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PRIVATE CLIENTS

INDIVIDUAL RIGHTS IN A SITUATION OF ADVANCED DISEASE AND AT THE END OF LIFE

Above all, the patient has the right not to be subject to dysthanasia (the undue prolongation of life by artificial means in a person who cannot otherwise survive) through the application of measures that prolong or aggravate their suffering in a disproportionate way.

Law 31/2018 was published on 18 July and it grants a set of rights to people in the context of advanced disease and at the end of life, including the right not to suffer in a continuing, disruptive and disproportionate way.

The main changes introduced by the new law are summarised below.

■ PEOPLE IN A SITUATION OF ADVANCED DISEASE OR AT THE END OF LIFE

After being informed by health professionals and giving their consent, people who are suffering from an advanced disease or are at the end of their life have the right to information on matters relating to their state of health. This information must include the nature of their illness, the estimated prognosis, and the different clinical scenarios and possibilities for treatment.

In cases where an acute state of confusion or the exacerbation of a pre-existing state is clear, the patient has the right to chemical restraint of the symptoms by the use of the appropriate medicines. Physical restraint in the form of immobilisation and physical restriction is exceptional and temporary in nature.

■ THERAPEUTIC AND DIAGNOSTIC OBSTINACY

Another right that is now recognised is the right of the patient to be treated in accordance with their treatment plan, which defines care objectives and which was discussed in advance between the medical team and the patient, who now has a very active role in his or her treatment.

Above all, the patient has the right not to be subject to dysthanasia (the undue prolongation of life by artificial means in a person who cannot otherwise survive) through the application of measures that prolong or aggravate their suffering in a disproportionate way.

■ INFORMED CONSENT

When it comes to informed consent, people who are suffering from an advanced disease or are coming to the end of their life have the right to give their consent to the clinical treatments to which they are subject, provided they have been given information and explanations in advance by the doctor responsible for them and by the multidisciplinary team that is providing the treatment. This consent must be given in writing and it is necessary for two people to witness the signature in the case of treatment that could put the life of the patient at risk.

As long as the patient has been informed in advance and provided with any necessary explanation, the patient has the option, under the terms of the law, to refuse any artificial life support and the and the provision of any treatment that is not proportionate or appropriate to their clinical state. The patient may also refuse: (i) treatment of any nature that is not intended exclusively to reduce suffering and keep the patient comfortable, and (ii) treatment that prolongs or even exacerbates their suffering.

■ PALLIATIVE CARE

The new law establishes that people who are suffering from an advanced disease and people coming to the end of their lives life have right to receive palliative care through the National Health Service. This care is provided under the Base Law of Palliative Care and it includes spiritual and religious support. The assistance given to the family of the patient is also considered to be part of this palliative care.

The new law determines that palliative care is provided by a multidisciplinary team of professionals and may be provided in hospital, at the patient's home, or in a residential institution. The State, working in cooperation with the Ministry of Health and the Ministry of Work, Solidarity and Social Security, is required to give appropriate training and support to informal carers of persons suffering from advanced disease and or coming towards the end of their life, when the person is receiving care at home.

The correct registration of the patient in the National Care Network is now mandatory, and the healthcare professionals must also record all cases of persons suffering from advanced diseases or coming towards the end of their lives who are living at home without access to proper professional support.

■ LIMITED LIFE PROGNOSIS

Under the new law, people whose life expectation prognosis is estimated at weeks, or even days, with symptoms of suffering not controlled by palliative care, have the right to receive palliative sedation to alleviate their suffering. They will also be monitored on a regular basis by a team of qualified professionals. A person who is coming towards the end of their life has the right to refuse food or the provision of certain forms of personal hygiene care, thus respecting the natural and physiological process of the patient.

■ NON-CLINICAL RIGHTS

The new law also lists a series of rights that are non-clinical in nature to help people suffering from advanced disease and or coming towards the end of their life. These include the right to make a living will, and to appoint an attorney-in-fact or a primary carer for healthcare matters.

Another right that has been enshrined for people in these situations is the right to receive the social support and benefits that are due to them and to their families. They also have the right to be the only holder of the right to clinical information on their state of health.

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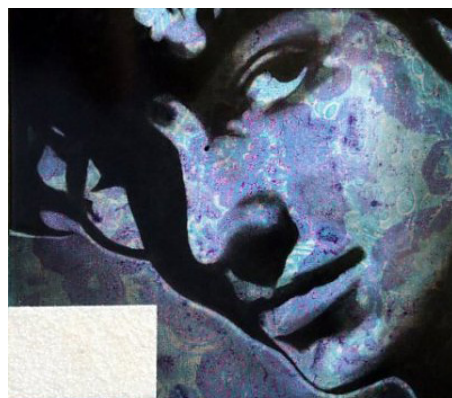
■ THERAPEUTIC DECISIONS

If patients so wish, their families and carers can assist them in taking therapeutic decisions. When patients do not have full use of their mental faculties, and if they are not being assisted by family members or carers, the doctor responsible for the patient and their team must make the clinical decisions. In this context, the doctor and their team must hear the family of the patient, but always act in the exclusive and best interest of the patient and in accordance with the patient's know wishes.

■ CONFLICTS IN RESPECT OF WISHES OR DECISIONS

The law also provides patients or the persons with the legal right to represent them with access to the ethical councils of the entities that provide healthcare, if there is an insurmountable disagreement between the patient or their representatives and the healthcare professional about the clinical measures to be applied. When the assistance is provided at the patient's home or at an institution that does not have an ethics council, the patient and those legally entitled to represent them are given access to the bodies responsible for ethics issues at the Portuguese professional associations for doctors, nurses and psychologists (Ordem dos Médicos, Ordem dos Enfermeiros and Ordem dos Psicólogos.

In summary, the new law seeks to consolidate the rights of individuals who are suffering from advanced diseases or are coming to the end of their lives. It expressly recognises the right not to suffer in a disruptive way while receiving palliative care, and the right to information on their clinical state.



FUNDAÇÃO
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ANA CRISTINA LEITE
 Sugar Cubes, 2003 (detail)
 Mista MDF - 30 x 30 cm

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