



Making medical decisions

Summary information for family and friends

Making medical decisions when someone is in a vegetative or minimally conscious state

This information sheet is for the family and close friends of someone who is in a 'vegetative state' or a 'minimally conscious state'. Someone who is in a 'vegetative state' shows no awareness of themselves or their surroundings. Someone in a 'minimally conscious state' shows extremely limited and inconsistent awareness of themselves and their surroundings. They are clearly unable to make their own medical decisions, so this information sheet is about who makes those decisions and how this is done.

These types of decisions can be very complicated and they come under a law called the Mental Capacity Act 2005. They may also be very difficult and emotional for you – the person's family/close friends – so we've tried to set things out clearly and simply here. If you'd like more detailed information about any of the issues covered below, there is a longer booklet mentioned at the end of this information sheet.

What sort of medical decisions might need to be made?

There are three types of decisions about treatment that might come up:

- 1 Treatments that will remove possible discomfort or pain, such as removing an ingrowing toenail or treating a dental abscess.
- 2 Treatments which may be needed for the person to survive, for example giving antibiotics for a life-threatening infection, or resuscitation if the heart stops beating.
- 3 Providing or removing tube feeding.

Doctors will want the person to be comfortable and not in any pain, so would normally carry out the first types of treatment. It is the other two types of treatment that may mean making difficult decisions and it is very important to know how these decisions should be made. This will depend in part on whether or not your relative made any formal plans about their treatment, before they had their brain injury.

Advance planning

Some people have made formal plans in advance about what they would like to happen if they are ever in a position where they can't make decisions for themselves. If your relative has planned in advance, read the section below; if not, you can go straight to section B.

A. If the person in a vegetative or minimally conscious state has made plans in advance

Some people have written down their wishes to refuse treatment in certain situations, and have had this statement signed by witnesses. This is called an 'Advance Decision to Refuse Treatment' and if they have done this in the right way, then this 'Advance Decision' must be followed. If it involves withholding or withdrawing tube feeding, it will need to be checked by the Court of Protection, so that everyone can be sure about what the person meant when they wrote down their wishes, and that what they said relates to their situation now.

Other people have drawn up a document which appoints a friend or family member to make their medical decisions for them, if they are ever unable to do that for themselves. This is called a Lasting Power of Attorney (Health and Welfare) or LPA. This enables the person who's been appointed to take important medical decisions on the ill person's behalf, including – if the document specifically says so – life and death decisions. Drawing up an LPA is a formal process; it is not the same as just naming someone as 'next of kin'. It is also not the same as a Lasting Power of Attorney (LPA) (Property and Finance) which appoints another person to handle their financial affairs if they are unable to do so themselves, but *not* make decisions about their medical care. So you don't have the right to make medical decisions about your relative just because you are 'next of kin' or have an LPA for property and finance. The Court can also appoint a Health and Welfare Deputy under the Mental Capacity Act to make certain decisions for the person. You can find out more information about these issues in the leaflet mentioned at the end of this information sheet.

B. If the person in a vegetative or minimally conscious state has *not* planned ahead

Most people who have a serious brain injury have not planned ahead. The injury is sudden and they were not expecting to lose the ability to make their own decisions. In this situation, it is doctors who make the medical decisions about them. The law says that family and friends are not allowed to make decisions about medical treatment for another adult (unless, for example, they have a Health and Welfare LPA or have been appointed by the Court to be a Health and Welfare Deputy – see Section A above). Even when you feel that you should be the one to decide what's best for someone you're very close to, the law may say that doctors (or the Court) have to decide. For some people, this may be hard to bear, but for others it may be a relief to have someone else making these very difficult decisions.

When doctors make decisions, they must always take into account what the person themselves would have wanted. This is why family and friends have a very important role to play and doctors need to consult them. The patient might have had a view about what they would want, so doctors need to find out from you – the patient's family/close friends – what that view would have been. This would apply to decisions like giving someone medicine to try to cure an illness that they could die of. If your relative/friend would have wanted to be allowed to die, then you should tell the doctors, and they should take that view into account.

One key point to remember is that you need to think about what *your relative* would have wanted for themselves, which is quite separate from what *you* think is best for them.

Can I refuse treatment on my relative's behalf?

No, you can't refuse treatment on your relative's behalf (unless you have a Health and Welfare LPA or the court has appointed you a Health and Welfare Deputy; see Section A above). The doctors have to make the decisions about the patient's treatment, but as it says above, you should tell the doctors about what your relative/loved one would have wanted.

Can I insist on particular medical treatment for my relative?

No, you can't make doctors treat them if they don't think the treatment is the best thing for the patient. But you can tell the doctors about what your relative/close friend would have wanted.

Do I *have* to be involved in these medical decisions?

No, not if you don't want to be. It is important to tell doctors what you think your relative would have wanted, but you are not responsible for these decisions, and you can decide not to be involved at all, if you prefer. You could also ask for a professional advocate to speak for

your relative if you don't feel able to do this yourself. This advocate is called an 'Independent Mental Capacity Advocate'. Some people find it easier if an advocate speaks for their relative, because they don't feel able to represent what their relative would want. Some people prefer doctors to make these decisions, because they think doctors probably understand more about their patient's condition and the chances of them ever recovering.

How will doctors decide whether or not to resuscitate my relative if she or he has a heart attack?

You may be asked to help the doctors in advance with their decision about resuscitation, because the medical staff will need to know what to do immediately if your relative's heart stops beating. If the doctors come to the decision (after discussing this with you) not to attempt resuscitation, then a note will be put in your relative's records saying 'DNACPR' – meaning 'Do not attempt cardiopulmonary resuscitation'. This does not mean that other kinds of treatment will be withheld – 'DNACPR' refers *only* to cardiopulmonary resuscitation. It does not mean that your relative would not be given antibiotics if they got an infection, or a ventilator if they had difficulty breathing.

Can doctors decide to remove my relative's feeding tube?

No, they can advise on this course but any decision about stopping tube feeding has to be decided by the Court.

If your relative is diagnosed as being in a 'permanent vegetative state', then it is necessary in law for doctors to consider stopping life-sustaining treatment, but a court will consider the evidence and make the decision. If the person is not in a permanent vegetative state but in a minimally conscious state, it may still be in their best interests to consider stopping life-sustaining treatment but, again, a court will consider the evidence and make the decision. The medical term for removing the feeding tube is 'withdrawing clinically assisted nutrition and hydration' (CANH).

How should doctors decide what's in someone's 'best interests'?

Doctors have to find out what their patient would have wanted, whether this was written down, or said to family or friends, or implied in their behaviour or attitude to life. This should be discussed between the doctors and the patient's family and close friends. If people have different opinions about what their relative/loved one would have wanted, then the doctors will have to make a decision based on the evidence available (which may not be the same as a 'majority opinion'). If you aren't happy about the decision being taken, or feel that doctors aren't listening to what your relative/loved one would have wanted, then you can do a number of things, such as ask the doctors to reconsider, or get a second opinion from

another doctor, or make a formal complaint to the hospital, or get a lawyer specialising in medical law to advise you. It may also be possible to ask for help, for example from an advocate such as an Independent Mental Capacity Advocate, mentioned above.

When does the Court get involved?

Most decisions on medical treatments can be taken after discussion between the family and the doctors. But if they don't agree, it can go to the Court of Protection and a judge can decide. Decisions about withdrawing the feeding tube always have to go to Court.

For more information about any of the issues discussed above, please read the longer booklet on this subject, called *Serious medical decisions regarding people in vegetative or minimally conscious states: the role of family and friends*, available online at www.rcplondon.ac.uk/pdoc/family

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