



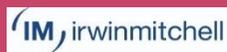
Shared Insights Prolonged disorders of consciousness

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Yogi Amin, National Head of Public Law & Human Rights, Irwin Mitchell Solicitors

Lisa Newbould, Named Professional in Safeguarding Adults and Mental Capacity Act, Lincolnshire Hospital NHS Trust

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brownejacobson LLP

Introduction

We were delighted to be joined at our regular Safeguarding Forum by Dr Judith Allanson, Honorary Consultant in Neurological Rehabilitation, Addenbrookes. Visiting Research Fellow Dept of Medicine, University of Cambridge, Locum Consultant, Royal Hospital for Neurodisability, Putney and Yogi Amin - National Head of Public Law & Human Rights at Irwin Mitchell Solicitors.

Judith explained that PDOC applies to people who have acquired brain damage and do not follow the natural recovery up to full wakefulness and consciousness - they are not locked-in but are in a vegetative state (VS) or minimally conscious state (MCS).

PDOC is an umbrella term covering a whole range of people of different ages/pre-existing conditions, as well as a range of disorders.

You can find the Royal College of Physicians National Clinical Guidelines on PDOC following sudden onset brain injury [here](#) and on clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent [here](#).

Judith explained that recovery from a coma is not linear and there is useful information on Coma Recovery Score on the COMBI website [here](#) with more information [here](#).

Judith explained that there are now several published series of people in PDOC that have been followed up for many years and a significant proportion of them have been found to have increased their awareness and ability to interact and a few have recovered almost fully.

Judith showed slides from her study and explained these studies demonstrate how hard it is to predict levels of recovery early on after brain injury but are starting to help inform discussions about prognosis during best interests meetings.

You can find lots of useful information on the British Society of Physical & Rehabilitation Medicine website [here](#).



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Legal framework

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Legal framework

Mental Capacity Act 2005

- Determines the legal test on capacity/best interests
- Section four requires best interests test - sets out factors to take into account:
 - Continue with treatment (in particular life-sustaining)
 - Apply all principles i.e. family consultation /individual's wishes and beliefs and values
 - Whether and when the person may regain capacity

Common Law

- Consent for treatment for patients
- Doctrine of necessity - where people lack capacity there is necessity to act in their best interests.

Human Rights Act 1998 and European Convention on Human Rights

- In end of life cases balancing Articles 2 and 3 (right to life and freedom from torture, inhuman or degrading treatment) while respecting Articles 8 and 9 (right to private and family life and right to freedom of thought, conscience and religion)

DOLS

All patients in PDOC should have full continuing CHC funding - social care funding is not required or necessary.

All patients in PDOC lack capacity to consent to their treatment and care.

Patients who are PDOC will always require DOLS unless they are in ICU. This can be done through the DOLS administrative process and they do not all need to go to Court.

[Serious Medical Treatment, Guidance \[2020\] EW COP 2 \(17 January 2020\) \(bailii.org\)](#) sets out the procedure to be followed when an application to court is required.

Case Law

[W v M&S and A NHS Primary Care Trust \(2011\)](#)

The court determined it can make a declaration to withdraw CANH where the patient is in a minimally conscious state (MCS) but refused the application here finding the right to life to carry great weight in any balancing exercise.

[M and Mrs N, Bury CCG and A Care Provider \(2015\)](#)

The first declaration by the Court of Protection that the withdrawal of life sustaining treatment from someone in MCS (not PVS) was lawful. Case turned on evidence as to wishes, feelings and values.

[Aintree Trust v James \(2013\)](#)

Established clear legal principle that the patient's own wishes are of central importance in best interests decision making, and consideration of P's welfare in the widest sense, not just medical but social and psychological, and what P's attitude to the treatment would likely be.

[Re N \(2015\)](#)

There is no right to die in the legal framework. The right is to live the days at the end of life in the way the patient would have wished. Here the Court authorised the right to end treatment.

[Briggs v Briggs and Ors \(2016\)](#)

Evidence from family that Mr Briggs would not have wanted to be kept alive in his MCS state. The court has to assess whether it can reach a conclusion as to what the wishes of P would have been. If it is able to reach a conclusion that should be considered alongside other relevant factors. The Court authorised to end treatment

[Y \(2018\)](#)

The Trust applied to the High Court as all agreed that the continuation of treatment was not in best interests. Court confirmed the Trust did not need to seek the endorsement of COP if all parties agreed. Case went to the Supreme Court and the Supreme Court upheld the judgment.

Practical considerations

Lisa Newbould,
Named Professional
in Safeguarding
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Capacity Act,
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How we can help

Practical considerations

Be careful that individual unconscious bias does not influence decisions.

We all need to make sure we have those conversations with our families about what we would want in this situation.

Remember to think about the family left behind - listen to, speak to and support them, whatever the conclusion is in a best interests meeting

Conclusion and Key points to consider:

- Advanced decisions to refuse treatment carry more weight than advanced views/statements of wishes and feelings and so it is imperative to have those made clear in a valid applicable Advanced Decision document.
- It is important to emphasise that it is very hard to predict likely quality of life and level of recovery.
- Well recorded and chaired best interest meetings can sometimes help avoid having to apply to Court
- Allow families time to make decisions
- Consider cultural issues for individual patients/families
- If possible identify a named individual so families have one point of contact as often there are multiple professionals involved
- PDOC patients should have an annual review if resources allow.
- There are many individuals “lost” in the system and it is important for all of us to be aware of the guidelines.

How we can help

- We have a large team of very experienced Court of Protection and mental health specialists. Browne Jacobson are always available to discuss any challenging cases that you may have, including those which may require Court oversight.
- We provide our clients with a 24 hour helpline for access to specialist advice whenever problems arise out of hours, 365 days a year.
- We can assist with any training needs.

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