their rights. I am involved in lots of projects and research including the evaluation of the Dementia Voices work. I also find time to be a wife, a mother and a grandmother.

Rachel Niblock

I was the Co-ordinator of the UK DEEP Network for 8 years. Before that I was an Occupational Therapist. Everything I have learnt about dementia has come from people who live with dementia.

From us to you…

"Do things that make you feel empowered–focus on what you can do, not what you can't."

"Use strategies to help you adjust: using new technology can help with reminders. I use Alexa, she reminds me about everything."

"Don't give up, and don't withdraw from what you like doing. Smile when you can and live for today."

"Carry on doing what you have always done as much as possible for you."

"See if you can get involved in helping others who have a diagnosis or who want to learn more about dementia, by talking to people about your own experiences."

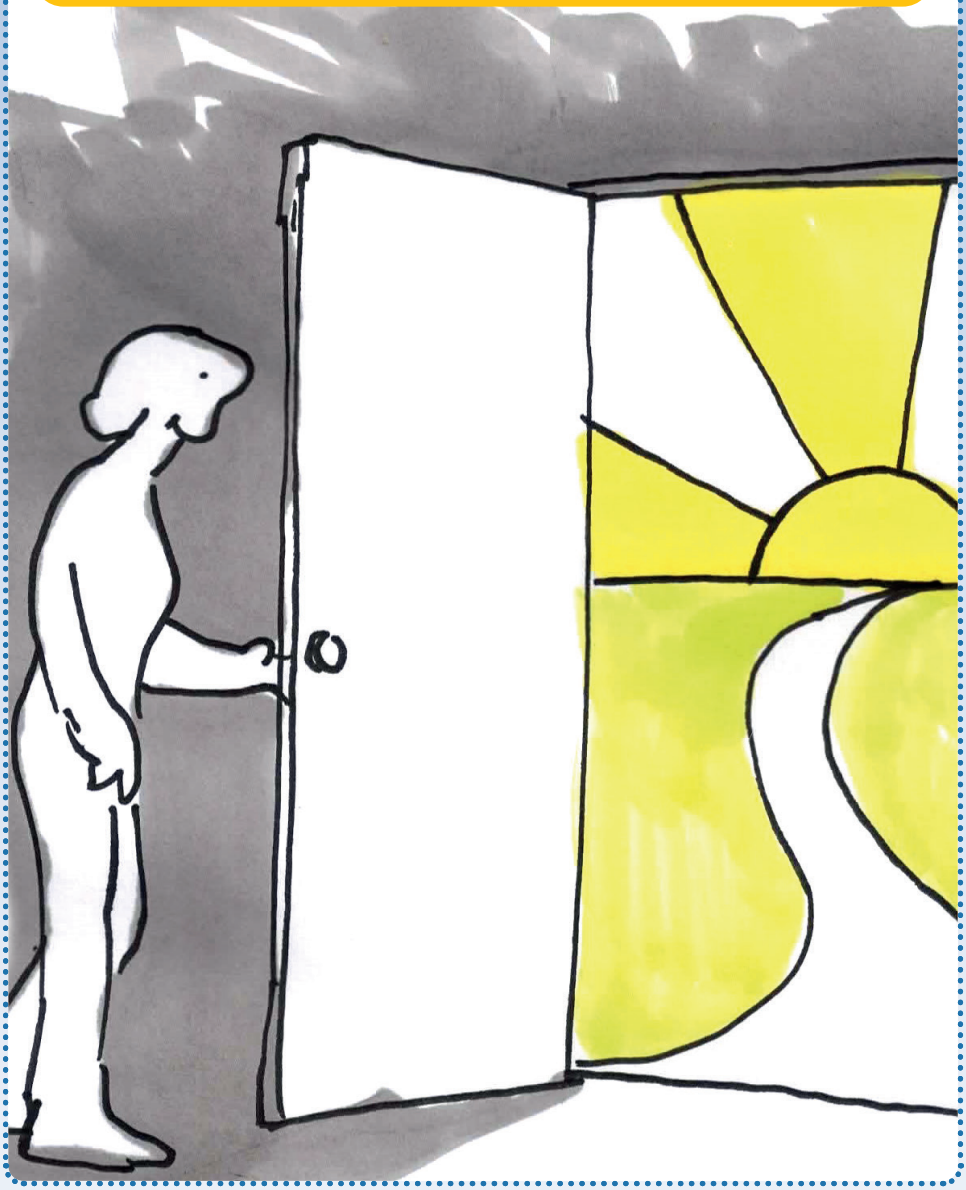
"If you feel tired or have a down day, take care of yourself and have a rest."

"It's okay to feel down sometimes, and it can help to talk to someone else going through the same thing."

"Connect with other people who are living with dementia. Peer support is invaluable."

"You may feel uncomfortable about applying for concessions, passes and other kinds of help. Try not to – they will be of enormous benefit to you and your companions in the long term."

“We can solve some of the problems when we know what support is available. We can learn, we can explore, we can work out what to do.”



Benefits and allowances

Personal Independence Payment (PIP) for under 65s

This is a government-provided allowance for disability, which is not means tested. It has two components, and both have two rates, basic and enhanced:

1) for day to day living needs

2) for mobility support needs

- It can be a gateway to accessing other types of support.
- We strongly suggest you get help to fill in the PIP form. The Citizens Advice Bureau can help you.
- Apply to the Department for Work and Pensions to see if you qualify.

https://www.gov.uk/pip

0800 917 2222

Attendance Allowance for over 65s

You might qualify for an Attendance Allowance from the Government. This helps with extra costs if you need someone to help look after you, and it is awarded to the person who has received a diagnosis of dementia. Check if you're eligible.

https://www.gov.uk/attendance-allowance

0800 731 0122

Care needs assessment

If you think you, or someone you know, needs help to cope day-to-day, the first step is to get a needs assessment.

Apply to the social services department of your local council (for free). They can recommend services to help you with things like equipment, home adaptations, practical help from a paid carer, and access to day centres and clubs.

Carer's Allowance: even if you don't like to think of having a carer, or think of yourself as a carer, have a look: it may help you in the future. This allowance is payable to a carer if the carer is working – conditions apply. Find out more information here:

https://www.gov.uk/carers-allowance/how-to-claim

Council Tax Rebate: 25% off UK wide, 100% if you live alone. Conditions apply. Check with your local council. This can be claimed under the (unfortunate) heading of “Severe Mental Impairment.” For more information:

bit.ly/3rqXmKl

Employment Support Allowance: UK wide long term sickness payment. Either contribution based or income based.

Contact **www.cas.org.uk** or **0800 0232581** for help with this.

Make the most of the services and support that are available to you. Even if you don’t think you need it now – make those connections. Knowing what is out there really can help you – Knowledge is Power!

Travel and mobility

Driving

Receiving a diagnosis of dementia does not automatically exclude you from driving. You **must** however inform the DVLA.

https://www.gov.uk/driving-medical-conditions
0300 790 6806

Driving is a hard activity to give up, but listen to the people around you if they notice any safety issues.

There is a self-assessment checklist available to help you think about whether you are safe to drive.

https://www.olderdrivers.org.uk/driver-assessment/self-assessment

You can request a Driving Assessment at a Driving Mobility Centre.

www.drivingmobility.org.uk

Blue Badge for car parking

A Blue Badge can give parking concessions to people with a disability, including dementia. You can park closer to venues, shops etc. Some car parks do not charge for vehicles with a Blue Badge.

Some people may become disorientated. Being able to park close to where you need to be, or in a designated space, absolutely justifies your entitlement to a Blue Badge.

The Blue Badge is for the person, not the vehicle. You do not have to own a vehicle to apply for a Blue Badge; carry it with you and use it in any car.

Apply at **www.gov.uk/apply-blue-badge**

Costs can vary up to £10, and badges last for three years.

Motability Vehicle through Personal Independence Payment

If you are in receipt of the enhanced mobility element of Personal Independence Payment, you can lease a car through Motability.

This means that Motability will take the mobility element of your payment and in return you get a car with no road tax to pay and no insurance to pay. Tyres and servicing are also included free of charge.

There may be an up-front deposit to pay, depending on the vehicle you choose.

This payment will be due at the time of ordering your vehicle but if the dealer is not a Public Limited Company (PLC), you may not have to pay the deposit until you collect your car. Enquire at the dealership.

www.motability.co.uk

Public transport

Bus Travel

Concessionary **Bus Passes** are available for free bus travel in England between 9.30am and 11.00pm on weekdays, anytime at weekends and on bank holidays.

Some local councils offer a reduced fare before 9.30am on weekdays, so check on your local council website.

Companion bus passes allow you to travel with a companion at the same rates.

Contact your local council for information.

https://www.gov.uk/apply-for-elderly-person-bus-pass

https://www.gov.uk/apply-for-disabled-bus-pass

Rail Travel

Disabled Person's Railcard gives 1/3 off rail travel for you and your companion nationwide.

The railcard costs £20 for a year or £54 for three years. You can buy it online at:

https://www.railcard.co.uk

Travel Assistance: is available at many stations for those who need it. A station staff member can help you and your luggage to a seat, meet you when you get off the train and help you get to other trains, taxis etc. Request assistance at the time of booking either online or at the station.

There is also a passenger assistance website and app.

www.passengerassistance.com

03456050525

Quiet Compartments

When booking your journey you can request a quiet compartment, the direction of travel for your seat and location near to toilets and end of carriage.

Ferry Charges

Some ferry operators, such as those to the Isle of Wight and CalMac in Scotland, offer discounts for Blue Badge holders. Check before you buy.

Assistance is available at ports for all ferries within the UK and Europe. Arrange this in advance.

Flying

Heathrow and the University of Plymouth have a very useful "Flying with dementia guide" which you can find here:

www.heathrow.com/content/dam/heathrow/web/common/documents/at-the-airport/accessibility-and-mobility/flying-with-dementia.pdf

Travel Insurance

It is possible, though sometimes difficult, and more expensive, to get travel insurance. This is because the insurance company may assess your risk as high to need medical cover and assistance. Search online using the search term "travel insurance with a pre-existing medical condition".

Guidance and Advice for Travel

The Alzheimer's Society has an excellent guide to transport and travelling tips when someone has dementia:

https://www.alzheimers.org.uk/get-support/staying-independent/transport-travelling-tips-dementia

Also take a look at the voice of accessible tourism in the UK:

www.tourismforall.co.uk

Access assistance

Just Can't Wait!

The "Just Can't Wait Toilet Card" is a card that provides access to toilets that are not usually available to the public. It is widely accepted at cafés, restaurants, shops and venues etc.

Free digital copy or £2.95 postage for a card.

www.bladderandbowel.org

0800 031 5406

Accessaloo App

This is an app for your phone that can help you find accessible toilets on-the-go.

It is helpful when you are out and about in unfamiliar towns and countries.

Key to Access Disabled Toilets

This is a key, sometimes known as a Radar key, that you can use to access public disabled toilets that are frequently locked.

Available from Amazon, Ebay and some mobility equipment shops.

Various prices.

Going out

Cinema Exhibitors Association (CEA) Card

The CEA card will allow your companion or carer to accompany you free of charge into most cinemas.

The card costs £6.00. You will need a passport-type photograph and a PIP or Attendance Allowance Award letter from the Department of Work and Pensions.

01244 526 016

Apply online at: **https://www.ceacard.co.uk**

CEA Card, PO Box 199, Deeside, CH5 9BW

Relaxed, Chilled or Dementia Friendly Entertainment

Many cinemas and theatres offer relaxed screenings and performances for those who require quieter performances.

Ask at your local venues.

Sunflower Lanyard, Wrist Band or Badge, for Hidden Disabilities

Wearing one of the Sunflower products shows others that you have a hidden disability. It makes it easier for people to recognise that you may need some extra support. It is increasingly recognised internationally.

You may feel a bit uncomfortable wearing a Sunflower lanyard at first but the benefits and the kindness will out-weigh the negatives.

The Sunflower lanyards are free at certain places like airports, stations, supermarkets etc. Ask at the information desks.

You can also buy them from:

https://hdsunflower.com

"The Sunflower lanyard really works and doesn't highlight you as vulnerable. It just highlights that you might need help! I use it all the time. It costs nothing but is worth everything."

Quiet Hours

You may find that being in a busy and noisy environment like a supermarket is hard to process and navigate. Many supermarkets offer quiet hours when the background music is turned off, and staff may be especially aware of the need for assistance for some shoppers.

Check with your local supermarket. If they don't have a quiet hour, enquire if they might be willing to start one?

Ask locally for details, or there may be posters at the venues/shops.

Free Entry for Companions or Carers

Many public venues such as museums, art galleries and visitor attractions offer free entry for your companion or carer if you are a member.

National Trust – Essential Companion Card – **www.nationaltrust.org.uk**

English Heritage – **www.english-heritage.org.uk**

Carers First have a Days Out online directory of information and a wide range of activities **www.carersfirst.org.uk**

Euan's Guide

An online site where ordinary people have reviewed venues for accessibility.

"We are the disabled access charity best known for EuansGuide.com, the disabled access review website. But we also make tens of thousands of accessible toilets safer, run the UK's largest Access Survey and lots more.

The aim of Euan's Guide is to empower disabled people by providing information that will give confidence and choices for getting out and about."

Euan MacDonald, Founder of Euan's Guide.

https://www.euansguide.com

Wheelchairs and mobility aids

Take a look at **www.nhs.uk** and search walking aids, wheelchairs and mobility scooters.

If you are using a wheelchair for more than occasional use, please ensure you have a proper assessment from an Occupational or Physio Therapist or a wheelchair service.

- You may be eligible for a wheelchair or walker. Ask your GP to refer you.
- Red Cross run a wheelchair hire scheme.

www.redcross.uk

0300 456 1914

Many public places have wheelchairs – always check they are safe and clean before use.

A mobility aid, like a walking stick or a hiking pole, may help you feel more confident in a busy environment. Some people will be affected by sensory and perceptual difficulties as a part of their dementia and a stick may help somebody to navigate around spaces.

Resources you might use

Carer's Emergency Card

This is a card that a carer can carry in case anything happens to them, to say that there is a person being cared for who may be alone at home. Available from local carers' organisations or your local council.

Message in a Bottle Scheme

The Lions Charity run a free "message in a bottle" scheme to store important information. It is a small white pot which contains a small form where you can write your contacts, diagnosis, and medication.

It is often stored in the fridge as a recognised place to look! There is also a sticker which is put by the front door, to make people (emergency services for example) aware that you have one.

The Herbert Protocol

The Herbert Protocol is a national scheme that encourages family and friends to put together useful information. This can then be used in the event of a vulnerable person going missing.

Contact your local police force online or by phone to obtain the form. Fill it in and keep it safe at home. This can easily and quickly be shared, if someone goes missing.

Medical ID

You can buy medical identification jewellery including writsbands and pendants to help show what your needs are if anything happens to you. There are many types available. It may provide peace of mind in case something happens when you are out and about.

Technology

Many people find gadgets like Amazon Alexa incredibly useful for reminders, news and connecting with others.

If you own an iPad or something similar this may meet your needs. You might not need an expensive gadget marketed at people living with dementia.

Telecare Devices

This is a personal alarm which you wear as a pendant or bracelet. It lets you call for help if you need it at home.

Contact your local council's adult social services department, and ask for a free care needs assessment. Depending on your needs, they may provide a telecare service.

Speak to your GP or an Occupational Therapist. They may recommend a telecare system as part of a continuing health or care package.

There's often a charge for telecare services.

Mobile Phone Apps with Tracking Systems

If you have a smart phone, you can get free phone apps with GPS tracking systems.

You may find there are ways for somebody else to track your phone. These apps will vary depending on the model of your phone. You can choose who you would like to track your phone.

"Keep going, keep up as much independence and activity as you can."

Future planning

Not everyone is ready to think about the future. It can take a while to sort out, but some of us feel more secure when we've tackled it.

There's help available. You can talk with people close to you, and you can take the time you need. In time, it may get harder to organise your thoughts and write them down. There are options – you can choose.

Advance Statement: decide what you do want

An Advance Statement will help people who might care for you to know more about you – what you need, what you like and dislike, your food preferences, what you want to be called and how you want to be cared for. An Advance Statement isn't legally binding, but it must be considered.

Advance Decision (Living Will): decide what you don't want

An Advance Decision (Living Will) is a form which lets you refuse any medical treatments in the future. It's only used if you are no longer able to tell people what you want. An Advance Decision can keep you in control of your life, and can make things easier for your family. It is signed and witnessed, and is legally binding. If you want other people to make these decisions for you, there's no need to make an Advance Decision.

For more information, go to
compassionindying.org.uk
Free phone line **0800 999 2434**

Lasting Power of Attorney: decide who can speak for you

You might want to decide who can make decisions about your wellbeing in the future if you. A Lasting Power of Attorney lets you name those people. They will need to agree to this.

There will be forms to fill in and there may be a fee. There are two kinds of Lasting Powers of Attorney: one looks after your health and wellbeing, and one looks after your financial and legal affairs. These are legally binding.

https://www.gov.uk/power-of-attorney

You can set all these up online, or on paper.

Support you may find helpful

Admiral Nurses

Specialist nurses support people affected by dementia. There are local services in some areas. There is also a national helpline.

bit.ly/463JZid

0800 888 6678

Advocates

Support you to speak up about what you want, your rights, and understand information to make your own decisions. Contact your local authority to find out who provides your advocacy service.

Audiologists

Can help with hearing difficulties and issues often experienced with increased sensitivity to noise.

Dementia Link/Support workers

Ask your GP or Memory Clinic if there are any Dementia Support Workers in your area.

Dieticians

Provide advice to help you with your nutrition.

Occupational Therapists (OT)

They will help you live life to its fullest by working with you. They focus on what you can do to maximise your safety and quality of life. They help you to do what you want to do, and may provide or recommend equipment if needed.

Physiotherapists

Can work with you and your carers to promote physical strength and activity and maintain your mobility and independence.

Podiatrists

Take care of your feet to help you to remain mobile, prevent falls and promote independence.

Psychologists, Community Psychiatric Nurses (CPNs), and Young Onset Dementia Nurses

Offer support with the practical and emotional aspects of living with dementia.

Social Prescribing Link Workers

Social prescribing connects people to activities, groups, and services in your community to meet the practical, social, and emotional needs that affect wellbeing. Look at your local NHS website to find out what there is in your area. Contact your GP practice to connect with your social prescriber.

Social workers

Can help you with needs assessments, helping you to find useful resources and services.

Speech and Language Therapists (SALT)

Can help with communication strategies. They also help people who experience swallowing difficulties.

Other Services

There are services which may also be available at home including dentists, and opticians.

Unfortunately, the services are not available everywhere. Many support services can now be accessed online or on the phone. If you don't know, don't be alone. So much information comes from talking with others in a similar situation.

Useful websites, resources, peer support and involvement opportunities

Age UK:
www.ageuk.org.uk

Alzheimer's Society:
https://www.alzheimers.org.uk

Carers Trust:
www.carers.org

Dementia Alliance International:
https://dementiaallianceinternational.org/

Dementia Carers Count:
www.dementiacarers.co.uk

Dementia Diaries:
www.dementiadiaries.org

Dementia Support Forum:
https://forum.alzheimers.org.uk/

Dementia UK:
https://www.dementiauk.org

Innovations in Dementia:
www.innovationsindementia.org.uk

Join Dementia Research:
www.joindementiaresearch.nihr.ac.uk

Lewy Body Society:
www.lewybody.org

Living with dementia toolkit:
https://livingwithdementiatoolkit.org.uk

Playlist for Life:
https://www.playlistforlife.org.uk/

Rare Dementia Support:
www.raredementiasupport.org

Reading Well on prescription (dementia):
https://reading-well.org.uk/resources/751
(list will be updated Spring 2024)

Re-imagining dementia:
https://www.reimaginingdementia.com/

Sporting Memories Network:
www.sportingmemoriesnetwork.com

TIDE – together in dementia everyday – a UK wide network for carers:
www.tide.uk.net

UK DEEP Network (Dementia Engagement and Empowerment Project):
www.dementiavoices.org.uk

Young Dementia Network:
www.youngdementiauk.org

3 Nations Dementia Working Group:
https://www.3ndementiawg.org

Useful phone numbers

Alzheimer's Society Helpline:
0333 150 3456

Dementia UK – to speak to a dementia specialist nurse (Admiral Nurses):
0800 888 6678

Useful blogs by people with dementia

Gail Gregory:
https://dementiaalzheimers.home.blog/

George Rook:
https://georgerook51.wordpress.com

Maxine Linnell:
https://www.maxinelinnell.com

Peter Berry:
www.peter-berry.com

Peter Middleton:
https://www.livingwithdementia.online/

Wendy Mitchell:
https://whichmeamitoday.wordpress.com

Recommended reading (booklets):

All booklets below are downloadable at:
bit.ly/4663xCv

Driving and Dementia (James McKillop):
bit.ly/3r4GKIb

Dementia & GP Services–Booklet (Alumni):
bit.ly/3P4Ew3A

Knowledge is Power (Scotland):
bit.ly/3LbRE5V

Knowledge is Power (Wales):
bit.ly/3Pi5bdw

Recipe for Life (STAND):
bit.ly/3EtYRdK

Sensory booklet (Agnes Houston):
bit.ly/44MoIrU

Self-Management (Alumni):
bit.ly/3LhuAmi

Talking Sense (Agnes Houston):
bit.ly/3sLviBM

Recommended reading list (books) by people living with dementia:

*** indicates that book is available as an audiobook**

Christine Bryden

Nothing about us, without us!

Who Will I Be When I Die?

Keith Oliver

Dear Alzheimer's – A Diary of Living with Dementia

Peter Berry

Slow Puncture: Living Well with Dementia

Walk With Me – Musings through the dementia fog.

Wendy Mitchell

One Last Thing: How to Talk About Death and Get on with Living *

Somebody I Used to Know *

What I Wish People Knew About Dementia: From Someone Who Knows *

There are further book recommendations on these websites:

Dementia UK

https://www.dementiauk.org/books-about-dementia/

Reading Well on Prescription (dementia)

https://reading-well.org.uk/resources/751

(The Reading Well list will be updated by Spring 2024)

DEEP – The Dementia Engagement and Empowerment Project

DEEP is a small but powerful network of voices of people living with dementia. There may or may not be a group in your area, but quite a few groups have been set up in recent years by people living with dementia. A group can be small and meet in a café or it can be big and be supported by a health trust or an organisation. But, at the heart of it, DEEP is about ensuring that people have the opportunity to share, learn and support, making sure those conversations happen about what matters to us. A phrase commonly used is 'Nothing about us without us'. Groups have the opportunity to be involved and be part of what happens or become more involved nationally. Many groups have become involved in research, campaigning and standing up for our rights.

Groups are encouraged to share, learn and support, connecting with other groups in the network to share their experiences and activities. Groups inspire, give hope, and motivate so many to share their voices.

Visit the DEEP website to find:

- The contact details of all the DEEP groups
- Latest News
- Our DEEP News in print and audio
- Resources and guides to support the DEEP values and practical processes for everybody.
- Inspirational films and stories
- We run monthly online ZOOM support sessions for DEEP facilitators.

deep
The UK Network of Dementia Voices

10 Anniversary 2012 - 2022

www.dementiavoices.org.uk

The Knowledge is Power series has been made possible by the voices of the DEEP Network.

If you run a group, or would like to set up a group, please make sure that you embrace the DEEP Values on the next page.

DEEP stands for Dementia Engagement and Empowerment Project

Be a part of **DEEP** – the UK Network of Dementia Voices

Deep Values – Hear us, See us, Join us

Hear us:

Unity – DEEP is a place where we come together as part of a network of groups

Opportunity to have a voice – DEEP provides equal opportunities for all voices in our groups to be heard, involved, and contribute about what matters to us

Respect – DEEP members respect different views and voices

Our Voices – DEEP is about more than one voice; it is a powerful, collective network

See us:

Busting the stigma of dementia – DEEP members respectfully challenge the stigma of dementia through our voices and our activities

Influence – DEEP members can aim for any level of influence in the dementia world, your home, your street, your country. No action is too small

Honesty – DEEP offers a safe place to be raw, emotional, and even angry, whilst being respectful and mindful of the needs of others

Join Us:

Love – DEEP groups encompass a sense of safety, belonging and unity

Humanity – DEEP members treat each other with kindness and respect

Anchor – DEEP provides a safe environment to belong and enable

Yellow “I want to speak please card” – cut out and use

“I want to speak please”

Excerpt from "What I Wish People Knew About Dementia" 2021 by Wendy Mitchell –

Wendy is a member of the York Minds & Voices DEEP group.

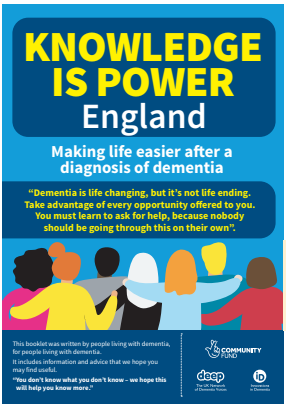
Photograph of Wendy courtesy of The Guardian

"Like many people I knew nothing about dementia at the point of my diagnosis. All I did know were the snippets that we pick up, through the media, newspapers, television, perhaps a secondhand tale from a friend. I was frightened, of course, like most people. I was terrified of the progressive illness and the planned trajectory that would, slowly, but surely, be revealed to me. I suddenly felt I had lost control of my own life, which is a very scary feeling – and also a very normal one.

What have I learned? Well firstly, that I actually had less to be afraid of than I thought. That yes, dementia is a bummer of a diagnosis, but, like everything in life, it has a beginning, a middle and an end. Who knows where I am on my journey with this disease? What I see now, from this vantage point, is just a slice of the final sum total of my story with dementia. Is that really that dissimilar to how any of us live our lives? After all, the only certainty I have is the same as what everyone else has, which is actually just today."

Thanks to Wendy Mitchell, Anna Wharton and Bloomsbury Publishing. For more information about DEEP and so much more please visit:

www.dementiavoices.org.uk



Knowledge is Power England is available as an online version with live links please visit:

https://bit.ly/3ZCPjqu

Additional information:

We have only been able to produce a limited number of hard copies of Knowledge is Power England, which we will try to distribute widely across England.

Your organisation can print your own copies of Knowledge is Power England. If you would like multiple copies of the booklet please contact us for a quote to cover printing and delivery.

We welcome any comments or feedback about anything we may have missed.

Contact us by email at **KiP@myid.org.uk**

The Knowledge is Power series:

This booklet is based on the original Knowledge is Power booklet created in Wales at Bangor University together with the Caban group, DEEP United Dwyfor & Meirionnydd, and Fuse & Muse, Swansea. For more advice on how to develop the Knowledge is Power booklet or to access other resources created in partnership with the Dementia Services Development Centre (DSDC Wales) at Bangor University please visit: **dsdc.bangor.ac.uk/products-created**

How it all started...

During a discussion around what it takes to be resilient with dementia at Bangor University, the Caban group talked about their diagnosis experiences, and how people often get either too much or too little information at the time of diagnosis. The group decided to create a helpful booklet with what they felt was 'just the right amount of information', to help others living with dementia. The bilingual Welsh/English booklet was first published in 2020, followed by Knowledge is Power 2 including helpful tips for day-to-day life in 2022.

DEEP groups in Scotland joined forces in 2020/2021 to create a Scots/Gaelic bilingual Knowledge is Power Scotland version, funded by The Life Changes Trust.

Now, thanks to funding from the National Lottery Awards for All, we can produce a version of Knowledge is Power for England in a printed booklet and an online version with live links.

DEEP thanks to Tony Husband for cartoons (originally created for the 'What is DEEP?' booklet).

The England edition is written and edited by Maxine Linnell, Lorraine Dunn, Peter Middleton, and Rachel Niblock. Thanks to everyone who has supported us in this project.

Have we missed something?

Thanks for reading this booklet. If you think of anything you'd like to add or change, do let us know! And if you want to tell us how this booklet has supported you, we'd love to know that too!

Please contact us with any comments at **KiP@myid.org.uk**

Wishing you well, Maxine, Lorraine, Pete and Rachel

Your own notes

Your own notes

“Knowledge is Power England is for anybody who has been, or knows somebody who has been, diagnosed with any form of dementia. We don’t believe that anybody should be alone. As people living with a diagnosis of dementia, we want to share with you some essential information that has helped us.”

COMMUNITY FUND

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