

Care planning when patients are unable to make decisions for themselves

This leaflet is intended to accompany the one entitled “No decision about me without me” Advance Care Planning. Details of additional information can be found at the end of the leaflet.

Introduction

We live in a world where life-saving medical breakthroughs mean that people often live for many years after serious illness is diagnosed. It is easy to put off making important decisions about how and where we want to be treated and cared for, sometimes until it is too late. As chronic illness progresses patients may need help with making decisions, or even reach a point where decisions need to be made on their behalf.

Decisions to be considered

When patients are unable to make decisions for themselves, informed decisions may need to be made for them. The ultimate responsibility for medical and treatment decisions rests with the health care professionals responsible for that patient’s care. However, these professionals may seek your views on a number of issues:

- Has your relative/friend ever expressed any preference about where they would like to live in the event they are having difficulty caring for themselves? For example, they may have strong views about remaining at home, or the suitability of a nursing home placement.
- If offered a choice, where would your friend/relative ideally like to be cared for if they were dying (hospital, nursing home, hospice, at home)? A recent study found that those patients receiving specialist end-of-life-care at home were twice as likely to die in a manner of their choosing. (www.nuffieldtrust.org.uk/publications/marie-curie-nursing)
- If a patient is discharged from hospital towards the end of their life, it is sensible and appropriate to plan for further deterioration in their health. This should involve discussions and advice on how to react to symptoms and side effects. For example, whether readmission to hospital would be in their best interests or whether providing specialist end-of-life-care in their own home would be preferable.
- Have they ever discussed resuscitation? This is the process where if the patient stops breathing or their heart stops beating, artificial and aggressive measures can be taken to try to revive them. Unfortunately, in patients with multiple or serious / terminal illness, this process is usually unsuccessful and is often distressing for both patient and family/friends.
- There may come a time where your relative/friend has difficulty eating and drinking. As dementia or other illnesses progress, a person’s desire to eat and drink often lessens and food and drink may no longer be wanted or needed. In this situation it may not be appropriate to artificially support them with feeding tubes or intravenous fluids. If the person has expressed views about this in the past, it is important that we are told about them.

- If your friend/relative is approaching death you may be consulted about the End of Life Care Plan. This is a care plan used to guide staff in ensuring that patients who are in the final stages of life receive the best possible care, regardless of where they choose to die. This is agreed by the patient's professional care team in full consultation with, and with the consent of, family/friends.
- Most patients will already have decided whether or not they would want to be an organ or tissue donor (e.g. donation of eyes, bone, skin and other connective tissues) after their death. This is often through carrying an organ donor card, or by registering on the National Organ Donor Register. Our policy is to support these wishes as they benefit others by the generous donation of tissue. If you think that this is something that your loved one had expressed as a wish, please speak to a member of staff or contact a specially trained nurse from NHS Blood and Transplant who will give you more information about tissue donation. They can be contacted via pager on 0800 432 0559, and you can leave a message.
- Would your friend/relative want anyone else to be involved in making decisions? For example, are there any other relatives or friends who would be able to represent their views and wishes? If so we need to be informed about them at an early stage.

These are some of the terms you may encounter and may be important in discussion

- The **Mental Capacity Act 2005** for England and Wales supports and protects people who may lack capacity to make some decisions.
- **Capacity** refers to the ability to make a decision. Assessing capacity and maximising capacity are essential aspects of the care planning process. Capacity is decision-specific and should be presumed, unless a person is unable to understand and retain information prior to reaching and communicating that decision.
- **Care planning** involves assessing a patient's needs, preferences and goals of care, and deciding about how to meet these. This can involve immediate or future needs, and making appropriate arrangements or contingency plans to address these. Where a patient lacks capacity to decide, care planning must focus on determining their *best interests*. If a patient who has lost capacity has a valid and applicable Advance Decision to Refuse Treatment (ADRT) and / or has registered Lasting Powers of Attorney (LPA), these must be respected. Anything done under the authority of the LPA must be in the patient's best interests. If a patient who lacks capacity has no close family or friends and has not recorded any choices about their care and treatment or made an advance decision to refuse treatment in advance of losing capacity, then an *Independent Mental Capacity Advocate* (IMCA) should be consulted.
- **Advance care planning** is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their *medical condition* may affect them in the future. This may include:
 1. **Advance statements** to inform subsequent best interests decisions;
 2. **Advance decisions to refuse treatment** which are legally binding if valid and applicable to the circumstances at hand;

3. **Appointment of Lasting Powers of Attorney** ('health and welfare' and/or 'property and affairs').

Best interests

When patients lack the capacity to make certain decisions, a decision needs to be made on their behalf. This is described as a 'best interests' decision.

If there has not been an appointed deputy, the 'decision-maker' is usually the person responsible for the person's care at that time. This is usually a health or social care professional, but can be a relative or partner. It is important when determining a best interests decision to consider:

- The patient's past and present wishes and feelings - these may have been expressed verbally, in writing, or through behaviour or habits.
- Any beliefs and values (e.g. religious, cultural, moral or ethical) that would be likely to influence the decision in question.
- Any other factors the patient themselves would be likely to consider if they were making the decision, or acting for themselves.

Talk to us

If you have any questions or concerns regarding the care of your relative/friend, then please raise them with a member of the specialist care team looking after the patient. If you have any comments about this leaflet in particular we would appreciate your feedback.

Other leaflets:

There are other leaflets available which you may find useful:

- 'No decision about me without me": Advance Care Planning - Information for patients, relatives and friends'
- 'The dying process (for relatives and carers)'
- 'Unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR). How it relates to the Mental Capacity Act (MCA) 2005'

More information about planning for the future can be found on:

www.nhs.uk/livewell/endoflifecare/documents/planning_your_future_care%5B1%5D.pdf

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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Next review due: January 2024

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