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## Best Practice & Research Clinical Gastroenterology



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### Artificial nutrition at the end of life: Ethical issues



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Artificial nutrition is a medical treatment that first of all needs a sound scientific base before prescribing it. This base is absent for dying patients and patients in the end stage of dementia. Because feeding is a very emotional and symbolical issue, patient and family may request this treatment despite the lack of evidence. These issues should be addressed in good communication with patient and relatives. For comatose patients and patients in a persistent vegetative state artificial nutrition is a necessary support to bridge the time until either recovery is imminent or improbable. At that moment artificial nutrition no longer contributes to the life of the patient and should be ceased. Artificial nutrition has no place in patients that voluntarily decide to stop eating and drinking in order to die.

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Artificial nutrition at the end of life is an issue that is riddled with emotions, probably more so than any other medical treatment. Eating food, sharing food, sitting at meals together, are significant social events in all cultures across the world. Feeding the young and the ill is a powerful instinctive act, which may be hard to suppress. If we do not eat, we die; this is a truth universally known, and felt. That the reverse is also true, the dying often do not eat, is less widely known and much harder to accept. Noticing the anorexia of terminally ill patients, many caregivers have an urge to press food and drink on

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them, and if these patients cannot feed themselves many caregivers, professional or not, will want to make sure they will receive nourishment no matter how. How to negotiate these powerful urges, and at the same time serve the best interest of the patient?

First of all it should be noted that in deciding on artificial nutrition at the end of life the four ethical principles (beneficence, maleficence, respect for autonomy, justice) are as important as they are everywhere in medicine [1]. These four principles are the cornerstones of medical ethics. The principle of beneficence implies that first it should be established whether the treatment will be beneficial. Treating patients should first of all lead to a benefit for that patient, and not serve any other primary goal. This may seem to state the obvious, but in practice there can be a lot of other reasons for doctors to treat a patient: to avoid a discussion with the patient, or to avoid any legal action, or because the family insists, or because they need the patient in their research, or because they are curious to see if it will work, or to acquire eternal fame. All these reasons can be legitimate, but only if the benefit of the patient is promoted as well. The principle of maleficence, also known as ‘do not harm’, requires a doctor to assess the risk of harm. Only if the chances of doing something good outweigh the chances of doing harm, the treatment should be given. Of course the risk-benefit ratio should be proportionate to the ailment. For an illness that is acutely lethal, more risks will be acceptable than for chronic treatment. The principle of respect for autonomy is the principle that demands that the doctor does not treat the patient without assuring himself that this is what the patient wishes. In many countries this is regulated by informed consent: the patient should receive information on the treatment goals, the chances of achieving these and the risks. The patient then has to decide whether he is willing to undergo this treatment. A capable patient should never be treated against his wishes. The principle of justice is different from the other three in that it does not regulate the relationship between one doctor and his patient, but between doctors and patients (plural). Formally the principle of justice is often phrased as ‘treat equals equally’. This immediately can lead to disputes over who are equals, and in which sense equality is relevant for the case in hand. However it is clear that two patients that are equal in all relevant aspects, and for many this would be ‘are in equal medical need’, should be offered the same treatment.

Good reasons based on the principle of beneficence for offering artificial nutrition (by which is meant feeding through a nasogastric tube, a percutaneous endoscopic gastrostomy (PEG)-tube, or total parenteral nutrition (TPN)) include: improvement in the quality of life, improving the length of survival, the prevention of malnutrition, and the prevention of pneumonia and bedsores [2]. However on the basis of the principle of maleficence this should always be weighed against the possible harms, which also exist and include risk of fluid overload, aspiration and aspiration pneumonia, and infections [3–5]. Considerations of justice should lead to questions such as: ‘should this treatment be available to all patients?’, and ‘is the treatment affordable in our local circumstances?’. Having established that the treatment indeed is good enough to be offered, that the possible benefits outweigh the harms and that justice is served by offering this treatment to the patient, we then have to respect the patient’s autonomy. This implies that the patient should be informed about the goals of the treatment, the likelihood that these will be achieved by the treatment, and which possible risks and burdens are attached to the treatment. The patient then can decide to take up or decline the offer. If a patient is incompetent, and did not express any clear wishes on the subject at an earlier stage, the best interest of the patient should be served.

I will discuss four end-of-life situations where decisions have to be made to start, withhold or withdraw artificial nutrition. The first and by far most common situation is the dying patient, who typically stops eating and drinking in the last days before death. Then I will say something about feeding the patient with advanced dementia. Thirdly I will discuss the situation of the patient who is comatose or in a PVS, and finally I will discuss the patient that refuses to eat or drink because of a death wish.

### **The dying patient who has either problems eating, or no appetite**

Persons that are in the final phase of life typically have no interest in food or drink anymore. The food may not taste well, they may have problems swallowing and or digesting, and they may not

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