

Dementia Care

A shared journey

A community version

Integrated Care Pathways:
Talking about support and services
for people diagnosed with dementia,
their families and carers.



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Betsi Cadwaladr
University Health Board



Introduction

Being admitted to hospital and having treatments or procedures can be difficult for anyone. However, for people with a diagnosis of dementia, their families and carers, there are more challenges and decisions.

This booklet tells you about our new **Integrated Care Pathway** to make our services more dementia friendly. It sets the care you and your family can expect from diagnosis to end-of-life care. There are some useful links at the end of this document.

Betsi Cadwaladr University Health Board

We are the largest health board in Wales. We provide primary, community, mental health, and acute hospital services for North Wales.

Our vision is to:

- improve the health of the population, with particular focus on the most vulnerable
- develop an integrated health service which provides excellent care delivered in partnership with the public and organisations
- develop our workforce to have the right skills and operate in a research-rich learning culture.

Our values are to:

- Put Patients first
- Work together
- Value and respect each other
- Learn and innovate
- Communicate openly and honestly.

In a report, the Health and Social Care Advisory Group advised us to follow the **All Wales Dementia Strategy**. It recommends:

- People understand the steps they can take to reduce their risk, or delay the onset, of dementia.
- The population understands the challenges people living with dementia face and are aware of the actions they can take to support them.
- People are aware of the early signs of dementia, the importance of a timely diagnosis, and know where to get help.
- More people are diagnosed earlier, enabling them to plan for the future and access early support and care if needed.
- People diagnosed with dementia and their carers and families can receive person-centred care and flexible support.
- Research is supported to help us better understand the causes and management of dementia.
- Staff have the skills to help them identify people with dementia and to feel confident and competent in supporting an individual's needs post-diagnosis.

Covid-19

Covid-19 has changed how care is provided. It has affected all services across health and care. But, having person-centred care for people living with dementia will remain the focus to planning at all stages.

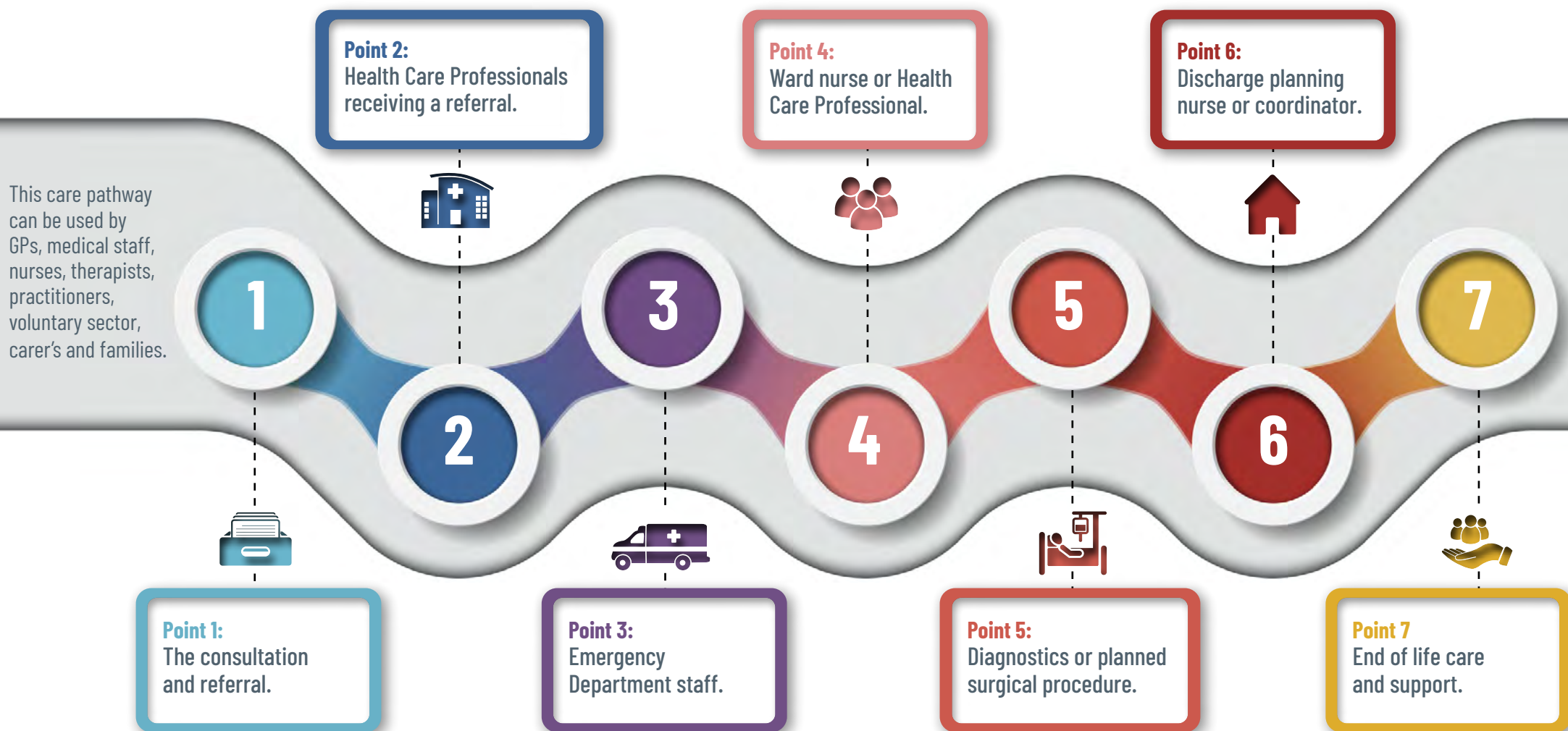


The pathway



This sets out what happens and who is involved at each step of your support and care. It's been put in place to give professionals guidance and support so they:

- **help you** access the care and treatment you need
- **help them** to make the best decisions possible.





Mental Capacity Act

Dementia affects people in different ways, including loss of memory, language, problem-solving and other abilities. As it develops, it can also affect people's abilities to make decisions. The **Mental Capacity Act** protects people. It requires professionals to act in the best interests of people who don't have the ability to make decisions about their care and treatment. It has **five** principles:

1. **Presumption of capacity.** Professionals must not assume someone can't make a decision.
2. **Supporting people to make their own decisions.** Professionals must support people.
3. **Unwise decisions.** People have the right to make unwise or eccentric decisions. People can't be viewed as lacking capacity for that reason.
4. **Best interests.** Anything done for a person must be done in their best interests.
5. **Least restrictive option.** Anything done should restrict someone's basic rights and freedoms as little as possible.

Talking about decisions and the future

It's to good talk about your plans for the future. It can reduce anxiety if you decide who is responsible for decisions if you can't be. If you have a family member or someone else you trust named in your advanced plans or give them Power of Attorney they can make sure everything is done in your best interests.



The consultation and referral

You and your family can expect:


- a quick diagnosis
- services to work together
- to be listen to and involved in decisions
- to communicate in the language you choose
- support to stay independent for as long as possible
- support for your physical and mental wellbeing
- support to deal with symptoms
- support to plan your care
- to be referred to services and organisations
- to be fully informed throughout the process.


All professionals should make sure your family or carer has all the support they need and not be left to cope on their own.

You and your family should:

- be involved in arranging the times of the appointments
- have all the information you need
- get information that's easy to understand
- have support to complete your **This is Me/About Me Plan**, (if you need help with this, contact your GP, dementia care and memory service or the Alzheimer Society)
- be told about Annual Health Checks
- be asked about and have support for your dental care and oral health needs
- be asked about hearing and eye tests, and any glasses or hearing aids that you need.
- have your medication and long-term conditions checked
- be told about treatments and procedures.

If you have power of attorney please make copies so you can pass them on if required. Don't pass on your original copies.





If you would like more information on **This is Me** please contact memory services or the Alzheimer Society. It's a useful document that can be copied and go with you if you have to go to other care settings.

Receiving a referral

You and your family can expect professionals to:

- check all your information and your details including the referral and GP letter
- know about your needs. For example, if you have communication needs, additional needs or transport issues
- make sure everything reasonable is in place to reduce your anxiety.

At a referral, you and your family should:

- be offered a quiet place if available
- be seen as soon as possible
- have support in the language of your choice
- get information in clear, easy-to-understand language
- have procedures and treatments clearly explained
- be fully informed and involved in decisions
- be treated as capable to make decisions unless you've had an assessment that says otherwise
- be shown where the toilets are
- be shown where to get food and drink.

Your family and carers can stay with you. They can get support and never have to cope on their own. Please ask about your concerns and consider contacting the Alzheimer Society for more information.





Emergency Department

Preparing for the Unexpected

Emergency admissions may not be avoidable. In preparation for unplanned events please consider asking about the Butterfly Scheme, Johns Campaign, make sure copies of the Power of attorney and This is Me are available. Consider asking for a Dementia Support Worker during a hospital admission.

You and your family can expect professionals to:

- see you as soon as possible
- communicate in the language you choose
- listen to all the information they are given by you or your family
- listen to the information from the ambulance team, if you used one
- ask for your **About Me/ This is Me Plan** and use the information
- involve you and your family in decisions
- explain what's happening and any treatments clearly
- explain the Open Visiting Policy
- provide a 'John's Campaign' Carer Passport, (ask staff about this)
- make sure your family members or carer get a comfortable chair if there isn't a separate family room
- give you a quiet area or room if possible
- let you walk around, or go outside if appropriate
- show you where the toilets are
- show you where to get food and drink
- support you and your family throughout the visit
- access your needs before you are discharged
- make sure you have any medication or equipment you need before you leave
- give you the right information to share with your GP and community support teams.





Ward nurses and health care teams

You and your family can expect professionals to:

- show you around the ward, including where the toilets are and where to get a drink
- introduce you to all your health care team
- explain the admissions process clearly
- communicate in the language you choose
- offer you a side room that is quiet, if possible
- use communication tools if needed
- ask you about using glasses or hearing aids
- fully assess your needs and make sure you feel comfortable
- explain any treatment or procedures clearly
- involve you and your family in decisions
- offer your family or carer a fold out bed for overnight stays if needed
- make sure all staff are updated on your needs at shift handovers
- keep you and your family up-to-date with any changes.

Everyone working on your health care team should be aware of your needs. They shouldn't move you around the hospital for a non-clinical reason.





Planned tests and surgical procedures

You and your family can expect professionals to:

- communicate and work together
- share appropriate details and explain your medical needs with departments
- carry out an assessment of your needs when you get to the ward
- make any reasonable changes that will help you and your family
- explain clearly any procedures or treatments
- involve you and your family in decisions
- access your capacity if they feel there is an issue with you giving consent for treatment
- always act in your best interests
- follow your **This is Me/About Me Plan**
- offer you and your family additional support, including support from a dementia support worker if needed.

Before you are admitted to the ward, you and family should be offered a visit.



Discharge planning

You and your family can expect professionals to:

- work together to reach the best outcomes
- talk to you and your family about the plan for your discharge from hospital
- make sure you can be discharged as soon as possible
- communicate in the language you choose
- make sure you have all the information you need, in ways that are easy to understand
- involve you, your family, your carer, your community support providers and other agencies in planning
- make sure you and your family have all the equipment and supplies you need on the day of discharge
- ask the pharmacist to review your medication and talk about the way you need to take them
- call your local GP practice so they know you're leaving hospital
- find out if your family and carers need any training to support you at home.

When you are discharged you should be given a pack with:

- an updated copy of their **This is Me/About Me Plan**
- an easy-to-understand discharge plan
- any medication or prescription information
- key contact numbers.





End of life care and support

You and your family can expect professionals to:

- take your wishes into account
- consider all your health care needs and support needs in the plan
- involve all your health care teams and care support providers in planning
- communicate in the language you choose
- make informed decisions using your **This is Me/About Me Plan**
- keep you and your family up-to-date with any changes
- make sure all arrangements and decisions are written down and available in your care plan
- listen to your Power of Attorney if you have one
- always act in your best interests.

End of life care can be difficult to talk about. But dementia is a terminal condition. Talking about what you and your family want as early as possible can make it easier for everyone.



Thanks for reading this

Other support help

If you or your family feel you need help to be heard, an advocate can help.

For Advocacy Groups in the local area go to:

bcuhb.nhs.wales/community-health-council

Links

This is Me PDF alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me.pdf

John's Campaign goldstandardsframework.org.uk

The Butterfly Scheme butterflyscheme.org.uk

The Herbert Protocol northwalessafeguardingboard.wales/information-for-adults/herbert-protocol

Your GP or hospital should also link you and your family to different professionals that can help you along this pathway. That includes:

- **The Community Mental Health Team and Memory Services.** They can offer support and guidance. For example, they can help complete or update their This is Me/About Me Plan.
- **Social care services** in your area.
- **Charities and organisations** like Carers Trust and Dementia Connect.

Acknowledgements

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