



Reading Time : 4 hours

DISORDERS

*Training for National Standards*



*ESSENTIAL STANDARDS*

*CARE CERTIFICATE*

*WORKBOOK NINE*

*MENTAL ILLNESS, DEMENTIA  
AND LEARNING DISABILITY*



# *13 Words that define and signify-MENTAL ILLNESS*

Definition of Mental Illness

*A condition which causes serious disorder in a person's behaviour or thinking*



*MIND*

*EMPATHY*

*NIHILISM*

*THOUGHT DISORDER*

*ANXIETY*

*LISTLESS*

*INTROVERSION*

*LABILITY*

*LISTLESSNESS*

*NEOLOGISMS*

*SCHIZOPHRENIA*

*STRESS*



# *8 Words that define and Signify – DEMENTIA*

## Definition of Dementia

Dementia is a chronic and persistent disorder of the mental process caused by brain disease or injury and marked by memory disorders, personality changes and impaired reasoning

***DELIRIUM***

***EMOTIONALITY***

***MEMORY LOSS***

***EATING HABITS***

***NEGLECT***

***TRAUMA***

***IMPAIRMENT***



# *18 Words that inform and signify-LEARNING DISABILITY*

## Definition of learning Disability

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty: understanding new or complex information, learning new skills and coping independently

*LACK*

*EXPRESSION*

*AUTISM*

*READING*

*NOISE*

*INTROVERSION*

*NEEDS*

*GRAMMAR*

*DYSPRAXIA*

*INABILITY*

*SOMATIC*

*ASPERGERS*

*BEHAVIOUR*

*IMPAIRMENT*

*LEARNING*

*TENDANCIES*

*YIELDING*



## Dementia Policy and Procedure

### Purpose

- To provide person centred and safe care to those living with dementia

### Scope

- All workers
- All processes within the service

**Definition:** Dementia is a loss of mental ability severe enough to interfere with normal activities of daily living, lasting more than six months, not present since birth, and not associated with a loss or alteration of consciousness.

**Description:** Dementia is a group of symptoms caused by gradual death of brain cells. The loss of cognitive abilities that occurs with dementia leads to impairments in memory, reasoning, planning and behaviour. While the overwhelming number of people with dementia are elderly, dementia is not an inevitable part of aging; instead, dementia is caused by specific brain diseases. Alzheimer's disease (AD) is the most common cause, followed by vascular or multi-infarct dementia.

The prevalence of dementia is difficult to determine, partly because of differences in definition among different studies and partly because there is some normal decline in functional ability with age. The prevalence of dementia roughly doubles for every five years of age beginning at age 60. Dementia affects about 1% of people between ages 60 and 64, 5-8% of all people between ages 65 and 74, up to 20% of those between 75 and 84, and between 30% and 50% of those age 85 and older. About 60% of nursing home patients have dementia.

The cost of dementia can be considerable. While most people with dementia are retired and are not affected by income losses from their disease, the cost of care is often enormous. Financial burdens include lost wages for family caregivers, medical supplies and drugs, and home modifications to ensure safety. The psychological cost is not as easily quantifiable but can be even more profound. The person with dementia loses control of many of the essential features of his/her life and personality, and loved ones lose a family member even as they continue to cope with the burdens of increasing dependence and unpredictability.

### Policy:

The service will adhere to the following principles while providing care for people with dementia:

- Care Planning and delivery will be person centred
- Care delivery will be by staff who have specialist training in dementia care, and who have access to specialist support
- Care delivery will focus on meeting needs and aspirations
- The Service will promote dignity and respect and maintaining human rights
- Closely coordinated between different professionals and services across health, social care and housing

### Procedure

**Techniques and environmental changes supporting good quality dementia care:**

- Risk Assessment

## Dementia Policy and Procedure

Tools are available for personal and environmental risk assessment, and these should be used comprehensively and assiduously when providing dementia care.

Within Care Planning, very detailed risk assessment should be carried out in relation to the Service User with dementia and their physical environment.

In general, Service Users with dementia are at raised risk of:

- Abuse
- Violent behaviour
- Disruptive behaviour
- Isolation
- Falls
- Malnutrition
- Accidents
- Depression
- Communication difficulties
- Inability to express wishes
- Inability to participate in Care Planning
- Inability to give informed consent
- Fast changing condition
- Tissue viability
- Security

### Life History

The use of life history (LH) research and recording is especially important in the care of persons with dementia. A full LH record, made available to all staff providing support to the Service User, enables the carer to more fully understand behaviours of the Service User, and suggest strategies for their management.

The life history can be obtained from the Service User and their family. It doesn't have to be taken all at once. After you have the initial conversation, they are likely to think of more details to add. It's particularly helpful to provide a form to the family members to take away and complete, that way they can provide thoughtful responses. The information sought after should assist in conversation with the Service User in the months and years to come as well as assist in facilitating activities.

- Friends and Family: It is important to record the names and details of the Service Users grandparents, parents, brothers and sisters, cousins, children, grandchildren, great grandchildren, nieces and nephews, etc. Focus on details of each that will bring back happy memories for the Service User. Record the ages of children and grandchildren.
- School and Education
- Working Life
- Hobbies
- Religious activities

### Memory Box

Accompanying the life history it is useful to ask the family to put together a personal memory box for the individual. The box could contain photos, newspaper cuttings, books, ornaments. If the person was a

## Dementia Policy and Procedure

gardener they could include favourite tools (if not a safety risk). If they were a chef or cooking fanatic they could include cooking utensils, etc. Memories relating to brothers and sisters are also very important. It is often the unexpected that brings pleasure and peace to people who's memories are fading.

### ABC Charting

This is a technique that is widely used. The approach can be defined as:

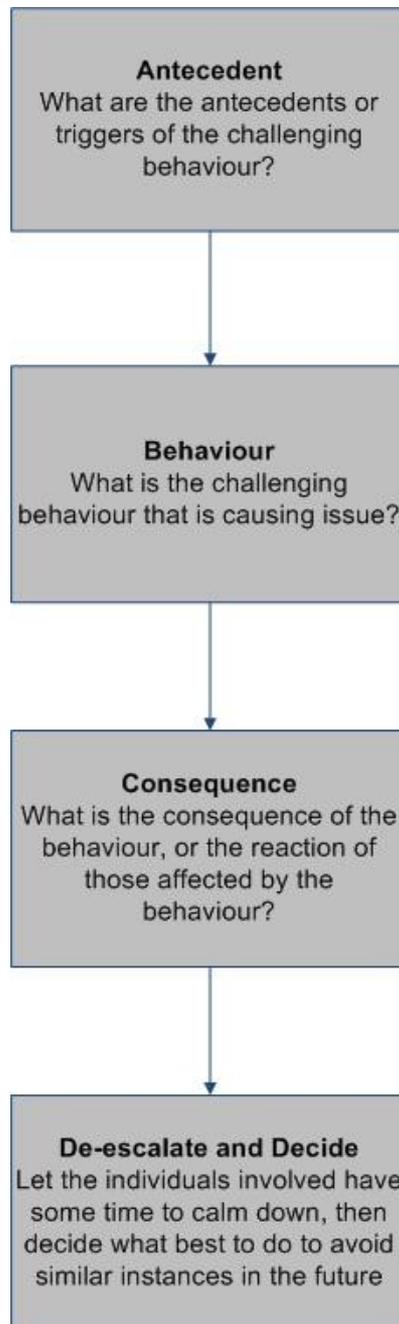
**"A"** – what are the antecedents or triggers of the challenging behaviour? The idea is that all behaviours are triggered by something; they are not random. The trigger could be an environmental issue (too hot, too cold, too noisy?), an unmet need (want the WC, hungry, thirsty?) or a disease (pain, headache, not-well feeling?)

**"B"** – is the challenging behaviour which is causing the problem.

**"C"** – is the consequence of the behaviour, or the reaction of those affected by the behaviour. The way that we react to challenging behaviours can have a large impact on whether that behaviour is more or less likely to re- occur.

And finally **"D"** for De-escalate and Decide. Once the situation has been diffused and calmed down, decide what you can do to prevent a similar situation in the future.

## ABC Charting



**MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY**

I forget to remember,  
Or is it the other way round:  
The other day I lost my way  
It was lucky I was found  
**John Eaton**

**1 NEEDS AND EXPERIENCES OF PEOPLE WITH MENTAL HEALTH CONDITIONS, DEMENTIA OR LEARNING DISABILITIES****1.1 List how someone may feel if they have:****1. MENTAL HEALTH CONDITIONS SUCH AS:****a. Psychosis**

Someone who develops psychosis will have their own unique set of symptoms and experiences, according to their particular circumstances.

However, four main symptoms are associated with a psychotic episode. They are:

- hallucinations
- delusions
- confused and disturbed thoughts
- lack of insight and self-awareness

These are outlined in more detail below.

**Hallucinations**

Hallucinations are where a person perceives something that doesn't exist in reality. They can occur in all five of the senses:

- **sight** – someone with psychosis may see colours and shapes, or people or animals that aren't there
- **sounds** – someone with psychosis may hear voices that are angry, unpleasant or sarcastic
- **touch** – a common psychotic hallucination is that you are being touched when there is no-one there
- **smell** – usually a strange or unpleasant odour
- **taste** – some people with psychosis have complained of having a constant unpleasant taste in their mouth

**Delusions**

A delusion is where a person has an unshakeable belief in something implausible, bizarre or obviously untrue.

Paranoid delusion and delusions of grandeur are two examples of psychotic delusions.

A person with psychosis will often believe that an individual or organisation is making plans to hurt or kill them. This can lead to unusual behaviour.

For example, a person with psychosis may refuse to be in the same room as a mobile phone because they believe they are mind-control devices.



Someone with psychosis may also have delusions of grandeur. This is where they believe they have some imaginary power or authority.

For example, they may think that they're the president of a country or that they have the power to bring people back from the dead.

### **Confused and disturbed thoughts**

People with psychosis often have disturbed, confused and disrupted patterns of thought.

#### **Signs of this include:**

- rapid and constant speech
- random speech – for example, they may switch from one topic to another mid-sentence
- a sudden loss in their train of thought, resulting in an abrupt pause in conversation or activity

### **Lack of insight**

People who have psychotic episodes are often totally unaware their behaviour is in any way strange, or that their delusions or hallucinations are not real.

They may recognise delusional or bizarre behaviour in others, but lack the self-awareness to recognise it in themselves.

For example, a person with psychosis being treated in a psychiatric ward may complain that their fellow patients are mentally unwell, while they're perfectly normal.

### **Postnatal psychosis**

Postnatal psychosis, also called puerperal psychosis, is a severe form of postnatal depression (a type of depression some women experience after having a baby).

It's estimated that postnatal psychosis affects around 1 in every 1,000 women who give birth. It most commonly occurs during the first few weeks after having a baby.

Postnatal psychosis is more likely to affect women who already have a mental health condition, such as bipolar disorder or schizophrenia.

As well as the symptoms of psychosis (see above), symptoms of postnatal psychosis can also include:

- a high mood (mania) – for example, talking and thinking too much or too quickly
- a low mood – for example, depression, lack of energy, loss of appetite and trouble sleeping

Postnatal psychosis is regarded as a medical emergency. Contact your GP immediately if you think that someone you know may have developed postnatal psychosis. If this isn't possible, call NHS 111 or your local out-of-hours service.

### **b. Depression**

The normal ups and downs of life mean that everyone feels sad or has "the blues" from time to time. But if emptiness and despair have taken hold of your life and won't go away, you may have depression. Depression makes it tough to function and enjoy life like you once did. Just getting through the day can be overwhelming. But no matter how hopeless you feel, you can get better. Understanding the signs, symptoms, causes, and treatment of depression is the first step to overcoming the problem.



Sadness or downswings in mood are normal reactions to life's struggles, setbacks, and disappointments. Many people use the word "depression" to explain these kinds of feelings, but depression is much more than just sadness. Some people describe depression as "living in a black hole" or having a feeling of impending doom. However, some depressed people don't feel sad at all—they may feel lifeless, empty, and apathetic, or men in particular may even feel angry, aggressive, and restless. Whatever the symptoms, depression is different from normal sadness in that it engulfs your day-to-day life, interfering with your ability to work, study, eat, sleep, and have fun.

The feelings of helplessness, hopelessness, and worthlessness are intense and unrelenting, with little, if any, relief.

If you identify with several of the following signs and symptoms, and they just won't go away, you may be suffering from clinical depression.

- you can't sleep or you sleep too much
- you can't concentrate or find that previously easy tasks are now difficult
- you feel hopeless and helpless
- you can't control your negative thoughts, no matter how much you try
- you have lost your appetite or you can't stop eating
- you are much more irritable, short-tempered, or aggressive than usual
- you're consuming more alcohol than normal or engaging in other reckless behaviour
- you have thoughts that life is not worth living (seek help *immediately* if this is the case)

Depression varies from person to person, but there are some common signs and symptoms. It's important to remember that these symptoms can be part of life's normal lows. But the more symptoms you have, the stronger they are, and the longer they've lasted—the more likely it is that you're dealing with depression. When these symptoms are overwhelming and disabling, that's when it's time to seek help.

#### Signs and symptoms of depression include:

- **Feelings of helplessness and hopelessness.** A bleak outlook—nothing will ever get better and there's nothing you can do to improve your situation.
- **Loss of interest in daily activities.** No interest in former hobbies, pastimes, social activities, or sex. You've lost your ability to feel joy and pleasure.
- **Appetite or weight changes.** Significant weight loss or weight gain—a change of more than 5% of body weight in a month.
- **Sleep changes.** Either insomnia, especially waking in the early hours of the morning, or oversleeping (also known as hypersomnia).
- **Anger or irritability.** Feeling agitated, restless, or even violent. Your tolerance level is low, your temper short, and everything and everyone gets on your nerves.
- **Loss of energy.** Feeling fatigued, sluggish, and physically drained. Your whole body may feel heavy, and even small tasks are exhausting or take longer to complete.
- **Self-loathing.** Strong feelings of worthlessness or guilt. You harshly criticize yourself for perceived faults and mistakes.
- **Reckless behaviour.** You engage in escapist behaviour such as substance abuse, compulsive gambling, reckless driving, or dangerous sports.
- **Concentration problems.** Trouble focusing, making decisions, or remembering things.
- **Unexplained aches and pains.** An increase in physical complaints such as headaches, back pain, aching muscles, and stomach pain.

Depression is a major risk factor for suicide. The deep despair and hopelessness that goes along with depression can make suicide feel like the only way to escape the pain. If you have a loved one with depression, take any suicidal talk or behaviour seriously and learn to recognise the warning signs.

**Warning signs of suicide include:**

- Talking about killing or harming one's self
- Expressing strong feelings of hopelessness or being trapped
- An unusual preoccupation with death or dying
- Acting recklessly, as if they have a death wish (e.g. speeding through red lights)
- Calling or visiting people to say goodbye
- Getting affairs in order (giving away prized possessions, tying up loose ends)
- Saying things like "Everyone would be better off without me" or "I want out"
- A sudden switch from being extremely depressed to acting calm and happy

**c. Anxiety**

**Generalised anxiety disorder (GAD) can affect you both physically and mentally.**

How severe the symptoms are varies from person to person. Some people have only one or two symptoms, while others have many more.

You should see your GP if anxiety is affecting your daily life or is causing you distress.

**Psychological symptoms of GAD**

GAD can cause a change in your behaviour and the way you think and feel about things, resulting in symptoms such as:

- restlessness
- a sense of dread
- feeling constantly "on edge"
- difficulty concentrating
- irritability

Your symptoms may cause you to withdraw from social contact (seeing your family and friends) to avoid feelings of worry and dread.

You may also find going to work difficult and stressful and may take time off sick. These actions can make you worry even more about yourself and increase your lack of self-esteem.

**Physical symptoms of GAD**

GAD can also have a number of physical symptoms, including:

- dizziness
- tiredness
- a noticeably strong, fast or irregular heartbeat (palpitations)



- muscle aches and tension
- trembling or shaking
- dry mouth
- excessive sweating
- shortness of breath
- stomach ache
- feeling sick
- headache
- pins and needles
- difficulty falling or staying asleep (insomnia)

### **Anxiety triggers**

If you are anxious as a result of a specific phobia or because of panic disorder, you will usually know what the cause is. For example, if you have claustrophobia (a fear of enclosed spaces), you know that being confined in a small space will trigger your anxiety.

However, if you have GAD, it may not always be clear what you are feeling anxious about. Not knowing what triggers your anxiety can intensify it and you may start to worry that there will be no solution.

## **2. DEMENTIA**

Dementia is not a disease but a collection of symptoms that result from damage to the brain. These symptoms can be caused by a number of conditions. The most common cause of dementia is Alzheimer's disease.

Common symptoms of Alzheimer's disease and other forms of dementia include:

- memory loss, especially problems with memory for recent events, such as forgetting messages, remembering routes or names, and asking questions repetitively
- increasing difficulties with tasks and activities that require organisation and planning
- becoming confused in unfamiliar environments
- difficulty finding the right words
- difficulty with numbers and/or handling money in shops
- changes in personality and mood
- depression

Early symptoms of dementia are often mild and may get worse only very gradually. This means that the person with dementia and those around them may not notice these signs or take them seriously for some time. Also, people with dementia sometimes do not recognise that they have any symptoms.

Dementia is progressive. This means that the person's brain will become more damaged and will work less well over time, and their symptoms will tend to change and become more severe.



For this reason, it is important to talk to your GP sooner rather than later if you are worried that you may have problems with your memory.

The speed at which symptoms get worse and the way that they develop will depend on the cause of the person's dementia, their overall health and their circumstances. This means that the symptoms and experience of dementia can vary greatly from person to person.

Some people may also have more than one condition – for example, they may have Alzheimer's disease and vascular dementia at the same time.

The symptoms listed above are common in all forms of dementia. However, some types of dementia have other distinctive features.

### **Symptoms of vascular dementia**

The symptoms of vascular dementia can sometimes develop suddenly and quickly get worse, although they can also develop gradually over many months or years. People with vascular dementia may also experience stroke-like symptoms, including muscle weakness or paralysis on one side of their body.

### **Symptoms of dementia with Lewy bodies**

Dementia with Lewy bodies shares many of the symptoms of Alzheimer's disease and people with the condition typically also experience the following:

- periods of alertness and drowsiness or fluctuating levels of confusion
- visual hallucinations
- becoming slower in their physical movements

### **Symptoms of fronto-temporal dementia**

Early symptoms of fronto-temporal dementia typically include changes in emotion, personality and behaviour. For example, someone with this type of dementia may become less sensitive to other people's emotions, perhaps making them seem cold and unfeeling.

They may also lose some of their inhibitions, leading to behaviour that is out of character, such as making tactless or inappropriate comments.

Some people with fronto-temporal dementia also have language problems. This may include not speaking, speaking less than usual or having problems finding the right words.

### **Symptoms in the later stages of dementia**

As dementia progresses, memory loss and difficulties with communication often become very severe. In the later stages, the person is likely to neglect their own health and require constant care and attention.



### **Memory symptoms in dementia**

People with advanced dementia may not recognise close family and friends, they may not remember where they live or know where they are. They may find it impossible to understand simple pieces of information, carry out basic tasks or follow instructions.

### **Communication problems in dementia**

It is common for people with dementia to have increasing difficulty speaking and they may eventually lose the ability to speak altogether. It is important to keep trying to communicate with them and to recognise and use other, non-verbal means of communication, such as expression, touch and gestures.

Read more about communication problems in dementia.

### **Problems with mobility in dementia**

Many people with dementia gradually become less able to move about unaided and may appear increasingly clumsy when carrying out everyday tasks. Some people may eventually be unable to walk and may become bedbound.

Read more about mobility.

### **Incontinence**

Bladder incontinence is common in the later stages of dementia and some people will also experience bowel incontinence.

### **Eating, appetite and weight loss**

Loss of appetite and weight loss are common in the later stages of dementia. It's important that people with dementia get help at mealtimes to ensure they eat enough. Many people have trouble eating or swallowing and this can lead to choking, chest infections and other problems.

## **3. LEARNING DISABILITIES**

The issues may be physical, social or psychological and will affect the individual in different ways.

### **Characteristics of a Learning Disability in Adults** **Characteristics of a learning disability in adults: Overview**

Characteristics of a learning disability in adults include auditory and visual deficits. Auditory and visual deficits affect a person's ability to develop and use language effectively. The effects are most apparent in reading, math, writing, and spelling skills. In both instances, the central nervous system is not processing symbols correctly. The individual usually demonstrates variable or unpredictable performance; has abnormal difficulty staying on task or using a procedure; is able to learn information presented in one way, but not in another; experiences severe underachievement in one or more of the basic academic areas (reading, writing, spelling, math); reveals an obviously uneven profile on a battery of tests (showing real strengths and real weaknesses); has generally poor work and organizational habits; and seems to lack resourcefulness.

### **Characteristics of a learning disability in adults: Assessment**

Adults who exhibit characteristics of a learning disability may never have dealt with the issues as children. Visual memory refers to the person's ability to store and recall what has been seen. Visual discrimination refers to the person's ability to retain a full mental image of what has been seen. In both instances, the central nervous system is not processing symbols correctly. Auditory discrimination involves the ability to recognize the differences between



sounds. The result of an auditory deficit is that the individual fails to hear vowel or soft consonant sounds in spoken words. Auditory memory refers to the learner's ability to store and recall what has been heard. Auditory and visual deficits affect one's ability to develop and use language effectively; the effects are most apparent in reading, math, writing, and spelling skills. Adults also suffer from oral and verbal expressive language. People with these traits omit or use words improperly, have problems explaining things logically, and have trouble expressing thoughts logically and concisely.

### **Characteristics of a learning disability in adults: Remediation**

Characteristics of a learning disability in adults also affect a person's reasoning and processing and ability. These individuals have difficulty absorbing major ideas from oral presentations (instructions, lectures, discussions); make frequent errors (verbal and written); need information to be repeated and reviewed; demonstrate poor decision making skills; have poor abstract reasoning; have trouble recognizing and learning from mistakes; have difficulty drawing conclusions, making inferences, dealing with abstractions and seeing the whole. Their organizational skills are also poor. They have trouble with basic details of everyday life, difficulty prioritizing and adjusting to change. We have proven training methods that can help you achieve success in many areas of your life.



### **Learning Disability Types**

Learning disabilities are neurologically-based processing problems. These processing problems can interfere with learning basic skills such as reading, writing and/or math. They can also interfere with higher level skills such as organization, time planning, abstract reasoning, long or short term memory and attention. It is important to realize that learning disabilities can effect an individual's life beyond academics and can impact relationships with family, friends and in the workplace.

Since difficulties with reading, writing and/or math are recognizable problems during the school years, the signs and symptoms of learning disabilities are most often diagnosed during that time. However, some individuals do not receive an evaluation until they are in post-secondary education or adults in the workforce. Other individuals with learning disabilities may never receive an evaluation and go through life, never knowing why they have difficulties with academics and why they may be having problems in their jobs or in relationships with family and friends.

Learning disabilities should not be confused with learning problems which are primarily the result of visual, hearing, or motor handicaps; of mental retardation; of emotional disturbance; or of environmental, cultural or economic disadvantages.

Generally speaking, people with learning disabilities are of average or above average intelligence. There often appears to be a gap between the individual's potential and actual achievement. This is why learning disabilities are referred to as "hidden disabilities": the person looks perfectly "normal" and seems to be a very bright and intelligent person, yet may be unable to demonstrate the skill level expected from someone of a similar age.

A learning disability cannot be cured or fixed; it is a lifelong challenge. However, with appropriate support and intervention, people with learning disabilities can achieve success in school, at work, in relationships, and in the community.



“Learning Disabilities” is an “umbrella” term describing a number of other, more specific learning disabilities, such as dyslexia and dysgraphia. Find the signs and symptoms of each, plus strategies to help below.

## SPECIFIC LEARNING DISABILITIES

### **Auditory Processing Disorder (APD)**

Also known as Central Auditory Processing Disorder, this is a condition that adversely affects how sound that travels unimpeded through the ear is processed or interpreted by the brain. Individuals with APD do not recognize subtle differences between sounds in words, even when the sounds are loud and clear enough to be heard. They can also find it difficult to tell where sounds are coming from, to make sense of the order of sounds, or to block out competing background noises.

### **Dyscalculia**

A specific learning disability that affects a person’s ability to understand numbers and learn math facts. Individuals with this type of LD may also have poor comprehension of math symbols, may struggle with memorizing and organizing numbers, have difficulty telling time, or have trouble with counting.

### **Dysgraphia**

A specific learning disability that affects a person’s handwriting ability and fine motor skills. Problems may include illegible handwriting, inconsistent spacing, poor spatial planning on paper, poor spelling, and difficulty composing writing as well as thinking and writing at the same time.

### **Dyslexia**

A specific learning disability that affects reading and related language-based processing skills. The severity can differ in each individual but can affect reading fluency, decoding, reading comprehension, recall, writing, spelling, and sometimes speech and can exist along with other related disorders. Dyslexia is sometimes referred to as a Language-Based Learning Disability.

### **Language Processing Disorder**

A specific type of Auditory Processing Disorder (APD) in which there is difficulty attaching meaning to sound groups that form words, sentences and stories. While an APD affects the interpretation of all sounds coming into the brain, a Language Processing Disorder (LPD) relates only to the processing of language. LPD can affect expressive language and/or receptive language.



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### **Non-Verbal Learning Disabilities**

A disorder which is usually characterized by a significant discrepancy between higher verbal skills and weaker motor, visual-spatial and social skills. Typically, an individual with NLD (or NVLD) has trouble interpreting nonverbal cues like facial expressions or body language, and may have poor coordination.

### **Visual Perceptual/Visual Motor Deficit**

A disorder that affects the understanding of information that a person sees, or the ability to draw or copy. A characteristic seen in people with learning disabilities such as Dysgraphia or Non-verbal LD, it can result in missing subtle differences in shapes or printed letters, losing place frequently, struggles with cutting, holding pencil too tightly, or poor eye/hand coordination.

## **RELATED DISORDERS**

### **ADHD**

A disorder that includes difficulty staying focused and paying attention, difficulty controlling behavior and hyperactivity. Although ADHD is not considered a learning disability, research indicates that from 30-50 percent of children with ADHD also have a specific learning disability, and that the two conditions can interact to make learning extremely challenging.

### **Dyspraxia**

A disorder that is characterized by difficulty in muscle control, which causes problems with movement and coordination, language and speech, and can affect learning. Although not a learning disability, dyspraxia often exists along with dyslexia, dyscalculia or ADHD.

### **Executive Functioning**

An inefficiency in the cognitive management systems of the brain that affects a variety of neuropsychological processes such as planning, organization, strategizing, paying attention to and remembering details, and managing time and space. Although not a learning disability, different patterns of weakness in executive functioning are almost always seen in the learning profiles of individuals who have specific learning disabilities or ADHD.

### **Memory**

Three types of memory are important to learning. Working memory, short-term memory and long-term memory are used in the processing of both verbal and non-verbal information. If there are deficits in any or all of these types of memory, the ability to store and retrieve information required to carry out tasks can be impaired.

**1.2 How the above conditions that may influence a person's needs in relation to the care that they may require.**

I will learn and know how the above conditions that may influence a person's needs in relation to the care that they may require whilst completing this standard

**1.3 The importance of understanding that the causes and support needs are different for people with mental health conditions, dementia and learning disabilities.**

I will learn and know how the why it is important to understand that the causes and support needs are different for people with mental health conditions, dementia and learning disabilities whilst completing this standard

**MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY**

**2 UNDERSTAND THE IMPORTANCE OF PROMOTING POSITIVE HEALTH AND WELLBEING FOR AN INDIVIDUAL WHO MAY HAVE A MENTAL HEALTH CONDITION, DEMENTIA OR LEARNING DISABILITY**

**2.1 How positive attitudes regarding mental health conditions, dementia or learning disabilities improves care and support**

Clients have a right to experience respectful and professional care, in a considerate and supportive environment, where their privacy is protected and dignity maintained. This principle should be promoted and supported by all health and social care organisations and professional bodies, enabling staff to provide a quality service. There are many complex factors relevant to the quality of patient and client experience. The following five areas have been identified as important towards ensuring a positive patient or client experience.

- ❖ **Respect**
- ❖ **Attitude**
- ❖ **Behaviour**
- ❖ **Communication**
- ❖ **Privacy and dignity**

This is not an exhaustive list and there may be overlap between the areas, however, all five relate to aspects identified by patients and clients as important to their experience. Any aspect of the client experience will, by its nature, require a variety of measurement approaches in order to appropriately capture the quality of the actual experience of clients. Continuous, objective and systematic monitoring and improvement against the standards described in this document will help give confidence to clients.

**Respect**

This standard will be recognised when all members of staff display a person centred approach in their care and treatment, or in their contacts with clients.

**This is demonstrated by:**

- Clients' wishes being respected
- Respect for diversity and difference
- Clients being actively involved in decisions regarding their care



- Members of staff providing care that is personalised
- Clients' interests being given priority by members of staff and teams
- An organisational culture where respect for the individual is valued.

**This is achieved when** clients report experience of being respected and involved in decision making regarding their care and treatment. Client representative groups report a client focus in their involvement in service development and improvement activities.

Evidence shows that the organisation values people. Staff members report that induction, ongoing learning and development activities promote respect for clients and a person centred approach. Clients report that unavoidable interruptions during care processes are managed sensitively.

### **Attitude**

All health and social care staff show positive attitudes towards clients. Experiencing positive attitudes from staff means feeling cared for as an individual. It is when personal approaches and responses to clients by all members of staff show care and compassion.

#### **It is demonstrated by:**

- Welcoming and approachable staff who demonstrate a willingness to help
- Staff understanding the effect their verbal and non-verbal communication has on others
- Staff demonstrating a non-judgemental attitude towards clients
- Staff being open-minded towards new or better ways of caring and working
- Organisational structures and processes that enable staff to take sufficient time to show positive attitudes to clients.

**This is achieved when** clients report experiences of positive attitudes towards them.

Clients and staff members report that the organisational culture is conducive to positive attitudes at individual and team levels. Staff members report high levels of satisfaction with learning and development activities aimed at improving and maintaining positive staff attitudes. There is evidence of well organised and managed environments with dedicated, compassionate and professional staff.

### **Behaviour**

Experiencing professional and considerate behaviour means feeling valued and safe. All health and social care staff show professional and considerate behaviour towards clients.

This is shown when all members of staff involve clients in their care, respecting their wishes and showing professional and appropriate behaviour.

#### **This is demonstrated by:**

- Staff seeking client consent when appropriate
- All staff being polite, courteous and professional
- Staff being open and receptive to feedback and challenge
- Clients being called by their preferred name
- Staff respecting the personal space clients.

**This is achieved when** clients report that they were asked for their consent where appropriate.

Clients report that they have been called by their preferred name. Clients report being treated in a polite, courteous and professional manner. Evidence shows that the organisation has implemented local policies that outline what is expected in the behaviour of all staff. Evidence demonstrates responsiveness to expressed views and challenges.

### **Communication**

All health and social care staff communicate in a way which is sensitive to the needs and preferences of patients and clients.

This is recognised when all staff members engage in effective verbal and non-verbal communication leading to clear information being exchanged between staff / clients.

#### **This is demonstrated by:**

- Staff adapting their verbal and nonverbal communication to be sensitive to individual needs
- Staff giving clear, correct information, using appropriate language
- Staff using effective communication skills such as active listening to check the clients' expectation and understanding
- Staff undertaking learning and development activities relevant to communication
- Important elements of communication exchange being recorded accurately
- Staff involving carers and family members where appropriate.

**This is achieved when** clients report that communication has been sensitive to their needs and respectful of their preferences. Clients report that they have been provided with clear, correct information using language they understand. Client documentation demonstrates that the important elements of communication exchange have been recorded appropriately. Staff members report that respectful and sensitive communications are part of the organisational values.

### **Privacy and Dignity**

Means feeling that your private moments are protected and you are treated with due respect and consideration All health and social care staff protect the privacy and dignity of patients and clients at all times.

This will be recognised when staff members ensure that all environments where care is provided protect the privacy and dignity of patients and clients.

#### **This is demonstrated by:**

- Staff ensuring that the modesty of patients and clients is protected, respecting cultural diversity
- Staff receiving training and development relevant to their needs to support the maintenance of clients' privacy and dignity
- Effective use of available resources in all health and social care environments to secure privacy and dignity for clients
- Staff ensuring that clients' personal information is collected, utilised and stored in a way that maintains confidentiality.

**This is achieved when** clients report that their privacy and dignity has been protected throughout their health and social care experience. Clients report that discussions relating to their personal information were held in a way that maintained their privacy and dignity.

Evidence shows organisational arrangements exist which are aimed at protecting privacy and dignity for clients. Staff report that maintaining patient and client privacy and dignity is encouraged and supported by the organisation.

## MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY

### 3 UNDERSTAND THE ADJUSTMENTS WHICH MAY BE NECESSARY IN CARE DELIVERY RELATING TO AN INDIVIDUAL WHO MAY HAVE A MENTAL HEALTH CONDITION,

#### 3.1 Adjustments needed for care is provided if someone has

1. A mental health condition such as: a. Psychosis b. Depression c. Anxiety

2. Dementia

3. Learning Disabilities

#### Discrimination in health and care services - duty to make reasonable adjustments

If you're disabled, you may find it more difficult to access healthcare or care services than other people. The **Equality Act 2010** says organisations such as hospitals, care homes and GP surgeries must take steps to remove the barriers you face because of your disability. The Act calls this the **duty to make reasonable adjustments**.

#### When must a healthcare and care provider make reasonable adjustments?

Places like hospitals, clinics and care homes must make sure you can access and use their services if you're disabled. They must take reasonable steps to remove the barriers you face because of your disability.

Someone has a duty to make reasonable adjustments if you're **disadvantaged** by something because of your disability and it's **reasonable** to make the changes. But they mustn't wait for you to ask them to do something. They should consider in advance what they need to do to make their services accessible to all disabled patients, clients and other people.

#### Is it reasonable to make the changes?

Healthcare and care providers must make changes or adjustments to how they provide their services if it's **reasonable** to do so. Whether something is reasonable depends on the size, resources of the organisation and type of service they provide. It also depends on what changes or adjustments are needed and how practicable or easy it is to do them. It's the courts who decide if something is reasonable or not.

#### What must a healthcare or care provider do?

There are three different things healthcare and care providers must do to make it easier for you to access their services.

#### Change the way things are done

A healthcare or care provider may have a certain way of doing things, like a policy, rule or practice which makes it more difficult for you to access or use their services. They should change these things if they are a barrier for you, unless it's unreasonable to do so.



## Change a physical feature

Sometimes a physical feature of a building, like a hospital or care home may make it more difficult for you to access or use it.

Here are examples of physical features:

- steps and stairs
- passageways and paths
- entrances and exits
- internal and external doors
- toilets
- signs.

A healthcare or care provider must do what's necessary to remove, change or provide a reasonable way of avoiding the barrier, if it's reasonable to do so.

## Provide extra aids or services

Sometimes you may need particular aids or equipment to help you access or use healthcare or care services. Or you may need additional services. The Equality Act calls these **auxiliary aids and services**.

Here are examples of auxiliary aids and services:

- a portable induction loop for people with hearing aids
- BSL interpreters
- providing information in alternative formats, such as Braille or audio CD's
- extra staff assistance.

## What can you do if you face barriers to access healthcare or care services?

You can ask your healthcare or care provider to make the necessary changes so you can access or use their services. If a service provider refuses to do this, it's discrimination and you can take action under the Equality Act.

## Next steps

- More about what counts as a disability under the Equality Act
- More about the duty to make reasonable adjustments
- Identifying discrimination
- Taking action about discrimination in health and care services

## Other useful information

**Equality Advisory Support Service (EASS)**

If you have experienced discrimination, you can get help from the EASS discrimination helpline.

- More about the EASS helpline

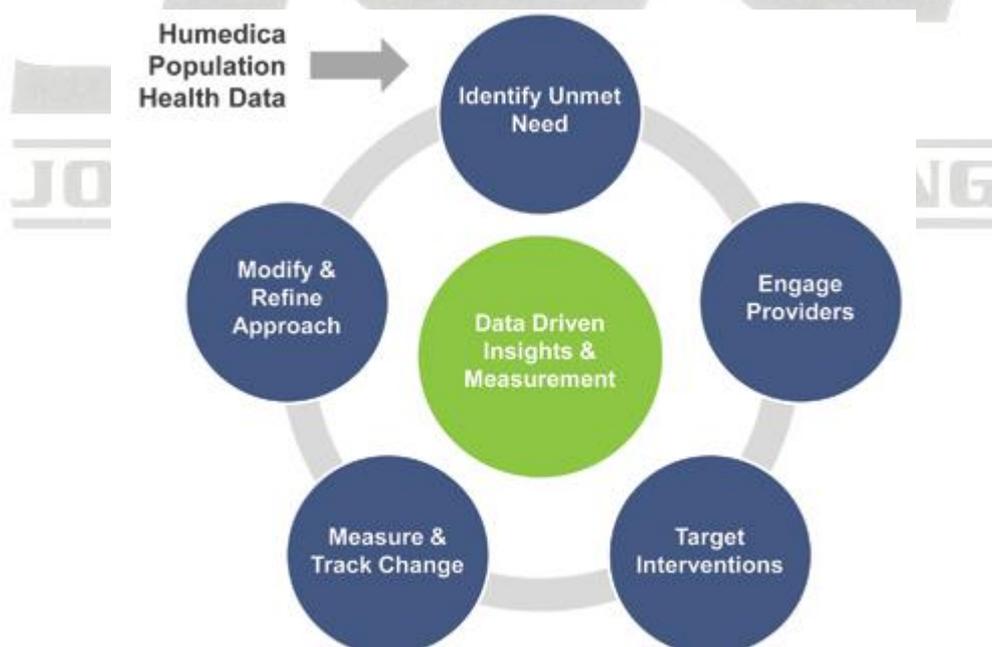
#### Equality and Human Rights Commission (EHRC)

- You can find useful information about discrimination on the EHRC website at [www.equalityhumanrights.com](http://www.equalityhumanrights.com).

### **3.2 Reporting concerns with any unmet needs from mental health conditions, dementia or learning disability through agreed ways of working.**

The concept of unmet needs refers to the difference between health services deemed necessary to treat a particular health problem and services actually received. A person who perceived the need to receive medical services—whether information from a health professional or a therapeutic procedure—but who has not obtained these services has unmet health care needs.

To a certain extent, this reflects the lack of access to health services. The hypotheses raised in this document will be the subject of more thorough analyses, the results of which will be published at a later date. The first section gives an overall description of the phenomenon of unmet needs: its scope, the profile of individuals reporting having unmet needs, the nature of health problems for which unmet needs are reported, and the outcome for persons who are not obtaining services. We then examine the factors associated with experiencing unmet needs, and we conclude with a discussion on aspects related to health services organisation.



Humedica's Physician and Patient Centric Clinical Data Can Empower Targeted Interventions Across Multiple Provider Organizations to Improve Population Health Outcomes



The concept of need is one of the most widely used terms in social and community care. It is also one of the most slippery to define. There is no agreement at a theoretical, policy or practice level on what it means or how it might be measured. Within the area of public policy also, need is understood differently in health and social care. Yet, a consideration of the meaning of 'need' cannot be left to the level of abstract debate, particularly since need and its satisfaction are intimately bound up with defining priorities and allocating resources.

**Theories of 'need'** At a general level, two very different approaches to defining need exist in the literature. One approach is based on the notion that there are objective or universal human needs. Doyal and Gough (1991), for example, define these broadly in terms of physical survival and personal autonomy. However, while few would argue that there are basic needs for economic and physical security, accommodation, food, clothing and social relationships that must be met in a civilised society, there is a relative dimension to need also. Thus, what is seen as adequate in terms of meeting basic needs, and the means through which they can be appropriately met, will vary over time, both historically and over the life course, as well as across different cultures. This understanding has led to a focus on the relative nature of need

**Professional conceptions of need.** It is notable that early attempts by professionals and local authorities to develop user-centred approaches to need assessment stemmed from the understanding that identifying need was not a simple question of asking people what they wanted. Rather, it was seen to involve a complex and negotiated process. This is because people's conceptions of their needs relate to their expectations, their view of what the agency can and should provide, what it is legitimate to ask for and their knowledge of the services that are available. There are, therefore, several layers of felt need on the part of older people that may not be expressed in requests for a service. These include the following.

- Needs are not expressed because people do not define them in service terms. For example, relatives of those in the early stages of dementia who are unsure as to what the problem is may delay seeking help. They may also be under pressure to deny the illness since the implications for the future may be too painful to acknowledge.
- Needs are not expressed because the services available are not considered appropriate. This is a specific problem experienced by black and minority ethnic elders). Other barriers to needs not being expressed include the quality of the service being perceived as poor (for example, respite provided within hospital wards or long stay residential care homes).
- Service users who do not receive sufficient or appropriate services.
- Non-service users experiencing barriers to access.

Again, in respect of dementia, there is a considerable amount of research indicating an array of internal and external obstacles encountered on the path to service provision. This is exacerbated by the fact that professionals in over-stretched services often do not renew the offer of help that was initially rebuffed by older people and their carers because of concern about losing their independence at a later stage.

Unmet need needs to be reported to

- Family
- Doctor
- Consultant
- Nurse
- Social Worker
- Senior Care
- Manager
- CQC
- And any other appropriate individual or organisation with appropriate consent

## MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY

### 4 UNDERSTAND THE IMPORTANCE OF EARLY DETECTION OF MENTAL HEALTH CONDITIONS, DEMENTIA AND LEARNING DISABILITIES

#### 4.1. Explain why early detection of mental health needs, dementia or learning disability is important

##### **Mental Health**

- The Importance of Early Detection and Appropriate Care for Mental Illnesses are: An important part of overall health
- Cognitive and emotional wellbeing
- Can be measured by functioning at home, work, school, in relationships, and in community
- Refers to all the different types of mental disorders, including disorders of thought, mood or behaviour
- Must cause distress and result in a reduced ability to function psychologically, socially, occupationally or interpersonally
- Range from Mild to Severe and Persistent Mental Illness

Common- up to 20 % of Adults will have a diagnosable mental illness each year. Early Age of Onset – depression, bipolar mood disorder, anxiety disorders, and schizophrenia often start in teenage-young adult years

Treatable- Most illnesses are very treatable, especially with early treatment initiation

Chronic—Most of these illnesses are now considered to have a chronic or lifelong course especially when there is a delay in detection and initiation of treatment Disability- mental illnesses are among the leading causes of disability

##### **Causes of Mental Illness**

- Certain Inherited Dispositions (Genetic) interact with triggering environmental factors
- Distinction between “physical illness” and “mental illness” can be misleading.

– Mental illnesses have a biological basis.

– Many “physical illnesses” can also have a strong emotional component.

##### **Importance of Early Detection and Effective Treatment**

- Early Treatment can keep illness from getting worse or lasting a long time
- Helps people return to their “normal selves” and restores functioning
- Minimizes disability
- This is true for depression, schizophrenia, bipolar mood disorder, alcohol and drug abuse, and many other illnesses.

##### **Barriers to Early Treatment**

- Public Lack of Awareness – of common symptoms of illnesses – Of effectiveness and necessity for treatment
- Stigma against seeking help increased for men, as a group, and for many minority groups
- Difficulty Initiating treatment – Primary care often not well connected with mental health resources
- Lack of resources – Access to mental health providers – Insurance to cover services and medications



- Non-insured
- Insured with lack of parity for mental health coverage – Inadequate numbers of hospital beds for mental illness – Inadequate urgent services in most communities Innovative programs at MSU
- Counselling Centre, Psychiatry, and Primary Care Services linked
- Question, Persuade, Refer training for housing, academic, advising, counselling and health care staff
- Goal is to provide web of services, many ways for students to enter services

### **Dementia**

Individuals may have been wondering what is happening to them and have been worried and anxious about the changes they have noticed. Although being diagnosed with dementia can be an upsetting experience, it can also be a relief because knowing the causes of your problems can resolve the anxiety felt by both the individual and their family.

\When someone is diagnosed as having the early stages of dementia, it feels like a terrible blow to both themselves and their spouse,, they are at least grateful to have had been told so that they could discuss the possible effects on their lives and plan how they could adjust to the situation..

#### **Receiving an early diagnosis of dementia will enables individuals to:**

- Gain access to information, resources and support
- Demystify and de-stigmatise the condition
- Maximise quality of life
- Benefit from treatments
- Plan for the future
- Explain to family, friends and colleagues what has changed in their life

On a practical level there is a lot that can be done:

- They may wish to review your financial situation. This might include arranging for bills to be paid.
- If they are still at work, they could think about reducing hours or switching to another job.
- Check on any state or social support that they or their family may be entitled to.
- It may be useful to start making enquiries about what support services are available in their area.
- It is advisable to check with their insurance company to see whether they are still covered for driving.  
They may wish to participate in an early stage support group and form new peer relationships to share feelings, information and coping strategies.

### **Learning Disability**

Learning disabilities can be hard to diagnose, because there is no definitive list of symptoms that fits every child. Also, many children try to hide the problem. You may not notice anything more obvious than frequent complaints about homework or a child who doesn't want to go to school.

However, the following may be signs of a learning disorder:

- Lack of enthusiasm for reading or writing



- Trouble memorizing things
- Working at a slow pace
- Trouble following directions
- Trouble staying focused on a task
- Difficulty understanding abstract ideas
- Lack of attention to detail, or too much attention to detail
- Poor social skills
- Disruptiveness

If a Learning disability is suspected, a child's GP, paediatrician or teacher may suggest having the child evaluated. It may be necessary to see several specialists before a definitive diagnosis is made. These specialists might include a clinical psychologist, a school psychologist, a developmental psychologist, an occupational therapist, or a speech and language therapist, depending on the problems the child is having. They will perform a variety of tests and assessments to get to the bottom of the problem.

### Early Detection of Learning Disabilities

Knowing the early signs of a possible learning disability can help parents get their child the help he or she needs as soon as possible. That's why it is important to pay attention to the child's developmental milestones. Delays such as late walking or talking or trouble with socialisation can be signs of a learning disorder in toddlers and pre-schoolers.

## **4.2 Adjustments to care and support when a mental health condition, dementia or learning disability is identified.**

Clients may be living at home, then an assessment may be that they require receiving home care services

The question is then 'Does your relative need additional support at home which their current care provider could supply?'

### Action

- If care is council-funded, contact social services for additional help.
- If your relative requires an additional carer or increased hours of help, their care plan may need to be reviewed and updated.
- If care is self-funded, contact the care agency directly about getting more support. The council or agency should then produce a revised care plan that provides the help your relative needs.
- If the need for care is substantial, home care services may no longer be the answer and it might be time to consider residential care.

### Living in sheltered housing

Is there an option to get more care while your relative lives in their current scheme?

**Action**

- Some schemes offer extra care or specific help for people with certain illnesses, such as dementia. It might be possible for your relative to get home care services to come in from outside.
- If care needs have changed dramatically, it may be time to consider a care home. Your relative should get a needs assessment.

**Living in a residential home (personal care only)**

If you feel that your relative's care needs have changed, speak to the care home manager. They can speak to the staff involved with your relative's care to ask for their feedback. They can also reassess your relative's needs to ensure that the care plan they have is still meeting their needs. If necessary, they can update your relative's care plan to provide the extra support they need.

If your relative's needs have changed substantially and they require nursing care, they may need to move to a different care home that offers nursing care in addition to personal care.

**Action**

- If your relative's residential care is funded (in full or part) by the council, contact the local authority for a review of their care needs.
- If your relative privately funds their own care, you may need to think about choosing a nursing home.

**Living in a nursing home**

If you feel that your relative's care needs have changed, speak to the care home manager. They can reassess your relative's needs to ensure that their care plan is still relevant. If necessary, they can update your relative's care plan to provide the extra support they need.

**Care planning, involvement and person-centred care**

This section explores two key themes that are central to care planning within the MCA framework: involvement, and keeping the wishes of the person at the centre of their care and support. It emphasises that building relationships and good communication are critical to meaningful involvement.

**Involving people in decisions about them**

Involving people in decisions about their care is intrinsic to the principles of the MCA and should be evident in every care and support plan.

Research on mental health and wellbeing demonstrates that involvement leads to improved service outcomes and enhances mental wellbeing. People who use services and their carer's are experts by experience. By bringing their knowledge and ideas, they give a fresh perspective on how their particular needs for care and support can best be met.

Providers and commissioners must challenge assumptions about how care plans are developed and the level of active involvement by the user. Supporting people to be involved in decisions about their care and treatment should be reflected in the ethos, management, policies and care practice of each service. All services should be able to show how they do this.

Meaningful involvement is based on a sharing of power between the person using the service and the provider. Involving people in designing their care plans means:



- having a conversation among equals who are working together to help one of them make a decision about their care and support
- that the person is considered as a whole in all aspects of their life
- that the plan belongs to the person, keeping them in control
- that the plan is only implemented or shared with others if the person gives consent (where they have capacity to do so).

It is identified as key elements in person-centred care planning for people with long-term conditions that care planning is a conversation between the person and the healthcare practitioner about the impact their condition has on their life, and how they can be supported to best meet their health and wellbeing needs in a whole-life way.

The care plan is owned by the individual, and shared with others with their consent. It is important that a discussion takes place, there is a record of it, and people know they have a plan.

Producing a shared written record of how the person will be cared for tells them (and others whom they wish to involve) what to expect. Giving this information clearly maintains the accountability of the service provider and enables people to raise any concerns about the care plan or its delivery.

#### What to look for

- The person or their family/friends are able to tell you how they were involved in developing the care and support plan and that they felt (and feel) listened to.
- The person and their chosen representative are aware of the care and support plan and have seen a copy.
- The care and support plan clearly explains how care and support will be delivered.

## MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY

### 5 UNDERSTAND LEGAL FRAMEWORKS, POLICY AND GUIDELINES RELATING TO MENTAL HEALTH CONDITIONS, DEMENTIA AND LEARNING DISABILITIES

#### 5.1 Main requirements of legislation and policies that are designed to promote the human rights, inclusion, equal life chances and citizenship of individuals with mental health conditions, dementia or learning disabilities

##### HUMAN RIGHTS ACT

The Human Rights Act 1998 is an Act of Parliament of the United Kingdom which received Royal Assent on 9 November 1998, and mostly came into force on 2 October 2000.<sup>[1]</sup> Its aim is to "give further effect" in UK law to the rights contained in the European Convention on Human Rights. The Act makes available in UK courts a remedy for breach of a Convention right, without the need to go to the European Court of Human Rights in Strasbourg. It also totally abolished the death penalty in UK law (although this was not required by the Convention in force for the UK at that time).

In particular, the Act makes it unlawful for any public body to act in a way which is incompatible with the Convention, unless the wording of an Act of Parliament means they have no other choice. It also requires UK judges to take account of decisions of the Strasbourg court, and to interpret legislation, as far as possible, in a way which is compatible with the Convention. However, if it is not possible to interpret an Act of Parliament so as to make it compatible with the Convention, the judges are not allowed to override it. All they can do is issue a declaration of incompatibility. This declaration does not affect the validity of the Act of Parliament: in that way, the Human Rights Act seeks to maintain

the principle of Parliamentary sovereignty (see: Constitution of the United Kingdom). An individual can still take his case to the Strasbourg court as a last resort.

Human rights are "basic rights and freedoms to which all humans are entitled. The doctrine of human rights aims to identify the necessary positive and negative prerequisites for a "universal" minimal standard of justice, tolerance & human dignity that can be considered the public moral norms owed by and to individuals by the mere virtue of their humanity. Such prerequisites can exist as shared norms of actual human moralities, as justified moral norms or moral rights supported by strong reasons, as legal rights at a national level, or as a legal right within international law. and human rights advocates seek the strong protection of human rights through their effective realisation in each of these ways. The claim of Human rights is therefore that they are universal, in that they are possessed by all by virtue of the fact that they are human, and independent in that their existence as moral standards of justification and criticism is independent whether or not they are recognized and by a particular national or international legal system. or government.

The general idea of Human rights has widespread acceptance, and the Charter of the United Nations which has been signed by virtually all sovereign states recognises the existence of human rights and it has been argued that the doctrine of human rights has become the dominant moral doctrine for regulating and evaluating the moral status of the contemporary geo-political order. However, debate and disagreement over which rights are human rights, and about the precise nature, content, justification and appropriate legal status of those rights continues. The Universal Declaration of Human Rights has acted as the predominant modern codification of commonly accepted human rights principles and many national many international documents, treaties and instruments that have expanded on its principles and act as a collective expression of widespread conceptions of human rights by the international community. Examples of rights and freedoms which have come to be commonly thought of as human rights include civil and political rights, such as the right to life and liberty, freedom of expression, and equality before the law; and economic, social and cultural rights, including the right to participate in culture, the right to be treated with respect and dignity, the right to food, the right to work, and the right to education.

#### **A REVISED CODE OF PRACTICE FOR THE MENTAL HEALTH ACT 1983 PROVIDES GUIDANCE FOR PROFESSIONALS.**

The code shows professionals how to carry out their roles and responsibilities under the Mental Health Act 1983, to ensure that all patients receive high quality and safe care.

There have been significant changes in legislation, case law, policy and professional practice since the last code was published in 2008.

The revised code aims to provide stronger protection for patients and clarify roles, rights and responsibilities. This includes:

- involving the patient and, where appropriate, their families and carers in discussions about the patient's care at every stage
- providing personalised care
- minimising the use of inappropriate blanket restrictions, restrictive interventions and the use of police cells as places of safety.

#### **The main changes to the code include:**

- 5 new guiding principles
- new chapters on care planning, human rights, equality and health inequalities
- consideration of when to use the Mental Health Act and when to use the Mental Capacity Act 2005 and Deprivation of Liberty Safeguards and information to support victims
- new sections on physical health care, blanket restrictions, duties to support patients with dementia and immigration detainees



- significantly updated chapters on the appropriate use of restrictive interventions, particularly seclusion and long-term segregation, police powers and places of safety
- further guidance on how to support children and young people, those with a learning disability or autism.

### THE CHILDREN ACT 1989

**The Children Act 1989** legislates for children in England and Wales. The intention of the legislation is that children's welfare and developmental needs are met, including the need to be protected from harm. Key principles of the Act do reflect certain aspects of the UNCRC; protection from harm, respect for a child's race, culture and ethnicity, parents' responsibility for bringing up children and for the first time the duty to take account of a child's wishes and feelings in decisions taken that affect them.

The fundamental premise however that decisions are taken on the welfare principle i.e. that the court/adult's determination of best interests are paramount can actively restrict children's autonomy and ability to exercise their rights independently.

The courts under the current welfare checklist are expected to achieve a result which most accords with adult notions of children's best interests, whether or not it accords with the child's wishes. A children's rights based approach recognizes that although consulting with children is very different from delegating decision-making to them entirely on each occasion, there must be a delicate balancing act between article 3 right (best interests) of the UNCRC and giving full consideration to a child's article 12 right (right to participate in matters that affect him/her) of the UNCRC.

There should be increasing recognition given both in practice and law to the child's status as a human being in his own right. It is inadequate if courts are making judicial decisions which give no consideration to a child's views or choose to ignore them completely. There should be a more systematic approach to considering a child's wishes in each case.

### EQUALITY ACT 2010

The Equality Act became law in October 2010. It replaces previous legislation (such as the Race Relations Act 1976 and the Disability Discrimination Act 1995) and ensures consistency in what you need to do to make your workplace a fair environment and to comply with the law.

The Equality Act covers the same groups that were protected by existing equality legislation - age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity - but extends some protections to groups not previously covered, and also strengthens particular aspects of equality law.

#### **The Equality Act is a mixture of rights and responsibilities that have:**

- **Stayed the same** - for example, direct discrimination still occurs when "someone is treated less favourably than another person because of a protected characteristic"
- **Changed** - for example, employees will now be able to complain of harassment even if it is not directed at them, if they can demonstrate that it creates an offensive environment for them

- **Been extended** - for example, associative discrimination (direct discrimination against someone because they associate with another person who possesses a protected characteristic) will cover age, disability, gender reassignment and sex as well as race, religion and belief and sexual orientation
- **Been introduced for the first time** - for example, the concept of discrimination arising from disability, which occurs if a disabled person is treated unfavourably because of something arising in consequence of their disability.

As a result, you may need to review and change some of your policies and practices. This page highlights the ways Acas can help you to identify where you need to take action.

### What's changing?

- Indirect discrimination
- Associative discrimination
- Perceptive discrimination
- Harassment
- Harassment by a third party
- Victimisation
- Positive action
- Pre-employment health related checks
- Extension of employment tribunal powers
- Equal pay direct discrimination
- Pay

### Overview

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society.

It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone.

### Discrimination: making a complaint

Before the Act came into force there were several pieces of legislation to cover discrimination, including:

- Sex Discrimination Act 1975
- Race Relations Act 1976
- Disability Discrimination Act 1995

If you wish to complain about possible unlawful treatment there are 2 separate processes, depending on when it happened.

### Complaints: before October 2010

If you were subjected to unlawful treatment (e.g. discrimination, harassment or victimisation) before 1 October 2010, the Equality Act won't apply. Instead, you'll be covered by the legislation that was in force at the time.

For example, if you experienced race discrimination on 30 September 2010 and want to make a complaint or bring legal proceedings, the Race Relations Act 1976 will apply, not the Equality Act.

This is also true of any legal proceedings. They will go ahead according to the legislation under which they were brought, even if they may have continued after 1 October 2010.



For example, if you experienced sex discrimination on 30 September 2010, which continued until 2 October 2010, the Equality Act will apply, not the Sex Discrimination Act.

### **Getting information to support your complaint**

If you feel you've been treated unlawfully you can also use the forms below to help get information from your employer or service provider. The forms provide a framework for individuals and organisations to ask and answer questions about possible complaints under the Equalities Act.

### **October 2010**

Equality Act provisions which came into force on 1 October 2010:

- the basic framework of protection against direct and indirect discrimination, harassment and victimisation in services and public functions, work, education, associations and transport
- changing the definition of gender reassignment, by removing the requirement for medical supervision
- providing protection for people discriminated against because they are perceived to have, or are associated with someone who has, a protected characteristic
- clearer protection for breastfeeding mothers
- applying a uniform definition of indirect discrimination to all protected characteristics
- harmonising provisions allowing voluntary positive action

### ***Provisions relating to disability***

- extending protection against indirect discrimination to disability
- introducing the concept of "discrimination arising from disability" to replace protection under previous legislation lost as a result of a legal judgment
- applying the detriment model to victimisation protection (aligning with the approach in employment law)
- harmonising the thresholds for the duty to make reasonable adjustments for disabled people
- extending protection against harassment of employees by third parties to all protected characteristics
- making it more difficult for disabled people to be unfairly screened out when applying for jobs, by restricting the circumstances in which employers can ask job applicants questions about disability or health

### ***Provisions relating to work***

- allowing claims for direct gender pay discrimination where there is no actual comparator
- making pay secrecy clauses unenforceable
- extending protection in private clubs to sex, religion or belief, pregnancy and maternity, and gender reassignment
- introducing new powers for employment tribunals to make recommendations which benefit the wider workforce

### **April 2011**

Equality Act provisions which came into force in April 2011:

- positive action - recruitment and promotion
- public sector Equality Duty (see section below)

Ministers are considering how to implement the remaining provisions in the best way for business and for others with rights and responsibilities under the act. Their decisions will be announced in due course.

Equality Act Provisions that the government has decided not to take forward:

- public sector duty regarding socio-economic inequalities
- gender pay gap information
- combined discrimination - dual characteristics

### Age discrimination

The Equality Act 2010 includes provisions that ban age discrimination against adults in the provision of services and public functions. The ban came into force on 1 October 2012 and it is now unlawful to discriminate on the basis of age unless:

- the practice is covered by an exception from the ban
- good reason can be shown for the differential treatment ('objective justification')

The ban on age discrimination is designed to ensure that the new law prohibits only harmful treatment that results in genuinely unfair discrimination because of age. It does not outlaw the many instances of different treatment that are justifiable or beneficial.

### Age discrimination: exceptions

Exceptions under the Order are:

- age-based concessions
- age-related holidays
- age verification
- clubs and associations concessions
- financial services
- immigration
- residential park homes
- sport

These specific exceptions are in addition to:

- general exceptions already allowed by the Act
- positive action measures
- 'objective justification'

There are no specific exceptions to the ban on age discrimination for health or social care services. This means that any age-based practices by the NHS and social care organisations need to be objectively justified, if challenged.

### Public sector Equality Duty

The public sector Equality Duty came into force across Great Britain on 5 April 2011. It means that public bodies have to consider all individuals when carrying out their day-to-day work – in shaping policy, in delivering services and in relation to their own employees. It also requires that public bodies:

- have due regard to the need to eliminate discrimination
- advance equality of opportunity
- foster good relations between different people

## 5.2 How legislation and policies listed may affect the day to day experiences of individuals with mental health needs, dementia or learning disabilities and their families

### Key legislation - Health and safety legislation

Safe practice is very important to the promotion of dignity in care. There are a number of legislative measures and regulations to support health and safety at work. These are intended to protect people in work, those using services and the wider public. The **Health and Safety Executive** (HSE), local authority Trading Standards and the **Care Quality Commission** (CQC) can all bring prosecutions against care providers who breach health and safety standards.

Case examples:

- A care home in South Lanarkshire was fined for breach of Section 3 of the Health and Safety at Work etc. Act 1974, following the death of Mrs Elizabeth Stevenson, 88. Mrs Stevenson broke her neck in a fall. 'BUPA Care Homes (Carrick) Ltd admitted to failing to review and update a risk assessment for Mrs Stevenson and failing to provide adequate instruction and supervision to their employees engaged in moving and handling residents' (Health and Safety Executive 2012).
- Essex County Council was prosecuted after a child with severe learning and physical disabilities almost drowned in his school's swimming pool. The council had failed to provide schools with adequate information and guidance on how to safely manage and run their swimming pools (Health and Safety Executive 2012a).

### Health and safety legislation and regulations

#### **Health and Safety at Work Act 1974**

The Act covers a wide range of issues relating to workplace health, safety and welfare across different sectors. Statutory instruments have developed to support the implementation of the Act and provide an interface with European regulations. The HSE holds enforcement powers which can result in unlimited fines and prison sentences. Employees have a general obligation under the Act to take care of others and cooperate with employers' health and safety requirements.

#### **Manual Handling Operations Regulations 1992 (amended 2002)**

Manual handling is a major issue for care providers as people with limited mobility need to be assisted safely to move and transfer. It is important this is done in a way that respects the dignity of the individual. While employers are required to ensure that they comply with the regulatory framework, this does not mean that an individual's human rights can be disregarded. What is required is a balanced approach that reduces risks for workers while at the same time maintaining the dignity, privacy and autonomy of those they are caring for. The problem of lifting an overweight person, for example, must be solved not ignored. For example, a county council, concerned for the health of its employees, imposed a blanket ban on manual lifting of people using services. Unfortunately this resulted in certain people not receiving the community care to which they were entitled. The court held that the guidelines on manual lifting did not prohibit manual handling of people, nor operate a cut-off above which they would be too heavy to lift manually. Failure to lift these people could leave them stuck in a bath or on a lavatory, or suffering from bedsores. This created a potential breach of Article 3 of the HRA (the right not to be subject to inhuman or degrading treatment). Care workers' rights to a safe working environment must be respected, but these require safe working practices to be devised, not blanket bans that restrict levels of service [R v East Sussex County Council (2003)].

#### **HSE: Manual handling guidance**



### **Control of Substances Hazardous to Health 2002**

In the care sector these regulations may apply to cleaning materials and medications that may be dangerous if not used properly. Care providers must protect staff and service users from harm by ensuring that potentially dangerous substances are safely stored and that staff that use them are properly trained to do so.

### **Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1995**

Employers, the self-employed and 'responsible persons' (people in control of work premises) have an obligation to report death or serious workplace accidents, occupational diseases and specified dangerous occurrences (near misses) to the HSE.

### **HSE: RIDDOR**

#### **Health and Safety (First Aid) Regulations 1981**

Employers must ensure that first aid equipment and trained first-aiders are present in the workplace and that employees are aware of first aid arrangements.

### **HSE: Code of Practice**

#### **Food Safety Act 1990, Food Safety (General Food Hygiene) Regulations 1995 and Food Safety (Temperature Control) Regulations 1995**

The Food Safety Act covers the preparation, storage and service of food and requires the registration of food businesses whether they are run for profit or not. A 'food business' includes canteens, clubs and care homes. The CQC requires that care services ensure that the food and drink they provide is handled, stored, prepared and delivered in a way that meets the requirements of the Act. The local authority is responsible for enforcement through environmental health and Trading Standards. The Food Standards Agency (FSA) can intervene where local authorities fail to meet the requirements and in emergency situations.

### **Food Standards Agency: Guide for Businesses**

### **Quality in care**

Circumstances that influence dignity, such as living conditions in care homes, are governed by a whole host of regulations. The CQC is the health and social care regulator. It has published guidance for compliance with the **Essential Standards of Quality and Safety**. However, personal assistants paid for through direct payments and personalised budgets and day services are unregulated.

### **PERSON-CENTRED CARE**

This policy offers best-practice advice on the care of people with dementia and on support for their carer's. There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline. The principles assert:<sup>[2]</sup>

- the human value of people with mental illness, dementia, and Learning Disability, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with mental illness, dementia, and Learning Disability,, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with mental illness, dementia, and Learning Disability,

- the importance of relationships and interactions with others to the person with mental illness, dementia, and Learning Disability,, and their potential for promoting well-being.

The fourth principle emphasises the imperative in mental illness, dementia, and Learning Disability, care to consider the needs of carers, whether family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is increasingly described as 'relationship-centred care'.

### **Capacity and mental illness, dementia, and Learning Disability,**

Treatment and care should take into account patients' needs and preferences. People with dementia should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act.

### **Involving others**

The views of people with mental illness, dementia, and Learning Disability, concerning who should and should not be involved in their care are important and should be respected. With the permission of the person with mental illness, dementia, and Learning Disability, carers and relatives should normally have the opportunity to be involved in decisions about care and treatment. If the person lacks the capacity to decide who should and should not be involved, health and social care professionals must act in his or her best interests, bearing in mind the provisions of the Mental Capacity Act 2005.

Health and social care staff should take account of the views of carers and relatives who describe behaviour that could be in keeping with dementia. This information, in conjunction with an assessment of the person concerned, will help with diagnosis and deciding on care. It will also help in the estimation of the person's capacity to make decisions. People with mental illness, dementia, and Learning Disability, should continue to have the opportunity to make informed decisions about those aspects of their care and personal lives for which they retain capacity.

Good communication between care providers and people with dementia and their families and carers is essential, so that people with dementia receive the information and support they require. Evidence-based information should be offered in a form that is tailored to the needs of the individual. The treatment, care and information provided should be culturally appropriate and in a form that is accessible to people who have additional needs, such as physical, cognitive or sensory disabilities, or who do not speak or read English.



## MENTAL HEALTH, DEMENTIA AND LEARNING DISABILITY

### 6 UNDERSTAND THE MEANING OF MENTAL CAPACITY IN RELATION TO HOW CARE IS PROVIDED

#### 6.1 Explain what is meant by the term "capacity".

'Mental capacity' means a person's ability to make their own choices and decisions.

Under UK law, someone's capacity is judged according to the specific decision to be made, so a person may have sufficient capacity to make simple decisions but not more complicated ones.

#### 6.2 Explain why it is important to assume that someone has capacity unless there is evidence that they do not

All adults, even those felt to be lacking mental capacity, have the right to make their own decisions and must be assumed to have capacity to make decisions about their own safety **unless it is proved (on a balance of probabilities) otherwise.**

In a democratic society, we all have the right to make our own choices and to be in control of our lives – provided we are not breaking any laws, or causing other people harm. This includes decisions about our own safety.

The key thing to consider when it comes to 'assumption of capacity', then, is whether or not someone has the capacity to make specific decisions about their own safety.

We need to consider the 'balance of probabilities'

#### The two-stage functional test of capacity

In order to decide whether an individual has the capacity to make a particular decision you must answer two questions:

**Stage 1.** Is there an impairment of or disturbance in the functioning of a person's mind or brain? If so,

**Stage 2.** Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

The Mental Capacity Act 2005 says that a person is unable to make their own decision if they cannot do one or more of the following things:

- Understand information given to them
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision

Communicating the decision could be done by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand. Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals.



The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? You should be able to show in your records why you have come to your conclusion that capacity is lacking for the particular decision.

### Activity

#### Who should assess mental capacity?

Professionals involved with a person at risk might include: doctors, care workers, social workers, physical therapists and others. With such a wide range of professionals involved, who is the best person to assess mental capacity?

### 6.3 Consent, and how it can change according to what decisions may need to be taken.

#### Assessing capacity to give consent

All adults are presumed to have sufficient capacity to decide on their own medical treatment, unless there is significant evidence to suggest otherwise.

**Informed consent** is the process of agreeing to take part in a study based on access to all relevant and easily digestible information about what participation means, in particular, in terms of harms and benefits

- To give truly informed consent, potential participants need to understand the following:
- the purpose of the research
- how long their participation will last
- who is involved in the research
- the practicalities and procedures involved in participating
- the possible benefits and risks of participation and, when appropriate, the alternative therapies
- how data about them will be managed and used
- how long and where the data will be stored
- the purpose of the consent form
- what is expected of them if they agree to participate in the research
- how information will be provided to them throughout the research
- that their participation is voluntary
- that they can withdraw from the study at any time, without giving any reason and without compromising their future treatment
- the insurance indemnity arrangements for the conduct of the research where appropriate
- that the research has been approved by a research ethics committee. Participants should also be given the following information:
- contact details, should they have further questions or want to withdraw
- details of the research sponsor and funding body. In addition, a participant information sheet should be prepared which:
- invites the reader to participate in the research
- uses language appropriate to the potential participant group, avoiding the use of technical language
- includes diagrams, pictures, tables and flowcharts if these contribute to explaining the research. It is also important to remember that written information is only one way to share information with potential participants.



- There may be circumstances when video, podcasts, recordings or other means of sharing information might be more appropriate. Ongoing consent as a process Informed consent is an ongoing process and consequently researchers must ensure that participants:
- continue to understand what the research is about and what their participation involves
- are provided with any new information which might influence their decision to continue their participation in the research
- continue to consent to participate throughout the research. Revisiting informed consent is often done informally, but on occasion it might be appropriate to formally re-consent research participants.

For example, during longitudinal research projects it might be wise to ask Informed consent is bound by ethical and legal frameworks, and the processes for obtaining it must be independently scrutinised and approved. In this section we take a look at the ethical and legal requirements regarding informed consent, and the bodies responsible for ensuring the processes for gaining consent are adequate and appropriate.

### The ethical framework

Freely given informed consent is at the heart of ethical research, and the national and international governance frameworks – including the World Health Organisation’s Declaration of Helsinki – state that researchers must make appropriate arrangements to obtain informed consent from research participants. The key ethical principle relating to informed consent in research is the belief that everyone should be treated with respect

Researchers must respect diversity when gaining informed consent and must take into account factors such as:

- ethnicity
- gender
- disability
- religious beliefs
- culture
- language
- level of understanding.

Informally, if participants are happy to continue their participation before commencing research activities.

Re-consenting is also appropriate if there is a significant change to a research project, or if there is new information which might alter an individual’s willing to participate in a research project. In these scenarios it would usually be expected that a new information sheet is provided and informed consent is revisited in a more formal manner

### ***6.4 Situations where assessment of capacity might need to be undertaken and the meaning and significance of “advance statements” regarding future care.***

#### ASSESSING CAPACITY

Consider the following factors when assessing an individual’s capacity to make a specific decision:

- Presume someone has capacity
- Understand what is meant by capacity and lack of capacity
- Treat everyone equally
- Support the person to make the decision for themselves.



## What is mental capacity and when might you need to assess capacity?

Having mental capacity means that a person is able to make their own decisions. You should always start from the assumption that the person has the capacity to make the decision in question (**principle 1**). You should also be able to show that you have made every effort to encourage and support the person to make the decision themselves (**principle 2**). You must also remember that if a person makes a decision which you consider eccentric or unwise, this does not necessarily mean that the person lacks the capacity to make the decision (**principle 3**). Under the MCA, you are required to make an assessment of capacity before carrying out any care or treatment – the more serious the decision, the more formal the assessment of capacity needs to be.

### When should capacity be assessed?

You may need to assess capacity where a person is unable to make a particular decision at a particular time because their mind or brain is affected by illness or disability. Lack of capacity may not be a permanent condition. Assessments of capacity should be time- and decision-specific. You cannot decide that someone lacks capacity based upon age, appearance, condition or behaviour alone.

### The test to assess capacity

#### The two-stage functional test

In order to decide whether an individual has the capacity to make a particular decision you must answer two questions:

**Stage 1.** Is there an impairment of, or disturbance in the functioning of a person's mind or brain? If so,  
**Stage 2.** Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things:

- Understand information given to them
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision – this could be by talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

Every effort should be made to find ways of communicating with someone before deciding that they lack capacity to make a decision based solely on their inability to communicate. Also, you will need to involve family, friends, carers or other professionals.

The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? You should be able to show in your records why you have come to your conclusion that capacity is lacking for the particular decision.

### Who should assess capacity?

- Anyone caring for or supporting a person who may lack capacity could be involved in assessing capacity – follow the two-stage test.
- The MCA is designed to empower those in health and social care to do capacity assessments themselves, rather than rely on expert testing by psychiatrists or psychologists – good professional training is key.

### ADVANCED STATEMENTS

However, in cases involving complex or major decisions you may need to get a professional opinion. This could be a general practitioner (GP) or a specialist (consultant psychiatrist or psychologist). Advance decisions and advance



statements ensure that your wishes are taken into account in the future. This factsheet explains how advance decisions and advance statements work, and what they can and cannot do. It also provides practical advice and a form to help you to draft an advance decision.

There are a number of things that you can do to plan for your care in the future. These are often referred to collectively as 'advance care planning'. The purpose is to enable you to make choices and decisions about your future care, in case there is a time when you cannot make these decisions for yourself, for example in the later stages of dementia. This can ensure that you are not given treatment that you do not wish to receive, or that your family have power to act on your behalf if you wish them to.

Advance decisions and advance statements are just one aspect of planning ahead. For example, you can decide if you would like to choose someone to manage your finances on your behalf if you are unable to in the future, or make decisions relating to your health and welfare. For more information see factsheet 472, Enduring Power of Attorney and Lasting Powers of Attorney.

Other things you may wish to think about are putting your finances in order and getting a will, or updating any previous will. This allows you to state who you want to inherit your estate. For more information, see factsheet 467, Financial and legal affairs.

The information in this factsheet is for people living in England and Wales, and is not intended for those living in Northern Ireland, where the laws governing advance decisions do not apply. For information about the laws that relate to Northern Ireland, see factsheet NI467, Financial and legal tips.

### **What is an advance decision?**

An advance decision gives you the opportunity to make decisions now about specific treatments that you may not want to receive in the future. The purpose is to ensure that, if you are not able to make decisions about treatment or consent yourself in the future, you are not forced to receive treatment that you would not want.

Treatment that can be refused includes life-sustaining treatment. For example, some people may write an advance decision to refuse a blood transfusion for religious or spiritual reasons, even if this will hasten their own death. Advance decisions are legally binding as long as they fulfil certain requirements, and this means that they must be followed by doctors and other medical professionals. This factsheet details these requirements so that you can ensure that any advance decision you make will be valid.

### **What is an advance statement?**

Advance statements are similar to advance decisions, but they are not the same thing. It is important to note that you can make both an advance statement and an advance decision.

An advance statement can be made verbally, or you can choose to write it down, which can be better because it is a permanent record. An advance statement gives you the chance to make more general statements about your wishes and views for the future, whereas an advance decision is about refusing certain treatments. Often an advance statement is referred to as a 'statement of wishes and care preferences'.

You could use an advance statement to express your wishes on future care options, such as where you wish to live, or the type of care and support you wish to receive.

An advance statement can also be used to express other wishes and preferences not directly related to care. Examples include stating food preferences, such as being vegetarian or not eating seafood, or your preference for



having a bath over a shower. If you have particular religious or spiritual views, an advance statement provides an opportunity to ensure that any relevant values that you hold are taken into account by the people who make decisions for you.

You could also include a list of people, such as your partner, family or friends, who you wish to be consulted by health and social care professionals who are making decisions about your care.

***Advance statements are not legally binding.***

### **Why should I consider making an advance decision or advance statement?**

There are a number of reasons why you may wish to make an advance decision or advance statement:

- It can be reassuring to know that, if you are unable to make a decision about your care in the future, you will not be given treatment that you do not want.
- They are a way of ensuring that your views and wishes are taken into account in the future.
- Creating an advance decision and/or advance statement can help to start conversations with doctors and nurses that you may not otherwise start.
- They can also help to prompt discussions with your family about your wishes, and making an advance decision and/or statement can take the burden away from your family, who otherwise may be asked to make these decisions for you.

### **Will my doctor have to follow my advance statement?**

An advance statement – unlike an advance decision – is not legally binding, so doctors and medical professionals do not have to follow it. However, it should still be taken into account by health and social care professionals when making decisions about care and treatment.

### **Will my doctor have to follow my advance decision?**

All medical professionals, including doctors, will have to follow your advance decision. However, this is only when your advance decision is 'valid' and also 'applicable'.

- **Valid** – In order to be valid, an advance decision must have been made at a time when you were able to make this decision. This is referred to as having mental capacity.
- **Applicable** – In order for the advance decision to be applicable, the wording has to be specific and relevant to the medical circumstances. If the wording is vague or there is a concern that it does not refer to medical conditions and/or practices that you are actually experiencing, then the advance decision may not influence the doctors' decisions at all.

### **The advance decision must also:**

- be clear and unambiguous
- have been made when you were over the age of 18, and fully informed about the consequences of refusal of treatment, including the fact that it may hasten death
- not have been made under the influence of other people
- be written down and be signed and witnessed if it relates to refusing lifesaving treatment.

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**What an advance decision cannot do**

An advance decision cannot be used to:

- refuse treatment at a time when you still have capacity to give or refuse consent
- refuse basic care essential to keep you comfortable, such as washing or bathing
- refuse the offer of food or drink by mouth (but it can be used to refuse feeding by tube, for example)
- refuse the use of measures solely designed to maintain comfort – for example, painkillers (which relieve pain but do not treat the condition)
- demand specific treatment
- refuse treatment for a mental disorder in the event that you are detained under the Mental Health Act 1983
- ask for anything that is against the law, such as euthanasia or assisting you in taking your own life.





