

Clinically-assisted nutrition and hydration: your role in decision-making

A guide for family and friends



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About this leaflet

This leaflet is for the family and friends of those for whom a decision is needed about whether to provide or continue to provide clinically-assisted nutrition and hydration (CANH) in England and Wales. Those who are able to make and communicate their own decisions can decide for themselves whether to accept or refuse CANH. This leaflet explains how decisions about care and treatment are made for those who are not able to express a view about what they would like to happen for themselves.

It includes information about what CANH is, why it might be provided, and your role in contributing to the decision about providing or not providing it.

You might find some of this information difficult to read, or not all of it might be relevant to you at the moment. This leaflet has been designed so that you can come back to it and find the relevant information when you need it.

This leaflet should not replace face-to-face discussions with the doctor who is in charge of your loved one's care, and you should make sure that you speak to him or her as well as using this leaflet for information. We have also included a list of useful resources at the end of this leaflet in case you want further information or support.

What is CANH?

Clinically-assisted nutrition and hydration (CANH) is provided when someone has a medical condition that means they are unable to swallow, and so cannot eat or drink in the usual way. If it is not provided, a person will die. With it, some people could possibly go on living for a long time, in some cases, many years.

CANH involves giving a person a liquid that contains nutrition or hydration. This can be given through a tube through the nose, a tube directly into the stomach (sometimes known as a PEG feed) or an intravenous drip (directly into a vein). It is different from helping people to eat or drink by mouth, for example spoon-feeding or helping someone hold a cup to their mouth.

Although some people do not see a difference between clinically-assisted nutrition and hydration and helping someone to eat or drink in the usual way (which is part of “basic care”), the law is clear that CANH is a form of medical treatment which, like all other kinds of medical treatment, can only be provided if it is in a person’s best interests to receive it.

If the doctor treating your relative does not agree with the law on this point, he or she may have a ‘conscientious objection’ to stopping (or not starting) treatment. There is professional guidance for doctors who have conscientious objections to particular treatment decisions: the General Medical Council says that they should hand over the care and decision-making for the person to a colleague, and you can ask for this to be done.

How are decisions about treatment made?

People who are able to make decisions for themselves can decide which of the treatments available they would want to receive. If a person is not able to decide for him or herself (if they “lack capacity” to decide), decisions must usually be made on their behalf, on the basis of what is in their best interests. The information in this leaflet only applies when a person lacks capacity – that’s when family and friends have a formal role to play in decision-making by providing information about their loved one to help the medical staff make a judgement about their loved one’s best interests.

When might someone receive CANH?

CANH can be provided when someone can no longer eat and drink in the usual way. Commonly, this will include:

- people who have a neurodegenerative condition, for example, Parkinson’s or Huntington’s disease, at a time where they are no longer able to swallow. Their condition means that they are on a decline, and will inevitably die, although some people can go on living for many years if provided with CANH.
- people who suffer a serious and sudden or a rapidly progressing brain injury, but at the same time are already so unwell that they are not expected to live for much longer. This might include a very frail and elderly person who experiences a severe stroke.
- people who were healthy but have suffered a very serious and sudden brain injury, for example, after a stroke or a road traffic accident. These people are sometimes referred to as being in a “vegetative state” (or VS), or a “minimally conscious state” (or MCS). This means they have no, or very little, awareness of their existence or surroundings.^a After a period of time, some people may regain a level of awareness and ability to interact but others will remain in that condition for the rest of their lives.

Sometimes CANH will be given for a short period to allow the person time to recover, or while tests are carried out to see how serious their injury or illness is. In other cases it could be continued for months or years.

It will usually be appropriate to give CANH to a person who is unable to eat or drink, in order to keep them alive. But sometimes, the doctors caring for a person will feel that their injury or condition is so bad that continuing CANH will no longer help them. Or family members or friends may feel that their loved one would not want to be kept alive with CANH, and that their loved one would want it to be stopped.

The doctor should provide you with unbiased, honest, and realistic information about the person’s condition, the provision of CANH, and the level of recovery that can be expected. You might want to take some time to think about the type of information you want to know, and what to ask the doctor about.

a We recognise that some people find the term “vegetative state” (VS) offensive or upsetting but we have used it here because it is the most widely used clinical term in the UK for this condition, and it is the term the medical staff are likely to use in their discussions with you.

A decision will then need to be made about whether the person would want CANH to be provided. If, after assessing the individual's best interests, the person's doctor takes the view that they would not, then another senior clinician will be asked to provide a second opinion. If they agree with the decision that CANH would not be in the person's best interest, it will be stopped and attention will be focused on providing high quality end-of-life care until they die.

Some people believe that not providing life-sustaining treatment is just euthanasia by another name, but the law in the UK is clear that the two are very different. Euthanasia and assisted suicide involve taking active steps with the intention of terminating a person's life. The intention behind a decision to withdraw treatment is to stop providing medical treatments and interventions that are not able to benefit the person, allowing them to die from their pre-existing condition.

Who makes the decision?

A lot of people assume that, as family members or "next of kin", they are allowed to make decisions on behalf of their relative, but this is usually not the case.

Some people may have made formal plans in advance to say what they would like to happen to them if, in the future, they cannot make decisions for themselves.

One way of doing this is by something called an Advance Decision to Refuse Treatment (an ADRT or "living will"), which allows a person to record any medical treatment that they do not want to receive in the future, in case they later lack capacity and cannot communicate a decision themselves. If this meets certain requirements, it is legally binding and doctors must follow it.

While they are still able to make decisions for themselves, some people choose to appoint someone close to them to be a Health and Welfare Attorney, with the power to make health decisions on their behalf. This is often referred to as a Lasting Power of Attorney, or an LPA. If the person has formally appointed you as a health and welfare attorney, and has given you authority to make decisions about life-sustaining treatments when they lack capacity, then you will be asked to make the decision that is in their best interests. The health care team is there to help and support you through the process. You can also find more information about how to act as an attorney at the website of the Office of the Public Guardian, at: <https://www.gov.uk/lasting-power-attorney-duties>

If someone else has been appointed as an attorney, you should still be able to provide information to help them make the decision that is right for your loved one.

If there is no LPA, someone in the medical team (normally the senior doctor) will be the "decision-maker" – but this does not mean that they are allowed to make any decision that they want. The decision must be made on the basis of the person's best interests – we explain more about what this means below.

What are best interests?

If a person lacks capacity to make a decision, then (unless they have already made that decision for themselves in an ADRT) that decision will be made by their doctor or health and welfare attorney. If this happens, decisions have to be made in the person's best interests.

A best interests decision is based on the person's past and present wishes, feelings, values and beliefs. It should be the decision the person would make for themselves if they could.

The Mental Capacity Act 2005 says that the decision-maker must consider:

- all the relevant information, including the potential benefits or risks of a particular treatment, or any long-term consequences of giving or withholding the treatment such as the impact on the person's quality of life;
- the person's past and present wishes and feelings, including any wishes they have previously expressed or written down;
- any values and beliefs they have that would be relevant to the decision; and
- the views of their family members, carers and other relevant people.

Who is involved in best interests assessments?

The Mental Capacity Act 2005 says that the people consulted should include “anyone named by the person as someone to be consulted on the matter in question or on matters of that kind” and “anyone engaged in caring for the person or interested in his welfare”. This is likely to include:

- family members
- friends
- anyone else who knows the person and might be able to provide relevant information about their views, such as a colleague or a neighbour
- anyone involved in caring for the person, such as doctors, nurses, therapists or carers.

The number of people who need to be involved in the discussions will depend on factors like how ill the person is, whether there is a chance of improvement in the person’s condition and how long they could live for if CANH is provided. If you are aware of other people who might have important information about the person to share – work colleagues or neighbours for example – you should let the doctors and nurses know.

The person making the decision also needs to find out who the person was as an individual, before they became ill – for example, what they did for work, what they enjoyed doing, their relationships with others and anything that was important to them, like religious or ethical beliefs. The aim is to try to agree whether the person would want CANH provided in the situation they are now in.

This doesn’t mean that you are being asked to make a decision or judgement about what should happen, or to say what you would want to happen to you if you were in a similar situation. You are being asked to share what you know about the person and what they might want so that the right decision can be made about their treatment.

Wherever you can you should provide examples or evidence to support your views. This could be comments made by the person in an e-mail or on social media, for example. If the person had experience of a family member with a similar condition, the doctor will want to know that. This type of information can be really helpful for doctors to assess whether the person had actually thought about the issue or was making a ‘throwaway remark’ that was not intended to be acted upon.

While doctors do their best to provide accurate information to families, not all patients respond in the same way and so it is often not possible to say for certain whether their condition will improve or not, and by how much. Instead, doctors will usually give you an idea of the “best” and “worst” outcome you can expect. So, when considering what the person would want you need to look at both of these possibilities.

What kind of information is needed?

What is the person's current condition?

What will happen if CANH is continued? What will their life be like?

What were they like before becoming ill?

What was their job? Did they have any hobbies?

How will their condition affect how they participate in activities or interests that are important to them?

What did they like or dislike? What was important to them?

Did they do or say anything which shows how they might feel about their current situation?

How aware is the person of what is happening?

Did they write anything down (in a diary, in e-mails/ letters, on social media)?

What will happen if CANH is withdrawn? What end-of-life care would be provided?

Did they have any religious or spiritual beliefs?



Clinical information



Personal information

This is a lot of information to think about and explain, and you might find it difficult to think about many of these questions. You might find it helpful to start thinking about these questions early on in the person's care, even if a decision isn't needed straight away. You might also like to take some time to think about it and discuss it with other people, or write it down – and your doctor should be happy with you doing that.

You might find that you and other family members and friends have different ideas about the person's personality and what he or she may have wanted. This is to be expected, because everyone knows the person in a different way and will have had different types of conversations with them. You should focus on sharing what you know about the person.

The doctor might also decide that it will be best to hold a formal "best interests" meeting. This is a meeting which brings together everyone who has an interest in the welfare of the person – including medical and other healthcare staff, and family members and others who know the patient well and have relevant information to share. It allows everyone to have their say and for everyone to work together to reach the right decision for the person.

Minutes of this meeting will be kept as part of the person's medical records and you should be given a copy. If you are not sent a copy of the minutes after the meeting, you should ask to be given a copy so that you can check it matches your understanding of what was said and agreed. If you do not agree with what is said, you should let the person who chaired the meeting, or the doctor in charge of your loved one's care, know.

Sometimes doctors – with your permission – will make an audio recording of the meeting, and they should share this with you afterwards. You can ask for a recording to be made, either by you or by the clinical team, if the possibility is not offered to you.

Do I have to be involved?

You might decide that you do not want to be involved in the decision-making process – perhaps because you do not feel you can comment on what the person would want, or because you don't want to feel responsible for contributing to the decision.

You are allowed to choose not to be involved in the decision-making process. If you do not want to be involved, you should make sure that you tell the doctor in charge so that they can record this in the person's medical records.

If all family and friends opt out of being involved in the decision-making process, then a doctor must appoint an independent mental capacity advocate (IMCA) who will represent the person's voice in discussions. You can find out more about what an IMCA does at: <https://www.scie.org.uk/mca/imca/do>

What if I disagree with the decision the doctor wants to make?

Most decisions can be made as a result of discussions between the clinical team and family and friends, but in some cases there will be disagreement or dispute about what is in the person's best interests.

If you do not agree with the decision that has been made, you should start by raising your concerns with the decision-maker, who may be able to give you more information and explain why they have come to the decision they have.

If you still disagree, you can request a second opinion or ask for a "case conference" to be held to review the decision. The doctor might also suggest asking a mediator, or someone else with experience of this situation, to help everyone involved in talking about the issues. You can also ask the doctor or someone else involved in the care of your loved one whether there are any sources of information or support to help you as part of this.

In some cases, if none of this resolves the disagreement, then the NHS body providing or funding your loved one's care might ask a judge at the Court of Protection to decide. If this happens, you may need to seek legal advice about what to expect and to help you through the process. There are other organisations that can help, such as the Coma and Disorders of Consciousness Research Centre – you can find out more about some of the support available at the end of this leaflet.

What to expect if CANH is continued

In some cases it will be decided that CANH is in the person's best interests and that it should be continued. Where this is the case, the decision should be reviewed periodically to make sure it continues to be the right decision for the person. In between these regular reviews, you can ask for another discussion if, for example, the person's situation changes, or you feel that the decision should be reconsidered.

What to expect if CANH is stopped

A decision to stop CANH does not mean that all other types of treatment, and care, will be stopped as well. Any decision to stop CANH should be made at the same time as deciding on a plan for how end-of-life care will be managed – including where that will take place and how pain or any other distressing symptoms will be handled. You might find it helpful to ask the doctor what this will involve and what you can expect, as well as any other questions about what will happen when CANH is withdrawn.

Families of people who have died following the withdrawal of CANH report different experiences of the death of their loved one, but many report that, with high-quality end-of-life care, their relative's death was "peaceful". You can watch videos of some family members describing what death following withdrawal of CANH was like at the Healthtalk website. You can find out how to access this below.

Families of people who have died following the withdrawal of CANH say that their experiences of bereavement can be quite different from other types of loss. Some people feel that they "lost their relative" a long time before the death, or that the death is a "release". For others it will be the end of a distressing period of time in which they may still have hoped for recovery. However it is experienced, you may want to speak to your doctor about any support services you might be able to access.

Further information

The following are resources which you might find helpful.

- [The Mental Capacity Act 2005 \(www.legislation.gov.uk\)](http://www.legislation.gov.uk) and its associated [Code of Practice \(www.gov.uk\)](http://www.gov.uk) – this states the law in this area.
- You can find more detailed guidance about the role of family and friends in making medical decisions in a [leaflet](#) from the Royal College of Physicians and the Coma and Disorders of Consciousness Research Centre (www.cdorc.org.uk). (Note that this leaflet is slightly older, and still refers to decisions having to go to the Court of Protection. This is no longer the case.)
- You can visit [Healthtalk \(www.healthtalk.org\)](http://www.healthtalk.org) to view filmed interviews with other family members who have been through a similar process, and read more information about how you might be feeling and the decisions you might be involved in.
- The research organisation that produced these videos is called the Coma and Disorders of Consciousness Research Centre. The Centre is able to provide help and support to families of patients in VS or MCS. There is a lot more information (including how to contact them for help or support) on their website: www.cdorc.org.uk
- The Royal College of Physicians and the British Medical Association have published guidance on how doctors should be making these decisions which you can find at www.bma.org.uk/CANH.
- The [Royal College of Physicians](#) has also published guidelines on the care of people in a prolonged disorder of consciousness (VS or MCS), which is much more clinical: www.rcplondon.ac.uk
- SCIE (Social Care Institute for Excellence) has useful information about Independent Mental Capacity Advocates (IMCAs) and their role: www.scie.org.uk/mca/imca/do
- Compassion in Dying is a national charity which supports people to plan for their treatment and care, in case a time comes when they cannot make decisions. You can find out more information about how they can assist by going to www.compassionindying.org.uk.

Glossary

Advance decision to refuse treatment (ADRT)

An ADRT allows an individual to record a wish not to receive particular forms of treatment in the future if they lack capacity to make decisions for themselves. If it is valid and applies to the person's situation, an ADRT will be legally binding.

Best interests

The Mental Capacity Act 2005 says that any decision made for a person who lacks capacity, and who does not have an ADRT, must be made in his or her best interests. The primary aim of best interests assessments is to find out about the person's past and present values, wishes, feelings and beliefs in order to make the decision that is right for that person.

Capacity

Capacity is the ability to make a decision for yourself. A person lacks capacity to make a particular decision if they have an impairment or disturbance of the brain (for example, because they are unconscious, have dementia, a mental health condition or a brain injury), and, as a result of that impairment cannot:

- understand information relating to a decision;
- retain that information for long enough to make a decision;
- take that information into account when making a decision; and
- communicate a decision.

By this definition, a large number of people who receive CANH will lack the capacity to make their own decision.

Coma

Someone is considered to be in a coma if they are unconscious for more than six hours. Being unconscious means that they cannot be woken and they do not respond to light and sound. Sometimes people recover from their coma. But if a coma lasts for more than a few weeks, it usually means that the person will die, or that when they emerge from their coma they will be in a vegetative state or minimally conscious state.

Court of Protection

The Court of Protection is responsible for making decisions on financial or welfare matters for people who cannot make decisions for themselves at the time they need to be made. Recent judgments from the Court of Protection are available on a public website here:

<https://www.bailii.org/recent-decisions.html>

End-of-life care

The total care of a person with an advanced incurable illness. The end-of-life care phase may last for days, weeks, months or even longer. It is defined as care that helps those with advanced progressive, incurable illness to live as well as possible until they die. It includes the prevention and relief of suffering through the assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Lasting Power of Attorney

A lasting power of attorney (LPA) allows an individual to appoint someone (an attorney) to make decisions on their behalf if, in the future, they become unable to make decisions for themselves. There are two types of LPA – one covering health and welfare decisions (which would cover medical treatment) and one covering financial matters.

Minimally conscious state

If someone is in a minimally conscious state, it means they are awake but have only a small level of awareness and minimal response to things around them. For example, they may be able to respond to simple questions with words or movements. However, such awareness can come and go. If someone shows these symptoms for more than four weeks, they are diagnosed as being in a continuing 'minimally conscious state'. It is difficult to diagnose when a minimally conscious state becomes permanent, but evidence suggests that it would be very rare for someone to recover to full consciousness after five years.

Vegetative state

If someone is in a vegetative state, it means that they are awake but do not have a conscious awareness of themselves or their surroundings. If the symptoms of a vegetative state last for more than four weeks, this is referred to as a 'continuing vegetative state'. If the symptoms persist for one year after a traumatic brain injury (caused by a trauma to the head), or six months after any other acquired brain injury (such as a tumour or a stroke), the person may be diagnosed as being in a permanent vegetative state. If someone is in a permanent vegetative state, this means that it is very unlikely that they will ever recover consciousness.

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British Medical Association, BMA House,
Tavistock Square, London WC1H 9JP
bma.org.uk

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