

Case 1 - The denying patient

56-year-old married engineer, his wife has a grown-up daughter.

Before ALS he was healthy, alcohol over-consumption. When referred to ASIH he can still walk but arms are weak, he is talking and eating. Difficulties to breathe, uses non-invasive ventilator at night.

Convinced that he will be a “Stephen Hawking”, living at least 15 years with ALS. Very negative towards facilities but accepts daily home care. Lives on second floor with no elevator – “it is good, it gives me training” he says.

His wife is insightful and worried. She travels a lot in her work. She became more and more annoyed over her husband refusing to face facts of the ALS disease.

The patient's drinking escalates. Nurses from ASIH are visiting once a day to help him with medication. His wife leaves for London for a week. One morning a nurse finds him in his bed, dead. The ventilator lies beside the bed and there is an empty bottle of wine in the kitchen.

To discuss

- Is it important that the patient faces reality?
- Did he commit suicide by removing the ventilator – and could we have avoided it?
- How deal with his wife?