

**NHS****Northern England**
Clinical Networks

Cumbria Dementia Pathway

Co-produced with partners county-wide to bring together useful information for health and care professionals, carers, families and anyone with an interest in improving the lives of people with Dementia.

This pathway is due for review in 2023.
Please email any comments you may have to
england.northernmentalhealth@nhs.net



Version 5, 2020

The Information in the Cumbria Dementia Pathway is correct at the point of publication so far as the authors are aware but cannot be guaranteed to remain valid until the next review point.

Cumbria Dementia Pathway	3
1. What is dementia?	3
Dementia	3
Types of dementia	4
Preventing Well (How to reduce your risk of dementia)	5
Younger People with Dementia	6
2. Diagnosing Well	7
Why diagnose Dementia?	7
Diagnostic features of dementia	7
The Primary Care Pathway: Timely identification and referral	8
Learning Disability	9
A Diagnosis of Dementia	9
Genetic Counselling	10
3. Supporting Well	11
Admiral Nurses	12
4. Staff Training and Development	13
Principles of care	13
Developing the workforce	14
5. Carers	15
Assessment and Support for Carers	15
Carers Contingency Plans (Cumbria Carers Emergency Card)	15
6. Specialist Intervention	16
Interventions to support living well	16
Non-drug-based interventions	16
Drug based interventions	17
Assessment of symptoms	17
7. Living Well (Promoting Independence)	18
Social Interaction and Maintaining Skills and Abilities	18
Physical Independence	18
Care and Support	19
The Herbert Protocol	20
Independent Advocacy	20
Lasting Power of Attorney	21
Daily Living Equipment and Adaptations	21
Telecare	21
Choosing Where to Live	22
8. Dementia Friendly Communities	23
9. Dying Well (End of Life Care)	25
10. Hospitals	26
11. Sources of further information	28

1. What is dementia?

Dementia has a major health, social and economic impact on individuals, families and the whole community.

In Cumbria, we want to:

- Improve public and professional awareness and understanding of dementia;
- Improve early diagnosis and interventions within a supportive framework;
- Provide better care and support to people with dementia.

This Care Pathway is designed to contribute to these objectives and be used as an information resource and guide to professionals, the public, people with dementia, carers, family members and to anyone working to support people with dementia.





Dementia

The term dementia is used to describe conditions that result in the progressive loss of mental abilities. Dementia will often affect a person's ability to remember, learn, think and reason and can cause the global loss of social skills. There are many different types of dementia.

Dementia is progressive, 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 differently. Although dementia mainly affects older people, it is not a normal part of ageing.

The NICE (National Institute for Clinical Excellence) definition is: "... a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function... people... can experience some or all of the following: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms (for example, apathy, depression or psychosis) and out of character behaviour (for example, aggression, sleep disturbance or disinhibited sexual behaviour, although the latter is not typically the presenting feature of dementia)."

Sometimes a **"Well Pathway"** for dementia is used to help us think about the different aspects of dementia that we need to consider.

Well Pathway

 Preventing Well	 Diagnosing Well	 Supporting Well	 Living Well	 Dying Well
Risk of people developing dementia is minimised	Timey accurate diagnosis, care plan, and review within first year	Access to safe high quality health & social care for people with dementia and carers	People with dementia can live normally in safe and accepting communities	People living with dementia die with dignity in the place of their choosing
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"

Types of dementia

Alzheimer's disease – the most common cause of dementia. During the course of the disease the chemistry and structure of the brain changes, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.

Vascular dementia – if the oxygen supply to the brain fails due to vascular disease, brain cells are likely to die, and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes. Vascular dementia and Alzheimer's disease frequently occur together, and they may often act in combination to cause dementia.

Dementia with Lewy bodies – this form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease.

Frontotemporal dementia (sometimes referred to as Pick's disease or frontal lobe dementia), damage is usually focused in the front part of the brain. This damage causes the typical symptoms which include changes in personality and behaviour and difficulties with language.

'Mixed dementia' is a condition in which a person has more than one type of dementia. Alzheimer's disease and vascular dementia is the most common type. Other combinations of dementias are also possible – particularly Alzheimer's disease and dementia with Lewy bodies.

Preventing Well (How to reduce your risk of dementia)

Research now shows that you can do several things to reduce your risk of developing dementia. **These include:**

- Taking regular exercise
- Stopping smoking
- Maintaining a healthy weight
- Reducing alcohol intake
- Keeping mentally active

Certain types of dementia, particularly vascular dementia, are linked to other conditions such as high blood pressure, high cholesterol and diabetes. By following any treatment provided for these conditions you may also reduce your risk of developing dementia.

If you are aged between 40 and 74 you may be eligible for a free NHS Health Check. This will assess your risk of developing a vascular disease such as diabetes, stroke, chronic kidney disease and dementia and will provide you with information on how to best reduce your risk. For more information contact your GP practice or visit **www.nhs.uk**





Younger People with Dementia

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia. The age of 65 is used because it is the age at which people traditionally retired. However, this is an artificial cut-off point as opposed to having any biological significance. The symptoms of dementia may be similar regardless of a person's age, but younger people often have different needs, and may therefore require different support.

Join Dementia Research

One of the big difficulties researchers face today is recruiting participants for their studies. At the same time, many people are looking for studies to contribute to and take part in, but don't know where to find out about them. This is why the National Institute for Health Research (NIHR), in conjunction with the Alzheimer's Society and Alzheimer's Research UK have developed Join Dementia Research, a service which allows people to register their interest in participating in dementia research and be matched to suitable studies. Everybody now has that chance to see what dementia research is taking place, both in their local area and across the nation. The service delivers new opportunities for people to play their part in beating dementia; connecting researchers with people who want to participate in studies.

For more information please see: <https://www.joindementiaresearch.nihr.ac.uk/>



2. Diagnosing Well

We want to raise awareness, tackle stigma and promote access to an early diagnosis. The process of receiving a diagnosis is a means to an end, not an end in itself. It is the first step to getting a comprehensive package of support in place and it is this package, tailored to the individual's needs and circumstances, which will help people to maintain their quality of life and cope with the symptoms of dementia.

Why diagnose Dementia?

Earlier diagnosis improves outcomes:

- People can be supported to live well at home for as long as possible
- While the person has capacity, they can make decisions for now and plan for the future
- Available treatments can begin
- Essential post diagnosis support can begin
- Support for best quality of life possible for those with dementia and their carers can be given as soon as possible

People will be asked if they wish to know their diagnosis in advance of any information being given to them. Those people who opt to receive their diagnosis will have a full discussion with a member of staff followed by written information.

As part of initial treatment options, Memory Services will also check with carers that they fully understand dementia and offer all carers routine screening for carer strain. There is evidence that early psychosocial interventions improve the well-being of the person with dementia, and his or her carer and family. This may delay the need for long-stay care later in the illness.

The overall aim is to help understand how services working together can best support the family and protect their quality of life.

If you are worried that you or a person you know is having difficulty with memory loss or may be showing early signs of dementia, make an appointment to see your GP.

They will then do an initial assessment and may refer on to a local Community Based Memory Assessment Service (Memory Service) for further assessment. Self-referral can also be made to the local Memory Service; however, contact will always need to be made with the person's GP.

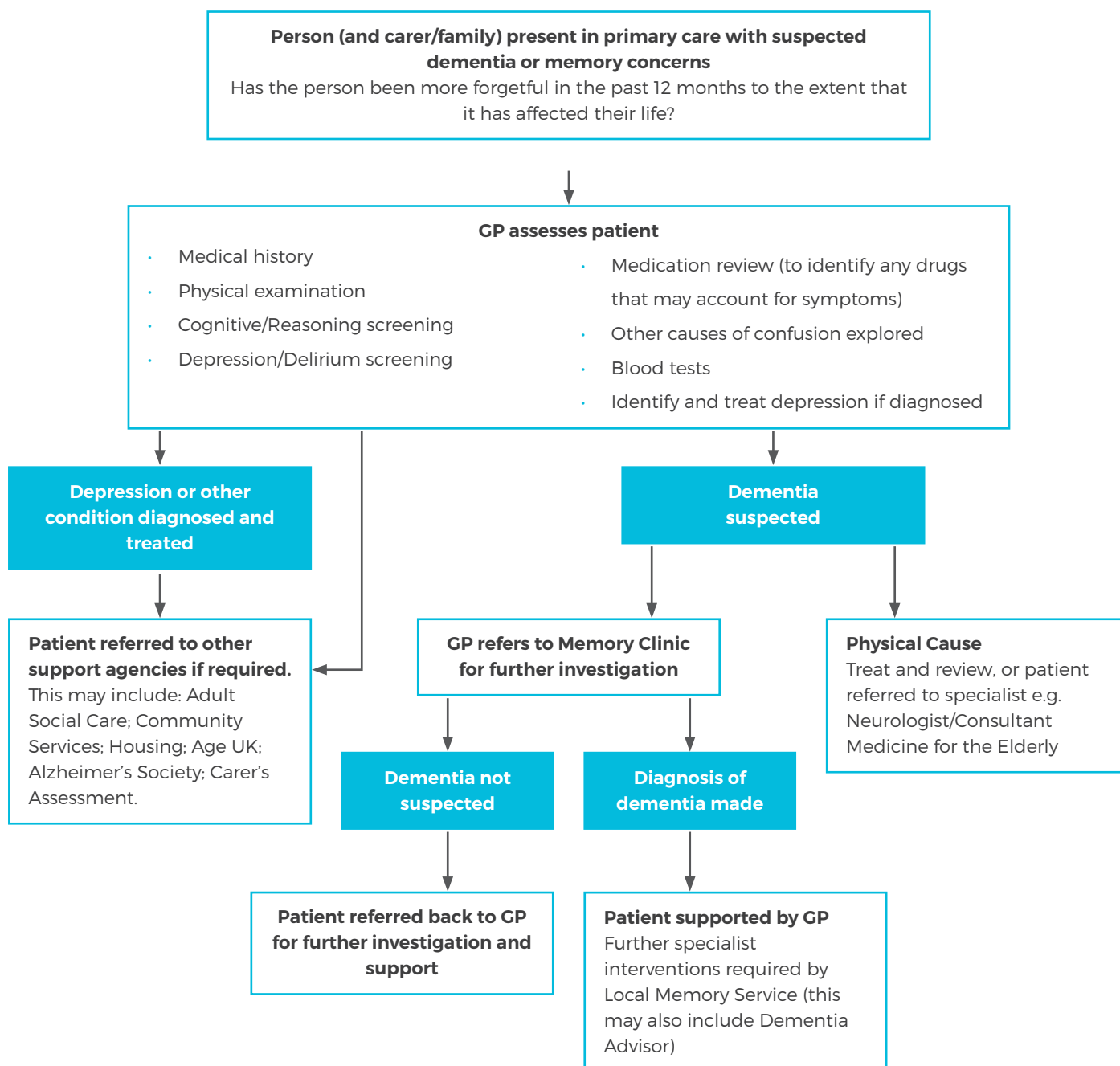
Diagnostic features of dementia

The most common symptoms of dementia are:

- Increasing difficulties with activities that require concentration and planning
- Increasing difficulty carrying out usual daily tasks
- Memory loss
- Changes in mood and thought processes, for example depression or agitation
- Changes in communication, comprehension and language
- Withdrawal from social activities
- Difficulty sleeping
- Changes in personality
- Disorientation
- Difficulty concentrating
- Impaired judgment and problem solving
- Urinary incontinence
- Shaking and trembling
- Slow and unsteady walk
- Stroke-like symptoms, such as muscle weakness or paralysis on one side of the body
- Some hallucinations (seeing things that are not there)



The Primary Care Pathway: Timely identification and referral



The Memory Service offers an individualised comprehensive assessment of suspected, new or worsening memory problems or dementia. This assessment may be in a variety of settings including the person's home, GP surgery, care home, clinic or hospital setting, dependent on the individual's need and choice. This service also offers a range of evidence-based specialist interventions for people with dementia and their families. It works closely with primary and community health care, Adult Social Care, and other community and Third Sector services to offer support to people with dementia and their carers and family.



Learning Disability

A learning disability refers to reduced intellectual ability and difficulties with everyday tasks such as household tasks, socialising or managing money. This affects someone for their whole life.

People with learning disability may be at increased risk of dementia, particularly those with Downs Syndrome. Individuals with Downs Syndrome will be offered a baseline cognitive assessment and regular follow up to promote early identification. Annual health checks are available for people with learning disability.

Individuals with learning disability often show different symptoms in the early stages of dementia and are more likely to have other physical health conditions that may not be well managed.

Dementia screening tools used in the general population are not always appropriate to use with people who have learning disability. Therefore, specialised tools designed for individuals with learning disability are used. These assessments include a range of direct cognitive assessments with the individual, indirect assessments conducted with carers/ family members.

Once diagnosed, anyone with a learning disability and their carers have access to the same care and services as everyone else and continued support from learning disability teams.

All the information and advice in this document is equally relevant to those with a learning disability as it is for everyone else.

For more information go to
<http://mentalhealth.org.uk/dementialearningdisability>



A Diagnosis of Dementia

Once a diagnosis of dementia is made, the local Memory Service will explain what having dementia might mean and the type of dementia that has been diagnosed. Follow up interventions and treatment will be discussed with both the person and their family, focusing on the person's quality of life and wellbeing, as well as ways to reduce the impact of dementia.

Several things will need to be discussed and considered, depending on the progression of the condition:

- Treatment
- Support groups and voluntary organisations for people with dementia and their families and carers
- Information and Advocacy services
- Financial and legal advice
- Capacity
- Lasting Power of Attorney
- Driving
- Care Allowances
- Practical support at home, for example meals, Home Care, and Respite for carers
- Risk Assessment
- Advanced Decisions, for example, to refuse treatment
- Housing and the home environment

Because dementia is a progressive condition, the Memory Service may arrange another appointment, perhaps after six months or a year. The Memory Service may also request the person's GP to prescribe any treatment that might be helpful for any other physical or mental health conditions.

All GP practices and Memory Services have access to the Alzheimer's Society Dementia Guide. Call the **National Helpline (0300 222 11 22)** for support and connection with local resources. Find out more about the Dementia Guide via **www.alzheimers.org.uk/dementiaguide**



Genetic Counselling

Some types of dementia are genetic, meaning they could be inherited. If a genetic cause of dementia is suspected, the person with dementia and their unaffected relatives may want genetic counselling. Examples include familial autosomal dominant Alzheimer's disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts, leukoencephalopathy (CADASIL) and Huntington's disease. If you are concerned and would like to explore genetic counselling, speak to your GP.





Once a person with dementia has received a diagnosis it is essential that they get appropriate post-diagnostic care throughout the course of their life, with the period immediately following diagnosis being a critical time for this to occur. This is needed to ensure that people living with the effects of dementia and their families and carers have the right information and support, so they can live as fulfilling lives as possible and prepare for the future.

Post diagnostic support for people living with the effects of dementia and their families and carers should be personalised, flexible, and culturally relevant. There is no one size that fits all, with different needs existing according to personal wishes and circumstances, the nature of the dementia and the course of the condition. The overall aim of post diagnostic support is to give people the opportunity to have the choice and control to manage their condition as far as possible and to live as well as possible with dementia.

The person with dementia and their close family and carers should be able to talk things over with relevant services and professionals and be fully supported. At the point of diagnosis, throughout the period following a diagnosis, and as their condition progresses, all people living with the effects of dementia and their families and carers should receive high quality support and information. This may include specialist, peer, group or specialist psychological support, as required.

Dementia Connect, from Alzheimer's Society

Dementia Connect is Alzheimer's Society's new personalised support and advice service for people with all types of dementia, their family, friends and carers. The service connects them to the support they need – on the phone, online and face to face. Free and easy to access, it's there whenever they need it. Alzheimer's Society can keep in touch, so people with dementia always have the help they need – only ever needing to tell their story once.

Phone support

Dementia Advisers are available on the phone seven days a week to tackle problems, share practical information or to just talk to someone who 'gets it'. They will listen, give advice and connect callers to the support they need, including help in their local area.

Keeping in Touch

People can choose to receive regular phone calls at agreed times to check in and see how they're doing. If something has changed for them, they can talk to someone who will offer advice and help them get the right support.

Face to face

Dementia Connect offers personalised face to face support, from practical advice and information, to someone to talk to - helping make things easier for them. They can signpost people to other support services in their local area too.

Side by Side

Side by Side connects people living with dementia to local volunteers, who help them keep doing the things they love and try new things in their community, like going to the shops, the football or the cinema.

Online support

Online support is available round the clock with information and advice on any dementia-related question. People can find information on the website, chat to others affected by dementia on the online community Dementia Talking Point, and search for services in their area.

Get support by calling on **0333 150 3456** or email at **dementia.connect@alzheimers.org.uk**





Dementia Advisers offer personalised support and advice on a range of topics, for example:

- Understanding dementia
- Understanding the diagnosis process
- Dementia drug treatments available
- Getting the right support, at the right time for them - at the point of diagnosis, throughout the period following a diagnosis, and as their condition progresses. This may include specialist, peer, group or specialist psychological support, as required
- Lasting Power of Attorney and Deputyships
- Assessments for care and support
- Support available from the GP and other healthcare professionals
- Benefits
- Paying for care
- Emotional support
- Sources of local support and activities
- Living well with dementia
- Making complaints

If people need further support and advice, they can be referred to the local support services they need in Cumbria.

Cumbria Support Directory

Use the online Cumbria Support Directory to find out details of services in your area.

www.cumbriasupportdirectory.org.uk

Admiral Nurses

Dementia UK's Admiral Nurses go beyond advice, offering the most comprehensive, specialist, expert service in the UK for families living with the complexities of dementia. Admiral Nurses are all qualified nurses with a professional specialism in dementia. Their extensive clinical training and experience means they can support families and people with dementia through the most complex of situations, such as offering advice on medication, on changing or worsening symptoms and on therapeutic interventions.

Admiral Nurses focus on the family as a whole, including making sure carers have the support and skills they need. They provide specialist carer education and training which equips carers with stress management techniques and coping strategies. They can also help them to contact local respite services.

Admiral Nurse Dementia Helpline
Call our Dementia Helpline for free on **0800 888 6678** or send an email to **helpline@dementiauk.org**
<https://www.dementiauk.org/>



4. Staff Training and Development

We want people with dementia and their carers to receive support from a trained workforce, with the right knowledge, skills and understanding of dementia.

Early diagnosis and appropriate medical intervention are important, but social, psychological and cultural factors are equally influential to support people to keep well, and thus “live well with dementia”.

Principles of care

There are a number of agreed care principles that all staff must follow:

- Value the person with dementia and their carers, promoting their citizenship rights and entitlements, regardless of age or cognitive impairment
- Treat people as individuals; appreciate that people with dementia have a unique history and personality, physical and mental health, and social and economic resources and that these will affect their response to neurological impairment
- Look at the world through the eyes of someone with dementia; recognise that each person's experience has its own psychological validity, that people with dementia act from this perspective and that empathy with this perspective has its own therapeutic potential
- Recognise that all human life, including that of people with dementia, is grounded in relationships and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth
- Understand and deliver support in accordance with the Mental Capacity Act

The Mental Capacity (Amendment) Bill entered parliament in July 2018 and gained royal assent on 16 May 2019. The act follows recommendations made by the Law Commission around mental capacity and deprivation of liberty and creates a new regime, Liberty Protection Safeguards (LPS). The LPS scheme replaces Deprivation of Liberty Safeguards (DoLS) as provided for in the Mental Capacity Act 2005.

For more information go to <http://nhsproviders.org/resource-library/briefings/mental-capacity-amendment-act-2019>





Developing the workforce

The original Dementia Core Skills Education and Training framework was launched in October 2015. In June 2018 a revised and updated version was released, entitled the **Dementia Training Standards Framework**.

The framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England (HEE) in partnership with Skills for Care. Development of the framework was guided by an Expert Group including a wide range of health and social care organisations, relevant Royal Colleges and education providers.

The framework sets out the core skills and knowledge which would be transferable and applicable across different types of service provision. It includes expected learning outcomes for training delivery, key policy and legal references and is aligned to related national occupational standards. The aim is to help ensure the quality and consistency of dementia training, and to help prevent unnecessary duplication of training.

The framework comprises the following subjects:

1. Dementia awareness
2. Dementia identification, assessment and diagnosis
3. Dementia risk reduction and prevention
4. Person-centred dementia care
5. Communication, interaction and behaviour in dementia care
6. Health and well-being in dementia care
7. Pharmacological interventions in dementia care
8. Living well with dementia and promoting independence
9. Families and carers as partners in dementia care
10. Equality diversity and inclusion in dementia care
11. Law, ethics and safeguarding in dementia care
12. End of life dementia care
13. Research and evidence-based practice in dementia care
14. Leadership in transforming dementia care

CHESS (Care Home Education and Support Service)

CHESS is a multi-award-winning service which aims to work closely with people with dementia in care homes to improve their quality of life and mental wellbeing. It is a rolling programme of mental health education for care home staff, combined with a practical outreach service which works alongside care home staff to improve their skills and abilities to support residents with dementia or other mental health difficulties. This reduces the need to admit residents unnecessarily to hospital and enables the person to remain in their placement of choice for longer.

A carer is someone of any age who provides unpaid support, usually to a family member or friend in their day to day life.

Input and support from carers can be critical to help the person with dementia maintain their ability to live well. Most care in the community takes place through family, friends and neighbours.

Many carers don't see their own health and support needs as a priority and they may need to be encouraged to seek appropriate help to reduce the strain of caring and to help them continue to care.

Assessment and Support for Carers

Many organisations provide support and advice for carers of people with dementia, for example the Alzheimer's Society, Carers Support Cumbria, Age UK and Dignity in Dementia.

Support for carers is available from Cumbria County Council as part of their statutory responsibilities. This includes a formal assessment of carers own needs, either from council staff or from Carers Support Cumbria within the voluntary sector.

The Carer's Assessment reflects the carer's individual needs, distinct from the person for whom they care. The assessment considers other important issues, such as whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially.

Support may include counselling and emotional support, befriending and sitting services, Respite Care, or access to the Cumbria Carers Emergency Card. A carer's budget or services to support the carer in their caring role may be arranged as part of support planning for the carer.

Carers Contingency Plans (Cumbria Carers Emergency Card)

The scheme is designed to give reassurance to the carer using pre-agreed arrangements in the form of an Emergency Plan covering a 72-hour (3 day) period. The Emergency Plan comes into action if something like an accident or sudden illness meant that the carer is unable to look after the person they care for. The Carers Contingency Plan is discussed as part of the Carer's Assessment, and more details are available from Carers Support Cumbria.

To find out more, either contact your local Cumbria County Council Adult Social Care office (or Children's Services office if you are a young Carer), or contact Carers Support Cumbria www.carerssupportcumbria.co.uk

Five Ways to Wellbeing

People who care for someone with dementia can help promote and protect their own wellbeing by incorporating the following five actions into their everyday lives.

1. Connect with the people around you, including family, friends, colleagues and neighbours;
2. Be active. Find a physical activity you enjoy and that suits your level of mobility and fitness;
3. Take notice of the world around you. Be curious and reflect on your experiences;
4. Keep Learning. Try something new or rediscover an old interest. Set yourself a challenge;
5. Give of yourself. Do something for a friend, neighbour or the community.

6. Specialist Interventions

Additional support may be required to support the person with dementia and their family.

Specialist and medical interventions are provided by local Memory Services and may be necessary if symptoms worsen. Specialist interventions are based on the person's (and their family's) needs following a comprehensive assessment.

Dementia symptoms can be classified into cognitive and non-cognitive groups. Put simply, cognition refers to thinking. Cognitive symptoms include memory loss, language problems, disorientation, and changes in personality.

Non-cognitive symptoms include hallucinations, delusions, marked agitation and anxiety, roaming, sexual disinhibition and shouting. These features often present as behaviour that challenges others. In addition, anxiety, depression, and sleep disturbance are common in people with dementia.

Interventions to support living well

When interventions are indicated, they will be guided by the presenting features and be person-centred. A holistic view is taken, with an assessment of non-drug measures made before considering whether medication will be used. The principle is to use drugs as a last resort, and only if no effective alternative is available.

In addition, some symptoms may in fact be representing other disconnected areas of a person's life history. It is essential therefore to understand the experience from the person's perspective rather than view all experiences as 'symptoms'. This will help offer effective ways to support the person and their family to live well.

All interventions and treatments must be part of a wider support package that considers all aspects of the person's quality of life. This helps the person continue to live well, helping to protect what matters most to the person. It is important therefore that all services work closely together to offer flexible and person-centred approaches.

Non-drug-based interventions

Non-drug based interventions for the behavioural and psychological symptoms of dementia are used to ensure that underlying causes of behavioural disturbance are explored and to provide personalised approaches to presenting problems. **Non-drug based interventions may include:**

- **Cognitive stimulation:** has been shown to improve both cognitive function and quality of life in people with mild to moderate dementia. The degree of benefit for cognitive function appears similar to that of some medications. Examples of cognitive stimulation include Reality Orientation, where the person is given regular cues and reminders about time and place, and Reminiscence Therapy which is the process of recalling memories.
- **Practical solutions** to improve day to day living, wellbeing and quality of life
- **Occupational interventions** and activities
- **Environmental modifications**
- **Psycho-social interventions** and life history



Non-drug-based interventions continued

- **Validation therapy:** is a unique form of therapy that involves listening to elderly seniors with dementia, connecting with them through empathy, and providing dignified care
- **Sensory stimulation:** is the activation of one or more of the senses including taste, smell, vision, hearing, and touch.
- **Complementary therapies:** these may include aromatherapy; exercise; reiki; massage; multi-sensory stimulation; therapeutic use of music and/or dance; animal assisted therapy. The use of complementary therapies has been shown to be of benefit in all stages of dementia.
- **Behavioural interventions:** aim to teach and increase useful behaviours and reduce or eliminate harmful behaviours
- **Working with voices or visions**

These interventions will be completed with the person and their family in a variety of settings

Drug-based interventions

Medication used in the treatment of dementia falls into two main categories, those that aim to slow the progression of the disease symptoms, and those that may help make the illness easier to live with.

At present no drug treatments can provide a cure for dementia. However, in recent years several drugs have been developed that assist the transmission of nerve impulses within the brain. For some people these drugs will temporarily slow the progression of symptoms in the early stages of the disease.

More information may be found on The National Institute for Health and Clinical Excellence (NICE) website. www.nice.org.uk

Assessment of symptoms

When someone is diagnosed with dementia, an early assessment is undertaken to identify factors that may influence behaviour and a support package is developed around this. If a person with dementia develops distressing non-cognitive symptoms or behavioural changes, the care plan will be amended to reflect new ways to better manage symptoms.

This assessment may be completed with the support of the person's family, and will involve looking at:

- Physical health
- Depression
- Possible undetected pain or discomfort
- Side effects of medication
- Individual biography
- Psychosocial factors
- Physical environmental factors
- Behavioural and functional analysis

The plan is reviewed regularly at a frequency agreed with the person, their carers and staff.

Specialist Dementia Assessment Units

Specialist dementia assessment and intervention is available via the Ruskin Unit in Carlisle and The Ramsey Unit at Dane Garth in Furness. The units offer person centred specialist assessment, treatment and interventions for people with dementia, often with highly challenging needs. The environment in these facilities takes account of the latest dementia technology and design principles. The Units work with multi-disciplinary staff and also work closely with Community based memory and CHES services.

7. Living Well (Promoting Independence)

In Cumbria all partners aim to help people with dementia to maintain control over their life and stay as independent as possible for as long as possible.

A number of factors can help people maintain their independence, including:

- Living healthily, safely and free from harm, abuse and neglect
- Being informed and advised in order to promote autonomy and exercise real choice
- The ability to manage, make decisions and be in control of your own personal and other daily routines
- Being involved and connected in family and wider community life, including hobbies and leisure

Social Interaction and Maintaining Skills and Abilities

Remaining physically and mentally active can help people with dementia maintain their skills and abilities.

- A holiday can provide a welcome break
- Carrying out simple everyday tasks can help the person feel better about themselves by providing a structure to the day and a sense of achievement
- Some types of activity can help someone to express their feelings - for example listening to music or writing something down
- Peer support is important and local activities like Singing for the Brain from Alzheimer's Society, or groups organised by Age UK can provide stimulation, and promote creativity
- People need to be supported to access the financial benefits they may be entitled to
- Creative practitioners offer friendly accessible opportunities for people living with dementia to enjoy art, poetry, music and dance along with their friends and family in a variety of community settings

Information about local groups and activities may be found via the Cumbria Support Directory: **www.cumbriasupportdirectory.org.uk**

Physical Independence

Maintaining physical independence for as long as possible is part of remaining active and healthy, and enabling people to retain their abilities. Our approach to working with people with dementia who need extra support to maintain independence is multidisciplinary and includes nursing, social care staff, and voluntary sector. Services and support offered allow people living with dementia to maintain their independence and stay in their own home or promote an early return from hospital. **It includes:**

- Rehabilitation Services from the NHS
- Support at Home Services (Home Care)
- Day Services and Day Opportunities
- Reablement, from Cumbria Care, part of Cumbria County Council
- Support for carers
- Dignity in Dementia provide a dementia awareness family carer course for family carers and a range of activities around the county for people living with dementia such as Community Come Dancing, Community Singing groups and Dementia Friendly walks



Care and Support

Care and support can include help with things like getting out of bed, washing, dressing, getting to work, cooking meals, eating, seeing friends, caring for families and being part of the community.

Adult Social Care is part of Cumbria County Council and is responsible for providing people with help to access the care and support they require. **This can include:**

- General information, advice and signposting to organisations that can assist
- Advice about housing including how to adapt your home and the range of accommodation options available
- Preventative services such as Reablement, Telecare and other equipment that can help people to remain independent at home
- Short-term services, for example, help when coming out of hospital
- A needs assessment, as part of the Council's responsibilities under the Care Act

A needs assessment is a discussion with a trained person from Adult Social Care which enables people to talk about their care and support needs. The council will use the assessment to discuss with the person how their needs could be met. Following the assessment, a care and support plan may be developed alongside a personal budget, which is funding that may be allocated to a person by the council to pay for care or support to meet their assessed needs.

Direct Payments and Individual Service Funds offer people greater flexibility, choice and control of their support. A person can take their personal budget as a Direct Payment, or an Individual Service Fund, (an agreement where people choose an approved Provider of services to arrange an agreed package of care and support) Alternatively, people can opt to leave the council to arrange services on their behalf.

More information on getting care and support from Adult Social Care is available via: **www.cumbria.gov.uk/healthandsocialcare/adultsocialcare/applyforsupport/applyforsupport.asp**





The Herbert Protocol

The Herbert Protocol is a national scheme adopted by Cumbria Constabulary and other police services across the country.

It encourages carers, families, friends or neighbours, to hold information about the person with dementia that can help the police find them if they do go missing. The basis of the scheme is for vital information about the person such as medication, description, photograph, significant places in the person's life and their daily routine, to be recorded on a form.

The form should then be stored safely – either in electronic format on a computer, or a printed version. It may need to be located quickly, at any time of day or night, by the person who needs the information to begin the initial searches.

When the form is complete, it will contain confidential information about a person so it should be stored securely. Any partner agency required to complete the form will become the data controllers and must store it appropriately.

The form can be downloaded at <https://www.cumbria.police.uk/Services/Services-Documents/Herbert-Protocol-form.docx>

The leaflet can be downloaded at <https://www.cumbria.police.uk/Services/Services-Documents/Herbert-Protocol-leaflet-Copy.pdf>

The police will only ask for the form, or the information in the form, if the person is reported missing.

The information will help the police and other agencies locate the missing person as quickly as possible and return them to safety.

Independent Advocacy

Independent Advocacy is provided by organisations which are independent from Health and Social Care Services and Care and Support providers. **Independent Advocacy is about supporting people to:**

- Understand their rights
- Explore options and choices
- Tell others what is important to them
- Access information and navigate systems and processes

There are several different Independent Advocacy services which people have a right to. This is called Statutory Independent Advocacy.

Care Act Advocacy

This advocacy supports people to be involved in care and support needs assessments, reviews and safeguarding enquiries. This advocacy is for people who have care and support needs and carers who would find it difficult to be involved without independent advocacy support.

Independent Mental Capacity Advocacy

This advocacy supports people who have been assessed as lacking capacity to make important decisions about moving home or serious medical treatment when they have no family or friends who can help.

Independent Mental Health Advocacy

This advocacy supports people who are detained under sections of the Mental Health Act. Advocates can support people to understand their rights under the Act, support people to appeal their sections and plan for discharge.



Deprivation of Liberty Advocacy (Liberty in Protection Safeguards)

This advocacy supports people who have been assessed as lacking capacity to consent to their care arrangements and those arrangements amount to a deprivation of their liberty. For example, someone who is under continuous supervision and control and they are not free to leave because the front door is locked. Advocates can also help relatives of people who are being deprived of their liberty.

If you would like more information on the different types of Independent Advocacy available in Cumbria and how to access this support, you can contact the People First Independent Advocacy Hub on **03003 038 037** or visit **www.wearepeoplefirst.co.uk**

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a way of giving someone the legal authority to make decisions on your behalf if you lack mental capacity at some time in the future or if you no longer wish to make decisions for yourself. The person who appoints an attorney in this way is called the “donor”. Any decisions made by the attorney must be according to the donor’s instructions or made in the donor’s best interests if they are deemed to have lost capacity to make particular decisions. There are two types of LPA:

- Property and financial affairs attorney;
- Health and welfare attorney.

Find out more at **www.gov.uk/lasting-power-attorney-duties**



Daily Living Equipment and Adaptations

There is access to individual assessment and advice and information relating to equipment and environmental changes that may help individuals optimise their ability and safety.

- Advice that addresses improvement to colour contrast to improve vision such as coloured contrast in the home or specialist equipment such as colour contrast toilet seats
- Advice on furnishings and decoration to assist with daily living
- Advice on memory aids that may be helpful

When people have physical needs in addition to cognitive problems there is a range of equipment to assist with activities of daily living.

Telecare

Telecare is usually based on a pendant worn around the neck or wrist and can be used in all types of living accommodation. This provides access to a 24-hour monitoring service offering an instant response at the touch of a button.

Telecare can be linked to a series of alarms or sensors offering an immediate early warning if something is wrong. For example, telecare can have sensors to detect if people have had a fall, if the property is very cold, if a tap in a sink or bath has been left on, or if the front door has been left open.

To find out more visit the webpage on Assistive Technology and Telecare on the Cumbria County Council website.

www.cumbria.gov.uk/healthsocialcare/stayathome.asp



Choosing Where to Live

As a person's dementia progresses, their home may not be suitable for their needs.

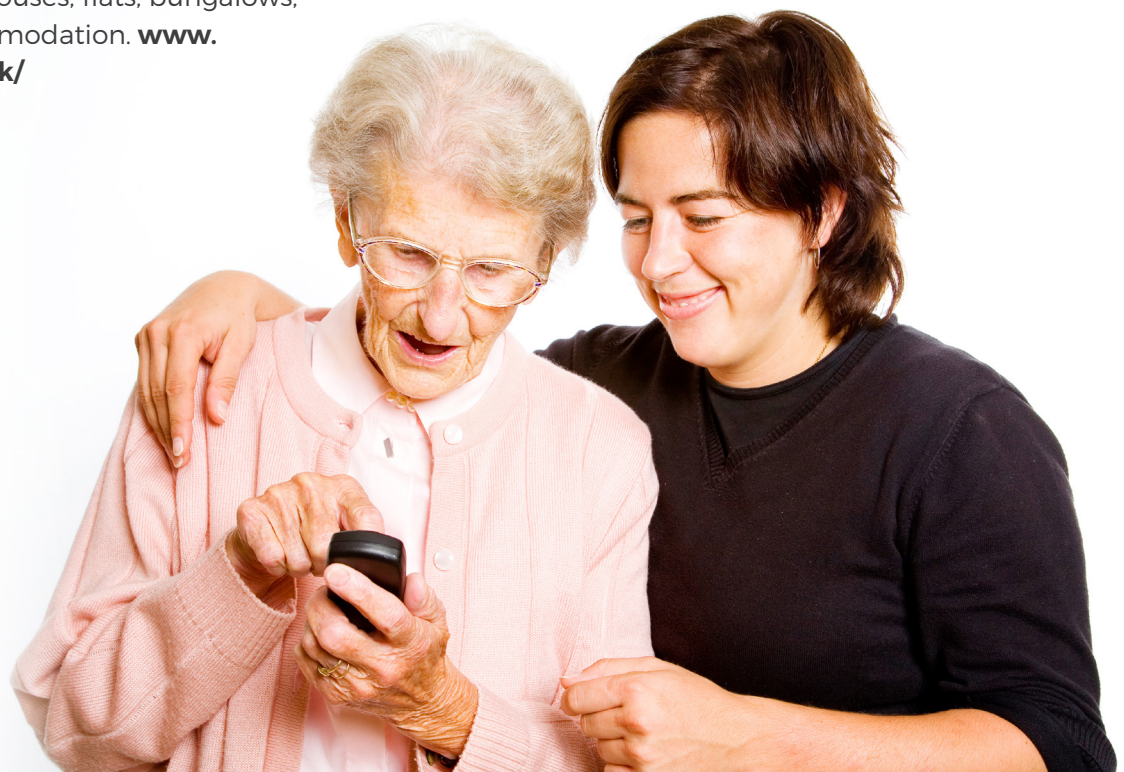
People may choose to:

Stay put: where advantages can include the security of familiar surroundings, links to family and community support, and good local knowledge. Environmental changes can make the person's home more dementia-friendly. Examples include simple changes such as different colours on walls and door frames, plain carpets that are similar in colour and texture and clear signage on rooms and cupboards which can help to reduce stress and anxiety levels for people living with dementia. Other examples of positive environmental changes include non-slip paths and raised flower beds in gardens to help people get out and about.

Move to a new house: perhaps to a more suitable property closer to relatives. This may include consideration of a move to Extra Care Housing, which is a type of sheltered housing which has a permanent care team within the building. Find out more via the Cumbria County Council website: www.cumbria.gov.uk/healthandsocialcare/adultsocialcare/longterm/housingoptions.asp or via the Cumbria Choice website, which has information on property to rent in Cumbria, including houses, flats, bungalows, and sheltered accommodation. www.cumbriachoice.org.uk/

Move into Residential Care: Residential placements are for people over the age of 18 who are unable to live independently at home. Residential care provides accommodation, meals, leisure activities, personal care and emotional support 24 hours per day, 7 days a week. The term 'care home' is used to mean any home that is registered with the Care Quality Commission (CQC). It includes local authority homes and independent homes. They are all inspected and monitored by the CQC based on national standards. Before making the decision to move to a care home, it is important to seek specialist advice. Most people do not need permanent care in a care home because their needs can be met in another way, perhaps by a combination of other kinds of care and support.

Move into Nursing Care: Nursing care homes are similar to residential care homes, but with trained nurses on duty. Consider a nursing home if regular medical attention is necessary. Nursing homes often provide specialist care for specific conditions like dementia.



8. Dementia Friendly Communities

The creation of Dementia Friendly Communities is a key part of raising awareness and reducing the stigma of dementia.

Improvement in public understanding of dementia helps create better support from the local community. This has a major impact on the day to day experiences of people living with dementia and their carers.

Activity in Cumbria includes:

- Working with networks of committed individuals and organisations across Cumbria through local Dementia Action Alliance movements. For more information on your local alliance please visit **www.dementiaaction.org.uk** and search for what's happening in your area. Some alliances have their own local web pages and social media presence, look them up on Facebook and Twitter;
- Organising and supporting information hubs and memory cafes where individuals can obtain advice and support from professionals and peers;
- Working with people affected by dementia to help build Dementia Friendly Communities. The experiences and views of people living with dementia need to influence and shape actions taken by organisations and communities.
- Promoting dementia awareness to help everyone understand what it's like to live with dementia and how to turn that understanding into action in our county.
- Supporting a wide variety of organisations and individuals with Dementia Friends Awareness Sessions. For more information visit **www.dementiafriends.org.uk** or contact your local DAA they will have a group of Dementia Champions ready to help.
- Helping all sectors in local communities become dementia-friendly. This includes work in schools to help young people understand dementia and how best to help, and across arts, community and faith groups.
- Encouraging organisations to take sustainable actions to ensure that they are as Dementia Friendly as possible. Organisations that sign up can receive recognition on an annual basis.

Churches Together

Churches Together in Cumbria is a forum through which various denominations of the Church in Cumbria come together to work towards common goals.

In 2016, Churches Together in Cumbria launched its Dementia Project with the stated aim that 'all churches throughout the County should be dementia friendly by 2020'. To this end, churches are striving to become places of acceptance, belonging, inclusion and welcome for all those affected by dementia, whether regular church goers, lapsed church attenders, or those who have never attended church before. The Project exists to help churches review and improve what they do, thinking especially about their welcome, worship and environment for those who may need extra help or support in order to participate.

Key to the success of the Dementia Project has been the recruitment of volunteers at local church level, known as Dementia Enablers. There is now a network of Dementia Enablers across the County each helping their church or group of churches to a) work towards these aims and b) consider how the work of the Project is embedded in the lives of their churches beyond 2020.

For more information about the Dementia Project please visit **www.churchestogethercumbria.co.uk**





Cumbria Library Service

Cumbria Library Service is free to join, and libraries offer a friendly and welcoming environment. Library staff attend Dementia Friends sessions as well as other Dementia training, and a range of resources designed for use by people living with dementia, and their carers, are available.

Reading Well Books on Prescription:

Dementia is a national scheme which consists of a range of books to borrow, aimed at providing support and information to people living with, or caring for someone with dementia.

Collections can be found in these libraries:

- Allerdale area – Workington, Cockermouth, Keswick and Maryport libraries
- Barrow area – Barrow Library
- Carlisle area – Carlisle Library
- Copeland area – Whitehaven Library
- Eden area – Penrith Library
- South Lakes area – Kendal, Grange and Ulverston libraries.

Books from these collections can be requested at any library in the county, free of charge.

Dementia Resource Bags are free to borrow for up to three weeks at a time. The bags are themed, with topics ranging from Childhood Days, Holidays, and Shopping through to Food, In the Garden and The Sixties. The bags contain a mixture of books, pictures, music and other resources aimed at stimulating memories and discussion. They are based in the 6 main libraries (Barrow, Carlisle, Kendal, Penrith, Whitehaven and Workington) but they can be requested at any library in the county free of charge.

Cumbria Library Service is also embracing the use of the latest technology, and Carlisle Library has a Tovertafel (“magic table”), which projects interactive games onto a table and is designed for people in the moderate to severe stages of dementia. The interactive games stimulate both physical and cognitive activity and encourage social interaction. The 6 main libraries (Barrow, Carlisle, Kendal, Penrith, Whitehaven and Workington) have extra-large tablets which can be used by individuals or in a group session, and they have a range of Dementia-friendly apps.

We hold a number of dementia-friendly activities in libraries throughout the year, including singing and reminiscence, as well as welcoming pre-booked visits from groups.

The Library Service understands the pressures carers face and offers a dedicated Carer’s ticket which has an extended eight-week loan period on books and talking books.

For further information please ask at your local library or visit www.cumbria.gov.uk/libraries



9. Dying Well (End of Life Care)

End of life care services support people with advanced progressive illness, usually in the last 6 to 12 months of their lives. This may include pain management, psychological, social, practical and spiritual support, as well as specialist services. It is important that the elements of good end of life care are also integrated into all health or social care settings.

People who are approaching the end of their lives may need to express their views and preferences in a personalised care plan. For people with some conditions, such as dementia, this should happen at an early stage, after a diagnosis is confirmed, in order to allow people to consider and plan for their future care and access the same End of Life Care services as anyone else.

People living with dementia should be enabled to die with dignity and in a place of their choice.

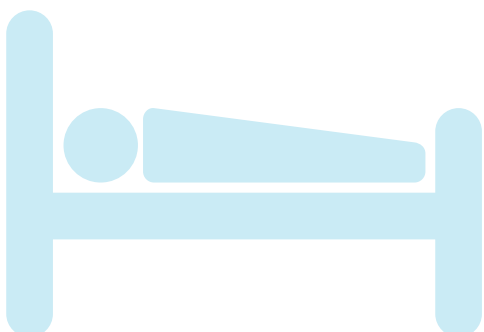
"Deciding Right" has agreed processes for professionals in Cumbria to use. It covers advanced care planning for End of Life Care; processes around the Mental Capacity Act 2005 and advice on matters such as making decisions about Cardio Pulmonary Resuscitation. www.northerncanceralliance.nhs.uk/deciding-right

Good planning processes include:

- **Choice and Capacity** - The right of individuals to choose their care preferences, either by deciding things now, in case they lose capacity in the future, or by having the right choices made on their behalf if they lack capacity to make some choices
- **Agreement** - The right decision comes from shared decision making which is a partnership between the individual and the professional
- **Right Documents** - Using the right documents to record people's wishes across every care setting means decisions are clear and centred on the individual, not the organisation
- **Education** - the right of everyone to have resources and understand their choices
- **The "Care for the Dying Patient Document" (CDP)**. The CDP document aims to improve end of life care for people in their last days of life by ensuring care delivered reflects the individual needs of patients and providing support to families and carers, irrespective of setting. The CDP document reflects the Priorities for Care of the Dying Person (Leadership Alliance for the Care of Dying People 2014)

Bereavement support for people living with dementia and their carers should be part of an on-going package of emotional and practical support that has been present throughout the care pathway.

Recent innovations in palliative and end of life care in Cumbria include the formation of a Cumbria Hospices Alliance, so there is a better understanding of how to offer support to people who need end of life care.



People with dementia who are admitted to hospital may find their new surroundings confusing and distressing. If admission is unavoidable, every effort will be made to ensure people living with dementia are treated with dignity and respect, have the best possible experience of care and do not stay longer than necessary.

Acute inpatient care in Cumbria is provided at a number of hospital sites, including the Cumberland Infirmary in Carlisle, the West Cumberland Hospital in Whitehaven, Furness General Hospital in Barrow and Westmorland General Hospital in Kendal.

Priorities for dementia care in Cumbria's hospitals include the completion of documents which gives staff advance information about their needs and requirements.

Some hospitals have specialist wards, for example, Ramsay Unit is a purpose built Dementia Assessment & Treatment Ward for 15 Older Adults based at Dane Garth, Furness General Hospital. The wards aim is to assess and treat people with different types of dementia, using a range of interventions. All the patients on the unit are acutely unwell with their dementia. Whilst there, people will be treated for their current individual needs and assessed for their future care requirements. The multi-disciplinary team on the unit aims to assess and identify future care needs for the person within a 28 day period however this may take longer depending on the complexity of their needs.

This Is Me

This Is Me is a national innovative scheme led by Alzheimer's Society, which allows people with dementia to tell staff about their needs, preferences, likes, dislikes and interests. Find out more via

www.alzheimers.org.uk/thisisme

The Butterfly Scheme

The Butterfly Scheme is designed for people who have memory problems and enables hospital staff to offer them the most appropriate care. Eligible patients, assisted by their Carer, choose to use a Butterfly symbol to alert staff they have memory impairment or dementia and need additional support.

<http://butterflyscheme.org.uk>

Morecambe Bay Health & Care Partners has its own unique forget me not passport of care for both community and acute hospital staff to use when ensuring person centred care is given to the person with dementia. As a paper copy, it stays at home with the person so can be updated as the persons needs change, but brought into hospital for use for use during inpatient/outpatient stay

The butterfly Scheme is now in place in the acute and community teams at Morecambe Bay Health and Care partners. The butterfly symbol can be found on the patients' electronic notes (under an alert on EMIS) and was launched to community teams in April 2019.

The butterfly scheme is also already in place across North Cumbria Integrated Care sites.



Other priorities include:

- People with dementia have support at mealtimes and drink enough
- People with dementia are not prescribed medications, including antipsychotic medication, unnecessarily
- The hospital environment is working to become 'dementia friendly'
- Discharge planning is initiated, at an early stage and takes full account of the needs and views of people with dementia and their carers
- Bed moves are avoided and should be for clinical reasons only

Dementia/Older Adult Specialist Liaison services are in all acute general hospitals to support assessment and treatment of people with new, suspected or existing dementia. They also liaise and offer support and advice to hospital staff regarding the care and management of people with dementia, as well as providing education, advice, support and specialist consultation. Diagnosing someone with dementia in an acute hospital is not best practice; therefore, liaison services will work closely with community memory teams to ensure any follow up regarding suspected dementia is completed after discharge.

Further training in recognition of dementia, delirium and depression is being rolled out across the county.

John's Campaign

John's Campaign was started to support the right for carers to stay with people with dementia in hospital. A carer is defined as the person who primarily supports the person with dementia. This is usually a family member but may include paid staff, e.g. a trusted Home Care Worker.

John's Campaign has the following guiding principles:

- Carers should have access to the patient whenever they are needed. This may be during the day or the night. The patient's needs are at the centre of this access principle
- Supporting personal well-being is likely to make medical treatment more effective for the person and will promote better discharge arrangements
- Carers are an essential and welcome part of the patient's care and support team
- Carers have a right – but not a duty – to be with the person they care for
- Carers are there to nurture, not to nurse

Ask a member of hospital staff whether the organisation is signed up to John's Campaign.



For further information on the support of people with dementia please see:

Adult Social Care- part of the Health, Care and Community Services Directorate, Cumbria County Council	www.cumbria.gov.uk/healthsocialcare/contact.asp
Age UK Barrow	www.ageuk.org.uk/barrow
Age UK Carlisle and Eden	www.ageuk.org.uk/carlisleandeden
Age UK South Lakeland	www.ageuk.org.uk/southlakeland
Age UK West Cumbria	www.ageuk.org.uk/westcumbria
Alzheimer's Society	www.alzheimers.org.uk/
Carers Support Cumbria	www.carerssupportcumbria.co.uk/
Carers Support South Lakes	https://carersupportsouthlakes.org.uk/
Carlisle Carers	www.carlislecarers.com/
Cumbria County Council	www.cumbria.gov.uk
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	www.cntw.nhs.uk
Cumbria Support Directory	www.cumbriasupportdirectory.org.uk
Cumbria Libraries	www.cumbria.gov.uk/libraries
Deciding Right	www.northerncanceralliance.nhs.uk/deciding-right
Dementia Connect Directory	www.alzheimers.org.uk/dementiasupport
Dementia Action Alliance	www.dementiaaction.org.uk/
Dementia Friends	www.dementiafriends.org.uk/
Dementia UK Admiral Nurses	www.dementiauk.org
Dignity in Dementia	www.dignityindementia.org
Eden Carers	www.edencarers.co.uk/
Furness Carers	www.furnesscarers.co.uk/
Gov.UK (Lasting Power of Attorney)	www.gov.uk/power-of-attorney/overview
John's Campaign	https://johnscampaign.org.uk/
Lancashire and South Cumbria NHS Foundation Trust	www.lscft.nhs.uk
NHS Health Checks (NHS Choices website)	www.nhs.uk/conditions/nhs-health-check/
NICE Guidelines: Dementia	www.nice.org.uk/guidance/CG42
North Cumbria Integrated Care NHS Foundation Trust	www.ncic.nhs.uk
People First Independent Advocacy	https://wearepeoplefirst.co.uk/
The Dementia Guide	www.alzheimers.org.uk/dementiaguide
The Royal College of Psychiatrists	www.rcpsych.ac.uk/
University Hospitals of Morecambe Bay NHS Foundation Trust	www.uhmb.nhs.uk
West Cumbria Carers	www.westcumbriacarers.co.uk/