



Supporting families to inform best interests decisions

Information for family and friends



A patient with a disorder of consciousness cannot consent to, or refuse, treatment. It is therefore usually the responsibility of the treating clinician to ensure that any treatment they give is in the patient's best interests. Any decision must be 'patient centred', informed by understanding the person as an individual. Families and friends therefore have a key role to play.

This information sheet introduces us and our work and outlines the support we can offer to help families and friends to contribute to the best interests decision-making process.

About us: We are Jenny Kitinger and Celia Kitinger, two academics who've done research with families of patients in vegetative or minimally conscious states. We also have personal experience after our own sister, Polly, was severely brain injured in a car crash in 2009. We now co-direct a research centre looking at what happens to patients and their families (see www.cdcc.org.uk). Alongside doing academic research we've produced a resource where you can see film clips of families talking about their experiences <https://healthtalk.org/family-experiences-vegetative-and-minimally-conscious-states/overview>

Families of patients often approach us directly for help. Others are referred to us by clinicians. Either way, we offer support on an entirely independent and voluntary basis. Our goal is to ensure that those close to the patient have access to information they need about how decisions should be made, and are appropriately involved in decisions.

We've helped people understand how the healthcare system works and put them in touch with relevant experts, e.g. to help them protect funding or to get assessments done. We've also supported dozens of families in best interests decision-making processes about life-sustaining interventions, including ventilators and feeding tubes.

One important part of our work is ensuring that doctors know about their responsibilities to consult families. We've contributed to developing guidelines and training (e.g. working with the British Medical Association – see https://www.youtube.com/watch?v=yw66KHs1g_0&feature=youtu.be.)

Note: This summary deals with decision-making in what is still (sadly) the most common situation, where the person hasn't put in place any advance planning for this situation. In some cases – and this should always be checked - there may be an "Advance Decision" where the patient recorded their own treatments decision before losing capacity, or a "Lasting Power of Attorney for Health and Welfare", through which the patient gave someone else the authority to make decisions. For more information see: <https://mydecisions.org.uk>. Some patients also have court-appointed Welfare Deputies: <https://www.gov.uk/become-deputy/who-can-apply-deputy>. We are also able to offer support when there are already legal documents like this in place.

Supporting families to produce written statements about the patient

Why are written statements useful? Understanding the patient as an individual should be part of everyday care. Family members are often invited to complete forms recording information about the patient. Healthcare staff should also ask about the patient's approach to life, and about their values, beliefs, wishes and feelings. However, full written statements in addition to such conversations can be very helpful in relation to specific decisions, or if family members or healthcare professionals are unsure about the right way forward, or there are disputes, or when decisions need to be reviewed by professionals who have not been directly involved before. If a case goes to court, for example, written statements are useful to the judge and barristers because they, unlike the clinical team, have not been able to build up a picture of the patient over time or get to know the family.

Writing a statement – how can we help? It can be hard to know what questions to address or just difficult to put pen to paper. This is where talking with someone else can help. We usually suggest a call to explore key questions such as: how you know the person, what they were like (e.g. their approach to life, their values and beliefs), what you know or witness about their current situation and what you think they might want given their likely future. Notes from that conversation are then returned to you, to use as a basis for a written statement. Doing this can be emotionally challenging, but people also tell us that it can be lovely to be able to talk about the person at length outside a clinical setting, and they often feel very relieved and pleased to have done this.

Who can contribute? Anyone who knew the patient well can be a useful source of information: this includes friends or colleagues for example. We'll discuss with you who else might be appropriate to consult.

Can the discussion be confidential? We're happy to have a conversation in confidence. You may just want to ask questions, for example, or talk through the issues before deciding whether or not to contribute. However, if a statement is submitted to the clinical team it then becomes part of the patient's records. It may be shared with anyone with an interest in their care and will be part of the evidence if the decision is referred to court.

What we don't do: We don't attempt to influence you or 'take sides' when family members have different views and we're not qualified to provide psychological counselling, medical information, or legal advice.

What we sometimes do: we are sometimes asked to help gather information about the patient and the best interests decision-making process, or to talk to doctors or to accompany families to meetings. If this might be useful we can discuss how to manage this. We've also attended many court cases either as "public observers" or to support families. We've published articles about some of these; we can give you more information or talk you through what court cases are like if this might be relevant.

Further information:

- how we conduct conversations with families and advice for clinicians - see: https://cdoc.org.uk/wp-content/uploads/2019/10/Guide-for-conversations-with-family_CDoC251019-1.docx
- the role of family & friends in decision-making - see: <https://cdoc.org.uk/wp-content/uploads/2020/03/Annex-4b-The-role-of-family-and-friends.pdf>
- managing the relationship between being academics and advocates -see <http://www.cdoc.org/your-info/>

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