

Health-Care Directive for the individual with ALS

I understand that with ALS, respiratory failure or the inability to take in enough food naturally are common causes of death. Being in possession of my faculties, and after careful consideration, I state in writing my wishes regarding invasive mechanical ventilation, feeding through a stomach tube and cardiopulmonary resuscitation (CPR). ***Should I no longer be in a position to decide on my medical care and treatment***, my wishes – indicated by a cross – are to be complied with.

I. Invasive mechanical ventilation (endotracheal intubation, “tube” directly into the windpipe)

(Choose one of the three main options A, B or C)

O A. Invasive mechanical ventilation should ***not*** be ***instituted under any circumstances***.

I understand that such a choice will almost certainly mean that my death will occur earlier than if such support is instituted. I also understand that some processes that might precipitate respiratory failure may be readily reversible and that, therefore, mechanical ventilation may not necessarily be long-term, yet I still do not wish to undergo mechanical ventilation even in such circumstances.

O B. Invasive mechanical ventilation should be used ***only*** when, in the judgment of a qualified medical personnel, the ***acute cause of respiratory failure is believed to be likely reversible***, e.g. in the case of pneumonia. If, on the other hand, respiratory failure is a result of the irreversible deterioration from ALS, I do not wish to undergo mechanical ventilation, knowing that such a choice will almost certainly mean that my death will occur earlier than if such support I instituted.

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If invasive mechanical ventilation is used and it becomes evident that long-term mechanical ventilation is required, then:

- ☐ 1) I wish for mechanical ventilation ***to be discontinued regardless of the circumstances***, knowing that this will result in my death.
- ☐ 2) I wish for mechanical ventilation ***to be discontinued*** if I should be diagnosed ***in writing by two physicians to be in a permanent unconscious condition***.
- ☐ 3) I wish for mechanical ventilation ***to be discontinued*** if I become ***permanently unable to effectively communicate*** ("locked in")
- ☐ 4) I wish for mechanical ventilation ***to be discontinued*** if I am ***unable to return to living at home***.
- ☐ 5) I wish for mechanical ventilation ***to be discontinued*** if I ***express my will*** by using a ***previously agreed signal*** (e.g. blink once for yes, blink three times for no).

☐ C. Invasive mechanical ventilation should be ***instituted in all circumstances for respiratory failure not treatable by other measures***, and long-term ventilation with a tracheostomy should be continued with the following exceptions:

- ☐ 1) I wish for mechanical ventilation ***to be discontinued*** if I should be diagnosed ***in writing by two physicians to be in a permanent unconscious condition***.
- ☐ 2) I wish for mechanical ventilation ***to be discontinued*** if I become ***permanently unable to effectively communicate*** ("locked in").
- ☐ 3) I wish for mechanical ventilation ***to be discontinued*** if I ***am unable to return to living at home***.
- ☐ 4) I wish for mechanical ventilation ***to be discontinued*** if I ***express my will*** by using a ***previously agreed signal*** (e.g. blink once for yes, blink three times for no).

II. Percutaneous endoscopic gastrostomy (PEG) = the endoscopically controlled insertion of a feeding tube through the abdominal wall directly into the stomach

(Choose one of the following two main options A or B)

O A. I do ***not*** wish placement of a feeding gastrostomy tube ***at any time during the course of my illness.***

O B. I wish for placement of a feeding gastrostomy tube ***at a time when it is necessary to provide me with nutrition and medications, as determined by my physician,*** regardless of my choice concerning invasive ventilation. It should be continued with the following exceptions:

- O 1)** I wish for for gastrostomy tube feeding ***to be discontinued regardless of the circumstances,*** knowing that this will result in my death.
- O 2)** I wish for gastrostomy tube feeding ***to be discontinued*** if I should be ***diagnosed in writing by two physicians to be in a permanent unconscious condition.***
- O 3)** I wish for gastrostomy tube feeding ***to be discontinued*** if I become ***permanently unable to effectively communicate*** ("locked in").
- O 4)** I wish for gastrostomy tube feeding ***to be discontinued*** if I am ***unable to return to living at home.***
- O 5)** I wish for gastrostomy tube feeding to be discontinued if I ***express my will*** by using a ***previously agreed signal*** (e.g. blink once for yes, blink three times for no).

In all cases where I choose not to start or to discontinue mechanical ventilation or nutrition via gastrostomy tube, I instruct my physician to provide me with adequate medication to relieve anxiety and discomfort that may occur during the final course of my disease.

III. Cardiopulmonary resuscitation (CPR – resuscitation after circulatory arrest or respiratory arrest):

- ☐ I consent
- ☐ I do **not** consent

Patient: Surname, First name / Date of birth / Date / Signature

Independent witness: Surname, First name / Date of birth / Date / Signature

This living will was prepared in collaboration with the ALS Association Switzerland.



This living will was reviewed by lic. iur. Monika Gehrer of EKOS.

References: Benditt, J., Smith, T., et. Tonelli, M. (2001). Empowering the individual with ALS at the end-of-life: Disease-specific advance care planning. In Muscle Nerve 24:1706-1709.

This is a translation of the original German version. In the event of any discrepancies, the original German version shall prevail.