

# ETHICS AND THE LAW: MENTAL INCAPACITY AT THE END OF LIFE

Rob George, Bridgit Dimond

We begin this regular feature on ethical and legal issues with the story of Jane. There are two reasons for analysing her case. First, Jane's situation is common, and second, between April and October 2007, the Mental Capacity Act 2005 comes into force. This law has wide-ranging implications for carers of patients who may be incapable of making decisions for themselves. The main features of the law are that: (1) It formalises the status of the family or friends the patient wishes to be consulted if the patient is incapable of making a decision about care; (2) It gives clear guidance on the factors that should be taken into account when professionals are attempting to decide what is in the patient's best interest; (3) It contains a section covering advanced refusals (what many will know as a 'living will'). For example, if there is a document that is specific and valid then it is legally binding. At present, 'specific' refers to the clinical problem and 'valid' means the person was informed, capable and uncoerced to make the statement concerned. How this will be determined and proved remains to be seen, but the responsible doctor will have to take the final judgment on that and be prepared to defend his/her position if challenged. We will cover advanced refusals in detail in a future issue.

## KEY WORDS

Best interests  
Consent  
Determination of mental capacity  
Life-sustaining treatment

### Ethical aspects of Jane's case

The core facts of the case scenario are straightforward. Jane is in the end stage of her malignancy. Her condition is deteriorating and the clinical signs indicate that she is beginning actively to die. Her wishes have not been clearly stated and her capacity to make them known is waning. From her actions, it seems that she realises she is dying and that she no longer wants any treatment.

Ethical aspects: Rob George is Consultant in Palliative Medicine and Senior Lecturer in Biomedical Ethics, University College London.  
Legal aspects: Bridgit Dimond is Emeritus Professor, University of Glamorgan

It may be that she wants to die as soon as possible. She appears sad, withdrawn and muddled, possibly from the toxic effects of her infection and she is in considerable pain. Certainly she is 'not herself', but there is no proof positive of mental incapacity. However, Jane's actions seem consistent with the general impression that she no longer wishes to receive active treatment.

These are the facts relating directly to Jane. Deciding on a course of action requires the construction of value statements such as what is best for Jane and what should or ought the team do.

### Conflicting interests

At this point, it is very important to remember that we all bring our own perspectives, beliefs and preconceptions to decision-making. These are our 'vested interests'. We all have them. Jane's case demonstrates the interplay of at least four sets of vested interests: Jane's interests, her father's, her friend Mary's and those of each member of the clinical team. The task for the clinical team is to identify and act in Jane's best interest.

The presence of Mary and Jane's father in this regard is a mixed blessing. On one hand, they may be of assistance because Jane's capacity to state her best interests cannot be relied upon. On the other, they may be expressing their own interests as Jane's. The dilemma may arise in deciding whether their statements arise from their investment in the decision to be made, rather than a proper reflection of what Jane's view would be were she capable. When faced with this common problem, one's inclination might be to listen to the 'loudest voice'. However, the correct course of action must begin and end with the patient.

### The duty of the health care team

So, to begin with Jane, the fundamental duty of care is very clear. The medical team must act in Jane's best interest. The best judge of Jane's interests is Jane, if she is capable. The duty of care also requires that there is a presumption that a person has the capacity to know what are his/her interests. In other words, Jane does not have to prove that she is capable of saying no to treatment. The medical team has to demonstrate that she is not capable, if it is believed that

an intervention, seemingly against her will, is in her best interest. Jane's actions and conversations, whilst limited, are consistent, pointing towards her refusal of further treatment.

This is the start point. Jane appears not to want treatment. Furthermore, Jane is beginning to die, despite treatment. Therefore, unless there is a good reason

to try and prolong her life, e.g. a critical family member is travelling to her bedside, there is little point in burdening her with any further curative treatment. The priority should be to manage her pain and promote her comfort.

#### Values and judgments

How is this judgment influenced by other views? Mary is against treatment,

while Jane's father wants everything done. Although these judgments are clearly stated, expressing a judgment does not mean that the values being applied to it are good. For example, although Mary agrees with the judgment that Jane should receive no further curative treatment, she seems to be going beyond proper professional values, such as avoiding harm from futile treatment, or respect for Jane's wishes. Instead, her actions and comments seem to point to values such as, 'it is better to be dead than dying'. It is possible to infer from her comments that she thinks, 'it is better to be killed than to be allowed to die'. These values are deeply suspect. They may lead to illegal actions.

Considering Jane's father, he may be insisting on treatment (action the medical team considers to be wrong) for the right reason. It may be that the last time he spoke to his daughter she 'wanted everything done' and he is assuming her change of mind is due to an untreated depression or infection and not the recognition that she is dying. Equally, he may be unable to face the truth of his daughter's situation, or the possibility that he has not 'done enough' because of emotional problems with his daughter.

There is an urgent need to communicate in detail with Jane's loved ones to address their anxieties as part of proper holistic care and in anticipation of helping each of them with their grief. It is also important that the facts are clearly known to them, i.e. that Jane is dying and that it would be best for all concerned if she remains an inpatient. The clinical team is absolutely entitled, or even has a duty, to keep Jane as an inpatient.

#### Summary

This case demonstrates that:

- ▶▶ Mental capacity is not an easy thing to assess.
- ▶▶ Right or good decisions do not necessarily mean that the values that led to them are right or good.
- ▶▶ Earlier and clear documentation in the notes regarding Jane's wishes would have been very helpful.

### Case scenario

Jane Stevens is a 36-year-old, single nurse who has been receiving treatment for breast cancer for the last 4 years. The cancer has now metastasised extensively. Jane is no longer able to work as a nurse. She has been admitted to an oncology/palliative care unit in a hospital. She is confused and dehydrated. She currently has a urinary tract infection that is being treated with antibiotics.

It is not clearly stated in the hospital notes who is to be regarded as Jane's next of kin. On a previous admission the notes state that it is her parents, but on a subsequent admission Jane has given the name of Mary, her flatmate.

On admission, it is not clear from Jane's records how extensively her diagnosis and prognosis have been discussed with her. Communication between Jane and the multidisciplinary team has not always been optimal. However, on this admission, Jane confided in a health care assistant to whom she is close that 'my time is up'. Her presentation is of a withdrawn and sad woman who appears muddled. During the last week Jane has refused food and has, on two occasions, attempted to tamper with the lines that were giving her fluids, antibiotics and analgesia.

Jane's flatmate Mary, who is also a nurse, is adamant that Jane should not receive further active treatment. She has on one occasion said to a member of staff that she is quite prepared to bring in 'whatever is necessary' and leave it with Jane.

Jane's parents, who live some 200 miles away, are elderly and are only able to visit infrequently. The staff members have the impression that the relationship between Jane and her family has been distant for some time.

Jane's father, a retired GP, spoke to the doctor in charge of her care. He was emphatic that Jane should be treated, and that if she continues to refuse food and treatment, a psychiatric opinion should be sought in order that 'she should be made to see sense'. The medical team acts on this request but, when the psychiatrist visits Jane to introduce herself, Jane shakes her head, says 'no' and turns away.

Mary has today informed the staff that she and Jane have agreed that Jane should be discharged home, further stating 'we can manage together'. Jane is now in considerable pain and speaks in monosyllables. The consensus among staff is that Jane has a short time left to live, probably days rather than weeks. When asked if she wishes to go home, Jane does not seem to hear the question, but makes a gesture, the meaning of which staff members are not able to interpret.

**Table 1**

**Factors to be considered when making a decision on behalf of another**

Not making unjustified assumptions on the basis of age or appearance, or a condition or an aspect of behaviour

Taking into account whether the mental incapacity is likely to be temporary or permanent

Taking reasonable steps to encourage the patient to participate or to improve their ability to participate in any decision-making that affects them

Taking into account the patient's past and present wishes and feelings, including any relevant written statement made when they had the requisite mental capacity

Taking into account the beliefs and values that might influence the patient's decision if they had the requisite mental capacity and any other factors that they would be likely to consider if they were able so to do

there is no evidence to rebut the presumption that she has the requisite mental capacity, then her wishes should prevail. It appears that, when she refused to be seen by the psychiatrist, she knew what she was refusing. An adult with the requisite mental capacity has the right to refuse treatment or examination.

If she has the mental capacity, then the views of Mary or of Jane's parents are irrelevant. It is Jane's views and wishes that should prevail, even if she is refusing life-sustaining treatment.

**If Jane lacks the requisite mental capacity**

If Jane is reasonably believed to be lacking the requisite mental capacity (and this would be determined on a balance of probabilities — the civil standard of proof), the provisions of the Mental Capacity Act 2005 apply. (The civil standard of proof contrasts with the standard used in the criminal courts where the prosecution has to prove the accused is guilty beyond reasonable doubt. This is a more difficult task than a balance of probabilities).

These statutory provisions come into force between April and October 2007, but in many ways follow the present common law (judge-made law or case law). Where adults are unable to make their own decisions because they lack the requisite mental capacity, then decisions have to be made in their best interests. There is no definition of 'best interests' in the Act, but certain factors are specified in the Act that must be taken into account when making a decision on behalf of another (Table 1).

In addition, where the decision relates to life-sustaining treatment, the person deciding what is in the best interests of the patient cannot be motivated by a desire to cause the patient's death.

**Views of Mary and Jane's father**

If Jane lacks the necessary mental capacity, then those making decisions on her behalf and acting in her best interests, have a statutory duty to take into account, if practicable and appropriate, the views of:

- ▶▶ Best practice includes care for a person's loved ones and, in the case scenario, seeing that Jane's interest is also served by taking care of those she cares about as she dies.

**Legal aspects of Jane's case**

Jane's case raises many legal issues:

- ▶▶ Jane's ability to consent if she is mentally incapacitated.
- ▶▶ The impact of the Mental Capacity Act 2005 on the action to be taken in Jane's best interests, if it can be demonstrated that she lacks the requisite mental capacity.
- ▶▶ The status of friends and relatives in decision-making.
- ▶▶ The criminal offence of aiding and abetting suicide.

**Mental capacity**

Crucial to all these topics is whether Jane has the requisite mental capacity to make her own decisions. There is a presumption that Jane has the requisite mental capacity to make her own decisions. This presumption will be put on a statutory basis (i.e. be contained in an Act of Parliament instead of being based on a case or common law) by the Mental Capacity Act 2005 when it comes into force. However, the presumption can be argued if evidence to the contrary can be provided. The validity of the evidence will be decided

by whoever is determining capacity and providing care.

If the presumption that Jane has the requisite mental capacity to decide stands, then Jane is entitled to make her own decisions, no matter how unwise her decisions appear to anyone else. The term 'requisite (necessary) mental capacity' is the legal term used. The term is applied to each decision made about care and each decision will be judged separately. For example, a person with limited capacity may be able to make day-to-day decisions such as deciding what to eat but be unable to make more significant decisions such as having surgery or deciding where to live.

**Does Jane have the requisite mental capacity?**

It would appear that, on admission, although withdrawn and sad, Jane appeared to be able to discuss her condition with a health care assistant. It may be that, at that time, she had the competence to understand the situation and the choices to be made. At this time she was refusing food and twice attempted to discontinue the fluid, antibiotics and analgesia.

Non-verbally she appeared to be communicating, 'I do not wish to receive this treatment'. If at this time

- ▶▶ Anyone named by Jane as someone to be consulted on such matters.
- ▶▶ Anyone engaged in caring for Jane.
- ▶▶ Anyone interested in her welfare.

This means that Mary and also Jane's father can give their views regarding what they believe Jane would have wished. This does not mean that their views should prevail.

#### Discharge of Jane

It would appear that, by the time the decision was made regarding whether Jane should be discharged back to her home with Mary, Jane was unable to make a decision or at least to communicate a decision. Inability to communicate decisions as a result of mental impairment or disturbance in brain function may result in the decision being made that the person does not have the requisite mental capacity. The medical staff must decide if it is in Jane's best interests to be at home for the last few days of her life. Mary should be warned that aiding and abetting suicide is a criminal offence. The Suicide Act 1961 decriminalised attempting to commit suicide but retained the offences of aiding and abetting another's suicide.

#### Resolving the dispute

Every effort should be made to determine what is in Jane's best interests if she is unable to make the decision herself. Account should be taken of her personal history and the wishes, feelings and views that she has expressed. Ultimately, if there is

no agreement as to what is in Jane's best interests, and after all reasonable practical steps have been taken to consult all parties involved and reach an agreement, then an application could be made to the Court of Protection. After October 2007, this will have extended jurisdiction, including matters of personal welfare. It could convene very speedily.

#### Conclusions

As long as Jane has the capacity to make her own decisions, she should be supported and encouraged so to do. In hindsight, during the 4 years of her illness, it is unfortunate that Jane was not encouraged to draw up advanced decisions regarding treatment during the terminal period of her illness or, in the event that she lost the requisite mental capacity, to express her wishes. In fact, there appears to be evidence of a failure to engage with Jane regarding the extent of her disease and her prognosis. Lack of communication when a person has the requisite mental capacity to make decisions can cause considerable difficulties when making decisions in that person's best interests if mental capacity has been lost.

#### Points for reflection

- ▶▶ Consider similar cases with which you are involved and whether there is adequate documentation of the patient's wishes for care, should the patient become mentally incapable.
- ▶▶ It is easy for nurses like Mary to experience difficulty when

caring for a friend. Reflect on her values and what implications they may have. **EOLC**

*If this case has raised certain questions for you and you would like an expert comment, or if you have been involved in a case that you would like to form the basis of an ethical and legal discussion please contact the Editor, Helen Scott, on [helen@healthcomm-uk.com](mailto:helen@healthcomm-uk.com)*

#### Key Points

- ▶▶ A mentally capacitated adult has the right in law to refuse life-saving treatment.
- ▶▶ Relatives and next of kin have no power to make personal welfare decisions when an adult has the mental capacity to make his/her own decisions.
- ▶▶ Where an adult lacks the capacity to make decisions, then relatives and health professionals must make decisions in the best interests of the adult who lacks capacity.
- ▶▶ Such decision-making will, from April and October 2007, be influenced by the Mental Capacity Act 2005.
- ▶▶ The Court of Protection will have an enhanced jurisdiction covering decisions on personal welfare and can appoint deputies to make such decisions after October 2007.

# Correspondence

## End of Life Care would welcome correspondence

If you would like to comment on any of the issues raised in the journal or on any other aspect of end-of-life care then please contact the Editor, Helen Scott, on

[helen@healthcomm-uk.com](mailto:helen@healthcomm-uk.com)