Anticipating loss of mental capacity and putting measures in place in good time

Caught out by unexpected events or the subtle change in mental capacity

There can be several events or triggers that place an individual in a state where their mental capacity is such that they are not considered fit in Law to make certain decisions for themselves. These could include: -

- motor accident resulting in a person being in a coma for some length of time
- major stroke
- vascular dementia
- Alzheimer's

A sudden event such as a stroke or a serious motor accident can come out of the blue and catch people out. Young and old could be caught out.

The current COVID-19 Pandemic has brought the need to prominence due to the many stories of people in Intensive Care Units in an induced coma on ventilation.

However, where mental capacity gradually degrades close family members for a variety of reasons: -

- unaware of the signs
- not wishing to upset their loved one
- unaware of the legal safeguards that could be put in to protect the best interests of the person affected

might take no action in good time or realise when it too late for the correct legal documents to be put in place where the individual concerned has failed to do so before.

It is the subtle decline in mental capacity that can catch people out and perhaps less excusable for inaction when steps can still be taken before it is too late!

Dementia and the signs that could be an amber light to ensure safeguards are put in place in good time to protect against loss of and mental capacity

Some people have problems with their memory or thinking but these are not bad enough to affect their everyday life. In this case, a doctor may diagnose them with mild cognitive impairment (MCI). This is not a type of dementia, but research shows that people with MCI have an increased risk of going on to develop dementia.

According to Alzheimer's UK there are currently around 850,000 people in the UK with dementia. It mainly affects people over the age of 65 (one in 14 people in this age group have dementia), and the **likelihood of developing dementia increases significantly with age.** However, dementia can affect younger people too.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The

specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

The most common types of dementia are: -

- Alzheimer's disease
- Vascular dementia
- Mixed dementia
- Dementia with Lewy bodies
- Frontotemporal dementia (including Pick's disease)

A person with dementia will have cognitive symptoms (to do with thinking or memory). They will often have problems with some of the following:

- day-to-day memory – for example, difficulty recalling events that happened recently
- forgetting names or faces
- concentrating, planning, or organising – for example, difficulties making decisions, solving problems, or carrying out a sequence of tasks (such as cooking a meal)
- language – for example, difficulties following a conversation or finding the right word for something
- repetitive odd behaviour such as walking around the home taking out a driving licence and putting it back several times a day and on several days or repetitively
- visuospatial skills – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions
- orientation – for example, losing track of the day or date, or becoming confused about where they are

A person with dementia will also often have changes in their mood. For example, they may become frustrated or irritable, apathetic, or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).

Progress of dementia – the pathway to be aware of

Dementia is progressive, which means the symptoms gradually get worse over time. How quickly this happens varies greatly from person to person.

As dementia progresses, the person may develop behaviours that seem unusual or out of character. These behaviours may include asking the same question over and over, pacing, restlessness or agitation. They can be distressing or challenging for the person and those close to them.

Knowing the type of dementia (for example, Alzheimer's disease or vascular dementia) is also important, partly because it may allow the person to get an appropriate drug treatment.

Every person with Alzheimer's experiences the disease differently, but people tend to experience a similar trajectory from the beginning of the illness to its end. The precise number of stages of Alzheimer's is somewhat arbitrary. Some experts use a simple three-phase model (early, moderate and end), while others have found a granular breakdown to be a more useful aid to understanding the progression of the illness.

The most common system breaks the progression of Alzheimer's disease into seven stages. This framework for understanding the progression of the disease has been adopted and used by healthcare professionals: -

Stage 1 No cognitive decline

Stage 2 Very mild cognitive decline

Stage 3 Mild cognitive decline

Stage 4 Moderate cognitive decline

Stage 5 Moderately severe cognitive decline

Stage 6 Severe cognitive decline

Stage 7 Very severe cognitive decline

The progression of dementia will be different for everyone. Knowing where a loved one falls on this scale can help to identify signs and symptoms so that action can be taken before it is too late.

Early signs might be: -

- social withdrawal
- misplacing things
- mood changes
- recalling stories from the past but not remembering things done in the present
- difficulty recalling information just learned (dates, events, information)
- rely on others as a memory aid

Assessing the impact on mental capacity

You must always assume that a person is able to decide for themselves, until it is proved that they cannot.

A person's capacity may be questioned if there is doubt about whether they can make a particular decision. This could happen if: -

- the person's behaviour or circumstances are making those around them doubt whether the person has capacity to make a particular decision
- a professional says they have doubts about the person's ability to make the decision – this could be a social worker or the person's GP
- the person has previously been unable to decide for themselves.

To work out whether a person has capacity to make a decision, the law says that a test must be made (often called an assessment) to find out whether they have the ability to make the particular decision at the particular time.

Before the person is tested, they should be given as much help as possible to make the decision for themselves. Those who are supporting the person to make the decision should find the most helpful way to communicate with the person. This may mean: -

- trying to explain the information to them in a different way
- helping them to understand the ideas that are involved in making the decision
- breaking down information into small chunks.

Not all decisions need to be made immediately. It is sometimes possible to delay a decision until a person has capacity to make it. However, this will not be possible for every decision.

Who can assess mental capacity in a person with dementia?

In general, whoever is with the person when a decision is being made will assess their capacity. However, this will differ depending on the decision that needs to be made – for example:

- **Everyday decisions** (such as what someone will eat or wear) – whoever is with them at the time can assess the person's capacity to make the decision. This is likely to be the person's family member, carer, or care worker.
- **More complicated decisions** (such as where someone will live or decisions about treatment) – a professional will assess the person's capacity to make the decision.

In general, family members and carers know the person with dementia best. They can often tell when the person is or is not able to make a decision. When a person has dementia, it is likely that they will have to do this more often as the person's condition progresses.

If the decision is complicated, the person's carer or family members can consult a professional, such as a solicitor or a health or social care professional. Note that certain professionals may charge for advice.

Whether it is someone close to the person or a professional, they must firmly believe that the person with dementia cannot make their own decision before taking action to make the decision for them.

For more insight concerning the assessment and challenges of an assessment visit https://www.alzheimers.org.uk/get-support/legal-financial/assessing-mental-capacity-dementia

The Mental Capacity Act requirements – loss of mental capacity

As their condition progresses, people with dementia may become unable to make some decisions for themselves. When this happens, the person is said to lack the 'mental capacity' to make the specific decision at that time.

The Mental Capacity Act is the law in England and Wales that protects and supports people who lack capacity to make a decision. It also outlines who can and should make decisions for them.

The Mental Capacity Act covers important decision-making about a person's property, financial affairs, and health and social care. It also covers everyday decision-making, such as decisions about what a person wears, what they eat and their personal care.

It does not cover decisions such as voting, making a will, marriage, or divorce.

The Mental Capacity Act is based on five key principles or rules. These are: -

1. A person has the right to make decisions for themselves. You must assume that someone is able to make their own decisions, unless it is shown that they cannot do this

2. A person should not be treated as being unable to make a decision unless they have been given all reasonable help and support to make and communicate their own decision

3. A person should not be treated as being unable to make a decision just because other people think they have made a bad decision

4. If a person lacks capacity, any decisions that other people make for them must be in the person's best interests

5. If a person lacks capacity, the people making the decision for them must consider the option that is the least restrictive to the person's rights and freedoms

Does the person have mental capacity to make a decision?

When a person has 'mental capacity' it means they can make a specific decision at a specific time. People who cannot do this are said to 'lack capacity' to make the specific decision. This might be due to an injury. Or they might have a learning disability, a mental illness, or a condition that affects their brain – such as dementia.

To have mental capacity a person must be able to: -

- understand the information that is relevant to the decision they want to make
- keep the information in their mind long enough to make the decision
- weigh up the information that is available to make the decision
- communicate their decision in any way – including talking, using sign language, or through simple muscle movements such as blinking their eyes or squeezing someone's hand.

How might mental capacity be affected in a person with dementia?

When a person has dementia their **mental capacity can change over time**. It can also change in both the short term and the long term. For example, there might be days or even times of the day when the person can think more clearly. This means they **may have capacity to make a decision at some times but lack capacity at other times**.

A person **may also have the capacity to make some decisions but not oth**ers. For example, a person may be able to decide that they want to go on holiday but not be able to make choices between transport or accommodation options. This is because some decisions involve having to take in more information, which may be harder for the person to process or understand.

Some decisions, such as whether to move into a care home, also involve many factors to weigh up and this may also be harder for the person to consider.

Therefore, the **assumption should not be made that a person lacks the mental capacity to choose simpler decisions** such as what they want to wear or eat just because they cannot make difficult financial or medical decisions.

Who should make decisions for someone with dementia who lacks mental capacity?

The type of decision that needs to be made will affect who should make the decision. The following list has examples about who can make certain types of decisions for a person with dementia: -

- Everyday decisions about washing, dressing, eating or activities – whoever is with the person at the time can make these decisions, such as a carer, family member or care worker

- Complicated decisions about finances or property – if the person has an attorney or deputy for property and financial affairs, they will make these decisions

- Complicated decisions about where the person will live, their care or treatment – if the person has an attorney or deputy for health and welfare, they can make the decision. If not, a professional such as a social worker or doctor will make the decision

- Decisions about life-sustaining treatment – if the person has appointed an attorney for health and welfare and given them this power, the attorney they may be able to make the decision. If the attorney cannot make the decision then it will be made by an appropriate doctor or consultant

- If there is not someone who knows the person with dementia well, the Local Authority may appoint an independent mental capacity advocate (IMCA) to speak on the person's behalf. This will happen when a major decision needs to be made, such as whether the person should move to a care home or have serious medical treatment. An IMCA is also sometimes involved if there is conflict between family members.

Should the person with dementia be consulted when the decision is being made?

The person has a right to be involved in decisions that are made about them (unless that is inappropriate, for example if someone refuses to be consulted). This is very important. Just because someone cannot make the decision themselves, this does not mean that they will not have preferences and feelings about what they would like to happen.

Should the family and carers of the person with dementia be consulted?

Family members, friends and carers also have a right to be consulted and involved in the decision, where appropriate. This is important and can be helpful because they often know the person best. They can say what they think is in the person's best interests, as well as what the person's preferences and views are.

What if the decision is complicated and the person with dementia lacks mental capacity?

There may be a 'best interests meeting' if the decision is more complicated, such as decisions about where the person will live. This is not always needed.

However, when it is, a meeting can be a good way to consider all the different issues involved in the decision. This includes the views of the person and their family members.

Sometimes family members or the person's representatives will be invited to the best interests meeting. If family members disagree, the views from both sides of the argument should be taken into account.

At other times, family members will not be invited to the best interests meeting. Often, the person themselves is not invited to attend. If the person and their family are not invited, their views should still be considered during the meeting.

How this is done will depend on the situation – for example, they could offer their views in writing or through someone else, such as an IMCA. Or the person with dementia or their carer could meet with a professional before the meeting to share their views.

How can someone with dementia plan ahead using the Mental Capacity Act?

Mindful of the mental capacity issues involved there are some straightforward steps that can be taken or might have been taken to ensure the best interests of the person concerned are protected in terms of their property, finances, health, and welfare rather than leaving things to chance and having to resort finally to the Court of Protection. **An existing Power of Attorney ceases to be valid once the person is judged to have lost mental capacity.**

Use of an existing Enduring Power of Attorney (EPA)

If an Enduring Power of Attorney (EPA) exists and is still valid it can still be used but remember that it will only relate to property and financial matters not personal health and welfare. Thea EPA must have been made properly and signed before October 2007, it can still be registered and used.

For details about registering an EPA visit https://www.gov.uk/enduring-power-attorney-duties/register-an-enduring-power-of-attorney Currently it costs £82 to register an EPA, unless applying for help with fees.

Making a Lasting power of attorney (LPA)

Where no valid Registered EPA exists or there is no existing Lasting Power of Attorney (LPA) then making an LPA is an appropriate step to take.

An LPA enables a person to appoint someone they trust to make decisions for them in future if they cannot make a certain decision or decisions for themselves. The person (or people) they appoint will become their 'Attorney'.

To make an LPA, a person needs to have mental capacity at the time and submit a specific application form. This form needs to be signed and witnessed by various people before it is registered with the Office of the Public Guardian.

An LPA must be registered before it can be used. Bear in mind that the Attorney or Attorneys have to have mental capacity themselves when they come to operate the LPA and be alive. It is possible to guard against that risk by nominating a Replacement Attorney at outset to protect against that risk.

There are two types of LPA. They each relate to different decisions. A person can have both types of LPA, but to do this they will need to complete both forms.

The two types of LPA are: -

LPA for property and financial affairs

- gives the Attorney or Attorneys the power to make decisions about things like selling the person's house or managing their bank account
- can be operative while the person has mental capacity or only becomes active when they lose mental capacity
- can only be used once Registered

LPA for health and welfare

- gives the Attorney or Attorneys the power to make decisions about the person's health and personal welfare, such as day-to-day care, medical treatment, or decisions about where they might live so that they can receive care and support, such as a care home
- must have been Registered
- can only be used once the person has lost mental capacity

For more detail concerning creation of an LPA, the safeguards built in such as objections, referral to chosen named people (person to notify), certificate provider who confirms no duress is being exercised on the maker, and witnesses to the LPA, the registration procedures and current level of Registration Fees and any exemptions visit https://www.gov.uk/power-of-attorney/make-lasting-power

It need not be an expensive task as the paperwork can be completed online or the forms downloaded and then completed. Registration fee is £82 for each LPA (February 2021). If someone feels out of their depth and does not know anyone who can help them in the process then they can engage the services of a professional such as a Solicitor.

Creating an advance decision

The Mental Capacity Act also enables someone to create an advance decision to refuse treatment. This allows them to state the types of treatment they do not want to have if they do not have the mental capacity to decide this for themselves in the future. This may include refusing life-sustaining treatment.

A valid advance decision is legally binding. This means health professionals must follow it if the treatment and circumstances that are set out in the advance decision apply to the specific situation the person is in. To be valid, an advance decision must be made in writing. It must also be signed and witnessed.

It can help if the person has a conversation with their GP before they make an advance decision. This is to make sure that the advance decision covers what the person wants it to.

This sort of decision or guidance can be included in the LPA for health and welfare.

Creating an advance statement

Another way that people can plan ahead is by creating an advance statement. This is where they can set out their wishes and preferences for the future, including both what they want and what they do not want to happen.

The statement could include: -

- their preferences about their care
- where they will live
- what they like or do not like to eat
- daytime activities they enjoy
- who they do and do not want to visit them.

Advance statements can be made verbally or in writing. They are not legally binding. However, if someone is making a decision for a person who has made an advance statement, they must take the statement into account when they make the decision.

How can decisions be made for someone with dementia if they have not planned ahead? The Court of Protection and appointment of a Deputy

If a person with dementia loses the ability to make some decisions and they have not made an LPA or EPA, it can become difficult for those who are trying to help them. This is especially true for financial decisions because **only someone who has a legal power (such as an LPA, EPA, or Deputyship) can completely manage another person's finances.**

Therefore, if you someone caring for a person who has not made an LPA or EPA, will need to apply to the Court of Protection to become their Deputy to be able to manage their finances for them. Do note that it can take several months for this to be set up and the process is more expensive, with a higher cost for applying and ongoing fees after they have been appointed to pay for supervision. In February 2021 the fee levels were: -

- Application fee £365 (some exemption / reduction might apply) or £485 if Court decides a Hearing is necessary
- £100 assessment fee if a new deputy
- Annual supervision fee depending on what level of supervision is needed
    - £320 for general supervision
    - £35 for minimal supervision - this applies to some 'property and affairs' deputies managing less than £21,000

A deputy may have to pay to set up a 'security bond' before they can be appointed as a 'property and affairs deputy'.

For details visit https://www.gov.uk/become-deputy

It is also possible to become a person's Deputy for health and welfare decisions. You will need to show the court that the person needs to have a deputy. You can do this by showing that ongoing decisions need to be made about the person's welfare that only a deputy can make.

The court does not appoint as many Deputies for health and welfare. This is because professionals and family members can sometimes work together to make decisions in the person's best interests so that Deputyship is not needed.

Sources of Information: www.gov.uk and Alzheimer's UK