

# Dementia Practice Guidance

## Using this guidance

This guidance has been written by tri.x to support practitioners to understand the needs of people living with Dementia and think about some of the ways that they may need to adapt their practice to maximise their involvement in care and support processes.

It should be used as supplementary guidance to available procedures, and all statutory requirements of the Care Act 2014 apply.

## What is Dementia?

Dementia is a complex syndrome (a group of related symptoms) associated with a progressive decline in brain function, which gradually reduces a person's ability to carry out everyday tasks.

Common symptoms of most Dementia include:

- a) Loss of memory;
- b) Difficulty in understanding people and finding the right words;
- c) Difficulty in completing simple tasks and solving minor problems; and
- d) Mood changes and difficulties managing emotional responses.

Symptoms typically worsen as the condition progresses to more areas of the brain, and in later stages of Dementia a person may experience significant difficulties with bodily functions including mobility, swallowing, continence and speech.

There are different types of Dementia that can be diagnosed, depending on the cause. The most common are:

- a) Alzheimer's Disease;
- b) Vascular Dementia;
- c) Dementia with Lewy Bodies; and
- d) Frontotemporal Dementia.

### **Alzheimer's Disease**

Age is the greatest risk factor for Alzheimer's disease, with the risk increasing significantly after the age of 65. Over time, the chemistry and structure of the brain changes gradually, leading to the death of more brain cells. Associated symptoms get progressively worse. There is no cure for Alzheimer's disease although symptoms in the earlier stages can sometimes be managed with medication to delay the progression of the condition.

### **Vascular Dementia**

Vascular Dementia is the second most common type of Dementia and occurs when the brain cells die because they have been starved of oxygen. This can be following a Stroke but can also be caused by a blood clot or a disease of the blood vessels in the brain. Unlike Alzheimer's Disease,

Vascular Dementia symptoms suddenly worsen each time the brain is starved of oxygen and, depending on the area of the brain affected, symptoms may be localised to the functions that particular area of the brain controls.

### **Dementia with Lewy Bodies**

Lewy Bodies are small deposits of protein that appear in nerve cells in the brain, causing the Dementia. Lewy Bodies are also associated with Parkinson's Disease and people with Lewy Body Dementia may experience the symptoms of both conditions depending on whereabouts in the brain the Lewy Bodies are deposited. Hallucinations, delusions and sleep problems are more common in people with Lewy Body Dementia than with other types of Dementia.

### **Frontotemporal Dementia (FTD)**

Frontotemporal Dementia (FTD) is a less common type of Dementia and tends to start at a younger age. It occurs when the brain cells in the frontal and temporal lobes of the brain are damaged. These areas of the brain are responsible for behaviour, personality, speech and language. Unlike other forms of Dementia memory impairment is only affected in later stages.

## **Mental Capacity**

It is important **not** to make assumptions about mental capacity. In the early stages of Dementia people are often able to, either independently or with support:

- a) Be involved in care and support processes;
- b) Provide an insight into their needs;
- c) Make decisions about care or treatment;
- d) Decide how best to manage risk; and
- e) Set their own goals and outcomes.

If any of the following indicators are present the person *may* not be able to make their own decision:

- a) Lacking a general understanding of the decision that needs to be made, and why it needs to be made;

- b) Lacking a general understanding of the likely consequences of making, or not making the decision;
- c) Being unable to understand, remember and use the information provided to them when making the decision; and
- d) Being unable to, or unable to consistently communicate the decision.

Where the above indicators are present, a mental capacity assessment **must** be completed to confirm the person's ability to make the decision.

If capacity is present, the person should be supported to make their own decision. They should also be encouraged to think about the ways that their views and wishes can be promoted in the future, for example whether they wish to make an Advance Decision to Refuse Treatment or appoint a Lasting Power of Attorney.

Rethink Mental Illness provides helpful guidance when considering planning for the future, see: [Advance statements and advance decisions.](#)

If capacity is lacking, the person should still be involved in care and support processes, but the principles of the Mental Capacity Act should be applied to ensure that decisions made are in their Best Interests.

## Preventing, Delaying and Reducing Needs

A person with Dementia will usually find it harder to carry out activities of daily living as their condition progresses (for example personal care routines, cooking, socialising and taking medication).

This can happen for a range of reasons, including:

- a) Forgetting how to carry out some/all of the task;
- b) Forgetting that the task needs to be carried out;
- c) Losing the skills required to carry out the task adequately or safely; and
- d) Losing the ability to maintain focus when completing the task.

The loss of independence can have a direct impact on the person's safety, but also on their mood and mental health, for example by causing anxiety, confusion, anger, frustration, fear, isolation and withdrawal.

Interventions that promote independence should always be considered and provided in a timely way to ensure the greatest positive effect.

Prevention services such as Reablement, Occupational Therapy and Technology Enabled Care (TEC) can be used to:

- a) Assess the person's abilities to carry out tasks;
- b) Develop strategies to promote independence and reduce risk; and
- c) Support the person (and carer) to implement the strategies.

The abilities of a person with Dementia can also fluctuate, so it is important that prevention services are provided flexibly, intervening at the optimum time, and adapting to changes in ability in a timely way.

### Specialist Information and Advice

The person with Dementia, their families and carers will likely have a lot of questions about the condition.

Steps should be taken to ensure that they have access to the information and advice that they need, or that would be of benefit to them.

#### **The Alzheimer's Society Support Line**

The Alzheimer's Society has a dedicated support line, open 7 days a week. The number is 0333 150 3456.

Callers who do not use English as their language of choice can arrange a simultaneous language translation service by calling the helpline number, saying the English word for their preferred language, and ending the call. An interpreter will then call them back, usually within 5 minutes.

Callers with speech or hearing difficulties that have a textphone or adapted computer can use text relay to call 18001 0300 222 1122.

For further information about the support line, and other help available, see: [Alzheimer's Society](#).

### Independent Age

Independent Age also has a dedicated line and can provide information and advice to older people on a range of topics including care and support, money and benefits and health and mobility. The number is 0800 319 6789.

For further information see: [Independent Age](#).

## Effective Communication

It is important that communication with a person who has Dementia:

- a) Is accessible;
- b) Maximises their involvement in the process being carried out;
- c) Supports them to make, or be involved in a decision to be made; and
- d) Is sensitive and appropriate to their needs.

Depending on the person's unique needs, the table below offers general guidance to support effective communication.

Interaction	A person with Dementia can....	Do	Avoid
Meet and greet	Forget names and faces  Misplace the context of a face	Introduce yourself, your role and the purpose of your visit each time	Expect the person to have remembered you

<b>Getting to know you</b>	Feel socially uneasy  Find it difficult to start a conversation	Spend time 'getting to know' the person at each visit, by inviting them to talk about something that interests them	Go straight into the formal purpose of the visit
<b>Gain my attention</b>	Not realise you are talking to them unless you are explicit	Routinely use the person's name and wait for recognition before speaking to them	Provide information to the room if it is meant for the person
<b>Help me feel at ease</b>	Become anxious, confused, angry, scared or upset by the actions of others	Sit where the person can see you, do not stand over them, do not appear from behind  Use a calm tone, smile, use positive body language and be friendly	Use authoritative body language or verbal tone
<b>Value, Respect and Dignity</b>	Easily feel isolated, ashamed, worthless and devalued by the actions of others	Speak to the person, not a family member of carer  Speak to the person as an adult  Seek their views and listen to what they have to say, even if it doesn't appear to make sense	Talk over the person, ignore them or whisper to others
<b>Avoid distractions</b>	Find it difficult to focus when there are a lot of things	Keep distraction to the minimum from	Proceed regardless of any distraction

	happening around them	TV, radio and other people in the room	
<b>Help me remember</b>	Find it hard to retain new information	Summarise key information  Be prepared to say something more than once or answer the same question several times	Expect the person to retain information without support
<b>Help me understand</b>	Find it hard to understand the meaning and context of communication  Misinterpret information	Use uncomplicated language and break things down  Explore alternative communication, e.g. pictures and objects of reference  Give time to process information	Use inaccessible formats to provide information
<b>Sometimes words are not enough</b>	Struggle to find the right words  Forget what they want to say	Be reassuring  Offer helpful alternatives - would it be easier to show me?  Explore alternative communication, e.g. pictures and objects of reference	Assume to know what the person wants to say  Assume a lack of capacity
<b>Work in the here and now</b>	Sometimes find it hard to understand the concept of the 'future', anticipate	Set timeframes to achieve outcomes that are meaningful to the person	

	future needs and advance plan		
<b>Manage my anxiety</b>	Become overwhelmed by information, and this can lead to changes in mood, behaviour and engagement	Rephrase something  Take a break  Change the environment or go for a walk  Change the subject for a while	Exclude the person from the conversation
<b>Don't challenge my reality</b>	Have a false perception of reality that is very real to them	Accept the person's reality  Use the information to inform the assessment  Consider assessing mental capacity	Correct or challenge them as this can cause confusion, anger and anxiety and serves no purpose

To maximise the involvement of a person with Dementia in care and support processes, such as assessment, Care and Support planning, review, and safeguarding, it is likely that the format of such functions will need to be adapted, and, if the person's communication needs are complex or fluctuating seek the support of a Speech and Language Therapist.

### Recognising and Managing Pain in Dementia

Pain in people with dementia may not always be recognised as the person may be minimising typical facial expressions and may struggle to communicate their pain due to a cognitive decline. This can lead to pain being demonstrated through behaviours which is often misunderstood for symptoms of dementia.

Dementia UK provide resources for caregivers on recognising and responding to pain in people with dementia. For further information see: [Pain and dementia](#)

Skills for Care offers a guide on [supporting people with dementia and other conditions](#) covering a range of conditions alongside dementia, including pain.

## Supporting Behaviour and Emotional Difficulties

### Emotions when diagnosed

Someone recently diagnosed with Dementia can experience a range of emotions. These may include grief, loss, anger, shock, fear, disbelief or even relief. For example, they may feel afraid about the future, scared about moments of forgetfulness or confusion, or upset about the impact their Dementia is having on those around them.

Some people may struggle to deal with their emotions. Some people may experience depression or anxiety. It is important that people can express their feelings and access any therapeutic or mental health services they may need.

### As the Dementia progresses

Depending on the type of Dementia, as the person's condition progresses it is likely that they will experience changes to their mood or behaviour. They may also find it harder to regulate their emotions. Examples include:

- a) Increased confusion;
- b) Periods of distress;
- c) Periods of joy;
- d) Fear and anxiety;
- e) Frustration and anger;
- f) Physical aggression towards self and others;
- g) Suspicion and paranoia;
- h) Isolating behaviour;
- i) Loss of inhibition;
- j) 'Wandering'.

Some of these changes will be physiological, meaning they are a symptom of their condition as it progresses. However, some will not be.

Many behaviour and emotional difficulties are instead related to:

- a) A loss of independence, choice and control;
- b) A loss of physical and cognitive ability;
- c) A lack of stimulation or increased boredom;
- d) A lack of verbal communication; and
- e) Misinterpretation of the communication and actions of others.

Behaviour and emotional difficulties that are not a direct symptom of the Dementia condition can often be managed or improved by making positive changes to the person's environment or nature of support that will help them to:

- a) Maintain their independence;
- b) Communicate more effectively;
- c) Understand and manage the changes that are happening to them.

Where relevant a referral to a communication or behaviour specialist should always be considered and made.

## Monitoring and Review

Depending on the type of Dementia, changes in need can be:

- a) Gradual over time;
- b) Sudden after a period of stability; or
- c) Fluctuating.

Where gradual deterioration is likely, appropriate and proportionate arrangements should be made to monitor the person's situation, and to respond in a timely way to any change in need to maintain independence for as long as possible.

Where sudden deterioration is anticipated there should be a contingency plan in place to ensure that any additional support needs can be met in a timely way, and the likelihood of a crisis averted.

If the person has needs that fluctuate the Care and Support Plan should be agreed with this in mind and should provide support to meet the person's needs during periods of fluctuation and periods of stability.

### NHS Continuing Healthcare

As Dementia progresses so does the likelihood of the person's eligibility for NHS Continuing Healthcare.

It is good practice to consider the need to complete an NHS Continuing Healthcare checklist at each review of a Care and Support Plan, and whenever there has been a change in the person's Dementia related symptoms.

### Joint Work

Dementia is a complex health condition, and it is important to establish which professionals and organisations are involved (or need to be involved), consult with them appropriately (and in line with confidentiality) and co-operate with any requests to joint work with others.

### Supporting Carers

The impact of caring for a person with Dementia should not be underestimated and every carer of a person with Dementia is likely to need support at some point over the course of their caring role.

Carers may experience a range of emotions from the point of diagnosis and beyond, including grief, loss, anger, shock, fear, disbelief, relief, and guilt. Some carers may experience depression or

anxiety. In the same way as it is important for the person with Dementia, carers should also be able to express their feelings and access any therapeutic or mental health services they may need.

Carers are at particularly high risk of breakdown if they have limited informal networks of support, or their own health needs to manage. They are also at increased risk if the person they care for:

- a) Has fluctuating needs;
- b) Is repetitive;
- c) Does not comply with care routines (e.g. medication, eating, bathing);
- d) Seeks constant reassurance or attention from the carer;
- e) Makes regular accusations against them (e.g. of hiding things, or stealing);
- f) Is verbally or physically aggressive to the carer or others;
- g) Is restless in the evenings;
- h) 'Wanders' and is at an increased risk of going missing;
- i) Needs constant supervision;
- j) Is awake overnight.

Where a carer is known to be at high risk of breakdown it is essential that:

- a) They are offered a carers assessment under the Care Act 2014;
- b) They are provided with regular opportunities to talk; and
- c) They receive good information and advice about the support available to them.

If a carer declines an assessment, appropriate and proportionate monitoring arrangements should be agreed, and they should be offered an assessment whenever they change their mind, their circumstances change, or it appears an assessment would be of benefit to them.

Support groups can provide safe places to share experiences as well as offer practical advice and can reduce the feeling of isolation. The following organisations offer online groups and meetings in person dependent on location:

- [Alzheimer's Society](#)
- [Carers UK](#)
- [Age UK](#)
- [Rethink](#)

In addition, carers can speak with their GP surgery, social worker, or dementia adviser for information on local carer support groups.

## Herbert Protocol

One of the things that can cause significant anxiety for carers is a worry that the person with Dementia may go missing and come to harm. [The Herbert Protocol](#) can help alleviate this worry. It is a form that can be completed in advance by the carer and then provided to the police if the person with Dementia goes missing. The form assists the police to find the person as quickly and safely as possible - it contains information such as a recent photograph, medication, mobile number, favourite places to visit, places previously located and any other information that the carer has deemed relevant. Each police force will have their own form.

### Further Reading

For further guidance on understanding and supporting people with Dementia and their carers see:

[Department of Health: A manual for good social work practice: Supporting adults who have dementia.](#)

[Department of Health and Social Care: Supporting people living with dementia to be involved in adult safeguarding enquiries.](#)