Clinical approaches to the withdrawal of nutrition and hydration

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ABSTRACT – The request for withdrawal of nutrition and hydration from the vegetative patient is rare, but when it occurs it causes considerable anxiety for the clinical team. This anxiety is exacerbated by the need to seek a declaration from court that withdrawal of treatment would be legal. This paper discusses the process from the time of the request to the withdrawal of the tube feeding, and the actions the clinical team needs to take.

KEY WORDS: counselling, declaration, ethics, hydration, nutrition, vegetative state, withdrawal

Introduction

Withdrawal of nutrition and hydration is a difficult issue for doctors. The ethical dilemmas for the treating team are such that there are often very strongly held views so discussions should be treated with due sensitivity. The added need for a declaration from a court creates further anxiety.

However, there are occasions, fortunately rare, where a clinical team is faced with a suggestion that nutrition and hydrations should be removed from a patient who has been in a vegetative state for a prolonged period of time. This is so rare that most doctors will not be faced with the dilemma, but when it does occur it causes considerable anxiety among the clinical team.

Since the case of Tony Bland,[1] it has been a requirement that the decision to withdraw nutrition and hydration should be referred to court for a declaration that it would be legal for the doctor to withdraw the tube feeding. This applies to England and Wales, but not to Scotland where different rules apply.

So if the situation does arise, where does the treating clinician start? First, there are two excellent booklets – one from the General Medical Council[2] and the other from the British Medical Association[3] – which plainly discuss the ethical and legal issues involved. These are an excellent starting point.

Process on approach

Experience shows that most requests for withdrawal of nutrition and hydration come from the family of the patient rather than from the clinical team. So what should the lead clinician do when approached? The first step is to meet the family and find out what their views are and how they understand the situation. For example, they are usually unaware of the legal process that needs to take place. It is essential at this stage to find out if there are other relevant members of the family who are not present but who may hold different views. At this point, the clinician's role is more to help the family understand the facts rather than advise for or against the withdrawal of the tube.

It is, however, necessary at this stage for the lead clinician to make a decision on whether s/he agrees morally with the decision to withdraw nutrition and hydration. If the clinician has strong moral views which would prevent him or her from being involved, then it is essential that the care of the patient be passed to another clinician who would be willing to withdraw treatment, should the court declare it legal to do so.

This is also the time to involve the health trust's legal department and seek advice about proceeding with an application to the court.

What information will the court require?

It is important to know what information the court is likely to want. The following are some of the questions that usually need to be answered:

- *What is the diagnosis?* Is it clear that the patient is in the vegetative state as assessed by experts in this field?
- Are there any factors that might be influencing the patient's ability to demonstrate awareness? For example, is the patient receiving high levels of sedating drugs or is s/he medically unstable?
- *What is the prognosis for recovery?* If nutrition and hydration continue to be provided, is there a chance of any improvement and to what level?
- *What is the life expectancy if nutrition and hydration are not withdrawn?* Is the patient likely to live only a short time because of frequent chest infections, status epilepticus or other medical or surgical problems; or is his life expectancy likely to be several decades?

- *Has everything been done to achieve improvement?* Is the patient medically stable and has s/he had the advantage of a specialist rehabilitation/disability management programme in a neuro-rehabilitation setting? This is not always essential but the clinician should be able to demonstrate that an active programme has taken place.
- *What will happen if the tube is withdrawn?* How long will it take the patient to die and will this be painful or distressing? The clinician should be able to state what the medical management would be during this period.
- *What will happen of the tube is not withdrawn?* Some patients will have frequent chest infections and technical difficulties with feeding, and require total care in all aspects of daily function.

Is the diagnosis correct?

This is one of the fundamental questions to be answered. The criteria are well laid down in the original definition of the persistent vegetative state by Jennett and Plum[4] and by subsequent working parties.[5–7] These criteria need to be met.

There is, however, some evidence that misdiagnosis is common.[8–10] The court will need to be reassured that any factors influencing possible misdiagnosis have been considered. These include a long enough assessment period, and discussion with relatives and carers to ensure that the windows of opportunity are not being missed. With a fluctuating level of consciousness, a one hour or so assessment by a clinical expert could miss those periods when the patient is able to demonstrate awareness. Other factors include failure to examine under optimal conditions – including postural control, distracting extraneous stimulation, periods of assessment that are too short, and the inexperience of the observer.

So far the courts have not considered a patient in the minimally conscious state, largely because the condition has only recently been described.[11] The possibility that the patient might be in the minimally conscious state has, however, been raised in a number of court cases, and therefore it is important that the treating clinicians and expert witnesses have considered this diagnosis and know what the criteria are.

Is it in the best interest of the patient to withdraw 'treatment'?

'Best interest' is not an easy concept to understand. The best interest of the patient is not just 'what the doctor thinks'. One aspect of 'best interest' is that where the treatment is not benefiting the patient, then the treatment is not in the patient's best interest. This, however, is a complicated issue in nutrition and hydration, where it is clear that the 'treatment' is having the desired effect in providing maintenance of healthy tissues. The difficulty is in deciding whether it is benefiting the patient in the broader sense, in that it cannot recreate consciousness or any return of the 'person'.

Key Points

Withdrawal of nutrition and hydration is a difficult issue for doctors

The decision to seek a directive from the Courts for withdrawal of treatment requires a knowledge of the process

Best interests of the patient require careful investigation

The decision involves family and the clinical team

Full support for those involved is required

The other aspect of best interest lies in finding out what the patients would have wanted. There are three main levels to this. First, has the patient clearly expressed wishes, when mentally competent, as to what s/he would want in this situation, ie is there an advance directive? If there is not, then the lead clinician has a responsibility to find out if there were any factors in the patient's life which, if s/he were able to do so, would influence the patient's decision-making process – did s/he have strong religious or cultural views, or had s/he expressed views about similar end-of-life situations in other people? The family are usually involved in finding this information but it could be sought from the patient's GP or other relevant people outside the family. It is important to emphasise in discussions with the family that they are being asked about what the patient would have wanted, and not what they want for the patient.

I have taken the view in court cases that any views I have on the appropriateness of withdrawal of nutrition and hydration are no more than those of the 'man in the street'. All the clinician can do is advise the court on whether there is any clinical reason why the feeding tube should not be withdrawn. In effect, this means advising on whether the condition is permanent and, if there is any potential for improvement, to what level. It is the court's responsibility to make the decision on the best interest of the patient.

What are the criteria for proceeding to law?

The process for seeking a declaratory judgement from the court authorising the withdrawal of nutrition and hydration is laid down in a Practice Note from the Official Solicitor's Office.[10] The document states that the 'diagnosis should be made in accordance with the most up-to-date generally accepted guidelines for the medical profession', by which they usually mean those of the Royal College of Physicians (RCP).[7]

The RCP[7] list four preconditions which must apply before a diagnosis can be considered:

1 The cause of the condition should be established as far as possible.

2 The possibility that the persisting effects of sedative, anaesthetic or neuromuscular blocking drugs are responsible in whole or in part should be considered.

3 The possibility that continuing metabolic disturbance is responsible for the clinical features must be considered and excluded.

4 The possibility that there is a treatable structural cause should be excluded by brain imaging.

These are primarily medical requirements to ensure that there has not been a misdiagnosis due to the medical instability of the patient.

The usual process is for someone to make an application to the court. According to the Official Solicitor's guidelines, this can be the next of kin, another individual closely connected with the patient or the health authority (nowadays usually the primary care trust). In any case, the health authority should be a party in the application – primarily because the declaration is that it would be legal for the *clinician* to discontinue treatment (ie the nutrition and hydration).

The independent expert

There is a requirement for two independent experts to be appointed – normally one for the person or authority making the application and one for the Official Solicitor. There have, however, been several instances where the court has accepted that one expert would to be used by all parties.

The guidelines for experts are:

- to assess the patient
- to perform a neurological examination and examine the results of investigations
- to write a report clearly describing the details of the assessment and the conclusion reached
- to question the other clinical staff involved, the family and carers about any responses they have seen.

The guidelines emphasise that there is no urgency in making the diagnosis and, if there is any uncertainty, the diagnosis should not be made and the patient should be reassessed.

There have been occasions when it has been necessary to make an urgent decision – for example, when the gastrostomy tube had fallen out or where there were technical difficulties in maintaining nutrition. It is important for treating clinicians to note that the court expects an application to be made in these cases. The tube 'falling out' should not an excuse to bypass the judicial process.

Team involvement

Withdrawing nutrition and hydration is a major decision, not just for the lead clinician who must make the final decision, but also for other members of the clinical team caring for the patient. It is important to involve those who are actively treating the patient – usually nurses and therapists – in the discussion about withdrawal of nutrition and hydration. They may well raise questions about diagnosis, appropriateness and effect on team morale which are worth taking into consideration. In any case, the Official Solicitor's officer is likely to want to talk to staff working with the patient and therefore it is useful to ensure that staff have an informed view.

Supporting the family and team

Whilst the lead clinician has an important role in supporting the family and certainly in providing them with information on clinical and legal procedures, it is recommended that formal counselling support be available for the family. This is best organised through the GP of each family member since support is likely to be required long after the patient has died.

It is also important for the staff on the unit, whether the patient is in hospital, nursing home or at home, to have access to counselling services. Whilst many hospitals will have staff trained in counselling, it is probably better for the counsellor not to be a member of staff. Health authorities usually have access to occupational health counselling services, but for nursing homes and hospitals in the independent sector or where the patient is at home, it is likely that an external counsellor will need to be appointed.

One person usually forgotten in provision of support is the lead clinician. There seems to be an assumption that the doctor making the decision may be stirred but not shaken by the whole process. It is important that there is someone to support the clinician throughout this difficult period. The process is likely to be a new situation for the lead clinician, and it is advisable that s/he has access to someone very experienced in the clinical diagnosis and court procedure to ensure that the correct procedure is followed through and to help answer questions from family and staff.

Practical process for the unit

There are several practical issues for the unit to consider. First, it is very useful if the patient can be placed in a single room. This helps to maintain the confidentiality of this very sensitive issue; it enables the family to visit without feeling that everyone is looking at them; and it allows staff to feel more secure.

Secondly, all staff involved must be aware that the discussions about and the procedure of withdrawal of treatment are confidential information to the patient. It should be made clear that they should not discuss the case with colleagues who are not involved in the treatment or with anyone else.

It will also be necessary to identify members of staff who are comfortable about being involved in the process of withdrawal of treatment. Some will have strong moral and cultural views and these should be respected; they should be given the opportunity of moving to another unit during this period. In my experience, staff who do not wish to be involved usually want to stay on the ward and are willing to provide cover for other patients normally looked after by staff who are willing to be involved in the procedure.

There is nothing different about the care required after withdrawal of tube feeding – normal standards of care for a dying patient should be observed. It may be advisable to gain advice and support from the local palliative care service.

The court

The court procedure is probably the most anxiety-provoking part of the process of withdrawing treatment. However, the team and family should be aware that the legal proceedings take place in the Family Division of the High Court, which is much less adversarial than other courts.

The Official Solicitor will usually have been appointed to act on behalf of the patient. One of the Official Solicitor's officers (a lawyer with experience in this field) will investigate the case. They will need expert medical advice from someone not involved in the management of the patient. The Officer will visit the patient, examine the records and talk with family and staff involved in the treatment of the patient – this includes nurses and therapists as well as the doctors. This is carried out sensitively and most staff find the process supportive.

The health authority, or in rare cases another individual, will appoint solicitors who will manage the legal aspects of seeking a Declaratory Judgment and also seek expert medical opinion.

The court procedure, whilst formal, is generally sensitively handled. It is normal for the judge to prevent the names of the patient, the family, the treating clinicians and the hospital from being stated in court or published, though this protection does not apply to the expert witnesses.

It is usual for at least one of the expert witnesses to give evidence from the witness box. Sometimes the treating clinician will also give evidence. If the family wish to give evidence they may do so, though this does not seem to occur often; indeed, it is not necessary for the family to be present.

As in other courts, the witnesses will be questioned by counsel for each party represented. These questions are usually points of clarification, unless there is doubt about the diagnosis, though such cases rarely get to court.

What will happen when the tube is removed?

The removal of the tube is a simple procedure, though obviously a major step for all concerned. Once the tube has been removed, the care is straightforward – good nursing care of the dying patient. Some believe that giving sedation or analgesia would meet any concerns that the patient may feel pain or distress, and the advice of a palliative care service would be helpful in making such decisions.

It is important that both nutrition and hydration are removed: death will be due to the effects of dehydration rather than those of undernutrition. If fluids are provided but not nutrition, the dying phase will be prolonged by weeks or months.

Death normally occurs in 10–14 days and it is usually peaceful.

Conclusion

Withdrawal of nutrition and hydration in the vegetative patient is not an easy decision to make. It requires the process of law and creates many anxieties within the family and the treating clinical team. It is, however, an important part of the clinical management of a person and requires as much caring and sensitivity as the clinical management of any patient.

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