

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

Cumbria Dementia Pathway



This pathway is due for review in June 2019. Please e-mail any comments you may have to Donna Story at donna.story@cumbria.gov.uk

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The Information in the Cumbria Dementia Pathway (version 3) 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, planned for June 2019.

1. What is dementia?

Dementia is set to have 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 patients, 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 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. 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)."

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 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.

Fronto-temporal dementia (including Pick's disease) – in fronto-temporal 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.

Can dementia be prevented?

Research now shows that you can undertake a number of 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 <https://www.nhs.uk/oneyou/checking>.

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: <http://www.alzheimersresearchuk.org/about-dementia/helpful-information/getting-involved-in-research/?gclid=CNefi-34sc8CFUsW0wodaQIOpA>

2. Assessment and Diagnosis

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.

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 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

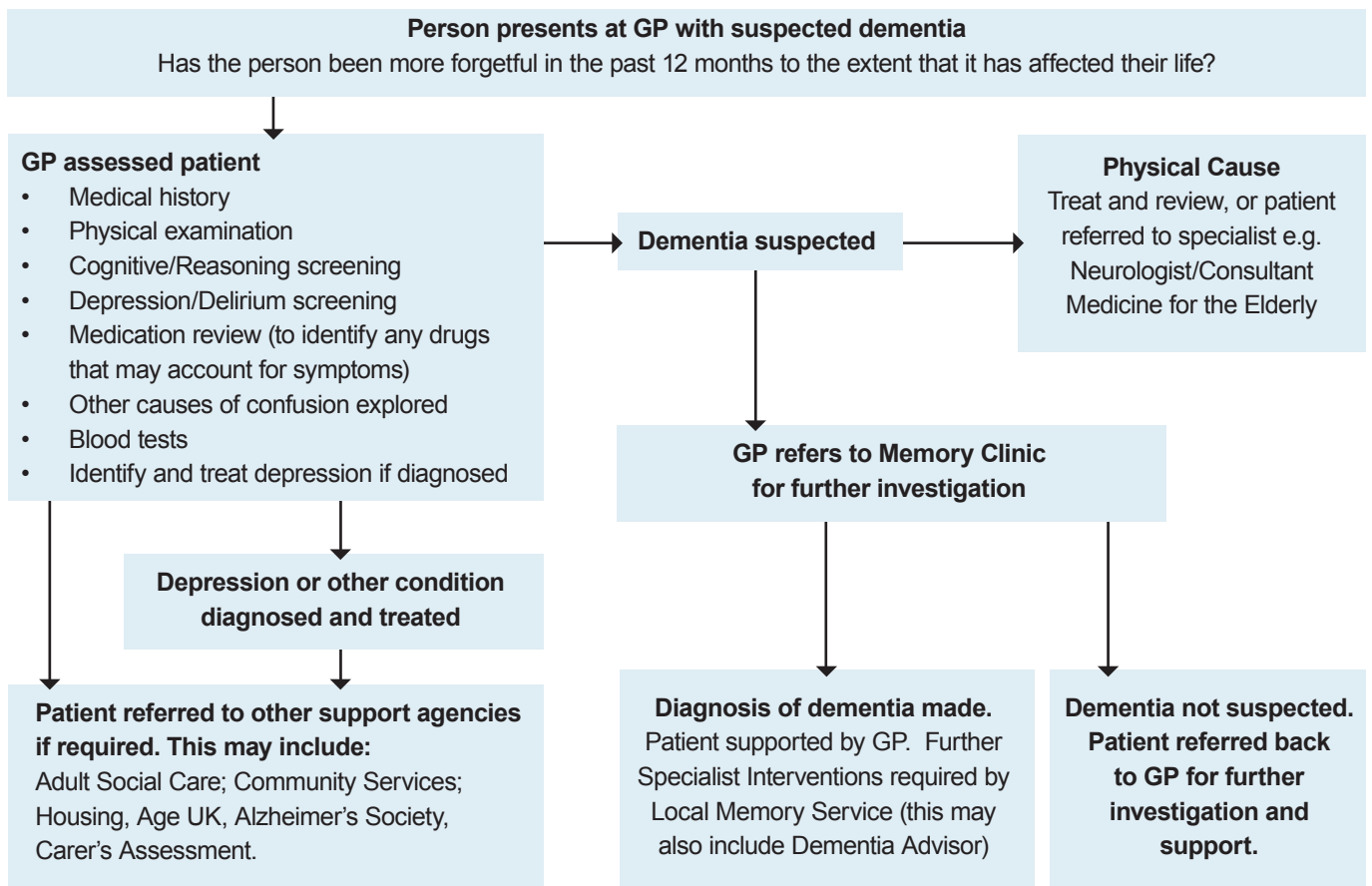
The most common symptoms of dementia are:

- Increasing difficulties with activities that require concentration and planning;
- 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 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.



The Primary Care Pathway: Early Identification and referral



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.

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

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 Disabilities 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.

Individuals with Learning Disabilities (LD) 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 LD. Therefore specialised tools designed for individuals with LD are used. The assessment offered by Cumbria Partnership Community Learning Disabilities Service includes a range of direct cognitive assessments with the individual, indirect assessments conducted with Carers/family members and post diagnostic support

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.

A number of 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 on demand and will be encouraged to direct patients to the National Helpline for support and connection with local resources. Find out more about the Dementia Guide via <https://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 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, leukoencephalopathy (CADASIL) and Huntington's disease. If you are concerned and would like to explore genetic counselling, speak to your GP.

3. Post Diagnostic Support

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. All people living with the effects of dementia and their families and Carers should receive high quality support and information, available 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.

Alzheimer's Society National Dementia Helpline provides information, advice and support to anyone affected by dementia. The Alzheimer's Society is currently offering an extended service to people who do not have access to a Dementia Adviser or a Dementia Support Worker. This extended service will comprise of a series of telephone appointments where people will be able to discuss dementia related topics with a trained Helpline Adviser. The aim is to provide the information and support the person need at the time when it is most needed. Some of the topics the Adviser can support with are:

- What is dementia;
- Diagnosis process information;
- Dementia drug treatments available;

- 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 with dementia;
- Making complaints.

Access the service by calling the Alzheimer's Society National Dementia Helpline on 0300 222 11 22. If you inform the Adviser that you would like to use the Extended Helpline Service, the Adviser will be able to book your first appointment for you. Following this call, a letter will be sent confirming the date and time of the appointment.

The National Dementia Helpline is open at the following times:

Monday to Wednesday	9am – 8pm
Thursday and Friday	9am – 5pm
Saturday and Sunday	10am – 4pm

Support Directories in Cumbria

Cumbria Support Directory

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

www.cumbriasupportdirectory.org.uk/kb5/cumbria/asch/home.page

Dementia Connect

Alzheimer's Society's new and improved dementia services directory for anyone affected by dementia www.alzheimers.org.uk/local-informat/dementia-connect

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 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;
- 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 2005.

For social care, workforce development will be aligned to the Dementia Core Skills Education and Training Framework, which is structured in three tiers and designed to accommodate integration between health and social care services and their respective workforces.

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.

The table below gives more information:

Health and Health Education England (HEE) tier	Matched social care workforce group
Tier 1: dementia awareness raising, in terms of knowledge, skills and attitudes for all those working in health and care settings	Group 1: all of the social care workforce – dementia awareness
Tier 2: knowledge, skills and attitudes for roles that have regular contact with people living with dementia	Group 2: people working in social care who are providing personalised direct care and support to people with dementia
Tier 3: enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles	<p>Group 3: registered managers and other social care leaders who are managing care and support services for people with dementia</p> <p>Group 4: social care practice leaders and managers who are managing care and support services and interventions with people with dementia which includes social workers, and occupational therapists working in social care</p>

(Dementia Core Skills Education and Training Framework 2015)

Developing the workforce

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

- Dementia awareness;
- Dementia identification, assessment and diagnosis;
- Dementia risk reduction and prevention;
- Person-centred dementia care;
- Communication, interaction and behaviour in dementia care;
- Health and well-being in dementia care;
- Pharmacological interventions in dementia care;
- Living well with dementia and promoting independence;
- Families and Carers as partners in dementia care;
- Equality diversity and inclusion in dementia care;
- Law, ethics and safeguarding in dementia care;
- End of life dementia care;
- Research and evidence-based practice in dementia care;
- Leadership in transforming dementia care.

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 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. CHES is currently being rolled out across Cumbria.



5. Carers

A Carer is someone of any age who provides unpaid support, usually to a family or a 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 in order 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 and Age UK.

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 <http://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;
- Reality Orientation;
- 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;
- Validation therapy and Reminiscence;
- Sensory stimulation;
- Complementary therapies;
- Behavioural interventions;
- 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. <https://www.nice.org.uk/>

Assessment of symptoms

When someone 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 behaviour that challenges, 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.

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.

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. 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.
- 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.

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 sign-posting 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: <https://www.cumbria.gov.uk/healthandsocialcare/adultsocialcare/applyforsupport/applyforsupport.asp>

Statutory Advocacy Services

Advocacy Services are confidential and independent of health and social care services. Advocates work alongside people supporting them to:

- Explore options and choices;
- Share feelings and wishes;
- Access information and services that may be able to help.

People have a legal right to advocacy services in some circumstances. For example, they may have the right to an Independent Mental Capacity Advocate (IMCAs) provided under the Mental Capacity Act (2005) if they lack capacity to make an important decision in their life and they have no family or friends who are able to help. Alternatively some people have the right to an advocate as part of their needs assessment under the Care Act.

For more information please visit the Advocacy Section of the Cumbria County Council website: <http://www.cumbria.gov.uk/healthandsocialcare/adultsocialcare/informationandadvice/advocacy.asp>

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 a wide range of equipment available to help people maintain their independence:

- Simple equipment, such as bath boards which sit across a bath, grab rails around the house, raised toilet seats, chair raisers, etc.;
- Specialist equipment, such as bath lifts, hoists, pressure cushions and mattresses, etc.; and
- Adaptations, such as widening doors, ramps for wheelchairs, stair lifts, level access showers, etc.

Telecare

Telecare is based around a pendant worn around the neck or wrist. This provides access to a 24-hour monitoring service offering an instant response at the touch of a button from anywhere in your home or garden.

Telecare can be linked to a series of alarms or sensors in key parts of your home 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. <http://www.cumbria.gov.uk/healthandsocialcare/adultsocialcare/telecare/telecare.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 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: <http://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. <https://www.cumbriachoice.org.uk/Data/ASPPages/1/30.aspx>

Residential Care

Residential placements are for people over the age of 18 who are unable to live independently at home due to disability. Residential care provides accommodation, meals, leisure activities, personal care and emotional support 24hours 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) to provide a service. It includes local authority homes and independent homes, which may provide nursing care as well as personal care. These 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. The majority of adults do not require permanent care in a care home and it may be that needs could be met in another way, or by a combination of other kinds of care and support.

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 <http://www.dementiaaction.org.uk> and search for what's happening in your area;
- 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 with Dementia Friends Awareness Sessions. For more information visit www.dementiafriends.org.uk
- 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;
- 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.

Churches Together

Churches Together in Cumbria (CTiC) is a forum in which all the various denominations and Churches in Cumbria come together to work towards common goals.

CTiC has established a Dementia Reference Group with the aim of making "Every Church in Cumbria Dementia Friendly by 2020".

The Group is committed to making all churches and all aspects of church life and associated activities welcoming, inclusive and as supportive as possible to people living with dementia; thereby enabling them, their families and carers to feel safe, valued and able to stay involved in the church, both within the church setting and out in the community.

Each church or group of churches is being encouraged to appoint a "Dementia Enabler" who will take responsibility for enabling progress towards making their church (or churches) dementia –friendly. Currently over 60 Dementia Enablers have been appointed and received training in the role. More sessions for prospective Enablers are being planned.

If you wish to know whether there is a Dementia Enabler appointed for your church please contact your church direct.

For further information about the initiative visit www.churchestogethercumbria.co.uk/dementia-friendly.html

Cumbria Libraries

Cumbria Library Service is free to join, and libraries offer a friendly and welcoming environment, with a range of resources designed for use by people living with dementia, and their Carers.

Reading Well Books on Prescription: Dementia.

This 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.

The six main libraries also offer Dementia Resource Bags, which are free to borrow for up to three weeks at a time. The bags are themed, with topics ranging from Growing Up to Gardening, and all contain a mixture of books, pictures, music and other resources aimed at stimulating memories and discussion.

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. 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. <http://www.nescn.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.

10. Hospitals

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. Examples include **This Is Me**; 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. 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.

Find out more via: <http://butterflyscheme.org.uk/> and <https://www.alzheimers.org.uk/thisisme>

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 located 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.

11. Sources of further information

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/healthandsocialcare/adultsocialcare/contact/localascoffices.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/
Cumbria County Council	www.cumbria.gov.uk
Cumbria Support Directory	www.cumbriasupportdirectory.org.uk
Cumbria Partnership NHS Foundation Trust	www.cumbriapartnership.nhs.uk/
Cumbria Libraries	www.cumbria.gov.uk/libraries
Deciding Right	www.nescn.nhs.uk/deciding-right/
Dementia Connect Directory	www.alzheimers.org.uk/local-information/dementia-connect
Dementia Action Alliance	www.dementiaaction.org.uk/
Dementia Friends	www.dementiafriends.org.uk/
The Dementia Guide	www.alzheimers.org.uk/dementiaguide
IMCA services	www.cumbria.gov.uk/adultsocialcare/mentalcapacityact/imca.asp
Gov.UK (Lasting Power of Attorney)	www.gov.uk/power-of-attorney/overview
NHS Health Checks (NHS Choices website)	www.nhs.uk/conditions/nhs-health-check/
NICE Guidelines: Dementia	www.nice.org.uk/guidance/CG42
The Royal College of Psychiatrists	rcpsych.ac.uk/
Carers Support Cumbria	www.carerssupportcumbria.co.uk/
Carlisle Carers	www.carlislecarers.com/
Eden Carers	www.edencarers.co.uk/
Furness Carers	furnesscarers.co.uk/
South Lakeland Carers	slcarers.org.uk/
West Cumbria Carers	www.westcumbriacarers.co.uk/

