



DementiaUK
Helping families face dementia

Capacity and decision making



Introduction

Admiral Nurses are dementia specialist nurses who provide the compassionate one-to-one support, expert guidance and practical solutions that help families face dementia with more confidence. This leaflet has been written by Admiral Nurses to help you understand the issue of capacity.

Dementia is a progressive condition which can effect a person's ability to make decisions and to look after themselves. As dementia progresses, the person might need the help of their family and friends to make decisions about their health, their care, their finances and their living arrangements.

What is capacity?

Capacity is a legal term, concerning whether someone is able to make important decisions.

It should always be assumed a

person has the capacity to make the decision in question unless evidence clearly proves otherwise.

To have capacity to make a decision, a person must be able to understand the information relevant to the particular decision they are making; be able to retain that information long enough to make the decision; weigh up the information as part of their decision making process; and be able to communicate that decision to others.

For a person with dementia, there may come a time when they no longer have the capacity to make decisions concerning their health, or finances – but this can change, depending on the decision to be made, and the person's health status at the time. For example, a person might lose capacity due to a period of illness but regain it again afterwards. They might also have capacity to make some decisions but not others.

Who decides whether a person has capacity?

If there is doubt about a person's capacity, a trained health or social care professional can carry out a Mental Capacity Assessment (MCA). It is important to note that a capacity assessment only extends to the particular decision being made at that time – for instance, whether a person has the capacity to make a decision about their individual care needs. For any other

decisions regarding the person's finances, or health care, or living arrangements, a separate capacity assessment will need to be carried out.

Planning for the future

There are two types of important document which can help with planning for the future.

An Advance Care Plan (ACP) is a document in which the person sets out their wishes for their



future medical and personal care, including long term care.

Lasting Power of Attorney (LPA), of which there are two types, is where the person with dementia appoints an Attorney to manage their ‘Health and Welfare’ or ‘Property and Financial’ affairs – as and when they no longer have the capacity to do so. (see ‘Sources of support’ at the end of this leaflet for Dementia UK’s information on both ACP and LPA).

If possible, it is very important to establish an Advance Care Plan (ACP) and Lasting Power of Attorney (LPA) while the person living with dementia has capacity. This will make the process of organising suitable care and managing the person’s finances less complicated.

If the person has capacity, it is therefore advisable to establish an ACP and LPA as soon as practical after a diagnosis of dementia. This means their wishes for future

care and support are taken into consideration in any decisions that need to be made; and decisions can be made in advance about how their finances could be managed, if they become unable to manage these themselves.

Who should make decisions for a person found to not have capacity?

Some decisions, such as selling the person’s home, or considering a move into residential care, can be very difficult to make and can cause disagreements. When a person with dementia lacks capacity to make big decisions themselves, these decisions should be made in their best interests, through discussion with close family members, and where relevant, alongside social workers or other health professionals involved in the person’s care. The best outcome is where all parties are able to come to a consensus about the best interests of the person.

Making decisions in a person's best interests

When a person with dementia can no longer make informed decisions for themselves, the family and health and social care staff may have to make a 'best interests decision'. A meeting should be arranged so all parties to the decision can discuss what is in the best interests of the person with dementia. This meeting should include the person with dementia, the family, health and social care staff and any other person who is actively involved with the person with dementia.

Attempts should be made to involve the person with dementia as much as possible, to find out their wishes and views regarding the decision to be made. The person's culture and beliefs should be taken into consideration in the decision making process. If the person has a LPA and/or ACP, these should be taken into account during the meeting, and be reflected in

any decisions made.

Any decisions made in the best interest of the person should be the least restrictive option possible. For example: if the person's wishes are to go out regularly for walks, but they are vulnerable and a safety risk, the best interest decision would be to arrange for the person to be accompanied on their walks, rather than deciding the person cannot go out.

Deprivation of Liberty Safeguards

Deprivation of Liberty Safeguards (DoLS) apply in England and Wales only.

DoLS are an extension of the Mental Capacity Assessment (MCA) and provide a framework within which it is only legal to deprive an individual of their liberty, by placement in a care home or hospital, if it is in their best interest. An MCA would first need to be completed, indicating that the person lacks capacity, and

a best interests meeting would then need to take place. All factors should be considered during the assessment, and the outcome can be challenged by anyone who feels that the wrong decision has been made. For more information on DoLS see 'Sources of support' at the end of this leaflet.

Making big decisions for a person with dementia can be daunting, and family disagreements are not uncommon. The dementia specialist Admiral Nurses on

our Helpline have a wealth of experience in helping families anticipate what questions to ask, and what considerations might help establish the person's best interests. Anyone can call for free on **0800 888 6678** or email helpline@dementiauk.org from Monday to Friday, 9am-9pm and at the weekends, 9am-5pm.

Sources of support

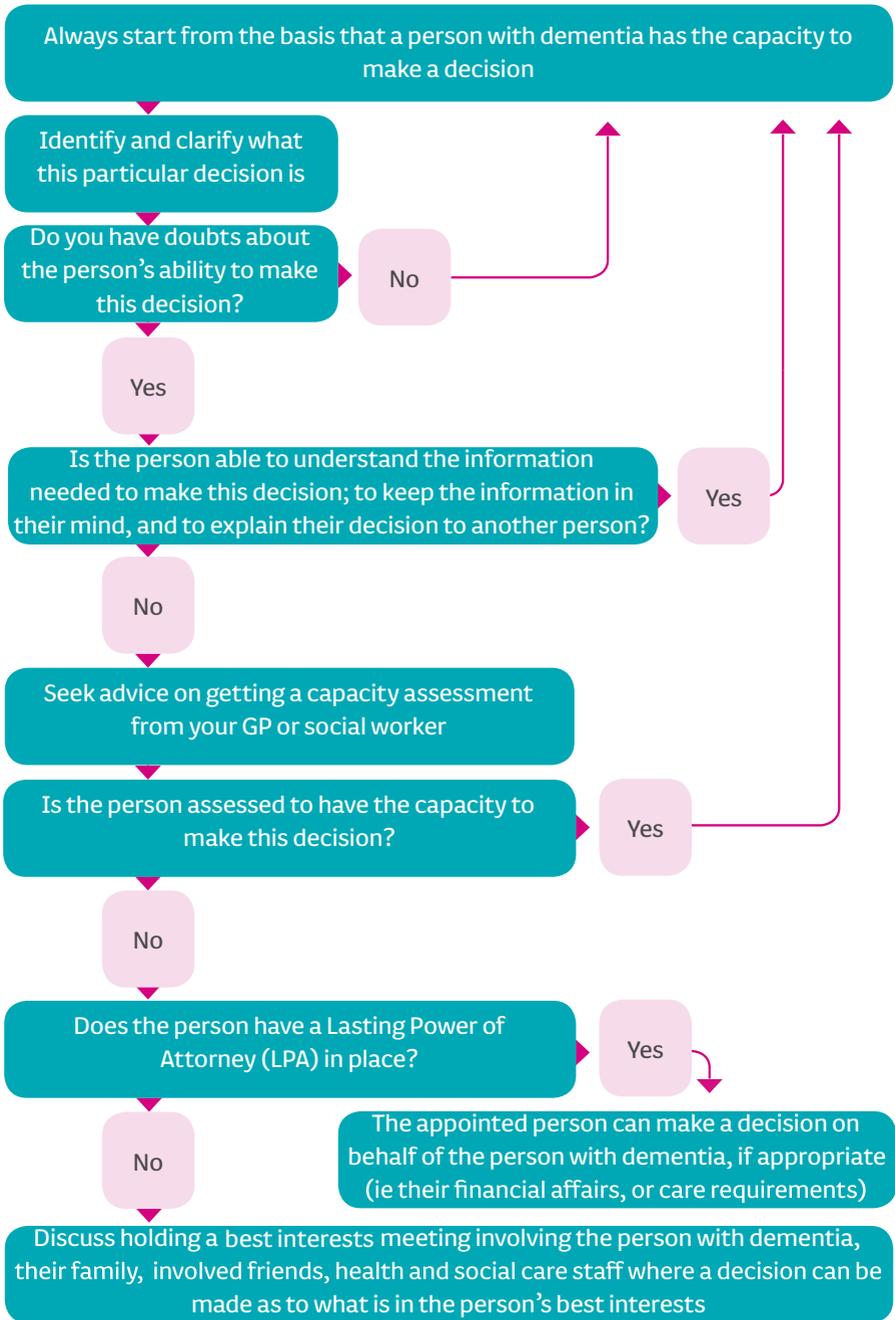
Dementia UK resource on Advance Care Planning:
www.dementiauk.org

Dementia UK leaflet on Lasting Power of Attorney:
www.dementiauk.org

Information on Deprivation of Liberty safeguards (DoLS)

from the UK Government:
www.gov.uk/government/publications/deprivation-of-liberty-safeguards-forms-and-guidance

Information on DoLS from the Social Care Institute for Excellence: www.scie.org.uk/mca/dols/at-a-glance



The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit www.dementiauk.org/donate or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.



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Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm

www.dementiauk.org • info@dementiauk.org