

Cumbria County Council and NHS Cumbria, working with partners county-wide

# Cumbria Dementia Pathway

This pathway is due for review in January 2014.  
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# 1. What is dementia?

Dementia has major health, social and economic impacts 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 to be used as an information resource and guide to people living with dementia, carers, family members and friends, 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 affects a person's ability to remember, learn, think and reason, and also their social skills. There are many different types of dementia and not all result in permanent disability.

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.

The National Institute for Health and Care Excellence (NICE) defines dementia as *"...a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function ... with some or all of the following features: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self neglect, psychiatric symptoms (e.g. apathy, depression or psychosis) and out-of-character behaviour (e.g. aggression, sleep disturbance or dis-inhibition of sexual behaviour, although the latter is not typically the presenting feature of dementia)."*

## Common 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 change, 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.

**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.

**Fronto-temporal dementia (including Pick's disease)** – in fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.

The Mental Capacity Act provides for a role of Independent Mental Capacity Advocate (IMCA). The IMCA provides an independent safeguard to support particular vulnerable people who lack capacity to make important decisions and who have no-one to appropriately consult regarding certain decisions. For more information on IMCA services in Cumbria please visit Cumbria County Council website.

## 2. Assessment and Diagnosis

Dementia can be difficult to diagnose, especially if symptoms are mild.

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. Your GP will then do an initial assessment, and may refer on to a Community Based Memory Assessment Service for further assessment.

In Cumbria, the specialist **Community Based Memory Assessment Service** offers an individualised comprehensive assessment of suspected, new or worsening memory problems or dementia. This assessment will be in a variety of settings including the person's home, GP surgery, care home, clinic or hospital setting, dependant on the individual's need and choice. This service also offers a range of evidence based specialist interventions for people with dementia. It works closely with colleagues in primary and community care, Adult Social Care, other community Services and Third Sector services to support people with dementia and their carers and family.

### Why is it important to 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.

More information is available on diagnosis and assessment on the Alzheimer's Society website at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).

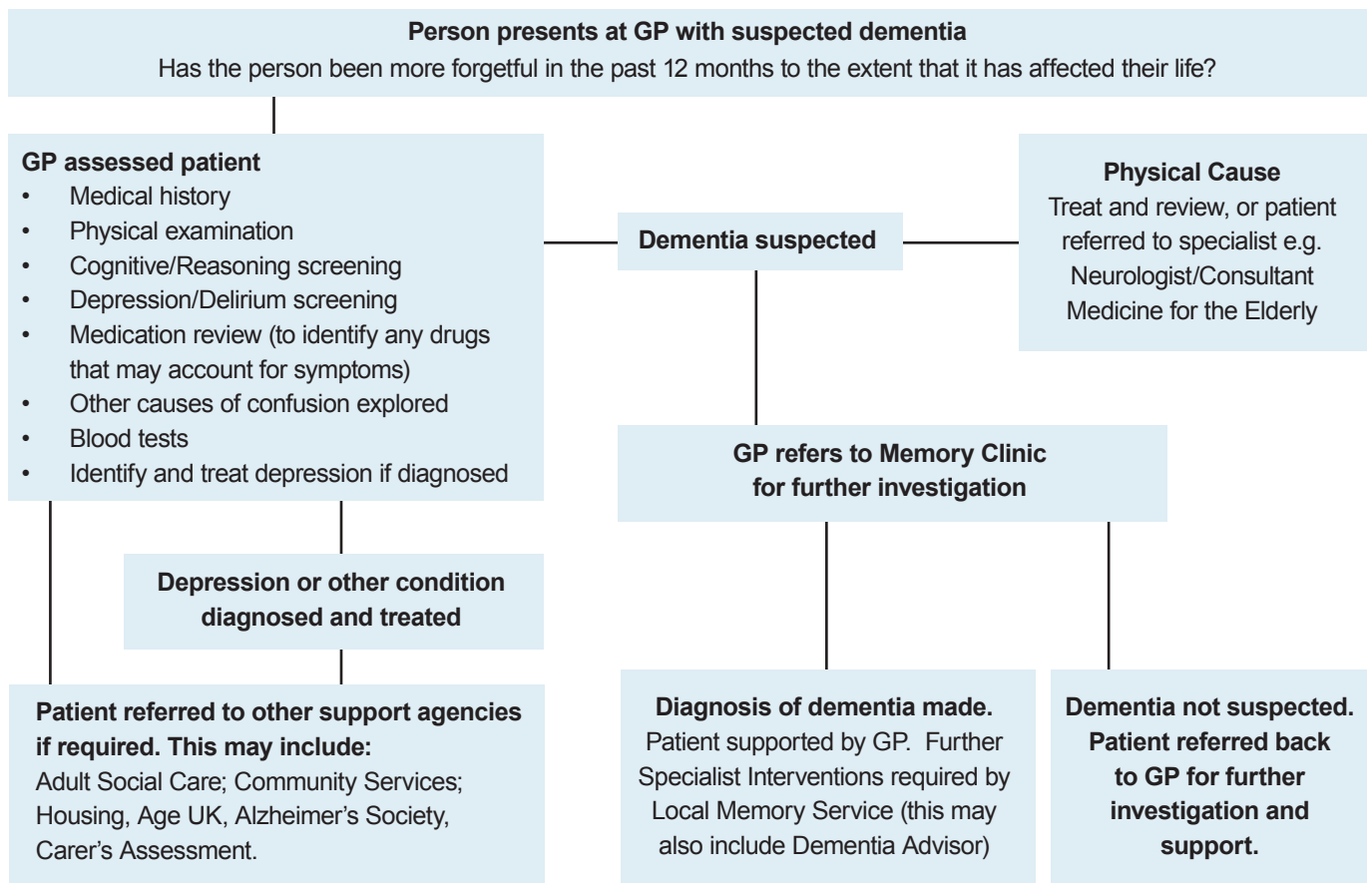
### Diagnostic features of dementia

The most common symptoms of dementia are:

- Increasing difficulties with activities that require concentration and planning
- Difficulty carrying out usual daily tasks
- Memory loss
- Changes in mood, for example depression or agitation
- Difficulty sleeping
- Changes in personality
- Mental confusion and 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)
- Abnormal thoughts e.g. delusions



## The Primary Care Pathway: Early Identification and referral



### A diagnosis of dementia

Once a diagnosis of dementia is made, the GP or specialist will explain what having dementia might mean and the type of dementia that has been diagnosed. Once a diagnosis is made, further appointments will be made with the GP to review the patient.

Because dementia is a progressive condition, the doctor may arrange another appointment with the specialist service, perhaps after six months or a year. The GP and the specialist may also jointly prescribe any treatment that might be helpful. A number of things will need to be discussed and considered, depending on the progression of the condition:

- Treatments;
- Care and support services in your area;
- Support groups and voluntary organisations for people with dementia and their families and carers;

- Advocacy services;
- Where you can find financial and legal advice;
- Capacity;
- Lasting Power of Attorney;
- Driving;
- Care Allowances;
- Meals;
- Home Care;
- Respite;
- Information Sources;
- Risk Assessment;
- Advanced Decision to refuse Treatment;
- Housing and environment.

Many people with dementia also have other health conditions. People with dementia and their carers will be offered an appointment with their GP at least every 15 months to review their physical and mental health, to ensure they receive appropriate care for any other conditions, and to enable them to live as well as possible with dementia.

Your GP, Social Worker or support organisations such as Age UK and the Alzheimer's Society can provide advice and support on the next steps and on-going support available following a diagnosis.

## Awareness Raising and Early Identification

We want to raise the profile of dementia 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. For that reason early identification and diagnosis of dementia is a critical first step of the journey.

If diagnosed early, treatment may be available to help reduce the symptoms of the condition.

A wide range of information is available to help people with dementia live their lives and make decisions about the support they need.

## Spotting the signs of dementia early

To help identify people who have dementia an "awareness question" has been agreed for Cumbria for professionals to ask "Has the person been more forgetful in the last 12 months to the extent that it has significantly affected their life?"

- People who are concerned about their own cognitive function or that of a family member should seek help from their GP;
- People with Learning Disabilities may be at increased risk of dementia and will be offered a baseline cognitive assessment and regular follow up to promote early identification;
- People with existing vascular disease are also at higher risk of developing dementia, as are people who have had a stroke or have a neurological condition such as Parkinson's disease so will be monitored by health professionals;
- A comprehensive training package and dementia screening tool (3Ds) is being rolled out across all GP practices, Community Hospitals, Community staff and Adult Social Care staff.



## 3. Risk Factors and Prevention

The biggest risk factor for dementia is ageing, which we cannot prevent. However, we can take measures to prevent the second most common form of dementia, vascular dementia, by keeping our arteries healthy.

### A healthy heart

What is healthy for the heart is healthy for the mind. The following measures can help prevent vascular dementia, as well as heart attack and stroke:

- Regular exercise;
- Maintaining a healthy weight, eating a healthy diet and keeping salt intake low;
- Stopping smoking and excessive alcohol use;
- Treatment of hypertension, diabetes, and high cholesterol.

Everyone is at risk of developing heart disease, stroke, type 2 diabetes or kidney disease. But these diseases can often be prevented, and the NHS Health Check can help you by assessing your risk and giving you personalised advice on how to reduce it. People aged 40-74 are eligible for a free NHS Health Check from their GP or local pharmacy. It can help to detect vascular and other risk factors for dementia.

More information about NHS Health Checks is available via NHS Choices at [www.nhs.uk](http://www.nhs.uk).

### Genetic counselling

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



## 4. The workforce and the principles and values of care

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

All health and social care staff involved in the care of people who may have dementia must have the necessary skills to provide the best quality of care in the roles and settings where they work. This is to be achieved by effective and relevant basic training and continuous professional and vocational development in dementia, allied to an understanding of the dementia care pathway and the range of resources available to support people with dementia and their carers.

Managers encourage a culture that values and supports staff to be able to interact with people with dementia and their carers in a holistic way, with emphasis on the importance and quality of social interactions, and an understanding of best practice in dementia care.

### Principles of care

There are a number of agreed care principles that all staff 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 from 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;
- Support the quality of life of people with dementia and to enable them to die with

dignity and in their place of choice. A palliative care approach should be adopted from diagnosis until death. This should consider physical, psychological, social and spiritual needs;

- 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;
- Services must be commissioned and delivered in accordance with the Mental Capacity Act 2005.

### The Mental Capacity Act 2005: Five key principles.

1. **A presumption of capacity** – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
2. **Supporting individuals to make their own decisions** – a person must be given all practicable help before anyone treats them as not being able to make their own decisions
3. **Unwise decisions** – just because an individual makes what might be seen as an unwise decision, they should not be assumed to lack capacity to make that decision
4. **Best interests** – an act done or decision made under the Act, for or on behalf of a person who lacks capacity, must be done in their best interests
5. **Least restrictive option** – anything done for or on behalf of a person who lacks capacity should only be done after considering if there is another option that is less restrictive of their basic rights and freedoms.



There are some simple guidelines that can reduce the instance of behavioural and psychological symptoms. These are based on the principles of person-centred care (care tailored to the specific person's needs) which for dementia are integral to the care and treatment provided:

- Treating the person with dignity and respect;
- Understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests;
- Looking at situations from the perspective of the person with dementia;
- Providing opportunities for the person to have conversations and relationships with other people;
- Ensuring the person has the chance to try new things or take part in activities they enjoy.

## Developing the workforce

It is important that staff are knowledgeable, confident and understand their role in the following areas:

- The social causes of dementia, e.g. alcohol;
- Early signs and symptoms suggestive of dementia and its major subtypes;
- Understand interventions appropriate to different types of dementia,
- Signs and symptoms, and prognosis;
- Alternative conditions with similar presenting symptoms, e.g. depression, delirium;
- Impact of the condition on the person with dementia and carers, family and social network;
- Nutrition;
- Physical care;
- Importance of the care environment;
- Assessment and treatment, including administration of medication and monitoring side effects;
- Person-centred care in dementia;
- Communication skills;
- Assertive outreach techniques for people not engaged with services;

- Roles of staff and agencies involved in care including how they should work together;
- Safeguarding in Cumbria;
- End of Life care and dementia;
- Appropriate quality standards, e.g. NICE Quality Standards in Dementia;
- Social impact of dementia;
- Mental Capacity Act;
- Mental Health Act;
- Planning, e.g. Lasting Power of Attorney.



## 5. Support for Carers

**A Carer is someone of any age who provides support to family or friends who could not manage without this help. With dementia, this could mean caring for an older relative or partner.**

Carers input and support is critical in helping the person with dementia maintain their ability to live well.

Many carers don't see their own health needs as a priority and they may need to be supported to seek appropriate help in order to reduce the strain of caring.

### Assessments and support for carers

Cumbria County Council is committed to supporting carers. We recognise that most care in the community takes place through family, friends and neighbours.

Many organisations provide support and advice for Carers alongside the person with dementia, for example the **Alzheimer's Society** and **Age UK**.

Carers have the right to a formal Carer's Assessment which reflects their individual needs as set out in the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004.

In Cumbria formal assessments for carers of people with dementia are usually carried out by Adult Social Care, which is part of Cumbria County Council, and the Carers Organisations countywide. People have a choice of assessor.

In Cumbria, carers can access a wide range of support opportunities either individually or as part of a group via Community Mental Health teams and the third sector. Services will need to put carers in control, recognising that it is carers who are best placed to articulate their own aspirations.

To find out more, you can either:

- Contact Customer Services at your local Cumbria County Council Adult Social Care or Children's Services office;
- Speak to your social worker, occupational therapist or community psychiatric nurse (if you have one); or
- Contact your local carers organisation.

If you or the person for whom you care do not currently have a social worker, you can contact Cumbria County Council's Customer Services Team, who will ask you for some details about yourself and the person you care for (if they would like to be involved) and will arrange for someone to visit you.

### Types of support available

Even if you feel you do not need it yet, you may want to know what help might be available should you need it. If we cannot offer help, we will try to put you in touch with someone who can.

The services and support available for carers through a range of statutory and voluntary organisations includes:

### Information and advice

- Access to information and advice services
- Benefits advice
- Advice on home care
- Occupational therapy to advise on equipment and adaptations in the home of the person to help you care for them;
- Telephones and telecare alarm systems
- Car badges for disabled drivers and passengers.

## Breaks

- Breaks for carers – sometimes called respite care
- Befriending and sitting type services
- A break for the person being looked after via a stay away from home which may offer a chance to meet other people. Normally a stay in residential or nursing care would involve an assessment of the person cared for by Adult Social Care

## Emotional Support

- Referral to organisations who can provide time to listen with carers and help identify their needs
- Psychological support
- Help for people facing aspects of end of life care and bereavement
- Other specialist support through funding, such as counselling or specific therapies.
- Carers of people with dementia who experience psychological distress and negative psychological impact have access to psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.

## Support for carers

- Carers' Support Groups
- Specialist support for carers, such as through the Alzheimer's Society
- Support to access training and educational opportunities. Examples are;
- Understanding dementia;
- Stress awareness and relaxation techniques;
- Specialist training for carers of people living with dementia.

## Support for former carers

A carer's role may change if they suffer bereavement or the person they care for moves into residential care. Support can be maintained by some organisations in order to:

- Continue existing social networks and effectively maintain mental health and well-being;
- Assist in dealing with changes of circumstance;
- Reduce isolation and thus maintain mental health, including helping to limit depression;
- Provide an experienced group of people who understand the caring role and can contribute to co-production of plans and services, staff induction, training or volunteering.

We will discuss the range of support available to you after your assessment of need when we agree your care plan.

## 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. Medical interventions for dementia patients

Further interventions may also be required to support the person with dementia and their family, where the persons' needs are greater. This may help the person to live well with dementia, helping them to continue to live a fulfilling life, while also helping their family deal with the impact of symptoms.

Specialist interventions and medical interventions are provided by local Memory services. These are based on the persons (and their family's) needs following a comprehensive assessment. Details of interventions are outlined below.

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, including anxiety and depression, and sleep disturbance are common in people with dementia.

### Interventions for maintenance of function

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.

### 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;
- Reality orientation;
- Practical solutions to improve day to day living, wellbeing and quality of life;
- Occupational activities;
- Environmental modifications;
- Psycho-social interventions;
- Validation therapy;
- Reminiscence;
- Sensory stimulation;
- Complimentary therapies; and
- Behavioural interventions.

### Drug based interventions

Medications used in the treatment of dementia fall 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 on all these medications can be found on The National Institute for Health and Clinical Excellence (NICE) website at [www.nice.org.uk/CG42](http://www.nice.org.uk/CG42)

## Assessment of symptoms

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

1. Physical health;
2. Depression;
3. Possible undetected pain or discomfort;
4. Side effects of medication;
5. Individual biography;
6. Psychosocial factors;
7. Physical environmental factors;
8. Behavioural and functional analysis in conjunction with carers and care workers.

The care plan is reviewed regularly at a frequency agreed with carers and staff.

## Cognitive stimulation

Cognitive stimulation therapies have been shown to improve both cognitive function and quality of life in people with 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.

## 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.



## 7. Promoting Independence

**In Cumbria all partners work to help people with dementia to stay as independent as possible for as long as possible and live well with their condition. People with dementia can live well in their own homes, with family carers and in residential or supported housing settings**

A number of factors can help this:

- 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, leisure.

In addition, a number of factors can promote independence in people living with dementia. The NHS and Adult Social Care are working hard to ensure that environments and packages of care are tailored so that people get the best possible support to maintain control over their life and limit symptoms where possible.

### Self-Directed Support with Personal Budgets

Self-directed support is about people being in control of the support they need to live the life they choose. You may have heard it being referred to as ‘personalisation’ or ‘personal budgets’. There are different ways to describe it, but it’s about giving people real power and control over their lives, allowing people more scope to choose how they are supported at home.

For more information please visit the Social Care section of the Cumbria County Council website ([www.cumbria.gov.uk](http://www.cumbria.gov.uk)) and the leaflet “Contributions to Personal Budgets and Non Residential Services. How Much will I Pay?”.

### Dementia Friendly Environments

A safe dementia-friendly environment has a large part to play in helping people living with dementia to remain independent for as long as possible, with choice and control over their lives through all stages of their condition. It can also help to make up for impaired memory, learning and reasoning skills and can reduce stress levels.

At home, a safe, well designed living space is a key part of providing the best care for people with dementia. In care homes, simple steps such as increasing the size of signage, the use of plain flooring and contrasting colours to aid identification can improve the orientation for people with dementia and help them to live well in their environments. The NHS and Adult Social Care are supporting care settings to make environments dementia friendly. Further information on this is available from the Cumbria County Council webpage **Implementing the Dementia Strategy in Cumbria**.

### Dementia Friendly Communities

Lack of awareness among the public and poor understanding in communities has a major impact on the experience of people with dementia. The creation of dementia-friendly communities is a key part of raising awareness and reducing the stigma of dementia. We are supporting the creation of dementia friendly communities by:

- Working with communities to raise awareness and de-stigmatise working with and supporting people with dementia. This is supported by holding special assemblies

in schools, involving libraries, local community groups and working groups and reference groups for people with dementia to educate about the condition

- Developing dementia friendly indoor environments
- Outdoor environments - open spaces and short, well-connected, gently winding streets with good visual access. Footpaths are wide with smooth, plain, non-slip, non-reflective paving. Signs are simple and explicit and located at decision points, such as road crossings

Assistive technology and **Telecare** also have a role to play in keeping people safe and ensuring they can access help in an emergency.

**Occupational Therapy Services** will help people with dementia live well by carrying out an assessment, then providing equipment that can assist with daily tasks, e.g. handrails, bath boards, etc.

## Redesigning spaces

Anyone trying to create a dementia-friendly environment must first ask how people living with dementia experience their world. Some of the common features of living with dementia are.

### It impairs our memories:

- We can forget where we put things.
- We can forget we have done something and so repeat doing or saying things.

### It impairs our reasoning:

- We can find abstract notions like money and value confusing.
- We can misunderstand the pattern on the floor.

### It impairs our ability to learn:

- We can find new places disorienting.
- We can have difficulty getting used to unfamiliar objects or routines.
- We forget where basic things like the toilet are.

### It raises our levels of stress:

- We can find large groups difficult.
- Too much noise makes us confused.

### It makes us very sensitive to built and social environments:

- We can be very sensitive to the emotional atmosphere.
- We benefit from calmness.
- We need good lighting to give us as much information as possible about our surroundings.

### It makes us more and more dependent on all our senses:

- We may need to be able to smell, feel and see things.
- We can get agitated if we get too hot.
- We can get confused if there is not enough light.

All these characteristics of dementia should be considered when developing a dementia friendly space.



## Social interaction and maintaining skills and abilities

Remaining physically and mentally active can help us all and particularly people with dementia live well – it's important to have an approach that focuses on what a person can do:

- 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 the person to express their feelings - for example listening to music or writing something down. In Cumbria we have a range of peer support groups for people with dementia as well as specific projects like Singing for the Brain, physical activity, sensory stimulation, and ideas around reminiscence. Both Alzheimer's Society and Age UK have factsheets which give practical advice around many aspects of living with dementia and local groups will provide support and access to these activities.
- Day Services and one-to-one community support services are available in Cumbria for people with dementia.

The Cumbria Support Directory ([www.cumbria.gov.uk/adultsocialcare/supportdirectory/](http://www.cumbria.gov.uk/adultsocialcare/supportdirectory/)) draws together information including social opportunities and events to promote independence.

## 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, voluntary sector staff like carers' organisations and Age UK, therapeutic staff and assistants who work as one team across localities. The 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:

- Short term intervention service and other Rehabilitation Services from the NHS
- Support at Home Services (Home Care);
- Day Services;
- Reablement;
- Carers Assessments.

## Financial independence

People with dementia and their carers may need support to access information on money matters. People need to be supported to access the benefits they may be entitled to and to challenge unfair decisions. Age UK, Alzheimer's Society and Carers Organisations in Cumbria can assist with advice and support on money matters to minimise poverty and exclusion, and maximise income in retirement.

Choosing the right bank or building society account to allow people to access their money, helping people get good advice on their investments and on releasing equity, and helping people protect their identity and combat fraud as well as choosing the right providers for utilities are all part of helping people maintain financial independence.

## Property and affairs Lasting Power of Attorney

You can make a property and affairs Lasting Power of Attorney to enable someone you trust (the attorney) to make decisions on your behalf about your property and affairs at a time when you are no longer able or lack the mental capacity to take those decisions yourself. This can include paying your bills, collecting your income and benefits or selling your house, subject to any restrictions or conditions you might have included. It can only be used once it has been registered at the Office of the Public Guardian (OPG). Further information is available at [www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney).



## 8. Coordinated Care Services

Services to support people with dementia aim to work closely together and as a partnership to ensure that people with dementia and their carers are given up-to-date information on local arrangements (including inter-agency working) for health and social care, including the independent and voluntary sectors, and on how to access such services. Partners include:

- Primary care;
- Support at Home Services (Home Care);
- Day Services;
- Carers Assessments;
- Assistive technology and Telecare;
- Mainstream and specialist Residential and Nursing care;
- Rehabilitation and Reablement services
- Hospital services;
- Specialist mental health services.

There are some statutory functions which some partners have and the right of people to access these must be upheld. Adult Social Care has a statutory duty, as detailed in the Community Care Act, to safeguard adults at risk and assess the needs of individuals whose circumstances mean they may need support. Practitioners from Adult Social Care will work with the individual and their carer(s), offering professional support to produce an outcome based support plan (which may require multi professional input) aimed at retaining or regaining an individual's independence. Adult Social Care can also provide advice and information or contact with relevant preventative support.

### NHS Funded Care

NHS continuing healthcare (also known as NHS continuing care and fully funded NHS care) is a package of care arranged and funded solely by the NHS. It is awarded depending on whether a person's primary need is a health need. It can be provided in a range of settings, including an NHS hospital, a care home or someone's own home. It's free of charge and can be provided solely by the NHS or jointly with Adult Social Care.

### Assistive Technology

Dementia makes day-to-day life more difficult. Little things like mislaying keys, forgetting to turn off the taps or leaving the gas unlit can prove frustrating or even create hazards. Technological developments can help make life easier for people with dementia and their carers in certain situations. The NHS and Adult Social Care are working together to support people with dementia to access more devices and assistive technology to assist with everyday living.

#### **This is me leaflet – tool for people with dementia receiving professional care**

Good transition between care settings is vitally important for people living with dementia. "This is me" is a simple and practical tool that people with dementia can use to tell staff about their needs, preferences, likes, dislikes and interests.

A hospital or care setting, and the change in routine that being in a new environment brings, can be confusing for a person with dementia. Completing the "This is me" leaflet enables health and social care professionals to see the person as an individual and deliver person-centred care that is tailored specifically to the person's needs. It can therefore help to reduce distress for the person with dementia and their carer.

This is me was first developed by the Northumberland Acute Care and Dementia Group and is supported by the Royal College of Nursing.

### Support from the Dementia Adviser Service

The Cumbria Dementia Adviser Service provides people with dementia and their carers with a named contact person who can give

information, advice and support, and signpost to and facilitate health, social care and other support services. This service is hosted by The Alzheimer's Society. To find out more about your local dementia adviser service please contact **01539 742631** or email **lakes.admin@alzheimers.org.uk**.

## **CHES (Care Home Education and Support Service)**

CHES (provided by Cumbria Partnership NHS Foundation Trust), 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 comprises of 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 manage residents with dementia or other mental health difficulties. This reduces the need to admit residents un-necessarily to hospital and enables the person to remain in their placement of choice for longer. CHES is currently being rolled out across Cumbria.

## **9. Accommodation**

**The condition of someone's home is a key influence on their health and wellbeing.**

The NHS, Housing and Social Care teams are working closely together so that more care is provided closer to home and that people are supported to remain independent in their own home. To achieve this, the home needs to be suitable and safe, affordable and warm, as well as adapted if necessary.

A home that needs adapting has the potential to increase falls and accidents. Many homes need work to make them energy efficient, reducing heating bills and pressures on people's budgets.

For people diagnosed with dementia planning ahead and considering a range of options such as equity release, downsizing or moving to supported accommodation can pay dividends and help towards living well with dementia.

### **Housing Options**

Housing options for people with dementia may include:

- Living at home;
- Deciding whether to rent or buy;
- Making decisions on adaptations to the home and planning ahead for repairs;
- Living with family members who may become carers;

- Living in specialist supported or extra care housing, which may offer independent living with additional support on site;
- Residential or nursing home care.

A safe dementia-friendly environment has a large part to play in helping people living with dementia to remain independent for as long as possible, with choice and control over their lives through all stages of their condition.

### **Disabled Facilities Grants**

In Cumbria, the County and District Councils work with both Health and Social Care to adapt homes so they are safe and warm. When a home and its facilities become difficult to access, Disabled Facilities Grants (DFG) provide adaptations and equipment such as stair lifts or level access showers. Grants of up to £30,000 are available, and those who receive help are means tested. In 2010-11, 873 people had a major adaptation to their home using a DFG, a rise in demand from 470 people helped in 2007-08.

Assessment of eligibility is done by Occupational Therapy services from Adult Social Care.

## 10. Hospital care

We want to prevent unnecessary admission of people with dementia to hospital whenever possible. When admitted, people with dementia may find their new surroundings confusing and distressing. If admission is unavoidable, every effort will be made so 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.

### Hospitals in Cumbria

Two NHS hospitals trusts provide acute inpatient care in Cumbria: **North Cumbria University Hospital NHS Trust**, which delivers care at the Cumberland Infirmary in Carlisle and the West Cumberland Hospital in Whitehaven; and **University Hospitals of Morecambe Bay NHS Foundation Trust** which delivers care at Furness General Hospital in Barrow, Westmorland General Hospital in Kendal and the Royal Lancaster Infirmary.

The **Cumbria Liaison and Assessment Service** assists staff in these hospitals in the care and management of people with dementia, as well as providing education, advice, support and specialist consultation.

In addition there are nine community hospitals in Cumbria at Alston, Brampton, Cockermouth, Keswick, Maryport, Millom, Penrith, Wigton and Workington, and 'Step Up Step Down' is provided at several sites across the county. Step Up Step Down is a ward based service designed to maximise support for independence. People living with dementia may be admitted from home - Step Up - for 24-hour short-term nursing help, or from a hospital ward - Step Down - for extra nursing to facilitate a safer transfer home. When people with dementia need specialist inpatient assessment and care this is available at the Ruskin Unit in Carlisle and The Ramsey Unit at Dane Garth in Furness.

Community hospitals, Step Up Step Down and specialist inpatient mental health units are provided by **Cumbria Partnership NHS Foundation Trust**.

### Dementia care priorities in Cumbria's hospitals

- There are named clinical leads for dementia;
- Staff are appropriately trained;
- When people with dementia go into hospital for planned and emergency care, they are encouraged to complete a document which gives staff information about their needs
- People with memory problems are identified on admission, assessed and referred on as appropriate;
- Bed moves are avoided and should be for clinical reasons only;
- Care plans are person centred and developed with involvement where appropriate of family and friends, to include assessment of: nutrition; pain; continence; comfort; dignity; activity, rehabilitation and end of life care;
- 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 integral to care planning, is initiated whenever possible before admission or within 24 hours of admission, and takes full account of the needs and views of people with dementia and their carers;
- Appropriate use is made of Cumbria's Step Up Step Down, rehabilitation and reablement services, to support return to home from hospital whenever possible.

## 11. End of Life Care

End of life care services support people with advanced progressive illness in the last six to 12 months of their lives and into bereavement. 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. For dementia, these may be introduced earlier because of the nature of the condition.

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

The **Joint Commissioning Strategy for End of Life Care for Adults in Cumbria** sets out aspirations for good end of life care, including an opportunity for people who are approaching the end of their lives to express their views and preferences in a personalised care plan, which, for people with some conditions, such as dementia, 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.

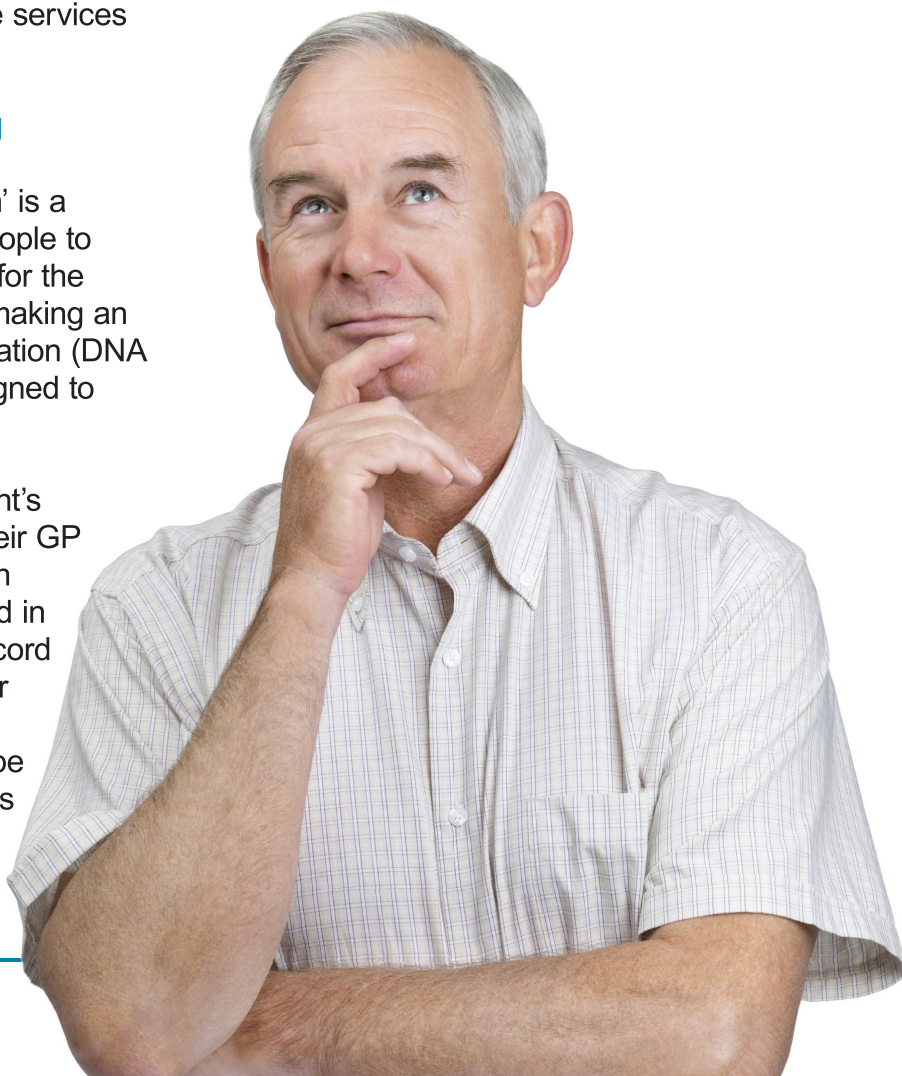
### End of Life Care Planning

The 'Preferred Priorities of Care Plan' is a key planning document that helps people to think about and record their choices for the future. This may include the patient making an advanced decision to refuse resuscitation (DNA CPR). An Easy Read version is designed to help people with learning disabilities.

Once agreed, the record of the patient's choices is held by the person and their GP and should be accessible to all health and social care staff who are involved in delivery of the care package. The record should follow the patient through their care into a variety of differing health and social care settings and should be reviewed and updated as the patient's condition, choices or preferences change. Responsibility for ensuring

that both copies of the care plan are updated rests with the worker who has instigated the review. This may be an informal conversation that has led to a change in choice being expressed.

Information on end of life care is available from the National End of Life Care Programme website at [www.endoflifecare.nhs.uk](http://www.endoflifecare.nhs.uk).



## 12. Sources of further information

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

**Age UK [www.ageuk.org.uk](http://www.ageuk.org.uk)**

**Alzheimer's Society [www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

**Dementia UK [www.dementiauk.org](http://www.dementiauk.org)**

**NICE Guidelines: Dementia [www.nice.org.uk/guidance/CG42](http://www.nice.org.uk/guidance/CG42)**

**Royal College of Nursing [www.rcn.org.uk](http://www.rcn.org.uk)**

**The Royal College of Psychiatrists [www.rcpsych.ac.uk/](http://www.rcpsych.ac.uk/)**



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If you require this document in another format (e.g. CD, audio cassette, Braille or large type) or in another language, please telephone 01228 606060.

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