

Case 2 - A more than usually challenging patient

66-year-old singer who is active in the local Church. She is a widow and mother of one son who lives in the same house. Her son has criminal connections and intermittent drug abuse, he also owns a dog, a Pitbull terrier.

The first symptoms of ALS difficulties were to swallow. After some time, singing becomes difficult and eventually impossible. Diagnosis bulbar ALS is made in September 2010

The patient is connected to ASIH soon after diagnosis mostly for nutritional need. She refuses PEG. Instead of PEG she gets an SVP and TPN is started.

ASIH made a considerable work to persuade her to accept a PEG but without success. Enteral medication, like laxation is impossible.

The patient is using a wheelchair, but arms are fully functional, she communicates by writing on an iPad.

As time goes, she deteriorates and becomes more and more difficult to cherish. She acts very bitter, angry, and disappointed." Cancer patients get all attention, but nobody cares about ALS patients" she says.

The patients get TPN every night and enema once a week. Massage by physiotherapist on a regular basis. Once a week, at least one hour conversation with the ASIH doctor – a real challenge for the doctor.

The patient gets a pneumonia and is referred to unit for palliative care at Stockholm's Sjukhem. She hates the place and wants to go home, "I will never return, I promise" she says. At home she refuses to become bedridden, stays in her wheelchair all day long. Her legs become very swollen.

The Pitbull terrier often stays in her apartment, also when her son is not present or at home. The ASIH staff fear the dog and are afraid that it might attack them, particularly if the patient becomes acute disoriented or confused. The ASIH staff refuses to come if the son is not at home taking care of his dog. This decision from ASIH made the patient very angry" You ruin my life; you have taken away my only joy" -she says.

The patient also says that Jesus yearns for her death, he wants to meet her in heaven. The situation for the ASIH staff becomes more and more challenging. ASIH need to have an extra Staff-meeting once a week about this case. The nurses only stand out a couple of weeks working with this patient and one nurse even got a burned out and quit her job.

When the responsible physician has five weeks off no other doctor visit the patient.

Eventually the patient becomes more and more tired to get up and stays in bed. TPN treatment ends and is replaced by Glucose. The patient suffers from anxiety. The son and

friends gather around her, and in the last days of life she is never alone. she is never alone. She is regularly treated with Midazolam and Methadone with a subcutaneous pump, and all iv infusions are stopped. Finally, she dies peacefully.

To reflect

- Should we have been more persistent to get the PEG?
- Was it wrong to forbid the dog (personally I was very afraid of it)?
- How could one avoid the burnout?
- What could we have done better?