Appendix 1

Cases as clinical vignettes

Beatriz, 50 years old, diagnosed with esophageal squamous cell carcinoma 5 years ago. She underwent esophagectomy and neoadjuvant chemotherapy. Recurrence with bone and peritoneal metastases. Underwent palliative radiotherapy for treatment of bone metastases and celiac nerve block for pain relief. Effective pain control with pharmacotherapy. Clinical condition constantly worsening and refractory to treatment for nausea. Totally dependent on her husband to perform activities of daily living and with unbearable suffering. Unwilling to continue with her own life, she asks her oncologist for euthanasia. All alternatives are evaluated and the practical procedures carried out in the euthanasia process are reviewed. The patient maintains her decision, in which she has her husband's full support. ²²

Paulo, 35 years old. Quadriplegic due to complete spinal cord injury at C6-C7 level, after a car accident 10 years ago. Loss of anal sphincter tone. Autonomic dysfunction below the level of injury with need for permanent urinary catheterization due to loss of bladder function. Chronic neuropathic pain in all 4 extremities even under attempted drug control. In continued rehabilitation program, but without significant improvement. Has an adapted wheelchair. Needs constant assistance by a team of caregivers, who feed him, perform his hygiene and support him in his daily life activities. Frequent complications resulting from spasticity, repeated urinary tract infections, and pressure ulcers. He describes his suffering as intolerable and constant, presenting euthanasia as the only solution for relief. He has no associated mental illness, and demonstrates the capacity to make an informed decision. He claims that if he is not granted the right to end his life, he will be condemned to live "in agony, trapped and without any dignity" (sic). 23,25,29

Maria, 92 years old, with good quality of life, with no suffering or disabling disease. She announces to her physician her conscious and informed will to be euthanized. She lost her husband 9 years ago with whom she lived 60 years of her life. She has found herself increasingly isolated by the disappearance of friends and family. After evaluation by several doctors, depressive disorder and other mental and neurological illnesses are excluded. When the patient's perspective is evaluated, she considers her life complete and meaningless. She appeals for the right to choose the moment of her own death. 31

Miguel, 69 years old, with a family history of Alzheimer's disease. About 20 years ago, remembering his family history and facing the fear of dependence and loss of autonomy, he would have already evaluated the possibility of an early end of life with his family doctor. The following year the patient provides, in an Advance Directive of Will, the specific circumstances under which he considers he no longer wants to continue with his life. These would be: if there were hostile behaviors, if the time came when he was unable to recognize his loved ones, if he was in such a state of dementia that he was considered to be in extreme suffering or just "waiting to die," if the degree of disability was such that he was totally dependent on others. The patient was diagnosed with Alzheimer's Disease at the age of 60, and has maintained the same will regarding hastened death ever since. Currently, the patient suffers from permanent behavioral, personality, and mood changes, agnosia, apraxia, depression, and periods of intense agitation. He is constantly disoriented and totally dependent on his wife for care, and no longer recognizes her. His wife, as health care proxy, refers to the doctor the existence of the patient's Advance Will in his Living Will. 27

Ana, 16 years old, relapsed of Acute Myeloid Leukemia. After the first diagnosis 3 years ago, she underwent chemotherapy followed by stem cell transplantation and relapsed. The patient is in extreme and constant distress, with fatigue, pain and nausea refractory to treatment, plus the fact that she feels a loss of control over her life. After analyzing all the alternatives with her doctor, and in view of the terminal nature of her illness, she expresses a conscious, free and informed will to end her own life. The patient is considered competent to make a conscious decision, in light of her own interests. Parents are involved in the decision-making process, and give informed consent. 26

- Raul 10 years old, diagnosed with Juvenile Huntington's disease at age 6. The patient suffers from a high degree of bradykinesia and myoclonias accompanied by rigidity and spasticity of the limbs. The extension of spasticity of the lower limbs makes it impossible to abduct the hip, so that the family has to carry him to the bathtub to perform his needs causing trouble in the hygienic process. Complex management of neuropathic pain, currently requiring SOS opioids. Increasing dysphagia complaints. Given the risk of aspiration, at 8 years of age, a tube was placed through Percutaneous Endoscopic Gastrostomy (PEG). Psychotic features with hallucinations and deliriums, increasingly frequent, that course with great agitation and irritability. Currently with grand mal seizures refractory to pharmacological treatment. His mother is unemployed and represents his primary caregiver, always advocating for her son's best interests. Need for complex care, which relies with the collaboration of the Palliative Care team. Euthanasia is requested to the palliative care team that accompanies them, due to the extreme suffering of the child, the overwhelming prognosis of his illness, and the will clearly expressed by the child, euthanasia is requested to the palliative care team that accompanies them. ²⁴
- Newborn. Surveilled and uneventful pregnancy. He underwent a cesarean section at 38 weeks due to intrauterine fetal distress. APGAR index of 5 at 1st minute and 6 at 5th minute. Immediate treatment with airway aspiration and artificial ventilation. He required immediate transfer to neonatal intensive care unit due to severe respiratory distress. Facial and phenotypic dysmorphisms compatible with genetic syndrome. On neurological examination he presented hypotonia and absence of primitive reflexes. Echocardiography demonstrates atypical presence of congenital heart disease (concomitant ventricular septal and arterial defect with HTP). Genetic sequencing demonstrates mutations of the MAGEL2 gene. compatible with Shaaf Yang Syndrome. In view of the rare and severe phenotypic spectrum, the prognosis is considered very poor and the probability of survival minimal. Given the high probability of suffering of the newborn, both the parents and the physician consider anticipating the end of life as the only option for alleviating his potential condition. 30
- José, 50 years old. He was diagnosed with schizoaffective disorder with psychotic features during adolescence, with several hospitalizations for long periods of time since then. He attempted suicide 10 years ago. Since then, electroconvulsive therapy has been tried. He showed good cooperation with proposed therapies but has been refractory to all lines of treatment. Comorbidity with anxiety disorder and episodes of reference delusions and paranoia. He has no purpose in life and no coping strategies, facing prolonged and unbearable suffering with no prospects of improvement. He asks his psychiatrist for euthanasia, considering it the only reasonable hypothesis. His clinical prognosis along with other alternatives are discussed in different consultations, but the patient maintains his will. After evaluation by psychiatry, there is consensus on the diagnosis and on the patient's competence to make a decision regarding euthanasia. 28