



## Treatment strategies for Life Support in Intensive Care

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## Treatment strategies for Life Support in Intensive Care

### Background

As medical skills and technology improve it is becoming possible to offer elective and emergency treatment to an increasingly elderly and morbid patient population. For the most severely ill patients, these efforts may simply prolong suffering instead of helping them to return to a way of life and a quality of life that is acceptable to them. There is therefore an increasing need for individual evaluation of the expected result of on-going or future treatment.

Data from the Swedish Intensive Care Registry (SIR) show that withdrawing intensive care leads most often to the patient dying in the intensive care unit (ICU), and as others die later in the wards of the same hospital, only a very few leave the hospital alive, and they are usually transferred to another healthcare institution.

This document from the Swedish Society for Anaesthesia and Intensive Care (SFAI) is a revision of the 2007 document *Withholding or withdrawing treatment in Swedish Intensive Care* that is intended to bring current guidelines into agreement with the new regulations in *Life support treatment (SOSFS 2011:7)* issued by the Swedish National Board of Health and Welfare with effect from August 2011. The objective of SOSFS 2011:7 is to guarantee a high standard and safety of care for patients with life-threatening conditions, an area for which legally binding regulations have not previously existed.

### Guidelines

The present guidelines are intended to assist and guide the intensive care physician in selecting an optimal treatment strategy for patients with life-threatening conditions. The guidelines also contain guidance on the procedures that should be observed in various practical situations when curative care is abandoned and palliative care begins.

### Concepts

#### Life threatening condition

A condition in which disease or injury constitutes a threat to the patient's life.

**Life–support treatment**

The treatment afforded a patient with Life Threatening Disease in order to keep the patient alive.

**Curative treatment**

Treatment intended to cure a disease or promote recovery from injury.

**Palliative treatment**

Treatment or care intended to alleviate suffering and improve the quality of life in patients' suffering from progressive, incurable disease or injury, which takes into account their physical, psychological, social and existential needs and organised support for those who are close to the patient. The primary goal of palliative treatment for patients in the final stage of life is alleviation of suffering rather than prolongation of life.

**Optimal care**

The best possible treatment and care for the patient, taking into account the individual's condition, needs, goals and the treatment alternatives available.

**Withholding life-supportive medical treatment**

An active decision to withhold, i.e. to not initiate, a specific life-prolonging treatment. The decision can be made either prior to, or during a period of intensive care.

**Withdrawing life-supportive treatment**

An active decision to withdraw, i.e. to not continue, the specific life-prolonging treatment that is in progress.

**Adequate medical decision time**

A time period designed to permit a thorough consideration of the patient's condition and of the available treatment alternatives. This includes the time needed for information gathering, diagnostics, treatment and evaluation. The purpose of providing adequate time for this process is to ensure that the best possible basis is available for the decision on how to proceed.

***Treatment strategy***

A treatment strategy is a long-term and comprehensive plan for the medical procedures that will be undertaken and implies that there will be no limitations unless it includes clearly specified limitations.

**No limitations of medical procedures**

This treatment strategy is always applied if nothing else is specified.

**Limitations are to be specified as either -**

- withholding a specified medical treatment
- withdrawing a specified medical treatment

## ***The foundations for decisions concerning treatment strategy***

The choice of appropriate treatment strategy must be based on ethical principals, scientific knowledge and proven experience.

There is no ethically valid distinction between withholding a treatment and abandoning a treatment that had been initiated but was later judged to be no longer beneficial for the patient. The two strategies are listed separately only because they emotionally and psychologically are often not perceived as equivalent by patient, family and health care providers, and because they differ in terms of their practical application.

### **Ethical principals**

1. **Autonomy.** All humans are endowed with equal inherent value and have equal rights to take decisions that affect their own life.
2. **Avoidance of harm.** Health care must not inflict harm or suffering on the patient. Negative side effects can sometimes be acceptable if the benefit of the treatment outweighs the harm.
3. **Beneficent to health.** Health care should strive to restore the patient to good health. If this is not possible the goal must be to alleviate suffering.
4. **Justice.** Everyone is equally entitled to health care.

### **The need for in-depth ethical analysis**

The four ethical principles listed above are a simple way of identifying ethical problems. They are however ambiguous, they are not ranked in any order of significance and they can sometimes be conflicting. For example, many patients in intensive care are not fully autonomous – they may be unconscious or unable to communicate rationally for other reasons. A more in-depth ethical analysis may be required when there are gaps in knowledge or other uncertainties. There are several models for this, such as a structured analysis of the interests of the principal parties, and the effects on them of a given action (“Aktörsmodellerna”). Another model is a structured analysis of goals and obstacles (“Mål- och hindersanalys”). In both of these models the abovementioned four ethical principals are applied.

### **Scientific knowledge and proven experience**

1. **Prognosis for an acute disease**
2. **Prognosis for a chronic disease**
3. **Therapeutic failure.**

The treatment is no longer beneficial to the patient, and is simply prolonging the natural process of dying.

### **Family**

The family and relatives need to be close to the patient, to participate in caring for the patient and to be told the truth. They need time to understand and absorb what they are told. They also need time to gather their courage and to receive support from their surroundings.

### **Who is responsible for what?**

1. Decisions on treatment strategy in intensive care are somewhat different from those taken in other health care situations. The patient’s life-threatening condition is subject to dynamic change. The average length of stay in Swedish intensive care units does

not exceed 48 hours. This makes rapid judgments and decisions essential. A care provider (normally a physician from the patient's clinic) who is responsible for overseeing and coordinating multidisciplinary efforts ("Fast Vårdkontakt", hereafter called the "care-coordinating physician", also see Appendix III) will not always have been designated in time.

2. According to SOSFS 2011:7 the care coordinating physician is responsible for planning the patients' care. In the intensive care situation this responsibility is shared with the intensive care physician on the spot. Decisions must involve a dialogue between the intensive care physicians, the care-coordinating physician and other health care providers, the patient and the family.
3. In decisions regarding withholding or withdrawing on-going life support, the responsible intensive care physician or the care-coordinating physician must consult at least one other registered health care provider.
4. Decisions regarding withholding or withdrawing on-going life support must be based on a balanced assessment of the patient's condition and the available therapeutic options. The decision should therefore preferably be made by agreement between the intensive care physician and the treating physician or care-coordinating physician, if one has been designated.
5. Providing information to patient and family is the responsibility of all involved in the patient's care.
6. The decision should if possible be made in the daytime and after due consultation with the patient, family and other health care providers.

Decisions on treatment strategy may be based either on knowledge of the underlying condition or against the background of what intensive care in the current situation can hope to accomplish in improving the patient's prognosis.

- In the former case the treating physician or care-coordinating physician has the main responsibility.
- In the latter case the decision is taken by the intensive care physician after due consultation with the treating physician or care-coordinating physician.

### **Documentation**

The patients' notes must include all the relevant data that is needed to provide good and safe care. All deliberations, assessments and decisions to withhold or withdraw on-going life support must be carefully recorded. The record must contain the following:

1. The point in time that the decision was made, and the grounds for it.
2. Which specific treatment or other care modality is to be withheld or withdrawn
3. In what way the patient and family have been informed about the decision, and what attitude towards the treatment has been expressed by the patient and family
4. Which other health care providers the intensive care physician and the care-coordinating physician have consulted in reaching the decision.

Decisions concerning treatment strategy must be continually revised and updated in the notes.

### **Examples of different health care situations**

#### **A child's perspective**

Parents or custodians are charged with protecting a child's right to receive appropriate care if the child's health or development is threatened. The older the child, the more the child's own

ability to make decisions concerning health, treatment and care must be taken into consideration. Diseases that are not compatible with continued life in children are very unusual, hard to diagnose and the prognosis can be impossible to assess. Children's capacity to regenerate organ function and revive can at times be astounding.

Decisions concerning withholding or withdrawing the life-support given to a child, must always be taken after due consultation with, and if at all possible, in agreement with the child's parents or guardians. It can sometimes take time for parents or guardians to accept the information that their child is dying and that continued life-support is of no avail. Continued life-support when agreement is lacking must never entail unacceptable side effects or continued suffering for the child.

The process of withdrawing life-support from a child should be planned together with the parents or guardians. The main focus of the care is then to alleviate anxiety, fear, pain and other suffering. Appendix 1 provides a more comprehensive text.

### **Patients with reduced autonomy and the person representing them**

There is no law in Sweden that governs the appointment of a representative for a patient with reduced autonomy. It is the health care provider who has the responsibility of selecting the care option that, in accordance with the principle of everyone's equal inherent value, best meets the patient's need for good care, including maintaining the patients dignity and integrity.

### **Patients that have attempted suicide**

When a patient has attempted suicide it is important that adequate psychiatric assessment and treatment be provided. In such cases the physician must disregard the patient's continued desire to end his or her life until psychiatric consultation can be obtained.

### **Potential organ donation**

Caring for the deceased while waiting for an organ donation is part of intensive care.

1. When it is suspected that a patient undergoing ventilator treatment has suffered a total brain infarction, continued support of organ functions must be maintained until this diagnosis can be verified. If brain death is confirmed the goal of any continued treatment is to explore the possibility for organ donation.
2. Life supportive treatment may not be initiated solely for the purpose of organ donation.

### ***Withdrawing life-supportive treatment***

Withholding or withdrawing a specified treatment does not mean that the therapy now is palliative or that the therapeutic efforts not included in this restriction should be less intensive. Withdrawing life-support does not always or necessarily lead immediately to the death of the patient. The following recommendations pertain to situations where the withdrawal of life-support is expected to lead to the death of the patient within hours or days.

When withdrawing life-support, the responsible physician should consider the following:

1. It is crucial that the withdrawal of life support is preceded by a frank and open dialogue with the patient and/or family about the change in treatment strategy ("The crucial exchange")
2. Dying is an unpredictable natural process that must be allowed to take its time. This process must not be hindered by intensive care procedures when the patient is approaching the final stage of life.

3. The patient and family should be afforded as much privacy as possible, preferably in a private room.
4. The physician's presence and commitment is also important after the decision to withhold or withdraw life-support has been taken.
5. The patient's need for solace as well as for relief from pain and anxiety must be fulfilled. The family must be prepared for what is to come and afforded time and space to be with the patient and understand the situation. Spiritual, cultural and psychosocial support may be required.
6. The attending medical personnel must be continually updated on the treatment strategy so they can provide the patient and family with the best possible support.

**Guidance concerning specific procedures after a decision to withdraw on-going life-support has been taken**

**1. Breathing**

Spontaneous breathing without supplemental oxygen should be established if this can be done without increased suffering

When ventilator treatment (invasive or non-invasive) is withdrawn:

-Consider the need for anti-cholinergic treatment, leaving the endo-tracheal tube or tracheal tube in place or using a naso/oro-pharyngeal airway.

-Consider alleviating gasping. Adjust opioid and sedative dosage.

If ventilator treatment (invasive or non-invasive) is continued:

-Ventilate the patient with air and minimum support if this can be done without increased suffering. Adjust opioid and sedative dosage.

**2. Pain**

Treat with opioids and other analgesics in such a way as to achieve a specified effect.

**3. Anxiety**

Treat with anxiolytic and/or sedative agents in such a way as to achieve a specified effect.

**4. Dialysis**

Discontinue.

**5. Pacemaker**

Pacemakers and ICDs (Implanted cardiac devices) can and should be turned off.

**6. Vasopressors and Inotropic agents**

Discontinue at an appropriate rate.

**7. Other medication (antibiotics, antithrombotic treatment, insulin etc.)**

Discontinue if this can be done without increased suffering.

**8. Blood transfusions**

Discontinue.

**9. Nutrition and fluids**

Should normally be discontinued.

**10. Blood sampling and examinations**

Can and should be discontinued.

**11. Monitors**

Discontinue or reduce to a minimum. Turn off all alarms. Consider turning off the bedside monitor.

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**Appendix I:  
Withholding or withdrawing life-support in paediatric intensive care**

Parents or guardians have a duty and a right to make decisions concerning a child's personal affairs, including health care. Parents or guardians are charged with protecting the child's right to receive appropriate care if the child's health or development is threatened. The older the child, the more the child's own ability to make decisions concerning health, treatment and care must be taken into consideration.

The difficult decision to withhold or withdraw life-support from a child is fortunately a rare occurrence in Swedish intensive care. The medical considerations are the same as for adults. The decision must always be preceded by dialogue and, as far as possible by the achievement of mutual understanding, with parents or guardians. Continued life-support when agreement is lacking must never entail unacceptable side effects or continued suffering for the child.

The opposite situation, initiating or continuing life-support for children with what are sometimes extremely complicated conditions, for which the prognosis and the attainable life quality is not easily determined, entails equally difficult decisions.

Clinical conditions in children that are not considered compatible with continued life are often unusual and difficult to diagnose. The prognosis can be impossible or difficult to determine as can its effect on future life quality. Children's special capacity to regenerate organ function and revive can at times be surprisingly good.

The terrible news that a child is dying and that further treatment will not be beneficial for the child is extremely traumatising for the parents. Time stops. The news should be conveyed with the utmost respect and dignity by a physician who enjoys the parents' full confidence. Adequate time for the parents to come to terms with and accept the decision must be provided.

The process of withdrawing life-support from a child should be planned together with the parents or guardians. The main focus of the care is then to alleviate anxiety, fear, pain and other suffering. After the death of a child, it is important to provide the parents with support and any necessary health care.

## **Appendix II:**

### **Template for patient records in an electronic system**

To ensure good and safe care and to aid in the documentation of decisions on treatment strategy, the same template should be used for all patients in the same institution. This means that revised decisions must always be noted in a prepared template. The time history of multiple decisions must be traceable.

#### **Example of a template for patient data management system in intensive care**

1. Date and time of decision (updated for every revision) (*single choice*)

1.1. First decision

1.2. Revision of previous decision

2. Decision after consultation with

2.1. Registered health care provider

3. Patient participation

3.1. Patient consulted (*single choice*)

3.1.1. Yes

3.1.2. No

3.2. Family consulted (*single choice*)

3.2.1. Yes

3.2.2. No

Space for free text under respective heading for situations in which :

- Continued life-support is not consistent with available scientific evidence and time-proven experience
- The patient declines life-support

4. Decision (*single choice*)

4.1. No limitations of medical procedures

4.2. Limitation concerning certain specified life-supportive treatment

4.2.1. Withhold (*multiple choice*)

4.2.1.1. Intensive care

4.2.1.2. Invasive ventilator treatment

4.2.1.3. Non-invasive ventilator treatment

4.2.1.4. Dialysis/CRRT (Continuous renal replacement therapy)

4.2.1.5. CPR/Advanced-CPR

4.2.1.6. Surgery

4.2.1.7. Blood transfusion

4.2.1.8. Vasopressors and Inotropic agents

4.2.1.9. Antibiotics

4.2.1.10. Nutrition

4.2.1.11. Pacemaker

4.2.1.12. Other specified treatment

4.2.2. Withdraw (*multiple choice*)

4.2.2.1. Intensive care

4.2.2.2. Invasive ventilator treatment

4.2.2.3. Non-invasive ventilator treatment

4.2.2.4. Dialysis/CRRT

4.2.2.5. CPR/Advanced-CPR

4.2.2.6. Surgery

4.2.2.7. Blood transfusion

4.2.2.8. Vasopressors and Inotropic agents

4.2.2.9. Antibiotics

- 4.2.2.10. Nutrition
- 4.2.2.11. Pacemaker
- 4.2.2.12. Other specified treatment
- 5. Basis for a decision made by the care-coordinating physicians (ethical and/or evidence- and experience-based) (*multiple choice*):
  - 5.1. Patients own decision (autonomy)
  - 5.2. Prognosis of the acute disease
  - 5.3. Prognosis of the chronic disease
  - 5.4. Treatment failure
- 6. Failing organ systems (*multiple choice*)
  - 6.1. Circulation
  - 6.2. Breathing
  - 6.3. Neurology
  - 6.4. GI-tract
  - 6.5. Kidneys
  - 6.6. Liver
  - 6.7. Haematology/Coagulation

The above structure, terms and concepts (Decision = Standpoint; Withhold = Not commence; Withdraw = Not continue) are compatible with SOSFS 2011:7

Data from the above template titles and subtitles may be sent by participating intensive care units to SIR (The Swedish Intensive Care Registry), excluding any free text and names. The incidence of different decisions can be followed on the SIR open home page (<http://www.icuregswe.org/>) by participating intensive care units.

## **Appendix III: Definitions**

### **1. General recommendations**

These are general recommendations on how statutes can or should be applied and do not exclude the use of other means to attain the goals set down in the statutes.

### **2. Withdraw** on-going life-supportive treatment

The same as not continuing life-supportive treatment

### **3. Withhold** life-supportive treatment

The same as not initiating life-supportive treatment

### **4. Decision**

Determination, conclusion, formal judgement, making up one's mind (The Concise Oxford Dictionary). In this document the word "decision" is used to mean making up one's mind and assuming a position on an issue. SOSFS 2011:7 avoids the word decision, preferring to use "assuming a position".

### **5. Dying**

The stage in which an individual's vital functions fail and symptoms show that death is imminent

### **6. Care-coordinating physician** ("Fast vårdkontakt")

According to Swedish Law (The Health and Medical services act §29), the Head of Department is responsible for the security, continuity, coordination and safety of care for a patient. If deemed necessary to fulfil these obligations, or if requested by the patient, a Care-coordinating physician must be designated by the Head of Department. The Care-coordinating physician (SOSFS 2011:7) is then responsible for planning the patient's care, i.e. evaluating how the patient's need for care can best be met, setting up goals for the care and for the various treatments and therapies that comprise the care. The Care-coordinating physician continually updates, re-evaluates, follows-up and documents the planning of care in the patient's notes.

A patient can have several designated Care-coordinating physicians (In non life-threatening diseases or conditions the Care-coordinator does not have to be a physician, as any registered health care provider can be so designated). If a Care-coordinating physician has not yet been designated, a physician from the team providing the patient with care must apply the regulations.

The Care-coordinator is a named individual.

### **7. Regulations**

Regulations are binding rules

### **8. Life-supportive treatment**

Life-supportive treatment is a Treatment given in life-threatening situations to keep a patient alive.

Examples of life-supportive treatment:

1. Treatment supporting vital functions not sustained by the patient such as breathing, circulation or nutrition and fluid intake.
2. Certain surgical procedures such as amputation or laparotomy
3. Pharmacological treatment such as vasopressors, diuretics, insulin, chemotherapy and antibiotics

### **9. Family**

A person whom the patient has designated as related to or important to him or her can be either a relative or a friend. If no family has been designated by the patient a spouse, life-partner, child, parent or sibling can be considered family.

**10. Palliative care**

Treatment or care intended to alleviate suffering and promote quality of life in patients suffering from progressive, incurable disease or injury, taking into account physical, psychological, social and existential needs as well as organized support for those close to the patient. Palliative care sees dying as a normal process and aims to provide the patient best possible quality of life at the end of life stage, neither promoting nor postponing death. The primary goal of palliative care in end of life situations is alleviation of suffering rather than prolongation of life.

**11. Consultation**

Deliberation whose purpose is to reach agreement on a joint course of action, or a common position, if at all possible

**12. Guardian**

Parent or the person charged with custody of a child by a court of law.