HOSPICE ALS PATIENT – A CASE STUDY

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This case study is presenting importance to address an open truth based relation in the couple, reducing pressure and anger on both sides, and relations with health care professionals, protecting the patient's rights and dignity, respecting his will – how he doesn't wont to be treated – and understanding his personal needs trough the open dialogue, when coping with life threatening disease.

On suggestion of the Institute of Clinical Neurophysiology social worker, University Medical Centre Ljubljana, our Hospice started to follow for 10 months a 63 years old patient, after his wife called for our help. In May 2004 diagnosed ALS disease, two years later at Hospice introduction, the patient was hardly moving, unable to talk, using only one hand to communicate by his computer. Due to dysphaghia, PEG was placed for effective alimentation, but the patient prefers to take the food orally. Frequent salivation and the fear of suffocation during the night were great burden for him. The help from assisted ventilator was also refused. His wife took over all the difficult care by herself.

Living in a home setting with family – wife and two adult sons – he was trying to avoid any hospitalisation. For degradation of the patient, responsibilities and working pressure, his wife nearly burnt out. At that time family and the patient were convinced to win the battle with his illness, using several complementary and alternative methods and drugs.

Hospice team made a plan how to improve the primary care, and allow his wife to find some time for herself, therefore a Hospice nurse introduced other sources of care and 3 Hospice volunteers to stay with him almost every day during the week.

Reaching a deeper connection with the patient, our Spiritual Care professional, on his demand, a dialogue on life balance, euthanasia and his life values were addressed. Supporting his fears and difficult acceptance of complete control of his daily living and life decisions until the last days, he died peacefully at his home with his wife at bedside.

The family dynamic was guided by Family coordinator to acceptance and connection among all members, important for the patient. In collaboration with the Institute specialists, symptom management was sensitively followed by Hospice stuff, considering the patient consents.

Hospice goal was achieved creating the space for acceptance and peaceful dying, patient opening to his wife, surrounded by loving people and reaching the holistic healing, realising how dying is much more than a medical issue.