Scottish Council on Human Bioethics

24.04.2010 **Position Statement on:**

Palliative Sedation

A number of different terms are used to characterise the sedation of a person in the context of palliative care but because different people use similar expressions to cover different sets of practices some misunderstandings may arise. Without proper attention to what is actually being defined in the different terms, it is impossible to distinguish appropriate care from unethical practice.[1]

In this regard, palliative sedation is often used to characterise the sedation of a patient to relieve distress in the context of palliative care where neither the inducement of unconsciousness nor the hastening of death is the intent of the practice. It is typically contrasted with terminal sedation which does, or can, mean the use of sedation in the context of bringing about unconsciousness with the aim of provoking an early death (a covert form of euthanasia). However, other terms are sometimes used to describe both palliative and terminal sedation and the lack of agreement between definitions complicates ethical analysis.

1. Palliative Sedation is an appropriate intervention in the treatment of distress in the dying patient

To address the needs of a terminally ill patient for comfort and relief, healthcare professionals and patients may consider the use of palliative sedative medications in order to address distressing circumstances, such as delirium, non-curable bleeding, choking or breathlessness and occasionally existential distress.

Moderate sedation may relieve agitation and make the patient more themselves. The sedative medication may gradually be increased until the patient is comfortable and then maintained at that level. Stronger sedation makes the patient partially or totally unconscious while the disease takes its course. The illness may eventually lead to death but palliative sedation does not generally shorten life.[2]
It is also common for dying patients gradually to lose consciousness through the progress of the illness, without the use of sedatives.

2. Patients and their families should discuss the issues relating to palliative sedation

It is important to respond to people's distress compassionately. Sedation should generally take place in consultation with the patient if he or she is capable of making a decision.
Terminally ill patients should consider the possibility of palliative sedation sufficiently in advance. They should be encouraged and feel comfortable discussing their feelings and what to expect with their relatives, friends, doctors and palliative care team (who should document what has been discussed). In this respect, it is important to emphasise that the timing of death is sometimes difficult to predict and could be anywhere from hours to days after palliative sedation is initiated.

When sedation is prescribed for patients at the end of life to relieve anxiety, it is likely that they will already be on a Care Plan which includes discussions with the family. Relatives should be kept continually informed about developments during the dying process while discussing options. All management should be patient focussed and consistent with their wishes, assuming these are achievable.

3. Palliative care (including sedation when necessary) should always be provided to persons who are dying

All patients who are dying should receive palliative care if they are in any distress or experiencing suffering. Palliative care should always be initiated to patients who have started to refuse any kind of life sustaining treatment (including those refusing a treatment such as dialysis) and who are dying.

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[1] David Albert Jones, 'Death by Equivocation: A manifold definition of terminal sedation' in S. Sterckx, et al. Continuous sedation at the end of life: Ethical Perspectives; Cambridge: Cambridge University Press, 2013.

[2] The Journal of the American Medical Association, Vol. 294 No. 14, October 12, 2005, http://jama.ama-assn.org/cgi/content/full/294/14/1850

In other words, all patients who are dying whether or not they have refused life sustaining treatment should be treated in the same way.

4. There is substantial evidence that the practice of palliative sedation does not generally reduce a patient's life expectancy

Advocates of euthanasia argue that palliative sedation implies that the active ending of a life is also envisaged since the level of sedative used may hasten the death of the patient. In other words, there are two effects, sedation and the patient's death.

In response to this the SCHB notes that:

Morally good actions that also have negative consequences are part of daily life, and deliberation over complex outcomes is part of basic moral thinking. The Principle of Double Effect[3] merely describes the conditions operating in such moral thinking.
If the intention is to make the patient comfortable, sedative doses which are higher than the level required are not used though it may not always be possible to predict with accuracy the best dose to use at a given time. This would be completely different, however, to the situation where the intention is to end life and professionals deliberately administer a sedative dose to bring about an untimely death.

Moreover, a number of published studies indicate no significant reduction in survival among palliative sedated patients.[4] If this is the case, there is no reason to apply the Principle of Double Effect, as there is no secondary undesirable effect. More research would be beneficial to consolidate previous studies and to enable palliative care staff to be confident in the effects of their actions.

5. Nutrition and Hydration should not be withdrawn or withheld unless the patient's condition makes them futile

Advocates of euthanasia claim that sedation can be used while also withdrawing or withholding nutrition and hydration from sedated patients in order to hasten the dying process.

In response to this the SCHB notes that:

There is no need to withdraw or withhold nutrition and hydration unless clinically indicated in terms of their provision being impossible or significantly disruptive to the patient's comfort. The fact that someone is dying does not of itself justify failing to provide food and water. No patient under medical care should die from starvation or dehydration.[5]

It should also be noted that some patients do sometimes complain about having a dry mouth and actions should be taken to immediately address such discomfort. However, when appropriate care is provided, there is no statistically significant association between levels of hydration and these dry-mouth symptoms.[6]

6. Palliative Sedation should be proportional *(As much as necessary; as little as possible)*

The use of sedation must be proportional to the symptoms that the physician is trying to relieve. If a person can be made comfortable through the use of light sedation then it is an abuse to immediately employ deep sedation. This is because, to deny a person consciousness also means denying a person the option of changing his or her mind, of preparing his or her death with loved ones or even of indicating that his or her

[3] The Principle of Double Effect states that where an action has two effects, one good and one bad, the action is justified where the bad effect is not instrumental, intended, nor disproportionate to the good achieved.

[4] Sykes N and Thorns A (2003) The use of opioids and sedatives at the end of life. *The Lancet Oncology,* 4:312-318; Morita T, Tsunoda J, Inoue S , Chihara S, "Effects of High Dose Opioids and Sedatives on Survival in Terminally Ill Cancer Patients" (2001).

[5] Dying from dehydration should be distinguished from the decline of appetite and gradual shutting down of the system that is common in dying. Hence in persons who have stopped taking nutrition or hydration because of an underlying dying process, provision of Assisted Nutrition and Hydration may not do any good. It is also the case that oral feeding and hydration should be supported and a premature transition to tube feeding seems to be detrimental (see report of Royal College of Physicians and British Society of Gastroenterology. Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life. London: Royal College of Physicians 2010)

[6] John E. Ellershaw, Jane M. Sutcliffe, FRCP Cicely M. Saunders, Journal of Pain and Symptom Management, Volume 10, Issue 3 , Pages 192-197, April 1995.

pain has been relieved.

If, in the course of the disease, a dominant psychological or existential suffering becomes refractory to appropriate care, transient sedation may be appropriate if it is requested by the sick person, after repeated multidisciplinary evaluations, including those of a psychologist or a psychiatrist. The resumption of sedation including continuous sedation is only justified by the inability to find a response to the discomfort of the patient and after collective deliberation with written explanation of the reasons for such a decision.
The intention of palliative sedation therapy should always be to relieve the refractory symptom. Concern may be expressed when sedation is used for people who are experiencing existential suffering that may be effectively addressed without denying the person consciousness.

In the situation of a non-terminal phase of a serious and incurable disease and without any symptoms or refractory suffering, it does not appear appropriate to use continuous sedation for several weeks or months on patients. Clinical experience indicates how such demands vary and evolve over time. Palliative care and appropriate support generally have a positive impact. By contrast, a demand for continuous sedation until death, when the patient has not reached a terminal phase and without any refractory symptoms or suffering, places the person in a state of unconsciousness which does not allow him or her any change of mind.

7. Terminal Sedation

In 2013, the Oxford University Professor of bioethicist, Julian Savulescu, suggested that persons seeking assisted suicide in countries which prohibit such a procedure, may circumvent the law through what he terms 'voluntary palliated starvation'.[7] This entails the starvation of consenting patients whilst under heavy sedation. He indicates that *"any competent person has the right to refuse to eat and drink, leading to their death. And given that they will certainly die if they do not eat and drink, they are entitled to relief of their suffering as a part of medical treatment as they die. This can be achieved through palliative care involving sedation and analgesia ... This could be called Voluntary Palliated Starvation."*

He also indicates that: *"The conjunction of the right to refuse food and fluids and the right to relief of distress through provision of medicine (in this case, palliative care), may be tantamount to a right to assisted dying. This applies not only to people who have a terminal medical condition but also to people ... with a severe non-terminal physical illness."*

Savulescu finally notes that: *"According to medical ethics, competent people have the well established right to refuse medical treatment now and in the future by the formation of advance directives or living wills. This principle should apply to the refusal of food and fluids in advance ... This could be called a starvation advance directive."*

It is important to note that if the provision of assisted nutrition and hydration is considered as a medical treatment, then there would be no basis, in many European legislations, to stop persons who are not dying asking for such a treatment to be interrupted with the view of ending their lives through Voluntary Palliative Starvation.

However, the provision of continuous deep sedation to a person (who is not immediately dying[8] and is of sound mind with decision making capacity) before he or she interrupts his or her life sustaining treatment with the aim of bringing about his or her death should not be permissible. This is because:

- It would anticipate the death of the patient (who is not dying) and would mean that the healthcare professional agrees to participate in making this happen.

- It is not clinically indicated. i.e. there is absolutely no clinical reason to sedate a person who is in a stable situation. The artificial creation of a situation in which the life of a patient becomes dependent on life sustaining treatments with the aim of then interrupting these treatments to cause, with intention, the death of a person is not acceptable.[9]

[7] Julian Savulescu, A simple solution to the puzzles of end of life? Voluntary palliated starvation, *Journal of Med Ethics*, Published Online First: [18 July 2013] doi:10.1136/medethics-2013-101379

[8] Note: Persons who are dying could correspond to "*persons approaching the end of life*" defined by the General Medical Council as individuals who are likely to die within the next 12 months. Persons who are dying would certainly include persons whose death is imminent which usually means that they are likely to die within the next few hours or days.

[9] French Conseil d'État, La révision des lois de bioéthique, May 2009, http://www.conseil-etat.fr/cde/media/document//etude-bioethique_ok.pdf

- The refusal of a specific treatment by a patient who is of sound mind with decision making capacity may terminate some of the physician's associated obligations towards this patient[10] including the provision of additional treatments such as sedation. It also absolves the physician of any liability. The physician may, however, continue to provide other treatments to the patient for different ailments if they both agree that this is appropriate and acceptable.

When patients ask for information that might encourage or assist them in ending their lives, healthcare professionals should explain that they cannot respond because providing such information would mean breaking the law in the UK. Similarly, in respecting a patient's decision, healthcare professionals are not required to provide treatments which they consider to not be of overall benefit or which will harm the patient. Respect for a patient's decision making capacity cannot justify an illegal action.[11]

In addition, a physician's conduct may raise questions about his or her fitness to practise in the UK if this physician:[12]

- Encourages a person to commit suicide, for example by suggesting it (whether prompted or unprompted) as a 'treatment' option in dealing with the person's disease or condition,
- Provides practical assistance,
- Provides information or advice about other sources of information about suicide,
- Provides information or advice about methods of committing suicide, and what each method involves from a medical perspective.

However, if the sedation was provided to the patient (who is not originally dying) ***immediately after*** the intentional interruption of the life sustaining treatment with the aim of bringing about his or her own death, the situation would be different since the patient would now be dying.[13] But the patient would have to trust the doctor that he or she would initiate sedation (if appropriate) in these circumstances. This may also enable the patient to understand the ethical dilemma he or she has placed on the doctor.

If it was ever seen as acceptable for total sedation of a person to take place ***before*** his or her treatment[14] is interrupted with the aim of bringing about death, this would mean that the same procedure could also take place with the withdrawal of assisted nutrition and hydration which are considered as treatments in the UK. This would bring about Voluntary Palliative Starvation which is a form of suicide.

Healthcare professionals would also find themselves in very difficult positions if an individual started to suffer unbearably (of starvation and thirst) because they stopped eating and drinking (i.e non-assisted) with the aim of bringing about his or her own death.[15]

8. Pressures from the family

Medical professionals should consider the best interests of their patients and not put demands from their relatives first. Sometimes, the nearest relatives of patients can ask the health care professionals to 'do something' to end, what they consider to be, an inappropriate situation. However, faced with such pressures, health care professionals should resist doing anything that is not beneficial to the patients.

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[10] Timothy E. Quill and Ira R. Byock, Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids, Ann Intern Med. 2000;132(5):408-414.

[11] GMC, Consultation on Assisting Suicide Allegations Guidance, GMC, 2012, p.8. http://www.gmc-uk.org/Assisted_suicide_consultation_version_3_pub_0001.pdf_47681132.pdf

[12] GMC, Consultation on Assisting Suicide Allegations Guidance, GMC, 2012, p.11. http://www.gmc-uk.org/Assisted_suicide_consultation_version_3_pub_0001.pdf_47681132.pdf

[13] If the patient, who is not dying, is dependent on ventilation, palliative sedation should only be initiated once ventilation is interrupted. In this context, sedation can be provided almost immediately.

[14] Assisted nutrition and hydration are not generally recognised as treatments (however, since the Bland case (1993) in England and Wales assisted feeding can be considered, in law, as a form of treatment.

[15] It may be the case that the courts in Scotland would demand that sedation be provided to stop the individual experiencing unbearable suffering. Alternatively, it may be the case that a healthcare professional may be considered as assisting the suicide of a person in the above case. In this regard, it should be noted that the concept of assisted suicide is not defined in Scottish law and would be regarded as culpable homicide (a common law offence).

Scottish Council on Human Bioethics

24.04.2010 **Position Paper on:**

Palliative Sedation

1. Definitions and General Information

Palliative Care: The UK General Medical Council defines Palliative Care as**:** The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible.[16]

Palliative care does not only take place after active attempts of a treatment have ended but is a care addressed at symptoms and thus will often be present at the same time as curative treatment.

Analgesics (or painkillers): Any member of the group of drugs used to achieve analgesia — relief from pain (physical suffering). It should be noted that pain relief is different from sedation which does not primarily relieve physical suffering. A sedated patient could even have uncontrolled pain because they cannot make their analgesic needs known. Conversely, analgesics may not have any anaesthetic or sedative effect – they may not numb or calm but may simply block pain.[17]

Anaesthesia: The condition of having sensation (including the feeling of pain) blocked or temporarily taken away. The anaesthesia can be local or general. Only general anaesthesia aims at producing a complete loss of consciousness.

Hypnotics: Drugs whose specific effect is to induce sleep (they are not generally known as sedatives).[18] They should be distinguished from anaesthetics which cause a loss of sensation, either local or general. Hypnotics include soporifics, such as sleeping tablets, which facilitate sleep as part of a sleep-wake cycle.

Tranquilizers: Tranquilizers generally just have a calming effect on the mind but not the whole body. Sometimes, the difference between a sedative and a tranquilizer is one of the degree of effect.

Anxiolytics: Reduce anxiety and hence reduce agitation but not by calming the body in the way that sedatives do though part of the anxiolytic's effect is to enable a person to have a calmer body.[19]

Palliative Sedation: Sedation in the context of palliative medicine is the monitored use of medications to induce varying degrees of unconsciousness to bring about a state of decreased or absent awareness (i.e. unconsciousness) in order to relieve the burden of otherwise intractable distress.[20] Such treatment, though unusual, is generally given in the last hours or days of a terminally ill patient.

The aim or primary effect of a sedative is to allay irritability, agitation or nervous distress. Sedatives are calming agents. They are generally distinguished from tranquilizers in that they have a calming effect on the whole body (not just the mind).

[16] See: UK General Medical Council, http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

[17] Pain killers (such as opioids) are poor sedatives and can even cause agitation if used inappropriately.

[18] Many sedatives are the same medicines as hypnotics but used at different doses.

[19] Benzodiazepines are the most commonly used anxiolytics and hypnotics.

[20] Nathan I Cherny, Sedation for the care of patients with advanced cancer, Nature Reviews Clinical Oncology 3, 492-500 (September 2006)

Sedation is used in palliative care in several settings:[21]

- transient controlled sedation,
- sedation in the management of refractory symptoms at the end of life,
- emergency sedation,
- respite sedation, and
- sedation for refractory psychological or existential suffering.

Deep Sedation: Is a controlled state of depressed consciousness or unconsciousness from which the patient is not easily aroused. This may be accompanied by a partial or complete loss of protective reflexes, including the ability to maintain a stable airway independently and respond purposefully to physical stimulation or verbal command.

Continuous Sedation:[22] Characterises the partial or total palliative sedation usually until death of the patient. When patients are very distressed and agitated, and there is no reversible cause for this (this is usually in last days of life), then it may be necessary, for their own safety and to reduce distress, to use doses of sedation that will make the patient unconscious, usually permanently. In these cases, there is no hope of recovery and to not sedate would be regarded as ethically indefensible and exceptionally distressing for patient and family.
It should be noted that as patients are dying they are sleepy anyway, and in the majority of cases the doses of sedative drugs used would not be sufficient to cause sedation in themselves, rather they are used to manage minor restlessness at the end of life. Studies have shown that the average doses of benzodiazepines used at the end of life are relatively small. This does not stop occasional family members expressing concern that it is the drugs that are causing the sleepiness of their relative.

Continuous sedation at the end of life is increasingly being debated after receiving much attention when a U.S. Supreme Court ruling noted that the availability of continuous sedation made legalization of physician-assisted suicide unnecessary, as continuous sedation could alleviate even the most severe physical suffering.[23]

Terminal Sedation: A form of Passive Euthanasia whereby sedation to unconsciousness is undertaken at which point subsistence requirements such as nutrition and hydration are withheld or withdrawn with the intention of bringing about death.
As in other forms of euthanasia, this may be voluntary (where the person wishes to die), non-voluntary (where the person's wishes are not know) or involuntary (where the person does not want to die).

Subsistence requirements (also called Necessaries of Life): Elements which are necessary for the patient to remain alive such as hydration and nutrition but which are not considered as treatments.

Life Sustaining Treatments: Interventions which are necessary to keep the patient alive when his or her body can no longer address functions, such as artificial respiration, dialysis or assisted nutrition and hydration (in the UK).

Whether food and fluids are regarded as treatment may vary.[24] Sometimes it is possible to use fluids as a treatment such as in the management of an episode of dehydration or to manage side effects of opioids. Sometimes withdrawing fluids can be a helpful treatment. For example, in a patient who has developed heart

[21] Nathan I Cherny, Sedation for the care of patients with advanced cancer, Nature Reviews Clinical Oncology 3, 492-500 (September 2006)

[22] Continuous/intermittent and deep/mild sedation refer to the way in which the sedatives are given and the effects of these sedatives, not simply to the level of awareness or unconsciousness. It can also be noted that Primary sedation is when the drug has no beneficial pharmacological effects other than sedation, and Secondary sedation, where the drug has an effect in treating some underlying symptom but also has a sedative effect.
The manifold definition is in many ways a simplification. It assumes that each variable is binary, whereas there is, for example, a continuum between mild and deep sedation.

[23] Raus K, Sterckx S, Mortier F., Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide? Am J Bioeth. 2011 Jun;11(6):32-40. doi: 10.1080/15265161.2011.577510.

[24] The GMC guidelines indicate that Clinically assisted nutrition and hydration (CANH) includes nasogastric feeding and percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. PEG, RIG and nasogastric tube feeding also provide fluids necessary to keep patients hydrated. Clinically assisted hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), and nasogastric tube feeding or administration of fluid. The term 'clinically assisted nutrition and hydration' does not refer to help given to patients to eat or drink, for example spoon feeding.

failure or respiratory secretions at the end of life. Sometimes it would be wrong to use fluids. For example, in a patient with renal failure who has stopped dialysis and who would go into heart failure if fluids were given.

Intervention in the health field: Any intentional activity, withholding of activity or the withdrawal of activity in the health field. Interventions include:

Medical treatment: Any positive intentional activity designed to address a specific physical or mental disorder in the best interests of the person. Assisted nutrition and hydration are not generally recognised as treatments (however, since the Bland case (1993) in England and Wales assisted feeding can be considered, in law, as a form of treatment).

Extraordinary treatment: Any treatment which:

- holds no reasonable hope of benefit;
- would place disproportionate burdens on the patient in relation to likely benefit;
- is too expensive for the healthcare service in relation to its possible benefit.

Basic care: Any positive healthcare activity which is part of the fundamental needs of a person and does not specifically address a physical or mental disorder.
The UK General Medical Council accepts that there is no legal or commonly accepted definition of basic care nor of what is covered by this term. In the medical profession it is most often used to refer to procedures or medications which are solely or primarily aimed at providing comfort to a patient or alleviating that person's pain, symptoms or distress. It includes the offer of oral nutrition and hydration. A distinction is generally made between 'assisted' and 'oral' nutrition and hydration where food or drink is given by mouth, the latter being regarded as part of basic care[25]. Others, however, disagree with this distinction and suggest that clear distinctions are impossible to define.

Assisted Hydration: The provision of fluids, normally by intravenous infusion, for patients who are not able to maintain adequate hydration without this support. Solutions of salts and glucose are provided by assisted means in order to overcome pathology in the swallowing mechanisms. The solutions may be given parenterally as a temporary measure to prevent fluid depletion until a naso-gastric tube is inserted. As the sole treatment over weeks, their use is associated with progressive under-nutrition and eventually death.
To use fluids in a patient who is in the last days or weeks of life who has no appetite because of their illness, may provide comfort, and will not accelerate death as the patient is dying of their illness.

Assisted Nutrition: The provision of nutritious fluids, containing balanced proportions of fat, carbohydrate, protein, vitamins and trace elements, by assisted means in order to overcome a pathology in the eating or digestive mechanisms. It can be given through a naso-gastric tube or intravenously. Intravenous feeding requires considerable clinical skill and organisation since it is liable to major complications, particularly blood-borne infection. It is reserved for patients with intestinal failure.[26,27]

Suicide: The intentional ending of one's own life. Includes:

- The vast majority of cases where the person ending his or her own life is not of sound mind with appropriate decision making capacity.

- The very rare cases where the person ending his or her own life is of sound mind with appropriate decision making capacity. These cases include:

    - Suicides with an active intervention whereby persons (who are not dying and are of sound mind with decision making capacity) make a conscious and contemporaneous decision to actively bring about their own death.

    - Suicides without an active intervention whereby persons (who are not dying and are of sound mind with decision making capacity) make a conscious and contemporaneous decision not to

[25] General Medical Council, Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making, August 2002, http://www.gmc-uk.org/standards/default.htm; See also: http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

[26] Caroline Ashby, Nucleus, October 1999, pp 4-6

[27] With respect to food, it can be difficult to know what to do with patients receiving assisted nutrition who are dying, since patients who were not receiving such nutrition would have very little appetite if they were dying and commencing nutrition would be inappropriate.

accept or to withdraw from life sustaining treatment with the *intention* of bringing about or hastening their own death.[28] This form of suicide recognises the prerogative of a patient not to accept a medical intervention even if it may save his or her life. This prerogative is recognised in most countries.[29,30]

This kind of suicide is different from voluntary passive euthanasia in that the responsibility for the death rests solely with the person who dies.[31]

Assisted Suicide: The act whereby a person aids, abets, counsels or procures a suicide or an attempted suicide of another person while believing that this life ought to end. It also includes encouraging or assisting the suicide or attempted suicide of another person.

Euthanasia: Literally 'to die well' or 'a good death'. The term is generally understood as an intervention (an intentional act or omission) to end the life of another person due to the belief that it would be preferable for the person to die. Euthanasia has, as its first objective, the bringing about of the death of the person.

Principle of Double Effect: The Principle of Double Effect was developed in the 16th and 17th Centuries as part of moral theology. It states that where an action has two effects, one good and one bad, the action may be justified where the bad effect is not instrumental, intended, nor disproportionate to the good achieved.

Persons approaching the end of life: Individuals who are likely to die within the next 12 months.[32]

Persons whose death is imminent: Individuals who are likely to die within a few hours or days.

Autonomy: Persons have ability/capacity to make decisions but not regardless of their impact on others, which means that they do not have complete autonomy in the context of a society. In other words, a person's complete autonomy does not exist in a society.

2. Principles and Purposes

Providing sedation does not have a specific medical context as such. In palliative care it is understood as being synonymous with the appeasement or the attenuation of distress where a patient is, through the use of appropriate doses of drugs, put into a state where he or she is no longer completely aware of his or her situation. This can vary according to the drugs being used from making the patient drowsy to deep sedation.[33] It should be noted that a number of drugs in palliative care seek to address agitation, physical pain, feelings of anxiety, and sleep disorders, which means that the reduction of consciousness may only be a side effect.

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[28] Harris, J.D.F. 1995. 'Physician-Assisted Suicide and Euthanasia: Let Me Count The Ways'. *Canadian Medical Association Journal* 153(7):884-885. For example: Woman who refused treatment after losing 'sparkle' dies, 3 December 2015, http://www.bbc.co.uk/news/uk-34991931; http://www.bailii.org/ew/cases/EWCOP/2015/80.html.

[29] It is important to realise that a refusal of life-sustaining treatment is not necessarily suicidal. Someone approaching the end of life may refuse treatment because it is burdensome or risky or because they are not convinced of the benefits.

[30] In the case of Airedale NHS v. Bland, Lord Musttill indicated that "*If the patient is capable of making a decision whether to permit treatment and decides not to permit it his choice must be obeyed, even if on any objective view it is contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse consequences and even death will or may ensue ...*".
An example of an application of this judgement is given in the case where a woman paralysed from the neck down was given the right to die - BBC - 2002: http://news.bbc.co.uk/1/hi/health/1887281.stm
Another example was the decision by a young paralysed severely ill Swedish man (see end).
These cases may be defined by some people as forms of passive suicide.
Sometimes, where the device is situated may be important. As an example, consider a situation in which a patient requests a doctor to turn off a pacemaker located outside the patient's body. Such a request is generally regarded as a refusal of treatment and doctors in the United States are obligated to follow the patient's request. This is regarded as allowing the patient to die, but not killing the patient which is illegal in the US. However, now suppose the pacemaker is located inside the patient's body and he makes the same request. Is a doctor obligated to follow the patient's request? Should shifting the pacemaker from outside the patient to inside the patient make an ethical or legal difference?

[31] With voluntary passive euthanasia another person must agree that a person's life should be ended and takes responsibility for ending this life.

[32] General Medical Council, Treatment and care towards the end of life: Good practice in decision making, May 2010, p. 8.

[33] A number of reports on the topic lament the lack of a clear understanding of what constitutes sedation, and multiple definitions have been offered. This ambiguity is no doubt responsible for some the different results obtained in studies on palliative sedation.

Terminal illnesses can cause distressing symptoms, such as severe pain, mental confusion, muscle spasms, feelings of suffocation, and agitation. In some cases these symptoms may not respond to standard interventions despite skilled palliative care. In these circumstances, palliative sedation may be used to control severe distress and/or agitation in patients whose conscious level is already diminished by their illness. i.e. to increase comfort in dying rather than in any way shortening life.

It is also recognised that some patients may take up to 10 days or more to die in a semiconscious or unconscious state without drugs and therefore it should not be assumed that it is the drugs that are causing the reduced conscious level. It is possible to reduce or indeed discontinue sedative drugs with no alteration of their conscious levels.

Generally, sedatives are neither per se hypnotics or general anaesthetics, and if they are used to produce permanent unconsciousness then they are not being used as sedatives but as a kind of surrogate general anaesthetic. For this reason, when a doctor prescribes sedatives this is generally to alleviate distress and the reduction of consciousness is a side effect.
It may be, for example, that one sedative is more effective than another against agitation but with less suppression of alertness. Hence, it is the reduction of consciousness that is the means of reducing the distressing symptoms, unless sedatives are used deliberately to induce unconsciousness. However this use of sedative drugs to seek to induce unconsciousness (but not to address agitation) can be considered as a distinct practice, distinguishable both in terms of the doses which would be given, how dosage and effectiveness would be assessed, how much would typically be given etc. and in relation to intention - the reasons which would be given, the aim of the exercise.
This is often particularly apt in cases of terminal illness, where there is no cure.

In palliative care, sedative drugs such as benzodiazepines and antipsychotics are generally used for a variety of reasons:

- Primarily benzodiazepines are used for management of anxiety, not usually to induce sedation, or even sleepiness, but relaxation and a de-escalation of the often distressing anxiety that accompanies other symptoms such as pain or breathlessness. Benzodiazepines are also used to treat or prevent convulsions or fits, as a muscle relaxant. However, just because this group of drugs are used at end of life does not mean that sedation is always intended. Indeed only rarely is that the case. The intention is mainly to reduce anxiety/agitation and this is shown by the use of increasingly smaller doses.

- Antipsychotics, on the other hand, may be used for management of delirium or side effects of other medication, again with the intent of managing symptoms, though sometimes with the necessary side-effect of some sedation in a patient who may be a danger to themselves or others.

Someone administering sedative in proportion to how much is needed to allay agitation need not aim to reduce consciousness, and the reduction of consciousness may only be relative. Indeed because agitation and distress may cloud mental functioning, a mild degree of sedation may actually help someone be more aware of themselves and others.

Sometimes sedation is used to enable a good night's sleep. Sometimes it is used to allow short periods of respite from distress, often in patients who are approaching end of life. Occasionally it may be necessary to sedate a patient very deeply as a temporary measure while health care professionals seek to reverse a medical problem such as a drug side effect, when not to do so may lead the patient to experience harm. The sedation can then be reversed if possible.

Even when used for the management of agitation or delirium it is very seldom necessary to deeply sedate any patient continuously until they die, but usually only for periods of 12 or 24 hours at a time[34] (so-called intermittent palliative sedation).

Sedating people deliberately and completely to deal with their distress is not a common situation in the UK. In the situation of a catastrophic haemorrhage or choking, sedation is looked for immediately and is first line treatment and not after all other means to provide comfort and relief have been exhausted as in the generalist setting especially when there are no other options.

[34] Whatever the circumstances, morphine is not the drug of choice used for this sedation since it wears off rapidly, which is appropriate for patients seeking pain relief, but makes for a poor sedative.
Morphine and other opioids can also make agitation and distress worse by causing opioid toxicity.

In certain cases, sedation by hospital staff may be the consequence of an absence of a palliative care setting with the appropriate analgesic or support services. However, it should be emphasised that deep sedation can never be a substitute to palliative care. In other words, it cannot be seen as an easy solution which may be considered to address the absence of appropriate palliative care.

Generally, studies have found that the declared reasons for administering sedation in palliative care units can vary significantly. A 2000 study of palliative care units in Israel, South Africa and Spain[35] found that delirium was the most common reason for sedation in three of the four units examined, and that pain was the least common. In Spain, of all the sedated patients, almost one in ten were sedated because of distress, in either themselves or in their families. In the other units, this figure was one in a hundred. This raises the question of what symptoms justify palliative sedation and whose perspective should be taken into account. It is likely that personal and cultural factors will influence the answers given by individual medical professionals to these questions. But it is worth noting that, in all countries, suffering is rarely the reason for sedation, except in the Netherlands, where it is commonly the stated reason.[36]

Though sedation diminishes the capacity of the patient to interact, function, and, in some cases, live, there are no distinct ethical problems in the use of sedation to relieve otherwise intolerable suffering or distress in patients who are dying.

It is not yet clear that sedation itself shortens life expectancy of a patient. A number of studies have been published showing no significant reduction in survival among terminally sedated patients.[37]
For example, a 2001 retrospective study of 238 patients admitted to a palliative care unit[38] found no significant difference in duration of survival between patients receiving sedation and those who did not.
By reducing stress, sedation may actually delay the dying process.[39] Thus, if there is no life-shortening effect then there is no reason to apply the Principle of Double Effect.

The consideration of deep sedation can be seen as an indispensable supplement to the cessation of treatment, especially when this means an interruption of life sustaining treatment. This happens, for example, for dying adult and new-born patients affected by severe cerebral lesions, who by definition are incapable of expressing their wishes, and for whom a cessation of the treatment is decided.

The placement of these patients under deep sedation with a prior or simultaneous interruption of life sustaining treatment is aimed at eliminating all nervous perception of suffering which may result from this interruption. Indeed, in the present state of scientific knowledge, it is impossible to evaluate the intensity of suffering felt by such patients. Their placement under deep sedation is, in these circumstances, a sign of compassion, just as much from the patients' as from their relatives' perspective who want to be assured that no suffering takes place.[40]

It is important to note the gravity of the situations where palliative deep sedation is an option – times when all 'normal' life and thought can seem far away, when the usual rules and boundaries are faint, times of grief and profound questioning about life.

Deep sedation makes it impossible for the patient to eat or drink, so without assisted nutrition and hydration they will certainly die. But patients are usually sedated for no longer than a few days before death occurs, so these factors are generally not the cause of death.

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[35] Fainsinger RL, Waler A, Bercovici M *et al. "*A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients", *Palliative Medicine* 2000; 14: 257–65.

[36] Seymour J, Janssens R., 'An exchange visit to examine issues relating to technologies used to relieve suffering at the end of life', 2003. http://www.york.ac.uk/res/iht/internationalfellowships/SeymourFellowshipReport.pdf

[37] Bercovitch M. and Adunsky A.,'Patterns of high-dose morphine use in a home-care hospice service', *Cancer* Vol. 101, Issue 6 , pp1473 – 1477 (1999); Thorns AR, Sykes NP. 'Sedative use in the last week of life: the implications for end of life decision-making'. *Palliative Medicine* 2000; 14: 339; Sykes N and Thorns A (2003) The use of opioids and sedatives at the end of life. *The Lancet Oncology,* 4:312-318; Morita T, Tsunoda J, Inoue S , Chihara S, "Effects of High Dose Opioids and Sedatives on Survival in Terminally Ill Cancer Patients" (2001)

[38] Thorns A. Sykes N. The use of sedatives at the end of life. [Letter] Palliative Medicine. 15(4):347, 2001 Jul.

[39] Terminal Sedation, Centrum voor Ethiek en Gezondheid, 2004, p. 9, http://www.ceg.nl/data/download/Terminal_sedation.pdf

[40] French Conseil d'État, La révision des lois de bioéthique, May 2009, http://www.conseil-etat.fr/cde/media/document//etude-bioethique_ok.pdf

In addition, a particular prognosis can make the provision of nutrition and hydration futile. Thus, in some cases, nutrition or hydration is not supplied due to medical considerations. However, there remains concern that where sedation is not accompanied by nutrition and hydration for a long period, the effect is equal to hastening the death of the persons, leading some to call for a universal practice of providing hydration until death in all cases.[41,42]

It seems that without hydration, death within one month is a foregone conclusion, regardless of the predictions of doctors. Researchers highlight the vital functions that are suppressed by deep sedation, such as respiration, blood pressure, heart rate and airway and swallowing reflexes, and the fact that rapid dehydration increases restlessness, agitation and delirium which then require increasing sedative doses. They indicated that "*continuous deep sedation sets in motion a series of predictable, self-perpetuating pathophysiologic events that are not only directly linked to the desired mechanism of action (i.e. deep sedation) but also have direct life-shortening effects*."[43]

Continuous deep sedation should only be used if patients are in the last few days of life which is easier to predict in cancer patients but more difficult in non malignant diseases especially dementia. This is a clinical decision and not an easy one in many cases, so continuous sedation may be used in conjunction with rehydration until such times as a diagnosis of dying (last few hours-days) is made by the clinical team and discussed with family. It is a process rather than an event.

A more intricate question is that of the use of deep sedation with regard to patients who are not dying and who remain capable of expressing their will and who ask for such a procedure. They do this with the view of later obtaining, without suffering, the cessation of all life sustaining treatments (including assisted nutrition and hydration) with the intention of bringing about or hastening their own death. Such a request can be made by patients who experience a very intense psychological or existential suffering or patients who, for any other reason, refuse all care and request an ending of their lives through this means.[44]

Where there is an advance decision to refuse treatment and this is clearly valid and applicable to the situation, it is illegal to give treatment. This is similar to the situation of someone who is conscious and able to make the decision and who refuses treatment. Generally, the law forbids the doctor from imposing treatment in these circumstances, even if the treatment would save the person's life. This may be difficult to accept for a conscientious doctor who is committed to the best interests of those in his or her care.[45] Nevertheless, if there is a valid and applicable refusal of treatment, and if providing the treatment would have sufficiently grave legal consequences for the doctor, then he or she is not guilty of neglect for any harm that follows from not providing the treatment. This is because the law in effect removes this aspect of the person's care from the doctor's professional responsibility.

It is important to realise that a refusal of life-sustaining treatment is not necessarily suicidal. Someone approaching the end of life may refuse treatment because it is burdensome or risky or because they are not convinced of the benefits.
A refusal will only be suicidal if someone, who is not dying, refuses medical treatment with the specific aim of ending his or her life by this means. The aim or intention of the person who refuses treatment will not always be evident to others. In general, it cannot simply be 'read off' or deduced from the advance decision document itself, because the reason for the refusal will not usually be recorded. Thus, a healthcare worker should give a patient the benefit of the doubt and should not assume that a refusal reflects a suicidal intention.

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[41] Craig, Gillian, "Terminal Sedation", *Catholic Medical Quarterly,* February 2002.

[42] During the 2006 inquest into the death of Olive Nockels at the Norfolk and Norwich University Hospital, it was reported by Dr David Maisey that patients die of dehydration "all the time" although this claim was later disputed by the hospital, who claimed such deaths occurred perhaps once a month. (BBC news report, 9th November 2006, http://news.bbc.co.uk/1/hi/england/norfolk/6134358.stm)

[43] Rady, M.Y., Verheijde, J.L. 2010. 'Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death?' *American Journal of Hospice & Palliative Medicine* 27(3):205-214, p. 208.

[44] This is an option that is increasingly being accepted by bodies such as the Swedish National Council on Medical Ethics. See: Swedish National Council on Medical-Ethics, Patient autonomy in end-of-life decisions, November 2008, Reg. No14/08.
See also: The patient's possibility to decide about his/her own death, November 2008, Reg. no14/08, http://www.smer.se/Bazment/337.aspx

[45] The role of the clinical team when a patient refuses treatment is to ascertain whether the refusal is valid, ie: the patient is competent to make the decision, the patient has adequate information on which to base his decision, and he is not influenced by internal (fear, depression etc) or external (family, financial) factors. If the decision is valid, then that decision should be respected even if the doctor disagrees with it.

In rare cases where a refusal is clearly suicidal and is definitely valid and applicable it is important to understand the refusal on two levels: the refusal itself, and possible cooperation with this refusal. If a refusal of treatment is intended to bring about death then it is suicidal. Such a refusal is a self-destructive act that also harms society. Even if this refusal is legally permitted, it is not something that should be supported. In the rare case where a decision to refuse treatment is made clearly and explicitly for suicidal reasons then healthcare professionals should not do anything to imply approval of the decision.
A second and related question is to what extent it is appropriate to 'cooperate' with someone's suicidal refusal. For example, should a healthcare professional carry out the person's wishes by permanently withdrawing a feeding tube or by ordering others to withdraw it? In this situation, it should be possible for healthcare professionals to make it clear that morally they cannot implement an overtly suicidal request to withdraw treatment (with or without active sedation). Thus, in some cases, this may necessitate the healthcare professional's withdrawal from the patient's care.

It should also be noted that the law in countries, such as France, does not permit physicians to respect a specific request for sedation by a patient in every situation.
It all depends on the intentions which preside over the placement of the patient under deep sedation. If it is to address the distress or pain felt by a conscious dying patient, the placement under deep sedation can be considered as an appropriate form of palliative care. Taking into account the proximity of death, the cessation of the subsistence requirements which would follow may constitute the most appropriate solution for the patient.

On the other hand, in the case where the patient is not dying and his or her suffering can be treated through other means, the placement under sedation with the sole aim of making the patient dependent on life sustaining treatments, such as assisted nutrition and hydration, and then interrupting theses requirements in order to end his or her life, would no longer correspond to the provisions of French law. Indeed, legislation in countries, such as France, permits the interruption of any treatment which is keeping the sick person alive, but it does not authorise the artificial creation of a situation in which the life of the patient becomes dependent on the life sustaining treatments with the aim of then interrupting these to cause the death of a person.[46]

Acts of suicide whereby a person (who is not dying and is of sound mind with decision making capacity) makes a conscious and contemporaneous decision to decline or to withdraw from life sustaining treatment with the intention of bringing about or hastening his or her own death have already been undertaken in the UK and Sweden.[47] Because of this, legislation would likely have to take into account developments in the legal provisions on assisted suicide.
For example, the Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide issued by the Director of Public Prosecutions for England and Wales in 2010,[48] indicated that a prosecution is more likely to be required if "*the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not]*".

In this regard, it is difficult to see healthcare professionals deliberately considering such a chain of events with respect to the interruption of assisted hydration and nutrition with suicide as the outcome. It would also be unethical and irresponsible for healthcare professionals to put someone into deep sedation when more appropriate clinical alternatives are an option.

3. History

Sedation has been part of medical practice for centuries. Opium has been used since Roman times, and lavender filled pillows have also been employed to induce sedative effects in patients. In the 18th Century, sedation was believed to be part of a treatment for 'yellow fever'. In 1772 Joseph Priestley created nitrous

[46] French Conseil d'État, La révision des lois de bioéthique, May 2009, http://www.conseil-etat.fr/cde/media/document//etude-bioethique_ok.pdf

[47] In the case of Airedale NHS v. Bland, Lord Musttill indicated that "*If the patient is capable of making a decision whether to permit treatment and decides not to permit it his choice must be obeyed, even if on any objective view it is contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse consequences and even death will or may ensue ...*".
An example of an application of this judgement is given in the case where a woman paralysed from the neck down was given the right to die - BBC - 2002: http://news.bbc.co.uk/1/hi/health/1887281.stm
Another example was the decision by a young paralysed severely ill Swedish man (see end).

[48] Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide Issued by The Director of Public Prosecutions, Crown Prosecution Service, February 2010, http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf

oxide (laughing gas), which began to be used for pain relief in operations. However, this was replaced by ether in 1846, which was more effective and in 1847 James Simpson introduced chloroform. In the 20th century, less dangerous sedatives became available while the development of respiratory machines enabled patients in deep sedation to breathe.

The history of palliative sedation is bound up with that of palliative care. Although 'hospices for the dying' were established by a religious order in the 18th Century, it was not until the 1960s that the hospice movement started to grow, mainly in the UK. In 2005 there were around 1700 hospice services in the UK. The provision of this kind of medical care, where the primary aim is to relieve suffering and distress at the end of life, is at the foundation of the practice of palliative sedation.

4. England and Wales – Legislation, Case Law

4.1 Developments

In *Airedale NHS Trust v Bland,* the UK House of Lords held that there was no absolute obligation on doctors to prolong an incapable patient's life regardless of the circumstances or quality of life. Thus, medical treatment, including artificial nutrition and hydration or antibiotics, could lawfully be withheld from an incapable patient even though this would result in the patient's death, provided responsible and competent medical opinion was of the view that continuing provision was futile and would not confer any benefit on the patient.[49]
This classification of assisted nutrition and hydration as medical treatment, though not generally accepted, has however been adopted in other subsequent cases in England and Wales[50] and is now established common law. The British Medical Association has concurred with this since 1992.

Due to the emphasis on the Persistent Vegetative State in the Bland case, it is not clear that this ruling applies to other conditions such as advanced dementia, severe strokes, or cases of sedation, where assisted nutrition and hydration are required. Although there is no legal framework for these situations, a practice has developed where decisions can be taken as to whether continued intervention, including assisted nutrition and hydration, are of any benefit to the patient, and continued or discontinued accordingly.

At the beginning of 2000, the ***Medical Treatment (Prevention of Euthanasia) Bill*** was presented to the House of Commons. The aim of the bill was to clarify as unlawful the withdrawing or withholding of medical treatment, including assisted hydration and nutrition, where the purpose of doing so was to cause or hasten the death of the patient. Objections were raised on the grounds that the current law already included such provisions, and the bill was effectively blocked when it ran out of time for debate.

In July 2005, a 30-year-old terminally-ill Bristol woman, named Kelly Taylor, attempted to starve herself to death as an act of voluntary suicide. She had Eisenmenger's syndrome, which gave her chest pain and left her short of breath, and also had a spinal condition, Klippel–Feil syndrome, which restricted her mobility. Her condition was terminal but her death was not imminent.
After 19 days of starvation, however, she was in so much pain that she began eating again. In March 2007, when she had less than a year to live, Ms. Taylor subsequently launched a legal battle at the High Court to force doctors to sedate her until unconsciousness, and then to withdraw assisted nutrition and hydration in line with her 'living will' with the aim of ending her life.
However, her doctors refused her requests, saying that it amounted to assisted suicide.[51] After a few months in court, Ms. Taylor eventually withdrew her case after her request for an adjournment was refused.[52]

4.2 Present Situation

In England and Wales, there is no specific legal framework relating to palliative sedation. It is considered to be standard medical practice in response to symptoms.

In the UK it is illegal to intentionally bring about death by a deliberate act. But the Bland ruling suggests it is permissible to allow death to take place by the withdrawal of assisted hydration and nutrition, which were

[49] *Scottish Law Commission, Report on incapable adults, 1995, http://www.scotland.gov.uk/rightmoves/docs/ria-01.htm.*

[50] See, for example, Frenchay Healthcare NHS Trust v S [1994] 1 WLR 601, Re D (Medical Treatment)[1998] 1 FLR 411.

[51] Court battle over 'right to die' - BBC - 28.3.07 - http://news.bbc.co.uk/1/hi/england/bristol/6504395.stm

[52] Kelly Taylor drops case, Care Not Kinning, 9 May 2007, http://www.carenotkilling.org.uk/?show=412

defined in that ruling as medical treatments, and thus not obligatory where they are judged to be of no benefit to the patient. Hence withdrawal or withholding of assisted nutrition and hydration from a sedated patient is not illegal in the UK when its provision or continuance is judged to be of no benefit.

Dr Michael Irwin of the Voluntary Euthanasia Society (VES) has indicated that the practice of terminal sedation can give support to the case for euthanasia. In this regard he mentioned that "*For VES members, I believe it is important that we stress that terminal sedation, both voluntary and involuntary … is widely performed in this country, especially in hospices and nursing homes, and as it is totally uncontrolled, this procedure is open to abuse*."[53,54]

5. Scotland – Legislation, Case Law

5.1 Developments

The classification of assisted nutrition and hydration as medical treatment was adopted by the Court of Session in Scotland in *Law Hospital NHS Trust v Lord Advocate*, (1996)[55] and is now established common law.

The ***Adults with Incapacity (Scotland) Act (2000)*** was brought forward following a 1995 report by the Scottish Law Commission on incapable adults, and enacts many of the principles in that report, one of which is that any intervention in the life of an adult with incapacity must be for his or her benefit. However, the Act did not include provision for the withdrawal or withholding of treatment from incapable patients, as proposed by the Scottish Law Commission. This was omitted on the grounds that such a proposal does not "*command general support*" and because "*attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases*".[56]

5.2 Present Situation

Adults with Incapacity (Scotland) Act 2000

The withdrawing or withholding of nutrition and hydration is not specifically mentioned in the *Adults with Incapacity (Scotland) Act 2000*.

However, In para. 2.62 of the Code of Practice it is indicated that:

"Nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient.
During Parliamentary debate on the Act there was extensive discussion of this matter. Ministers made it absolutely clear that the Act does not permit any form of euthanasia, which remains a criminal act under Scots Law.

As the then Deputy Minister for Community Care, Iain Gray, said in the Scottish Parliament,
"Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law."

All interventions under the Act (including some omissions to act) must comply with the general principles that all interventions must benefit the adult, and that any intervention must be the least restrictive option in relation to the freedom of the adult. Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult.

In other words, the present situation in Scotland is that it would not be possible to sedate a person until unconsciousness and then withdraw subsistence requirements with the aim of ending his or her life.

[53] Irwin M., 'Terminal Sedation', in *Voluntary Euthanasia News*, May 2001 p 8-9

[54] This is an example of how definitions can be blurred and why accurate definitions are so important. Terminal sedation can be used to mean intending to kill but if used in the hospice setting it may mean continuous sedation at end of life to reduce distress with no intention to kill.

[55] Law Hospital NHS Trust v Lord Advocate, (1996) SLT 848.

[56] Making the Right Move: Rights and protection for adults with incapacity, Scottish Executive, 1999, http://www.scotland.gov.uk/rightmoves/docs/mrmm-07.htm, 6.14.

However, more generally, there is no explicit legal framework relating to palliative sedation since it is considered as an option at the end stage of terminal care with no need for any legislation. The withdrawal or withholding of nutrition and hydration is generally accepted where its continuation is futile and of no benefit to the dying patient.

6. Legislation, Case Law and Regulations – International

6.1 International

In a briefing for the UK parliamentary delegation to the Council of Europe in 2004, the UK government indicated that it felt that the withholding or withdrawal of medical treatment that has no curative or beneficial effect should not be confused with the act of deliberately killing a patient. An adult with capacity is able to refuse any form of medical treatment or care. Where the patient is incapacitated and has not made a relevant advance refusal of treatment, the treatment will be lawful if it is in the best interest of the patient. Hence, if the treatment is not in the best interest of the patient it will not be lawful to initiate or to continue that treatment. In line with good practice, decisions to withdraw medical treatment should be made only after discussions with the healthcare team and, wherever possible, those close to the patient.

In a 2006 study of the practice of palliative sedation in six European countries (Belgium, Denmark, Italy, the Netherlands, Sweden, Switzerland) it was found that palliative sedation occurred in between 2.5% and 8.5% of deaths, among patients with cancer and other diseases, and was provided in, as well as outside, hospitals. For the Netherlands, the estimated proportion was 5.6%.[57]
In between 35% and 64% of cases of palliative sedation, assisted nutrition and hydration were withheld (1.6-3.2% of all deaths).[58]

Other studies have shown widely varying levels of occurrence, up to as much as a 52% incidence of palliative sedation[59,60] with the majority of clinicians having carried out the practice. In other words, it appears that palliative sedation is not a rare occurrence in some countries.

6.2 Other Countries

Netherlands

In 2003, the Dutch government rejected the proposal that palliative sedation should be covered by the same legal controls as euthanasia. The Royal Dutch Medical Association supported the government's position that palliative sedation is normal medical practice.
However, as euthanasia is legal in the Netherlands, it has been reported that 17% of cases of palliative sedation, where nutrition and hydration are not provided or continued, have the express purpose of hastening death.[61]

In the Netherlands[62], cancer was the most frequent (66%) diagnosis for patients undergoing Palliative Sedation. More generally, the reasons most cited for Palliative Sedation were:

- Physical Pain (54%)
- Agitation (43%)
- Tightness of the chest (30%)

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[57] Miccinesi G, Rietjens JA, Deliens L, Paci E, Bosshard G, Nilstun T, et al. Continuous deep sedation: physicians' experiences in six European countries. *J Pain Symptom Manage* 2006;31:122-9.

[58] Miccinesi G, et al, on behalf of the EURELD Consortium. "Continuous Deep Sedation: Physicians' Experiences in Six European Countries"**,** Pain Symptom Manage. 2006 Feb;31(2):122-9.

[59] Cowan JD, Palmer T. Practical guide to palliative sedation. Curr Oncol Rep. 2002;4: 242-249.

[60] Rabruch, L "Reflections on the use of sedation in terminal care*" The European Journal of Palliative* Care, Vol. 9 No. 6, p238 (2002)

[61] Rietjens Judith A. C. et.al., "Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands" (2004), in *Annals of internal medicine* , vol. 141, no3, pp.178-185

[62] Van der Wal G, Van der Maas PJ. Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de meldingsprocedure. Den Haag: SDU Uitgevers, 1996

Van der Wal G, Van der Heide A, Onwuteaka-Philipsen BD ea. Medische besluitvorming aan het einde van hetleven. De praktijk en de toetsingsprocedure euthanasie. Utrecht: De Tijdstroom, 2003

- Anxiety (12%)

The extent to which life had been shortened was estimated at one week or less in 51% of cases, one to four weeks in 21% of cases and one to six months in 3% of cases. In 23% of cases, the decisions were not regarded as having shortened the patient's life.

In 2008, another study showed[63] that, in the Netherlands, the use of continuous deep sedation increased from 5.6% of deaths in 2001 to 7.1% in 2005 mostly in patients treated by general practitioners and in those with cancer (in 2005, 47% of sedated patients had cancer *versus* 33% in 2001). At the same time, the use of euthanasia fell from 2.6% of all deaths to 1.7%, representing a decrease of 1,200 cases. Such sedation was provided in conjunction with decisions that possibly hastened death (such as decisions to withhold potentially life prolonging treatment).
For 47% of all patients who received continuous deep sedation, the sedation was started in the last 24 hours before death.
Also 9% of those who received continuous deep sedation had previously requested euthanasia but their requests were not granted.
In addition, only 9% of the physicians had consulted a palliative expert which was reflected in that around 15% of the physicians used morphine without a benzodiazepine to attain sedation which is considered to be clinically inappropriate.
The authors note that: "*For patients with a longer life expectancy, there is a risk that labelling the decision as continuous deep sedation instead of ending of life might serve as a way to evade the procedural requirements for euthanasia.*"[64]

Sweden

The decision by a young paralysed severely ill Swedish man connected to a respirator to end his life in a "suicide clinic" in Switzerland started a debate in Sweden concerning the legal framework for a paralysed person to end his or her life with assistance.
According to Swedish law, persons have the right to decide whether or not they want to continue their treatment. In this case, the young man could have decided to turn off the respirator, leaving him to a painful death by suffocation. Debate then arose since it was unclear whether the physician in charge would have been legally entitled to put the patient to sleep before switching off the respirator in order to help him die a painless death. Finally, the Delegation on Medical Ethics of the Swedish Society of Medicine presented new guidelines about withholding and terminating treatment in March 2007. It was made clear that a physician could terminate treatment in these situations, and should also relieve a patient from pain in situations where the patient has decided to end his life by refusing further medical treatment.[65]

USA

In 1999 and 2000 the ***Pain Relief Promotion Act*** was under consideration. It aimed to amend the ***Controlled Substances Act*** by reinforcing the legitimate uses of controlled substances and promoting educational and research programmes. The goal was to promote palliative care without permitting assisted suicide and euthanasia. It received support from the American Medical Association, but was opposed by the American Nurses Association on the grounds that it allowed the Drug Enforcement Administration decision-making powers as to the intentions behind a particular use of controlled substances in a medical setting. The act was passed by the House of Representatives and by the Senate Judiciary Committee, but was not placed on the Senate schedule, and was never enacted into law.

Palliative sedation is legal in the USA when undertaken with the explicit consent of the patient or their designated decision-maker. If such consent is not given palliative sedation is illegal.
In *Vacco v. Quill* (1997), Chief Justice Renquist distinguished palliative sedation from euthanasia or assisted suicide on the basis of the intent of the medical staff.

[63] J. Rietjens**,** J. van Delden**,** B. Onwuteaka-Philipsen**,** H. Buiting**,** P. van der Maas**,** A. van der Heide**,** Continuous deep sedation for patients nearing death in the Netherlands: descriptive study, BMJ 2008; 336:810-813 (12 April), http://www.bmj.com/cgi/content/full/336/7648/810

[64] Nevertheless, the reasons behind the increase in Terminal Sedation in The Netherlands need not have involved a relation to euthanasia, for it seems that rates of Terminal Sedation are rising significantly in all countries, whether or not they have legalised euthanasia. It also seems that the terms and definitions used provide insufficient clarity to resolve the key clinical and ethical issues.

[65] Ethically Speaking, Issue 8, July 2007, Office for Official Publications of the European Communities, p.37.