

Case 3 - Invasive ventilation

45-year-old man, married, 2 children. Work as a taxi driver.

Healthy before ALS diagnosis. Referred to ASIH at a late stage. He is using a wheelchair and have help from assistants 24/7. The patient can hardly talk, PEG is used for enteral nutrition.

ASIH visits almost daily, mostly the nurses and occupational therapist. The patient had several infections which are treated with antibiotics. He quickly become worse and disoriented.

The wife is tired, sad, and worried. She says -" I love my husband so much, but he is not himself anymore". The wife talks to the relatives to get support.

There is a meeting at the hospital with a neurologist from the ALS-team. The patient can hardly talk, the conversation is very time-consuming. When he manages to ask for invasive ventilator for breathing, his wife becomes chocked. The neurologist, who has known the patient for a long time says there is no idea for ventilation, its to late.

The wife talks to the neurologist in private, she is very desperate. She cannot imagine a future with a totally paralysed husband who cannot communicate and who needs care day and night. "It is so scary" she says.

Life continues with slow impairment and the wife talks to the ASIH, she seems to be very exhausted.

Suddenly one day the patient becomes confused and got high fever, ASIH treat him with iv antibiotics given within 2 hours. He dies the day after, unconscious, as it seems without pain or anxiety. The wife is very, very sad, but relieved.

To discuss

- Invasive ventilation – pro and contra
- Did the wife get the support she needed?
- What do you say to the patient asking for invasive ventilation?
- And – how do you end it?