

Nutrition by artificial means

Introduction

A psychiatrist calls the Commission's advice service to discuss her concerns about a patient. Claire is a 13 year old girl who has had symptoms of an eating disorder for more than a year. She was referred to an outpatient child mental health service several months ago with a range of difficulties including refusing meals, hiding food, steady weight loss and preoccupation with her physical appearance. Family therapy sessions were commenced but as yet her family have not been able to engage in this and there are indications of bitter disagreement between her parents about the cause and nature of Claire's difficulties. Her condition has rapidly worsened.

Claire was admitted to a Young People's inpatient service one month ago but despite intensive support her condition is deteriorating with desperate attempts to negotiate smaller and smaller quantities of food and supplements. Her physical condition is now giving cause for very serious concern and she is refusing nearly all nutrition. The multi-

disciplinary team are considering the use of nutrition by nasogastric tube. Claire is very unhappy about this and her mother refuses to consent to the treatment. She feels Claire would be better off at home. The practitioner is looking for legal and ethical guidance in relation to her grounds for proceeding with nutrition by artificial means.

This scenario is an example of the kinds of call received by the Commission and describes the complex issues involved in safeguarding the welfare of an individual who, as a result of mental disorder, puts him or herself at risk by failing to take adequate nutrition. When the Commission receives a call like this it is our role to explore the circumstances of the individual, reflect on good practice in relation to the law and provide a view on a way forward that best safeguards his or her welfare. This aim of this document is to provide general legal and ethical guidance that will be of use to practitioners when they are considering the provision of nutrition by artificial means to a person

for a mental disorder and in the absence of consent. We also expect this guidance will be of interest to service users, carers and advocates.

While this document provides a legal and ethical framework it would be impossible to provide guidance for each set of circumstances a practitioner or a service-user may encounter. People who wish to discuss the implications of the law for specific individuals, can contact our telephone service for advice and information. They might also choose to seek their own independent legal advice.

Practitioners looking for guidance on medical or other clinical criteria for decision making in this area of practice, should refer to relevant documents produced by NHS Quality Improvement Scotland and NICE.

What is ‘nutrition by artificial means’?

In the context of this guide, nutrition by artificial means refers to nutrition by nasogastric feeding tube, percutaneous gastrostomy (PEG) tube or intravenous drip where this is as a treatment for eating disorder, or where there is refusal or failure to take adequate nutrition as a consequence of another mental disorder. There is an important difference between these artificial means and forcible feeding which involves using direct force to make an individual swallow food. The Code of Practice for the mental health Act makes it clear that forcible feeding should never be used.

Hydration is not considered part of nutrition for the purposes of this guide. Hydration by artificial means (for example by intravenous drip) is given as a treatment to save life. Any nutritional component in the fluids used is minimal and nutrition is not the purpose of such treatment. We have therefore chosen not to interpret artificial hydration

as ‘nutrition’ in the context of mental health legislation. We have however included guidance around the use of fluids, given by artificial means, in relation to the mental health Act.

The legislative context

The Mental Health (Care & Treatment) (Scotland) Act 2003

The Mental Health (Care & Treatment) (Scotland) Act 2003 makes specific reference to the provision of artificial nutrition in the absence of consent and gives the Mental Welfare Commission a role in safeguarding its use. The 2003 Act provides a set of principles that must be taken into account by everyone involved in providing care and treatment to a person who has a mental disorder:

- The person’s past and present wishes about his or her care and treatment;
- The care and treatment that will be of most benefit;
- The range of options available for care and treatment;
- The person’s individual abilities and background;
- The person’s age, gender, sexual orientation, religion, racial origin or membership of any ethnic group.

Where feeding by artificial means takes place without consent, it should only be when all other options have been fully explored.

People giving care should also make sure that:

- Any restrictions on a person's freedom are the least necessary;
- The person being treated under the Act should not be treated any less favourably than anyone else being treated for a mental illness or other mental disorder;
- The needs of carers are taken into account;
- The person being treated is getting services that are right for him or her;
- When a person is no longer receiving compulsory treatment, he or she should continue to get care and treatment if needed.

As the case study in our introduction demonstrates, these principles may come into conflict with each other. Where there are competing or conflicting interests or pressures, due consideration should be given to the need to balance the various principles in the Act. We believe it is important for practitioners to demonstrate how they have balanced the principles when making treatment decisions, where

the person lacks capacity and/or refuses treatment.

In law adults have the right to make decisions affecting their own life, including decisions about medical treatment. Where an individual has a mental disorder, or is considered to lack capacity to make decisions that are in their own interest, the law provides ways in which decisions can be made on that person's behalf. The Mental Welfare Commission's guide to Consent to Treatment discusses best practice in this area. This guidance on nutrition by artificial means should be considered alongside our previous guidance on consent.

Nutrition by artificial means may be included as part of an agreed treatment plan in collaboration with the person to be treated. In the treatment of an eating disorder the use of artificial means may be more acceptable to the person for a time than making the constant effort to eat. At the Commission, we would expect that this would be the usual context in which feeding by artificial means would occur. On rare

occasions however, it may be necessary to consider providing nutrition by artificial means without the consent of the person. The 2003 Act contains specific safeguards for this situation. We think any decision to treat in this way requires very careful consideration. The provision of safeguards in the 2003 Act and the provision of guidance for practitioners should not be seen as promoting this treatment option. Where feeding by artificial means takes place without consent, this should only be considered where other treatment options have been fully explored and exhausted.

The role of the Designated Medical Practitioner (DMP)

Nutrition by artificial means can only be given if the person consents, or where a second opinion from a doctor appointed by the Mental Welfare Commission (the DMP) agrees that the treatment is in the person's interests. DMPs receive induction training on their role from the Commission, this training includes details of current good practice guidance around nutrition by artificial means. Annual training meetings provide opportunities for DMPs to update their knowledge. The factors that DMPs should take into account when authorising treatment can be found on pages 2-3 of this guidance.

The Act includes provision for urgent medical treatment, which may be given without consent in order to save life or prevent serious suffering. In some circumstances this provision may cover nutrition by artificial means. These circumstances would be where a decision has been taken to provide the treatment and a DMP opinion has been requested but it becomes essential to the

person's safety to commence the treatment before the DMP has visited. Should this arise, the circumstances must be reported to the Mental Welfare Commission. When a request for a DMP visit has been made the Commission makes every effort to provide this as early as possible. We would expect that the provisions for emergency treatment would therefore only be used on rare occasions.

Where there is consent, a person must be considered capable of giving valid and informed consent. This consent must be given in writing. There is best practice guidance regarding assessing capacity in the Commission's guide to Consent to Treatment. There is also further discussion of some of the particular issues in relation to consent in the treatment of eating disorders on pages 9-10 of this guidance.

Where the person is incapable of consenting or refuses consent, a DMP must certify that the treatment is in the person's best interests. The DMP is required to "have regard" to the reason for refusal if that is known.

When an opinion is being given for nutrition by artificial means, we think it is important that the DMP considers carefully how long to authorise the treatment for. We would recommend that the maximum period that treatment should be authorised for is three months, in the first instance. The DMP may of course authorise treatment for shorter periods or attach particular conditions, for example that the RMO review the need for treatment after a certain period and request a further opinion. After the first three months it may be appropriate to authorise treatment for a longer period of time, again the DMP may wish to attach particular conditions to this authorisation. There are special provisions for children under the age of 18. In this case, where the child's own Responsible Medical Officer is not a child specialist, the DMP must be a child specialist.

Named person provisions

In order to help ensure that the views and wishes of a person with a mental disorder are considered in care and treatment decisions, the 2003 Act provides for the appointment of a 'named person'. The individual's named person has to be informed and consulted about aspects of his or her care and can also make certain applications on his or her behalf.

In relation to nutrition by artificial means given under the Act, the following named person provisions are particularly relevant:

- The named person has the right to be consulted when certain things happen such as when a short term detention or an application for a compulsory treatment order is being considered.
- The named person has the right to receive copies of certain records or information given to the person being treated, including the record that must be made if treatment has been given which conflicts with an advance statement.

- The named person has the right to make applications or appeal to the Mental Health Tribunal for Scotland, for example an application requesting that a compulsory treatment order be revoked or varied.
- A Designated Medical Practitioner must consult with the named person (amongst others), if practicable, before making a decision about authorising the giving of nutrition by artificial means under the Act.

Anyone over 16 and receiving care or treatment under the Act can choose someone to act as their named person, providing a witness can certify that he or she understands the effect of choosing a named person. Where a named person has not been appointed by the individual, the Act provides for this role to fall by default to the person's primary carer or nearest relative. There are very few situations in which an individual should not have a named person.

The situation is different for people under the age of 16. People under 16 are currently unable to choose

their named person, their named person will automatically be the person who has parental rights and responsibilities. In cases where it is thought that this person is inappropriate to act as a named person it is possible to make an application to the Tribunal to have that person removed and replaced. The local authority will be the named person if the child is being looked after under a care order under the Children (Scotland) Act 1995.

More information on named person provisions can be found in the Scottish Executive's publication 'The New Mental Health Act – Guide to Named Persons', 2005.

Advance statements

The 2003 Act gives a person the right to make a written statement setting out how he or she would or would not want to be treated should he or she be unable to make decisions as a result of a mental disorder. An advance statement can include details about which treatments the person feels work well and which ones do not. The statement may also include the person's view on particular medications, therapies or feeding by artificial means. Young people under 16 can make an advance statement, as long as they understand the nature and possible consequences of the procedure or treatment in question.

A valid advance statement **must** be taken into account when decisions are being taken about care and treatment. For an advance statement to be valid it must be made in writing, signed and witnessed. In brief the following are necessary for a statement to be valid:

- The person making the statement must have the capacity of properly intending the wishes specified.

- It must be witnessed by someone who is a clinical psychologist, medical practitioner, occupational therapist, person working in or managing a care service, a registered nurse, a social worker or a solicitor.
- The witness must certify in writing that in, his or her opinion, the person making the statement has the capacity of properly intending the wishes specified in it. The witness does not have to assess the overall capacity of the person, but witnesses that the person was able to make the statement at that time and understood the importance of this. The witness does not have to be involved in writing the statement, nor does he or she have to agree with what the statement says.

Anyone who knows the person well can help him or her write an advance statement and this can include an independent advocacy worker or a key worker/support worker.

An advance statement is best prepared when a person is well enough to discuss the content of the statement and the

implications of this with those involved in his or her care. A statement prepared during a time of crisis is unlikely to be an accurate reflection of the person's general wishes and feelings. When a person suffers from a chronic mental health condition, such as a long term eating disorder, which may influence his or her thinking and choices on an ongoing basis, there may be uncertainty as to when the person could be considered well enough to make a valid statement. However the presence of ongoing symptoms does not in itself mean that the person is not capable of properly intending the wishes expressed in an advance statement. Even where it is thought that the person's capacity to make treatment decisions is impaired, he or she is likely to retain the ability to make valid choices about some aspects of care. For example, decisions about where or how a particular treatment might be given may be less likely to be influenced by disruptions to the person's thinking than the decision to accept or reject the treatment itself.

The advance statement cannot require someone to do anything that is illegal or unethical and it cannot insist on particular treatments or services.

If a decision is made that goes against an advance statement then the person has to be given the reasons for this in writing. A copy of these reasons should also be given to the named person, any welfare guardian or attorney and the Mental Welfare Commission.

For further information about advance statements see the Scottish Executive publication 'The New Mental Health Act, a Guide to Advance Statements', 2005.

Adults with Incapacity (Scotland) Act 2000

The 2000 Act provides a legal framework for intervening in the affairs of adults, over 16 years, with incapacity in order to protect their welfare. Part 5 of the 2000 Act covers medical treatment. The Commission's guidance on Consent to Treatment includes an examination of how the Adults with Incapacity Act allows for treatment of mental disorder and how it interacts with the 2003 Act.

It is unlikely that the Adults with Incapacity Act will often have much relevance in the treatment of eating disorders. However, where a person lacks capacity and there is no need for detention or for force, then it may be appropriate to use this Act to provide nutrition by artificial means. For example, feeding by artificial means might be given if a person who lacks capacity is physically unable to swallow. It could also be used to treat people with severe mental illness who are too ill to be able to eat but who do not resist or oppose the treatment.

We would advise using the 2003 Act if it is necessary to give treatment and if the person requiring treatment resists or objects to that treatment (or would be likely to object if able to express a view).

Human Rights Act 1998

The Human Rights Act is an important and wide ranging law that includes a set of rights and freedom (Articles) which apply to many areas of life, including medical treatment. In particular these Articles set out the individual's right to life itself and the right to freedom from treatment which could be considered degrading or inhuman. When providing nutrition by artificial means it is essential that treatment methods take account of this and that treatment is provided in a way that could not be considered punitive or degrading.

Children and the law

Legislation contains particular provision for children and young people with regard to treatment for mental disorder and consent. We have already referred to special provisions for young people under the 2003 Act 2003. The principles of the 2003 Act also make clear that anyone providing care and treatment under the Act must act in a manner which “best secures the welfare” of a child or young person under the age of 18. This may be of particular relevance in considering treatment for eating disorder where there may be opposing views about what is best for a child or young person.

The Children (Scotland) Act 1995 contains general provisions for parental rights and responsibilities, including the right of parents (or a person who has been granted parental rights) to consent to treatment for a child under the age of 16, provided the treatment is in the child’s best interest. However, children and young people may also be able to consent to their own treatment. The Age of Legal Capacity (Scotland) Act

1991 gives particular rights to children over the age of 12 to have their views taken into account in legal proceedings. In addition it gives the right to children under 16 to consent to their own medical treatment where the child has been assessed as being capable of understanding the nature and consequences of that treatment.

Legal guidance is however less clear with regards to refusal of treatment. Where a child under 16 is not capable of consenting, a parent (or person with parental rights) may consent on his or her behalf. If a child is considered able to consent and refuses, then a person with parental rights cannot consent on the child’s behalf without a court order under the 1995 Act. Where a child is refusing treatment for a mental disorder there should therefore be careful consideration in each instance as to the child’s capacity and whether or not it is appropriate to rely on parental consent. For example, where a very young child does not have capacity to consent to his

or her own treatment, parental consent will often be appropriate. However for older children, and especially where the child is actively refusing treatment it is appropriate to consider using the 2003 Act.

Our view is that it would be very rarely appropriate to rely on parental consent as the legal grounds for providing nutrition by artificial means to a young person with an eating disorder in the absence of that individual’s consent. In this situation our view is that the 2003 Act provides a more appropriate legal mechanism and better safeguards for the young person.

A difficult situation can sometimes occur where the person with parental rights disagrees with the decision to use nutrition by artificial means and this treatment is thought to be in the best interests of the child. Anyone considering such treatment should take account of these views. There must be a full discussion of the reasons for the decision and the associated risks and benefits. Ultimately, where the child does not have the

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capacity to consent, the 2003 Act could be used in the face of such a disagreement. We would expect that this would be very rare and that most disagreements could be resolved by discussion.

Issues in practice

Deciding to provide nutrition by artificial means without consent

As stated in the introduction, it is beyond the scope of this guide to discuss in detail the clinical issues surrounding the decision to provide nutrition by artificial means in the absence of consent. However, there are some key principles which we think should form part of this decision making process.

The starting point should be that the team providing treatment should seek to engage the person in a sincere and voluntary alliance. Any decision to proceed to treatment without consent should only be taken when the physical risk clearly justifies this and all other possibilities have been considered. Assessment of risk must weigh up the risks versus the benefits of imposing treatment. With regards to physical indicators, there is unlikely to be one single factor that leads to a decision to provide nutrition by artificial means, practitioners should refer to NQIS and NICE guidance for further information.

It is essential that treatment is carried out in a setting where there is an appropriate level of expert knowledge and experience. Services should ensure that there are effective procedures and protocols in place to ensure that this happens. Those providing treatment should be familiar with current good clinical practice guidance and treatment should only proceed where the clinical team are confident that the necessary expertise is available.

When the person does not consent to nutrition by artificial means, it is essential that his or her individual needs and circumstances are taken into account before deciding to proceed with treatment. This includes careful consideration of the specific individual reasons that may be leading that person to refuse treatment at that time. There must have been effort to carefully explain the different treatment recommendations that are available, with the opportunity for the person to engage in negotiation around options that may suit her or him.

An approach which promotes autonomy should be adopted and one which respects the persons capacity to make choices as far as possible. For example even where there may not be overall agreement to the recommended treatment approach there should be negotiation as to the details of how, where and when treatment is provided as far as this is possible.

In keeping with the principles of mental health law, it is important to appropriately involve the person's family, or other key people in his or her life, in the decision making process.

The intentional use of tactics which may coerce or unnecessarily frighten the person into agreement must be avoided. Those providing treatment should also be alert to the possibility that coercion can occur covertly.

Overall, consideration of the quality of the relationship between the person and the team providing treatment – the therapeutic alliance – is crucial. It is our view that a decision to treat without consent should not be taken without thorough consideration of the quality

of the therapeutic alliance. There must be confidence that the decision is being taken in the best interests of the person.

Force and the use of restraint

The Mental Health Act 2003 allows for the use of force, but only where the person is in the hospital that has been authorised to provide treatment. Force should only be used if:

- treatment is necessary and cannot be achieved in other ways;
- the person persistently resists treatment. It is best to wait and try again at a later time unless the situation is urgent;
- the principles of the Act are applied.

In particular there must be very careful consideration of alternatives, consultation with appropriate others and minimum restriction of the person's freedom. Any force should be the minimum necessary and only for as long as necessary. There are particular challenges and risks in using physical restraint where the person is frail from an eating disorder. It is therefore important that

any care plan which may include the use of force is only carried out where there are sufficient numbers of appropriately trained staff available. A distinction should be drawn between the use of force as restraint and forcible insertion of a nasogastric tube. The code of practice for the 2003 Act says that force should not be used to insert a tube. There should be very careful consideration of the risks versus benefits of the use of force. Medication may be used as restraint and may be preferable in some situations but this depends on very careful assessment of the risks in each individual situation. Where force or restraint may be required it is of particular importance to consider how to ensure that methods used are not punitive or degrading.

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Providing hydration by artificial means

We think that hydration by artificial means is not part of nutrition for the purposes of medical treatment for mental disorder under the 2003 Act. The law however does include provision for urgent medical treatment for mental disorder, where a person is detained in hospital under the Act. In this situation treatment can be given, without consent, to save life or prevent serious harm. It is our view that hydration by artificial means may be given under this provision. Where it is necessary to continue with this treatment beyond the initial urgency (e.g. for longer than seven days) and where there is total refusal of both food and fluids, it is likely that the person will also require treatment with nutrition by artificial means. Where this is the case a DMP opinion will be required if the person is unable or unwilling to consent. This opinion should consider the use of both fluids and nutrition. If there is no need for the person to receive nutrition, e.g. where fluids alone are resisted as a consequence of the mental

disorder, then treatment can continue if the person's responsible medical officer determines that it is in the person's best interest.

Withdrawal of treatment

Consideration of withdrawal or withholding of life sustaining treatment in cases of severe eating disorder is controversial, both legally and ethically. Some expert opinion would hold that this should never happen. It is not possible to explore the arguments fully in this document, however we think that the following issues are important.

Feeding by artificial means in cases of eating disorder is an intervention aimed directly at sustaining life, but also aims to help the person gain enough weight to improve physical well being to an extent that will enable him or her to engage in therapy that can effect change on a longer term basis. As with all medical treatments, the grounds for continuing treatment must be regularly reviewed and this is particularly important when the person does not consent to the treatment. A capable person has the right to refuse life sustaining

treatment. It is currently considered acceptable, by the medical profession and the Courts, to withdraw or withhold life saving or life sustaining treatment in some situations. However, eating disorders are mental health conditions that can have a severe effect on the person's thoughts and cognitive functioning which will in turn affect his or her decision making ability. Any consideration of withdrawing or withholding life sustaining treatment needs to include very careful assessment of the person's capacity in respect to the decision to refuse treatment.

The Mental Welfare Commission would expect that withdrawal or withholding of treatment would only ever be considered where the person suffers from an unusually severe and chronic eating disorder; where all available treatment options have been exhausted and where the quality of life of the person was deemed intolerable to him or her. Legal advice and widespread consultation would be essential before any decision could be taken.

References

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