Focusing on the Future

DEMENTIA

Information and services for all people living with dementia and their families
Introduction
You have been given this booklet because you, or a loved one, have recently received a diagnosis of dementia. We know that this is a difficult time, and you may be worried, anxious and nervous. We have developed this booklet to help you to identify what services are available for people with dementia. Not everybody needs support at the same points in their journey, so please keep this booklet for the future.

D is for Dignity – that’s what you want from professionals, family, and friends.
E is for Empathy – that’s what you want from professionals, family and friends.
M is for Mentoring – that’s what you want from your support networks.
E is for Education and Empowerment – that’s what you want from your support networks.
N is for Nurturing – that’s what you want from professionals, family, friends and support networks.
T is for Targeted – facts that are relevant and delivered in a timely fashion from your support networks.
I is for Information – that is interesting, insightful and helpful from your support networks.
A is for Advice – always relevant to your situation from your support networks.

The dementia acronym was written by Ian Witterick (who cares for his wife with dementia) to support family and friends to understand a little about what to expect from dementia.
If you are concerned about your memory, your GP might:
- Check Life history
- Rule out physical causes
- Take bloods
- Referred to Neurologist

Hertfordshire Partnership NHS Foundation Trust (HPFT) Single Point of Access (SPA):
If you have been referred you will receive a triage telephone call from SPA to find out a little more about your needs so that you can be referred onward or signposted to the most appropriate service to meet your needs.

Involvement from voluntary sector/ possible self referral:
- Alzheimer's Society
- Carers in Hertfordshire
- Hertswise
- Herts Help
- Admiral Nurses
- Rare Dementia support

You will then be referred to the Early Memory Diagnosis and Support Service (EMDASS) team, which is part of HPFT, who offer comprehensive assessments and practical support to Hertfordshire residents who have concerns about their memory and are worried that they may be living with Dementia. During this time, you will have access to Specialist Nurses, Psychiatrists, Psychologists and Occupational Therapists. After triage you will receive either a home, specialist or local GP clinic appointment for further assessment. Your family and carers can be involved in every stage of this.

A diagnosis is then given. You will then be supported to access the following (depending on the diagnosis) You will also receive a letter confirming the diagnosis.

If you receive a diagnosis of Dementia

Your GP will look after your medical needs.

You may also be referred for:
- Cognitive Stimulation Therapy (CST)/ Psychology within HPFT
- The Hertswise Service and wider Voluntary Sector
- Adult Care Services (Social Services) referral may also be made to support you and your carer/family
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- Possible referral to GP Link Worker for sign posting for other support

Request an Annual Review from your GP
- For persons living with dementia
- Carers
- Mild Cognitive Impairment

If you receive a diagnosis of Mild Cognitive Impairment (MCI)

Your GP will look after your medical needs.

You may also be referred for:
- Further medical tests
- Adult Care Services (Social Services) referral may also be made to support you and your carer/family
- A Referral to the HPFT (NHS) team, or the Wellbeing Team
- A Voluntary Sector referral may also be made
- Possible referral to GP Link Worker for sign posting for other support

If NO Diagnosis

Your GP will look after your medical needs.

You may also be referred for:
- Make a referral to the voluntary sector
- Complete other necessary tests

Involvement from voluntary sector/ possible self referral:
- Alzheimer's Society
- Carers in Hertfordshire
- Hertswise
- Herts Help
- Admiral Nurses
- Rare Dementia support

At any point, you or your carer can self refer back to HPFT for support with Dementia or any other Mental Health Issues via 0800 6444 101

Review Date?
Following your diagnosis of dementia, the Early Memory Diagnosis and Support Service (EMDASS) may provide the following support to you in the first thirty weeks.

### Medication or Medical Follow Up

We may have given you a provisional diagnosis if we do not have all of the required tests when we saw you for your assessment. If this is the situation then we will offer you a follow up appointment in our clinic once we have the test results to confirm the diagnosis with you.

If we have prescribed your medication then we will offer you a follow up appointment to review how things have gone, whether the medication is effective and if there have been any side effects. We will also review the dose of the medication, so that you are taking the correct amount for you.

### Occupational Therapy

You may be offered an assessment with an Occupational Therapist. An Occupational Therapist is a health professional whose aim is to promote independence, enable you to carry out occupations that are important to you, and support your health and wellbeing. Their assessment will identify your strengths and skills, and work with you on strategies you could use to manage any changes in your situation and live well with Dementia. They also advise on adaptations or equipment that can help you carry out activities of daily living and assistive technologies to help you remain independent.
How do I contact you?

The Dementia Support Workers from Alzheimer’s Society (more details on page 10) will contact us if they identify something that EMDASS can help with but if you feel that you need the above please contact the number on your clinic letters, or 0800 6444 101, and speak to the Team Leader of the Early Memory Diagnosis and Support Service. They, or somebody from the team, will discuss your needs with you and agree a plan; this may involve a referral to another team or service.

After thirty weeks, you can still contact us on 0800 6444 101 but you will be passed onto our community services. More details about them can be found on page 8 in this booklet.
Community Mental Health and Dementia Services

Who are we?

We are a team of NHS professionals who specialise in working with people who have a mental health condition or a cognitive disorder (for example dementia), made up of nurses, doctors, occupational therapists, psychologists, and support staff.

What do we do?

We provide assessment and treatment for a range of mental health conditions, for example anxiety and depression. It is important to recognise that even with dementia, you could still be anxious or depressed.

We also provide assessment, advice and treatment when your dementia has progressed and may have caused you to be less like your usual self, which is often noticed by your family, friends or carer.

We may offer you:

- Advice and guidance, for example self-help, lifestyle changes or adaptations
- Medications
- Talking Therapy
- Group Therapy
How do we provide our service?

Your care is individually planned with you, and the people who support you.

We often visit people in their own homes but we may also ask you to come to one of our clinics or groups.

The community service will normally allocate a care coordinator to you, who will oversee your care and be your named professional for contact.

The crisis service will work in a more enhanced way with you; this could be as frequent as daily. As a team that works extended hours, you might see a different person each time.

How do I refer myself?

You can refer yourself, or the person who supports you can refer you to mental health services by calling 0800 6444 101. The person who answers your call will discuss your needs with you, and may ask another professional to call you to take more detail (this is called a triage). This allows the referrals team (also called Single Point of Access or SPA) to understand which team would be the best to meet your needs at that time.

Following the triage your care will be passed to the appropriate team:

- Community Mental Health Service (including our Crisis Service)
- Wellbeing Team
- Enhanced Primary Care Team

If you, or the person who supports you, feel that you might be experiencing a crisis related to your mental health please call 0800 6444 101 for support as soon as possible, so that we can support you quickly.
Alzheimer’s Society dementia support service provides one to one support to people with dementia, and people who support them. The service is tailored to your individual needs and can provide you with information and practical support to help you understand more about dementia and to live well following a diagnosis. We are here throughout your dementia journey, from point of diagnosis to advanced stages of dementia.

You will be offered access to this service via the Early Memory Diagnosis and Support Service (EMDASS), or alternatively, you can self-refer using the contact details below.

A dementia support worker will complete an initial assessment either via telephone or face to face, whereby they will discuss your personal circumstances and create a personalised support plan. They will work with you and support you to maintain your independence and make informed choices by:

- Listening to and answering any questions you have
- Providing accurate, clear and useful information
- Offering practical advice and coping strategies
- Empowering you to access and build wider support networks
- Ensuring you have the correct support by referring you to relevant organisations

Our dementia advisers can continue to provide telephone support to you via ‘keeping in touch’ calls at a time that suits you. This is where you can discuss any current concerns and ask any questions. You can maintain this contact for as long as you feel necessary and can self-refer back to into the service at any time.

Contact details:

- Tel: 01707 378365 or 0333 150 3456
- Email: central.herts@alzheimers.org.uk
- Web: www.alzheimers.org.uk
As a partnership of many organisations, our aim is to support people to live as well as possible within their local communities.

We provide support to individuals living with dementia, as well as their families and carers. Our aim is to ensure that people are able to easily access information and advice, activities and support regardless of whether they have (or want) a diagnosis of dementia.

**What is available?**

**Information and advice**

We provide information and advice for all aspects of a person’s life, such as assistance with benefit applications, Lasting Power of Attorney and other local services (via Age UK Hertfordshire’s Information and Advice Service).

**Hertswise groups**

Our sessions are generally about bringing people together, through structured activity:

- Crafts
- Discussion
- Gentle exercise
- Memory stimulation
- Reminiscence
- Singing

**One to One support**

This is person centred support that helps to develop people’s confidence, through one to one support.

**Carers’ support groups and advice**

This is delivered by Carers in Herts, please see page 17.
Young Onset Dementia
We also offer support for those under 65 who are living with dementia, including those who have a learning difficulty in addition to their diagnosis. Our teams can support you to explore your rights, entitlements, and access to other benefits and can provide support through groups and 1-1s for those that want this support.

Equality and Diversity
Hertswise has a dedicated team who can provide further support for people from Ethnic and LGBTQ+ communities to seek help and understanding around Dementia. We can provide support through groups and 1-1s for those that want them.

Training
Hertswise offers Dementia Awareness training to family and friends of people who are living with dementia and to organisations across Hertfordshire.

We also offer free courses and workshops to dementia carers. The sessions will run throughout the year, with requests from carers being instrumental in the type of courses/workshops that form the yearly program.

Contact details:
- Email: info@hertshelp.net
- Tel: 0300 123 4044
- Website: www.hertswise.org.uk
Age UK Hertfordshire

Age UK Hertfordshire is an independent local charity working to improve later life for thousands of older people, today and in the future. We work to alleviate loneliness, tackle poverty and build resilience for older people who need our help. We are one of the largest charities working with older people in Hertfordshire.

We provide a range of services, including:

• **Befriending** – Our volunteers provide friendship and a listening ear if you are feeling isolated in your own home.

• **InTouch** – if you need to talk to someone about the challenges of your life, our InTouch team are there to listen and support you.

• **Help in the Home** – if you need help around the house with a domestic cleaning service, with added companionship and carer break service.

• **Active Ageing** – if you want to enjoy some activities and meet like minded people.

• **Hospital and Community Navigation Service** – following a hospital stay or need some support at home.

• **Nutrition and Dietetics Service** – if you have concerns about your nutrition or overall health.

• **Information and Advice Support** – if you need help to explore your rights, entitlements or access to benefits and grants.
  - Support you to arrange Lasting Power of Attorney.
  - Support you in accessing Dementia Support.
  - Provide scams awareness information.
  - Provide basic IT Training.
  - Provide information on community care and health services, including access to equipment and aids, or housing options.
  - Provide information on your local services to help you stay independent and active in your community.

**Contact details:**

• Email: info@ageukherts.org.uk

• Tel: 0300 345 3446

• Website: www.ageuk.org.uk/hertfordshire
Adult Social Care (social services)

Adult social care services are there to help you to live a full and active life in your local community. This could be by putting you in touch with services like support for carers, meals on wheels, or technology in your home such as alarms and pendants. We might provide information for you about how to stay well and active and advice on things like avoiding falls. You may need an assessment or a carer’s assessment and extra support.

You can find out about our services on our website: www.hertfordshire.gov.uk/adults or call us on 0300 123 4042. There’s also advice on our website on choosing a care home and links to care home directories.

How can we help you

If you, or someone else on your behalf has contacted us, we will talk to you, or the person who supports you, about your wellbeing and care and support needs, this is called an Assessment. We will talk to you about the things that are most important to you, how you want to live and how you can achieve these aims.

We’ll discuss practical issues like managing better at home, moving around safely, getting out and about and equipment and devices that might be useful. We’ll also talk about family and friends and how they can help you, and local groups, services and activities open to you.

After this, we will give you the information and advice you need, tell you if you are eligible for support from the council and will plan with you the best way to get the help you need.

Longer term, if you need extra, or different support we can arrange a fuller assessment where we can plan together for the future and talk about the various options, how charges and funding works and about benefits and help you to claim.

We regularly check that things are working for you. We also work to ensure that people who need care are kept safe.
How to get help

You, or someone on your behalf, can contact us via our website or by phone.

Contact details:
- www.hertfordshire.gov.uk/adults
- or call us on 0300 123 4042.

You can report a concern through our website if you are worried about the care or safety of an adult. You can also make a comment, compliment, or complaint.

If you would rather talk to someone independent, you can call HertsHelp on 0300 123 4044. They can discuss your situation and find out what is important to you, explore local services and connect you to the right people and organisations that can help you to make positive changes to your life and feel more in control.

Carer’s Assessment

If you look after someone who could not manage without your support, you are a carer and can ask for a Carer’s Assessment. This is not a test of the ability of a carer to care but a conversation with a social care worker about the things that could make caring easier and an opportunity for the carer to talk about any concerns they have.

Carer’s assessments should enable carers to continue in their caring role, if this is what they want to do and to look at how to address any imbalances this may create in their own life. In this way a personalised plan is created and should:
- Outline goals the carer wants to achieve
- Be designed by the carer as far as possible and as far as they wish
- Be based on agreed health and well-being outcomes
- Focus on improving carer resilience and enhancing their circle of support and improving their connections with communities that are meaningful to them
Sometimes the best way to help a carer is for the person cared for to have an assessment of their own needs. This can be arranged with the consent of the cared for person. Outcomes from the assessment could be services for the cared for or the carer. However, the cared for person does not need to be eligible for services for the carer to be able to have a Carer’s Assessment. Carers can be supported to access services available in Hertfordshire or may be entitled to a carers direct payment to meet their assessed needs.

**Carer’s In Case of Emergency plan:**

This is a chance for a carer to consider and record what replacement care within their own support network might be required at short notice if they were unable to provide some or all of their caring role. Are there friends or family who could help? Even where a person cannot identify friends or family it is still important that a plan is recorded as this will provide important information about the cared-for person in any urgent situations.

The plan once completed can be stored on Hertfordshire County Council computer system and the carer will receive an “I am a carer card” which has the carer’s unique number on it that will link directly to their plan. Carers should then keep the card with them at all times so that it can be easily accessible in an emergency.

Carers can complete this plan online: www.hertfordshire.gov.uk/carers or if they wish further assistance and advice just contact 0300 1234 042.
Carers in Herts

About Carers in Hertfordshire

Carers in Hertfordshire is a charity which supports children and adults providing unpaid care to a relative or someone close to them, that needs their help because of an illness, such as dementia, a disability, frailty or addiction. The charity supports unpaid carers in Hertfordshire, or from elsewhere who care for someone in the county and also bereaved carers for three years after the death of the person they cared for.

We provide information and opportunities to connect with other carers or to have a break from caring. We also offer the chance for your voice to be heard by the people who plan or provide health and community services.

Support and services are provided over the phone, online and face to face – as appropriate – and are free to carers.

How we support carers of people living with dementia

We share information and organise meetings. This gives carers a chance to find out about surveys, services and issues relevant to them and to share their views, or feedback with Hertfordshire organisations that provide health, or other services.

Admiral Nurses (partnership with Dementia UK)

Our Admiral Nurses work specifically with the unpaid carers and family members of someone living with dementia. They are experienced dementia Nurses who work flexibly in the community to provide clinical guidance and practical solutions. For example, if communication becomes challenging, they can advise on techniques to stay connected to the person you support.

Carers’ Support and Training (partnership with Hertswise)

We run in-person and online groups and training for people caring for someone with dementia or mild cognitive impairment (with or without a diagnosis) as part of the Hertswise service.
Other support offered by Carers in Hertfordshire includes:

- Providing information - Carer Support Advisors can answer your caring related queries or help you plan your caring role. They can signpost you to more specialist support if required.
- Support in groups (e.g. Hubs) and one to one (Mentoring).
- Courses, events and workshops.
- A Carers’ Passport that can be used to identify your caring role and gives access to savings and offers from businesses supporting the service.
- Bereavement support.

For support contact Carers in Hertfordshire:

- Tel: 01992 58 69 69
- Email: contact@carersinherts.org.uk
- Website: www.carersinherts.org.uk
Common Abbreviations

ACP – Advanced Care Plan
ACS – Adult Care Services
BGH – Barnet General Hospital
CHC – Continuing Healthcare
CLCH – Central London Community Healthcare NHS Trust
CMHN – Community Mental Health Nurse
DA – Dementia Advisor
DOLS – Deprivation of Liberty Safeguards
DSW – Dementia Support Worker
EbE – Expert by Experience
EMDASS – Early Memory Diagnosis and Support Service
ENHT – East and North Hertfordshire NHS Trust
HCC – Hertfordshire County Council
HCT – Hertfordshire Community Trust
HPFT – Hertfordshire Partnership University NHS Foundation Trust
ICP – Integrated Care Partnership
ICS – Integrated Care System
ICT – Integrated Care Team
LPS – Liberty Protection Safeguards
MDT – Multidisciplinary Team
MHSOP – Mental Health Services for Older People
NHSE/I – National Health Service England/ Improvement
OT – Occupational Therapist
PCN – Primary Care Network
SW – Social Worker
WGH – Watford General Hospital
WHHT – West Hertfordshire Hospitals NHS Trust
Urgent Numbers

Adult Care Services (Social Care and Safeguarding): 0300 1234 042

Mental Health Helpline (24 hours): 0800 6444 101

This booklet was coproduced by people who have used the dementia pathway and people working in the following organisations

Hertfordshire Partnership University NHS Foundation Trust works toward eliminating all forms of discrimination and promoting equality of opportunity for all.

We are a smoke free Trust therefore smoking is not permitted anywhere on our premises.

www.hpft.nhs.uk
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