

## Electronic Annex 4b

# Decisions about life-sustaining treatment and people in prolonged disorders of consciousness: The role of family and friends

### 1 Who is this booklet for?

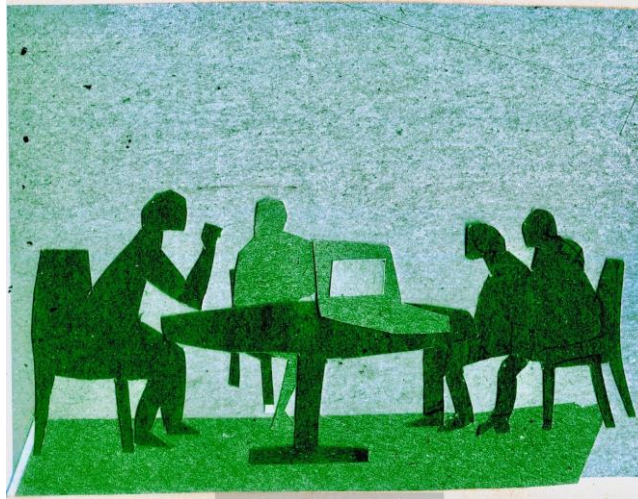
The aim of this booklet is to support family and friends of patients in a prolonged disorder of consciousness (sometimes referred to as ‘vegetative’, ‘minimally conscious’ or ‘low awareness’ state).

Friends and family do not have the legal right to make decisions on behalf of an adult who is unable to make decisions for themselves (unless the patient appointed you as their Health and Welfare Attorney). But you do have an important role to play in decision-making, and doctors need to consult you about the patient’s wishes, values, feelings and beliefs. This booklet will explain who should consult you and how you can best contribute. You also have the right to decide that you don’t want to be involved.

You might find some of this information difficult to read, or you may feel it isn’t 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 booklet should not replace face-to-face discussions with the doctor who is in charge of the patient’s care. If you have not had a discussion with him or her, or if you’re not sure who that person is, this leaflet will help you to make contact and to feel more confident about that conversation. If you are in conflict with that doctor, we have some information here to help you try to resolve the situation.

We’ve also included a list of useful resources at the end in case you want further information or support. We include a link to the Mental Capacity Act 2005: it is this act which provides the legal framework for decision-making on behalf of people who lack the capacity to make their own decisions.



## 2 What are 'life-sustaining' medical decisions?

'Life-sustaining' medical decisions are decisions about whether to start, restart, continue or withdraw treatments that might extend the patient's life.

These treatments can include:

- > cardiopulmonary resuscitation (CPR)
- > artificial ventilation
- > antibiotics for potentially life-threatening infections
- > return to the intensive care unit
- > the feeding tube (clinically assisted nutrition and hydration).

Sometimes a patient may be receiving other life-sustaining medications due to an underlying condition that may have existed before the disorder of consciousness (eg insulin for a type 1 diabetic; blood pressure medication for someone with hypertension). Preventative medical treatments (like flu jabs) are also potentially life-sustaining. The term 'life-sustaining' medical decisions covers all of these. (Note: It does not cover oral feeding – ie food or liquid given to the patient by mouth because this is not a medical treatment.)

It is generally presumed that staying alive is what the patient would want, and that giving life-sustaining treatments is in their best interests. But if there is strong evidence to show that the person would not want such treatments, then they can be stopped.

## 3 Who makes decisions about life-sustaining medical treatments?

People who are able to make decisions for themselves can decide which of the treatments available they would want to receive. Legally, a person has the 'mental capacity' to make decisions for themselves if they can:

- > understand information relevant to the decision to be made
- > remember it long enough to consider it during the decision-making process
- > weigh the pros and cons of deciding one way or the other
- > communicate the decision.

A patient is not showing that they have mental capacity to decide *in favour* of treatment simply because they passively accept or cooperate with the administration of treatment. Equally, a patient is not showing that they have mental capacity to decide *against* treatment simply because they resist treatment or pull out tubes.

By definition, a patient in a prolonged disorder of consciousness does *not* have the mental capacity to make decisions about life-sustaining medical treatment. This usually means that someone else has to make decisions on their behalf. The only exception is if the person has already made their own decision in a written ‘advance decision to refuse treatment’. Otherwise the decision-maker is usually the clinician with overall responsibility for the patient’s care, unless the person had previously appointed a Health and Welfare Attorney with the relevant powers.

It should always be clear who has responsibility for deciding whether a medical treatment should be provided or continued, and this information should be made available to everyone involved with the patient.

Once a person has lost the capacity to make medical decisions for themselves, the decision-maker may be:

- (a) still the patient (if they have produced a special type of written document in advance)
- (b) a particular individual appointed to make decisions for the patient
- (c) a named doctor (usually whoever has overall clinical responsibility for the patient’s care) – this is the default position if (a) or (b) has not been done.

Each of these is explored in the boxes 1–3.

**Box 1: Who is the decision-maker? – The patient**

An advance decision to refuse treatment (ADRT or 'living will') is a way someone can plan ahead for a situation where they may lack the capacity to make medical decisions for themselves in the future. It allows a person to record any treatment that they do not want to receive if they were to lack capacity to decide for themselves (eg 'if I'm ever in a prolonged disorder of consciousness I refuse clinically assisted nutrition and hydration'). If this meets certain legal requirements, it is legally binding and doctors must follow it. Giving the treatment that has been refused in a valid and applicable advance decision can be assault, battery or civil trespass.

Doctors should ask you whether the patient has an ADRT. If you know that they have an ADRT, you must give it to the doctors right away. The hospital doctors (or the GP at the care home) should also ask the patient's original GP whether there is an ADRT on file at the surgery. (It's worth checking that they've done this since sometimes ADRTs go astray and family do not always know that the person has made one.)

If there is an ADRT it's likely that the clinicians will check with lawyers that it is valid and applicable. If it is, they cannot give treatments that the person has refused. There is no need to have a 'best interests' decision-making meeting about whether or not that treatment is in the person's best interests – indeed, you cannot make a 'best interests' decision for the person, because they have already refused the treatment for themselves.

If you are told that the ADRT is not valid and applicable but you believe that it may be, it is a good idea to get independent advice on this (eg from a charity like Compassion in Dying or from a solicitor for the elderly). Sometimes NHS lawyers (or doctors) have decided an ADRT is not valid or not applicable, but it later turns out that it was. Even if it is agreed that the ADRT is not valid or applicable, it should inform *best interests* meetings (see below).

If you want to make an ADRT for yourself (many family members and friends of people in prolonged disorders of consciousness do!), there is a pro forma included as an annex to the guidelines and a charity called Compassion in Dying has an information line that can help you for free (see 'Resources').

### **Box 2: Who is the decision-maker? – Health and Welfare Attorney**

Another way people can plan ahead is by appointing someone they trust with the power to make decisions on their behalf. This is often referred to as a Lasting Power of Attorney (LPA). There are two different kinds of LPA – one for health and welfare and one for property and finance. If the patient has formally appointed you as a Health and Welfare Attorney (often abbreviated to simply ‘Welfare Attorney’ or ‘Health LPA’) and has given you authority to make decisions about life-sustaining treatments when they lack capacity, then you will be asked to make those decisions in their best interests. The healthcare team is there to help and support you through the process. You can also find more information about how to act as an Attorney here: [www.gov.uk/lasting-power-attorney-duties/health-welfare](http://www.gov.uk/lasting-power-attorney-duties/health-welfare)

If someone else has been appointed as a Health and Welfare Attorney, you should still be able to provide information to help them make decisions that are right for the patient. They have a responsibility to consult with others about what the patient would have wanted. If the patient did not appoint an LPA, it is not possible for one to be appointed after they have lost capacity, but in some circumstances it is possible for a relative or friend of the patient to be appointed by the courts as a Welfare Deputy. The role of Welfare Deputy, unlike the role of LPA, does not include the legal right to refuse life-sustaining treatments for the patient.

If you want to appoint an LPA for yourself in case you are ever in this situation in future you can do so via a solicitor or by completing the forms for yourself on this website: [www.gov.uk/power-of-attorney/make-lasting-power](http://www.gov.uk/power-of-attorney/make-lasting-power)

Note that the law does not permit appointment of a decision-maker by naming them in an advance decision to refuse treatment (ADRT) or advance care planning statement. Some older ADRT forms included a box where the person could name someone they wanted to be consulted or to act as a ‘healthcare proxy’. Any such person named on an ADRT should be consulted (along with other family, friends and those who care for the patient) but has no decision-making rights. All valid and applicable decisions made by the patient in the ADRT must be complied with. Decision-making power about decisions not covered by the ADRT will remain with the doctor and should NOT be made by anyone nominated by the patient as someone to be consulted. The only way of giving decision-making power to a family member or friend is by appointing them as a Health and Welfare Attorney.

### Box 3: Who is the decision-maker? – Doctors

If someone has not made an advance decision to refuse treatment (ADRT), and has not appointed anyone as their Health and Welfare Attorney, then all decisions about life-sustaining treatment are made by someone in the medical team, normally the senior doctor with overall responsibility for the patient's care. This doctor is 'the decision-maker'. You should be informed who this person is. Everyone close to the patient and the whole treating team should be involved in decision-making, but one particular individual should be named as having formal decision-making responsibility.

The decision-maker is not allowed to make any decision that they want simply on the basis of clinical judgement, for example, or what they believe is the right thing to do. The decision must be made on the basis of the person's best interests – and proper procedures followed to determine what those 'best interests' are. 'Best interests' is a term used in law, and it is explained in the Section 5 – and it includes careful consideration of what the patient themselves would have wanted.

The doctor should consult family and friends ('anyone engaged in caring for the person or interested in his welfare', Mental Capacity Act 2005) – because that is a way of finding out about the person as an individual, but in the end, it is then up to the doctor to determine what is in the patient's best interests. (See Section 7 on what happens if there is a disagreement between you and doctors about treatment decisions.)

## 4 The role of family and friends in decision-making

A lot of people assume that 'next of kin' have the legal right to make medical decisions for a loved one if that person can't decide for themselves. That is not the case. The phrase 'next of kin' has no legal meaning in this context. You may have been named as 'next of kin' on hospital forms or care home contact lists, but that is simply an administrative convenience so that staff know who to contact. You may even have been asked to sign forms giving your 'permission' for various treatments doctors have recommended or decisions they have made. These forms certainly give the impression that you have the power to give or refuse consent to treatment on behalf of your relative, but this is very misleading. You may have already discovered that, if you disagree with a course of action, doctors will explain to you that they are the decision-makers, not you.

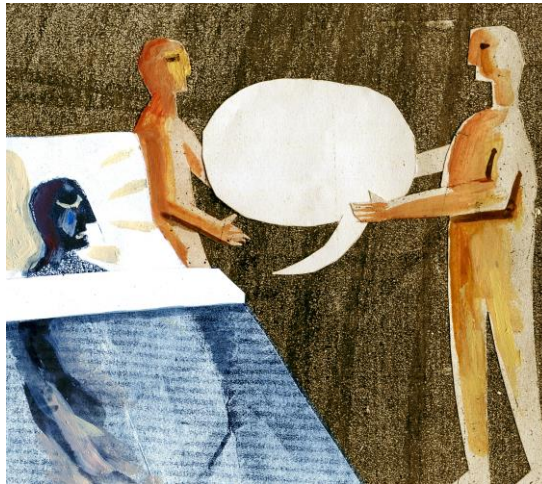
The idea of 'next of kin' also suggest that just one person is privileged to speak for the patient, or to have access to medical information about them. In fact, no one automatically has 'more say' than another simply by virtue of their status as the patient's parent, for example, or their spouse. The doctors should listen to everyone who has information to contribute about the patient's wishes and consider that information on its merits.

So, although doctors have formal responsibility for decision-making, family and friends have an important role to play by providing information about the person's values, wishes, feelings and beliefs so that the decision can be made in the person's best interests. The Mental Capacity Act 2005 doesn't specifically name 'next of kin' or 'family' or 'friends'.

It says that doctors are expected to consult:

- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- (b) anyone engaged in caring for the person or interested in his welfare,
- (c) any donee of a lasting power of attorney\* granted by the person, and
- (d) any deputy\* appointed for the person by the court.

[\*See glossary for definition of these terms]



This means that you (and the doctors) should consider all the people who might have relevant information to provide about what the person's wishes might be in this situation. This might include – in addition to family and close friends – neighbours, colleagues at work, people who did leisure activities with the patient, and member of clubs, societies, political groups or religious organisations that the person participated in. In any given case it may be appropriate to ask lots of people, or just a few people they were close to – depending on the sort of person they were and how they interacted with others. If you think someone might have something to contribute about the person's wishes, you can contact them and ask.

Doctors are responsible for providing you with information about the person's current situation and what the future holds for them. Unless the person has previously indicated that they do not want medical information revealed about them, it is reasonable for the doctor to share this information with everyone 'engaged in caring for the person or interested in his welfare'. You need unbiased, honest and realistic information about the person's condition and the level of recovery that can be expected before you can make a decision about whether or not they would have consented to treatment under these circumstances. 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.

While doctors do their best to provide accurate information to families it is often not possible to say with complete certainty whether a patient's 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 these possibilities – and factor in how the person themselves would have thought about risk and uncertainty in this situation.

It's often a good idea to put your views in writing (or make an audio or video recording). Remember that what you need to communicate is not what YOU would want if were in the patient's situation. You should say what you think the PATIENT would want. It is helpful if, wherever you can, you also provide examples or evidence to support your views. This may be based on how they lived their life, what they enjoyed, their habits and behaviour, or it could be comments made by the person in a conversation, an email or on social media for example. If the person had experience of a family member with a similar condition, and expressed views about what they would want for themselves in that situation, you should let the decision-maker know. This type of information can be really helpful for the decision-maker to assess whether the person had actually thought about the issue or was making a 'throw-away remark' that was not intended to be acted upon. Remember, you are not being asked to decide what should happen or to take responsibility for the decision, your role is to support patient-centred care by giving the decision-maker a clear impression of what the person was like.

You might find that you and other family members have different ideas about the person's personality and what she or he might 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. The fact that there may not be agreement within a family does not mean you should hold back in saying what you think. Try to represent the person as best you can – and it is up to the decision-maker to decide what to do.

## 5 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.

The primary aim of best interests assessments is to find out about the patient's past and present values, wishes, feelings and beliefs, both generally and as they relate to their current situation, in order to make the decision that is right for the individual patient. (BMA/RCP Guidance on CANH)

A *best interests* decision is based on the person's past and present wishes, feelings, values and beliefs. It should reflect 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 family members, carers and others who can provide information about the patient.



The decision-maker should hold a formal ‘best interests’ meeting which allows everyone who has an interest in the welfare of the person to contribute – 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 best possible decision for the person.

If people want their views considered but are not able to attend, they can put them in writing or attend via video link – often this can be set up informally on someone’s mobile phone. If you want to bring someone to support you at this meeting, you can bring a friend (or professional legal or psychological support if you have this available to you).

Before the *best interests* meeting, you should receive an agenda saying what will be discussed at the meeting and in what order and listing the people who are expected to attend and their roles. At a *best interests* meeting to make a decision about life-sustaining treatments you should expect participation from several different clinicians and carers who are currently involved with the patient, along with a palliative care expert who can explain what care will be provided if life-sustaining interventions are not continued. Sometimes (not always) a ‘second opinion’ expert will be brought in at this stage.

The meeting might be audio-recorded to help with writing the minutes and they should share this with you afterwards. If doctors don’t record the meeting, you can ask to record it yourself so that you can listen to it later if you want to remind yourself of what was discussed, or share it with someone who was not able to attend.

After the meeting, you should be sent the minutes – and if you are not sent them it is a good idea to 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 that the minutes are an accurate record of the meeting, you should let the person who chaired the meeting, or the doctor in charge of the patient’s care, know this as soon as possible.

## 6 Do I have to be involved?

Managing the decision-making process sensitively and appropriately in the difficult circumstances of severe brain damage can be challenging for clinicians and for families. 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 can 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.

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

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

Most decisions can be made 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 to help everyone involved in talking through the issues.

Sometimes doctors will suggest that an IMCA becomes involved at this point. Although this can sound like a threat, or a punishment for disagreeing, an IMCA is often very helping in working with you to sort out what the person would have wanted. The IMCA will focus on the patient's wishes and will not take sides with either the doctors or the family. (See [www.scie.org.uk/mca/imca/do](http://www.scie.org.uk/mca/imca/do)).

You might also want to get support from an outside organisation (eg the Coma and Disorders of Consciousness Research Centre which specialises in supporting families at times like this).

In some cases, if none of this resolves the disagreement, then the NHS body providing or funding the patient's care must make an application to the Court of Protection so that a judge can make the decision.

## 8 What if nobody arranges a *best interests* meeting? What if family and friends are never consulted about what the person would want? What if life-sustaining treatment just goes on being delivered whether the person would want it or not?

The law requires doctors to ensure that ongoing treatments delivered to patients who lack the capacity to consent to them are in the patient's best interests. Professional guidance from the British Medical Association and the Royal College of Physicians (endorsed by the General Medical Council) says that *best interests* assessments about decisions to provide clinically assisted nutrition and hydration (the feeding tube) should be regularly reviewed. Unfortunately we know that this is not always happening.

If you find yourself in this situation, the first thing to do is to identify who the 'decision-maker' is (or might be). Usually it will be the GP (if the patient is in a care home or nursing home) but it may be a consultant. You can write to that person (or to both/all of them if you are not sure who the decision-maker is) explaining that you do not think the person would want to continue to receive life-sustaining treatments, and asking for a 'best interests' meeting to discuss this. You should also write to the funding organisation responsible for paying for the treatments. You will find links to sample letters in the 'Resource' section (see: the Coma and Disorders of Consciousness Research Centre).

Sometimes life-sustaining treatments are continued without any proper *best interests* decisions because doctors are relying on out-of-date information (eg early family reports that the patient would want treatment) and they have not reviewed the situation to see if anything has changed (eg family members believe that at a later point in time the patient would not want treatment). This is why it is so important to regularly review decisions.

Sometimes doctors believe (wrongly) that they are not allowed to withdraw treatment if the patient will then die. It can be helpful to refer them to the professional guidance that explains the law to them (see the 'Resources' section).

Sometimes doctors know that the law permits withdrawal of life-sustaining treatments but they disagree with the law. They believe that 'sanctity of life' overrides all other considerations and do not want to be involved in any actions that would be followed by the patient's death. This is 'conscientious objection' and doctors who have conscientious objections to particular courses of action should hand over the care of the patient to someone else who is willing to implement the full range of legal options. If you suspect that the doctor responsible for your relative has conscientious objections to treatment-withdrawal, you can ask whether this is the case, and refer them to the guidance from the General Medical Council here. Another doctor should then take over and organise a best interests meeting.

## 9 What to expect if the decision is made that life-sustaining medical treatments should continue

In some cases, it will be decided that all or some life-sustaining medical treatments are in the person's best interests and should be continued. Where this is the case, the decision should be reviewed periodically (at least every year) to make sure it continues to be the right decision for the person. You can ask for another discussion sooner if, for example, the person's situation changes, or you feel that the decision should be reconsidered. Doctors may also ask for another discussion if the person's medical situation changes.

## 10 What to expect if the decision is made that life-sustaining medical treatments should stop

A decision to stop life-sustaining treatments does not mean that all other treatments and care for the patient will be stopped as well. Any decision to stop life-sustaining treatments (like clinically assisted nutrition and hydration) should be made at the same time as deciding on a plan for how end-of-life care will be managed – including where the person will be, and how pain or any other distressing symptoms will be handled. You might find it helpful to ask the doctor (especially the palliative care specialists who should be involved) what you can expect if life-sustaining treatment is withdrawn.

Families of people who have died following the withdrawal of clinically assisted nutrition and hydration report different experiences of the death of their loved one, but many say 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 the feeding tube was like at the Healthtalk website (see the 'Resources' section).

## Additional resources

1. The Brain Injury Group [www.braininjuryisbig.org.uk](http://www.braininjuryisbig.org.uk)
2. British Medical Association and Royal College of Physicians Guidance Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent [www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/clinically-assisted-nutrition-and-hydration-canh-guidance](http://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/clinically-assisted-nutrition-and-hydration-canh-guidance)
3. BMA/RCP podcast for families, 'The role of family and friends in decisions about CANH Podcast from the British Medical Association / Royal College of Physicians' <https://mail.google.com/mail/u/0/#inbox/QgrcJHsTnPTgJcqhdvplcTxTcJxmvkQQsDG?projector=1>
4. Coma and Disorders of Consciousness Research Centre <https://cdoc.org.uk/>  
(This site includes sample letters for families who want to request a *best interests* meeting)
5. Compassion in Dying (for ADRTs and LPAs) <https://compassionindying.org.uk/> (free information line: 0800 999 2434)
6. Healthtalk Online Resource: "Family experiences of vegetative and minimally conscious states" [www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/what-coma-and-what-vegetative-state](http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/what-coma-and-what-vegetative-state)
7. Royal College of Physicians (2019) *Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines* [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc)

## Glossary of terms

<b>Advance decision</b>	(Also known as <b>advance decision to refuse treatment (ADRT)</b> : In relation to life-sustaining treatment, this refers to a written document which must fulfil specific criteria of validity and applicability to be a legally binding refusal (see <a href="#">Compassion in Dying</a> for more information).
<b>Advance directive</b>	This term is often used (incorrectly) in England and Wales when the intention is to talk about advance decisions [See 'advance decision']. An 'advance directive' is a similar, but not identical, legal instrument, in Scotland and in the USA.
<b>Artificial nutrition and hydration (ANH)</b>	See <b>clinically assisted nutrition and hydration</b> .
<b>Clinically assisted nutrition and hydration (CANH) / Feeding tube / PEG / RIG / NG tube</b>	These are all different ways of referring to clinically assisted nutrition and hydration – or to the mechanisms through which this is provided, eg 'PEG' stands for ' <b>Percutaneous endoscopic gastrostomy</b> '; NG stands for ' <b>Naso-gastric</b> '. Note that the law does not differentiate between different methods of delivering clinically assisted nutrition and hydration so it makes no LEGAL difference in terms of decision-making about life-sustaining treatment whether nutrition and hydration is delivered via an NG tube or a PEG, for example. However, in practice, these two methods of CANH can feel different for both doctors and families.
<b>Decision-maker</b>	This refers to the person responsible for making a decision. It is important that everyone is clear who has this responsibility. If you do not know who is the decision-maker for a given medical treatment (eg CANH), you can ask the medical team. There should be a specific named person.
<b>Deputy</b>	This refers to someone appointed by a court when a person lacks capacity to make decisions. In order to have authority over medical treatment decisions the person must be a Deputy for Health and Welfare (not 'Property and Affairs').
<b>Donee of LPA</b>	See 'Lasting Power of Attorney'
<b>Lasting Power of Attorney (LPA)</b>	This refers of someone chosen by the patient in advance of their loss of capacity to represent them (the patient was the 'donor' of the LPA, the person now acting on their behalf is the 'donee'). In order to assign authority over medical treatment decisions the LPA needs to be for Health and Welfare (not 'Property and Affairs'). See Box 2. In addition, in order to have authority over life-sustaining treatment decisions a particular box needs to have been ticked in the original application to include this.
<b>Living will</b>	This term is sometimes used informally to refer to an advance decision – see 'advance decision'.
<b>Proxy</b>	This is an unhelpful and confusing term. If you see this word, you need to ask whether it is referring to someone with <b>Lasting Power of Attorney</b> (ie a Welfare Attorney), to a court appointed <b>Deputy</b> , or simply to someone the patient has named as a person to consult on an <b>advance decision</b> .