



Guidelines for palliative sedation at the end of life

The purpose of these guidelines is to help ensure that patients with treatment-refractory conditions are provided with sufficient palliation, while care is taken to prevent the sedation from expediting death. The guidelines must be seen in light of the manual Decision-making processes in the restriction of life-prolonging treatment (2013), issued by the Norwegian Directorate of Health.

These guidelines apply in situations where the patient cannot be helped unless his or her consciousness is reduced to a level at which communication with the patient is greatly reduced or has ceased. This will encompass a small number of patients in situations that can be designated as "extreme".

The guidelines do not apply to symptomatic treatment that is part of regular practice, such as treatment of anxiety and distress, dyspnoea and pain, for which sedation is part of the treatment.

If the doctor in charge finds that a departure from the guidelines is necessary, this shall be discussed with a superior doctor / the treatment team as relevant, and documented in the patient records.

Necessary acute sedation is regarded as symptomatic treatment. An assessment regarding whether the patient's situation falls within the scope of the guidelines must thereafter be undertaken without undue delay.

Guidelines

- 1.** By palliative sedation is meant pharmacological depression of the level of consciousness in order to alleviate suffering that cannot be relieved in any other way.
- 2.** Palliative sedation is administered as an exceptional measure as a response to intolerable suffering that stems from, and is dominated by, physical symptoms. Mental symptoms alone are only in rare cases an indication for palliative sedation.
- 3.** Palliative sedation shall normally be given only to patients with a life expectancy of a few days. If their life expectancy is somewhat longer, palliative sedation may be periodically attempted under continuous assessment of the situation.
- 4.** The causes of the patient's suffering must have been appropriately diagnosed. All other treatments of individual symptoms must have been tried, or at least have been carefully considered and found to provide insufficient benefit.

If an evident shortage of resources prevents optimal treatment and care without sedation, the doctor in charge must notify his or her management or the supervisory authorities. Reference is made to the obligation to notify pursuant to Section 17 of the Health Personnel Act.

If the health institution lacks resources and competence in palliative medicine, it must seek professional assistance from institutions that possess such competence.

5. The decision must be based on an overall medical assessment of the patient's situation, and be made after consultation with the nursing staff and with other doctors who are familiar with the patient or qualified to contribute.

The doctor in charge is formally responsible for the decision. Implementation must be based on necessary medical competence and reflection on the ethical issues involved.

6. The patient shall be provided with individually adapted information regarding his or her state of health and prognosis, what palliative sedation would involve (including information about the depth and duration of the sedation), risks associated with sedation as well as alternatives to sedation, if available.

The patient must consent to the treatment, provided that he/she is capable of doing so.

If the patient is not competent to give consent, for example because of extreme suffering, palliative sedation may still be given if, all things considered, it is assumed to be in the patient's best interests.

7. The patient's next of kin should be informed and heard in the decision-making process, provided that the patient is not opposed to this.

When the patient lacks capacity to provide consent, his/her closest next of kin are entitled to co-determine whether palliative sedation should be initiated. The closest next of kin shall be provided with information on the state of the patient's health and prognosis and what palliative sedation will entail. The closest next of kin shall have the opportunity to provide information on what he/she or they believe that the patient would have wanted. After assessing the input from the closest next of kin, the decision is made by the doctor in charge.

8. Patients shall only be sedated to a sufficient depth to satisfactorily alleviate suffering.

9. When it is most probable that the sedation will be maintained to the end of life, raising the patient's level of consciousness must always be considered, and as a main rule, attempted. If it becomes clear during the waking process that the patient's situation is still intolerable, it will be medically and ethically justifiable to recommence sedation without the patient regaining consciousness.

10. The patient shall be adequately monitored with respect to level of consciousness, maintenance of an unrestricted respiratory passage and the effect of the treatment. Monitoring shall also encompass adverse effects of the treatment, so that these can be dealt with.

11. Patients who have stopped drinking or drink very little will normally not need infusion of fluids. If the patient is still drinking significant amounts, and the sedation renders him or her incapable of this, fluids should be administered. If the administration of fluids was started before palliative sedation was initiated, it should normally be continued, although this must be assessed on an ongoing basis.

12. The treatment must be documented in the medical records in accordance with applicable legislation. The following issues shall be included:

- The grounds for concluding that palliative sedation was necessary
- The decision-making process, including ethical considerations
- Information to the patient and his/her next of kin
- The opinions of the patient and the next of kin regarding the treatment
- How the treatment was carried out and monitored
- Departures from the guidelines, if any