

# Timeline on administering and withholding/withdrawing treatment from severely brain injured patients:

The law and professional guidance

---



This is a Chronic Disorders of Consciousness Research Centre publication by Professor Celia Kitziinger (University of York) & Professor Jenny Kitziinger (Cardiff University). We would like to acknowledge Gunars and Margaret, family representatives on our healthtalk.org advisory group, who first alerted us to the necessity of producing a 'Timeline' and commented on an early draft. We also want to thank Professor Penney Lewis (Centre of Medical Law and Ethics, Kings College London) and Professor Derick Wade (Oxford Centre for Enablement) both of whom checked it for accuracy. Any remaining errors are of course ours alone.

Please send any comments or feedback to:

[celia.kitziinger@york.ac.uk](mailto:celia.kitziinger@york.ac.uk)

**How to cite:** Kitziinger, C & Kitziinger, J 2014. *Timeline on administering and withholding/withdrawing treatment from severely brain injured patients: The law and professional guidance*. Chronic Disorders of Consciousness Research Centre Publication. York/Cardiff.

Further copies of this booklet are available online at:

[www.cdcc.org.uk](http://www.cdcc.org.uk)

Copyright@Chronic Disorders of Consciousness Research Centre, 2014. Copyright: This booklet may be printed, photocopied and reproduced in any quantities necessary. However, applications to reproduce part of, or adapt, the publication should be made to the copyright owners in writing.

## Introduction

As part of our work with the Chronic Disorders of Consciousness Research Centre we have interviewed 65 people who have a relative who is (or was) in a long-term vegetative or minimally conscious state. We have also interviewed some professionals involved in the care of these patients, including rehabilitation specialists and lawyers. We have reported the results of this on-going research (and the details of our methodology) in several articles in academic and practitioner journals.

One of the findings of our research was that some families who have been through court cases for withdrawal of artificial nutrition and hydration from vegetative relatives believe that the possibility of treatment withdrawal should have been raised much earlier<sup>1</sup>. Some of the professionals who talked to us believed this too. Sometimes non-treatment options are not discussed because of continued hope for recovery. Sometimes people don't know that non-treatment is possible; others have religious or ethical objections. Doctors can be anxious about raising non-treatment options with families for fear of causing anger and distress. Family members can also be anxious about raising such issues. Treatment may then continue to be given to patients who cannot consent, simply by default and without proper thought and discussion.

Giving treatment to a patient who cannot consent to it is lawful only if (a) it is in the patient's best interests to receive it *and* (b) the patient has made no prior legal decision refusing it (such as an Advance Decision - see 'Resources').

In law, the key question is not whether withholding or withdrawing treatment from a severely brain injured patient is lawful, but rather whether it is lawful to administer treatments without consent. That question should be asked about every treatment the person receives.

The timeline presented in this booklet is a condensed and simplified representation of the legal situation as laid out in the Mental Capacity Act 2005 (together with its Code of Practice) and the professional advice given in the national clinical guidelines from the Royal College of Physicians. You can find information about how to consult these crucial legal and policy documents in the 'Resources' section at the end of this leaflet.

This booklet highlights a set of 'decision points' at which the legality of administering or continuing with life-prolonging treatments should be considered when a patient is unable to consent. The term 'life-prolonging treatments' covers a range of interventions that can include: assisted ventilation, antibiotics, suctioning, cardiopulmonary resuscitation, and artificial nutrition and hydration.

## The Timeline

Time after initial injury	Life-prolonging treatment considerations
Minutes/hours/days	<p>In the immediate aftermath of the brain injury the focus (for both family and doctors) is likely to be on saving life, stabilizing the patient, and establishing (so far as possible) the extent of the damage. These interventions are lawful UNLESS doctors are aware that the patient has made a valid and applicable Advance Decision to refuse treatment.</p> <p>If the patient has appointed someone with Lasting Power of Attorney for Health and Welfare and given that person the authority to make life and death decisions, then that person MUST be consulted and treatment is only lawful if they consent to it in the patient's best interests. (See 'Resources' at the end of this booklet for more information about Advance Decisions and Lasting Power of Attorney.) It is also lawful to withhold or withdraw treatment if it is apparent that treatment is futile (e.g. the person will die even if treatment is given).</p>

## The Timeline

<p>Days/ first few weeks</p>	<p>Treatment is lawful if it is in the patient’s best interests – and whether or not this is so should be established at a ‘best interests’ consultation with family members and others who care about the patient. A key question is: “would the person themselves want treatment in this situation?”.</p> <p>The extent of the person’s brain injury is often unclear at this stage – doctors may still think that a good recovery is possible. However treatment should not be given without a best interests consultation which should establish what a ‘good recovery’ would mean for this particular patient, and what the patient would decide in view of the risk (given continuing uncertainty about their prognosis) of an outcome that they would consider unacceptably bad (e.g. the vegetative state). Treatment is often given to keep the person alive and prevent further damage occurring, so that they can be properly assessed, but it is only lawful to do this if it is established as being in the patient’s best interests, taking into account their own prior values, wishes and beliefs (e.g. some people would never want to run even a small risk of a prolonged vegetative state and would want to refuse treatment even in the first few days after injury; others would hold out for any chance of survival).</p>
------------------------------	--

## The Timeline

One month	<p>The Royal College of Physicians' Guidelines state that a formal assessment of the patient should be completed at this point to establish an initial diagnosis (e.g. after 4 weeks a patient might be in a 'prolonged disorder of consciousness') and as a baseline to guide future management.</p> <p>This should again inform best interests decisions about whether or not to continue with life-prolonging treatments, using the same criteria as those considered in the first few days or weeks after injury (see above). For more information about 'best interests' decision-making see the booklet on <i>Serious Medical Decision Making for People in Vegetative or Minimally Conscious States: The role of family and friends</i> in 'Resources'.</p>
Six months	<p>Another formal assessment of the patient should be conducted at this point using standardized assessment tools such as the SMART or WHIM (as described in the Royal College of Physicians' Guidelines, see 'Resources'). This may not always be possible (e.g. if the patient is ill at the time) but the assessment should take place as soon as reasonably practical. Decisions about treatment after this assessment point will depend a great deal on family reports of the person's own values, wishes and beliefs combined with the kind of brain injury the patient has and the patient's diagnosis (both of which effect the likely extent of the patient's future recovery).</p>

## The Timeline

Six months

- **Vegetative – ‘non-traumatic’ brain injury (e.g. from oxygen deprivation following a cardiac arrest)**

A patient with non-traumatic brain injury who is still in a vegetative state at six months is likely to be in a Permanent Vegetative State (PVS) meaning that they are very unlikely ever to recover consciousness. This means that it may not be lawful for doctors to continue to give life-prolonging treatment (because it is not in the patient’s best interests to continue to receive it). If the assessment shows that a patient is in a permanent vegetative state at this stage (e.g. after complicating clinical factors have been ruled out) then treatment withdrawal should ALWAYS be considered (see the Royal College of Physicians’ national clinical guidelines in the ‘Resources’ section for how to proceed at this point). Although families are often concerned about withdrawal of artificial nutrition and hydration<sup>2</sup> (which requires a court hearing), families who have experienced a relative dying in this way often report that it was a peaceful and dignified death<sup>3</sup>.

## The Timeline

Six months

- **Vegetative - traumatic brain injury (e.g. from a blow to the head)**

Patients with traumatic brain injuries who are vegetative after six months are unlikely ever to recover to an independent life - but because recovery from traumatic injuries continues for at least the first year after injury, many doctors (and families) believe that it is in the patient's best interests to continue treatment for at least 12 months in hope of a better recovery.

This needs to be decided at a 'best interests' consultation which takes the patient's own likely view into account. It can be lawful to continue with life-prolonging treatments if that is decided to be in the patient's best interests, taking into account the patient's own prior values, wishes and beliefs. Unless it is established as being in the patient's best interests life-prolonging treatment should be withdrawn. (Court approval is needed to withdraw artificial nutrition and hydration.)

## The Timeline

Six months

- **Minimally conscious ('low awareness')**

If the patient is found to be 'minimally conscious' then (whatever the type of brain injury) the recovery process may continue for up to five years and they may recover consciousness completely (albeit probably with extensive physical and neurological disabilities). It is important to take into account the likely level of recovery the person may achieve, and whether this is a quality of life they would have found worthwhile (as ruled in the court decision in *Aintree v James*). A best interests consultation should consider the person's medical condition, their past – and where possible present – wishes, and their likely attitude to the risks associated both with treatment and with non-treatment.

- **Fully conscious**

The person may continue to recover and gain increased brain function. If the person becomes conscious and regains full capacity to make decisions then it is up to them to make all decisions about their treatment. But many patients with severe brain injuries who recover consciousness would not pass the test for mental capacity for accepting/refusing serious medical treatments. This means that even if the person appears to be accepting or refusing treatments, they are not treated by the law as having the mental ability to give or refuse consent, and a best interests consultation must take place.

*Continues over...*

## The Timeline

Six months	<p>A best interests consultation should consider the person's medical condition, their past – and where possible <i>present</i> – wishes, and their likely attitude to the risks associated both with treatment and with non-treatment. It is important to take into account the likely level of recovery the person may achieve, and whether this is a quality of life they would have found worthwhile and/or do find worthwhile. It can be lawful to provide life-prolonging treatments to the minimally conscious patient six months after injury, if this is determined to be in the patient's best interests. If they are not in the patient's best interests then life-prolonging treatments should be withdrawn (Court approval is needed to withdraw artificial nutrition and hydration.)</p> <ul style="list-style-type: none"> <li>• <b>Uncertain state of awareness</b></li> </ul> <p>Sometimes the diagnosis is uncertain<sup>4</sup>, i.e. it is not clear whether the patient is vegetative or minimally conscious. This uncertainty may not make a significant difference to what the patient might have wanted (e.g. they might have wanted to be kept alive no matter what; or they might not have considered any of the possible outcomes to result in a quality of life they would have considered worthwhile and might have wished to refuse treatment no matter what). Decisions about treatment withdrawal or continuation can therefore sometimes be made even if there is some uncertainty about the patient's exact diagnosis along a spectrum of degrees of awareness. But when the patient's diagnosis is believed to be important in making a best interests decision, it may be necessary to monitor the patient for a few more months and/or to repeat tests.</p>
------------	--

## The Timeline

<p>One year</p>	<p>A formal assessment of the patient should be undertaken using standardized assessment tools such as the SMART or WHIM (Royal College of Physicians’ Guidelines, see ‘Resources’). This may not always be possible (e.g. if the patient is ill at the time) but the assessment should take place as soon as reasonably practical.</p> <ul style="list-style-type: none"><li>• <b>Vegetative</b></li></ul> <p>If a patient is vegetative at this point then (whatever the cause of their brain injury) they are diagnosed as being in a Permanent Vegetative State, meaning that they are very unlikely to recover consciousness. This means that it may not be lawful for doctors to continue to give life-prolonging treatment (because it is not in the patient’s best interests to continue to receive it). If the assessment shows that a patient is in a Permanent Vegetative State (e.g. when any complicating factors have been addressed) then treatment withdrawal should ALWAYS be considered – and if appropriate an application can then be made to the courts (this is required for withdrawal of artificial nutrition and hydration).</p> <ul style="list-style-type: none"><li>• <b>Minimally Conscious, Conscious or Uncertain diagnosis</b></li></ul> <p>Minimally Conscious, Conscious or Uncertain diagnosis – the same considerations apply as at six months.</p>
-----------------	---

## The Timeline

Two years	<p>If the patient is still in either a vegetative or a minimally conscious state, then a formal assessment of the patient should be undertaken using standardized assessment tools such as the SMART or WHIM (Royal College of Physicians' Guidelines, see 'Resources'). Considerations relating to giving or withdrawing life-prolonging treatments are the same as at one-year post-injury, except that over time it becomes less and less likely that the patient will show any signs of further recovery.</p>
Three years	<p>A formal assessment of the patient should be undertaken using standardized assessment tools such as the SMART or WHIM (Royal College of Physicians' Guidelines, see 'Resources'). Considerations relating to giving or withdrawing life-prolonging treatments are the same as at one-year post-injury except that over time it becomes less and less likely that the patient will show further recovery. Additionally, patients who are minimally conscious (MCS or "low awareness") at this point can now (depending on individual circumstances) possibly be diagnosed as being in the "Permanent" Minimally Conscious State, meaning that it is very unlikely that they will recover further awareness. (Royal College of Physicians Guidelines, see 'Resources').</p>

## The Timeline

Four years	A formal assessment of the patient should be undertaken using standardized assessment tools (Royal College of Physicians' Guidelines, see 'Resources'). Considerations relating to giving or withdrawing life-prolonging treatments are the same as at one-year post-injury except that over time it becomes less and less likely that the patient will show further recovery. Additionally, patients who are "minimally conscious" (MCS or "low awareness") at this point can now (depending on individual circumstances) possibly be diagnosed as being in the "Permanent" Minimally Conscious State, meaning that it is very unlikely that they will recover further awareness (Royal College of Physicians Guidelines, see 'Resources').
Five years	A formal assessment of the patient should be undertaken using standardized assessment tools such as the SMART or WHIM (Royal College of Physicians' Guidelines, see 'Resources'). Considerations relating to giving or withdrawing life-prolonging treatments are the same as at one-year post-injury except that over time it becomes less and less likely that the patient will show further recovery. Additionally, patients who are minimally conscious (MCS or "low awareness") at this point can now diagnosed as being in the "Permanent" Minimally Conscious State, meaning that it is very unlikely that they will recover further awareness (Royal College of Physicians Guidelines, see 'Resources').

## The Timeline

<p>Longer than 5 years</p>	<p>Patients who are still in a vegetative or minimally conscious state more than five years after brain injury and who have not had a formal assessment of their level of awareness require urgent assessment and review so that appropriate best interests decisions can be made. The need is urgent because it is not legal to continue treatment if it is not in the patient's best interests.</p>
----------------------------	---

---

<sup>1</sup>Kitzinger, J. & Kitzinger, C. 2013. The 'window of opportunity' for death after severe brain injury: Family experiences. *Sociology of Health and Illness*, 35(7): 1095-1112 DOI: 10.1111/1467-9566.12020

<sup>2</sup>Kitzinger, C. & Kitzinger, J. 2014. Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives, *Journal of Medical Ethics* Online First doi:10.1136/medethics-2013-101799

<sup>3</sup>Families describe their experience of withdrawal of artificial nutrition and hydration (and other treatments) on our online resource – the healthtalk.org pages on “Family experiences of vegetative and minimally conscious states” (see especially the section on ‘artificial nutrition and hydration’).

<sup>4</sup>Nettleton, S., Kitzinger, J. & Kitzinger, C. 2014. A diagnostic illusory? The case of distinguishing between the ‘vegetative’ and ‘minimally conscious’ states, *Social Science & Medicine* 116: 134-141.

---

## Resources for families and professionals

### National Clinical Guidelines

- Royal College of Physicians. 2013. *Prolonged disorders of consciousness: National clinical guidelines*. London. [www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines](http://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines)

### Legislation, Code of Practice

- Mental Capacity Act 2005  
<http://www.legislation.gov.uk/ukpga/2005/9/contents>
- Mental Capacity Act Code of Practice  
<https://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

### Booklet for families about decision-making

- *Serious medical decisions regarding people in vegetative or minimally conscious states: the role of family and friends*. Royal College of Physicians 2013.  
[https://www.rcplondon.ac.uk/sites/default/files/annex\\_4b\\_role\\_of\\_family\\_and\\_friends\\_in\\_medical\\_decisions.pdf](https://www.rcplondon.ac.uk/sites/default/files/annex_4b_role_of_family_and_friends_in_medical_decisions.pdf)

### Booklet for clinicians about best interest meetings

- Wade, D. 2014. *Mental Capacity Act and best interests decisions: A practical guide primarily for hospital practitioners*. (CDoC Research Centre publication)  
<http://www.york.ac.uk/digital-editions/cdoc--best-interests-decisions-booklet/>

## Information about Advance Decisions and Lasting Powers of Attorney

- An *Advance Decision* (AD) is a legal document that enables you to refuse, in advance of losing capacity, medical treatments that you do not want. The charity *Compassion in Dying* offers free advice and information about *Advance Decisions* and templates for completing them:

<http://compassionindying.org.uk>

The charity also runs an information line and can answer questions about both *Advance Decisions* and *Lasting Powers of Attorney*: 0800 999 2434

- A *Lasting Powers of Attorney* is a legal document that lets you, at a point when you have mental capacity (the ‘donor’) appoint people (known as ‘attorneys’) to make decisions on your behalf if you lose capacity in the future. There are two different types – one for ‘property and welfare’ which enables your attorney to make financial decisions; one for ‘health and welfare’ which enables your attorney to make decisions about medical treatments and other issues like where you live and your day-to-day care. Next-of-kin (spouses, adult children etc) have no automatic right to do this. If you would like someone else (a family member or friend) to be able to make decisions about your medical treatments if you were to lose the capacity to do so in the future you can appoint someone as your “health and welfare” attorney. Information about how to do this is available here:

<https://www.gov.uk/power-of-attorney/overview>

Further copies of this leaflet are available online at [cdoc.org.uk](http://cdoc.org.uk)

If you have any comments on this leaflet please email:  
Celia Kitzinger at [celia.kitzinger@york.ac.uk](mailto:celia.kitzinger@york.ac.uk)

Copyright@Cardiff-York Chronic Disorders of Consciousness  
Research Centre 2014.

Copyright: This booklet may be printed, photocopied and reproduced in any quantities necessary. However, applications to reproduce part of, or adapt, the publication should be made to the copyright owners in writing.

