

# **Patients' right to self determination and Advance Directives**

## **Patients' rights to self determination**

Persons have the capacity to make choices about their care, treatment and how they wish to live. This is within their right to self determination. A person's right to self determination is grounded in the value of human dignity.

Persons who act autonomously, take decisions relevant to themselves, in accordance to their values, preferences and interests, after understanding what they are about to do and without any form of controlling influence. Persons bear the responsibility for these decisions.

This respect for patient autonomy (self determination) in clinical practice, is embodied in the requirement of informed consent for any medical intervention and for the patient to participate in healthcare decisions making. The free and informed consent of the patient is a fundamental right of European citizens, derived from the right to integrity of the person and is entrenched in the Charter of Fundamental Rights of the European Union.<sup>1</sup> The values of a person concerned and his or her conception of a meaningful life assume importance in deciding whether to consent to a treatment or refusal to initiate or continue a treatment. Giving a treatment without a patient's consent would thus be a violation of the physical integrity of the person and on his personal identity. The Oviedo Convention which is aimed at protecting the dignity and identity of human beings provides a legal framework for consent. Article 5 of the Oviedo Convention states "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it."<sup>2</sup> This right to informed consent also includes the possibility for the patient to refuse an intervention, a decision which might adversely effect their health or shorten their life. Moreover, it makes clear patients' autonomy in their relationships with healthcare professionals. This right to information and to participate in decisions about one's care is reflected in the Charter of patients' rights and responsibilities of the state hospital.<sup>3</sup>

Informed consent necessitates that patients:

- receive information about their condition, prognosis, nature of proposed treatment/intervention and alternatives and the respective risks and benefits in a language that they can understand. Information shall include the consequences of refusing an intervention;
- understand and evaluate the information given to them;
- after reflecting (thinking) make a voluntary choice of whether or not to accept the treatment/intervention, or which intervention they want, without any form of coercion either from a healthcare professional or from a relative or friend;
- are competent to make a choice and to take a decision;
- give their consent, or refuse, to undergo the intervention or the treatment proposed.

Patients may also decline to receive information and place their trust in their health care professionals and leave the decisions to them. This is within their rights to self determination.

Patients' right to self determination may conflict with healthcare professionals duty of care. Patients' refusal to take a life saving treatment, or to ask for a treatment to be withdrawn might be unreasonable to health care professionals as it is in conflict with their obligation to promote the patients' wellbeing. However the patient's decisions must be respected and takes priority.

This right to self determination does not mean that patients can take any decision without any constraints. Patients cannot demand a treatment to terminate their life. This is against the law. Moreover, the Code of Ethics of the Medical Profession and other health care professionals state that they should preserve life.

Patients do not live in isolation and in their state of vulnerability depend on the solidarity of healthcare professionals, close relatives, friends and the community in which they live. Commitment to solidarity should not be restricted to assistance and care but should enable patients to exercise their right to self determination, as agents of their own development.

### **Healthcare providers-patient relationship**

Medical decisions are taken within a relationship involving the patient, close relatives of the patient and the healthcare providers (health care team). This relationship between the patient and the health care provider has evolved from being a paternalistic one in which the healthcare provider made decisions on what he thought was best for the patient into one whereby the patient is an active protagonist in the decision taken.

Different models of this relationship advocating patients 'autonomy' have been proposed<sup>4</sup>. One such model is known as the "informative model" the objective of which is for the physician to provide patients with information that they need to enhance their self determination leaving patients to decide on their own. This model has been found to be unsatisfactory as can lead to a form of moral and professional abandonment by the physician<sup>5</sup>. This model leaves the patient to make a decision on his own, a role he is neither fit nor prepared for. Giving information is not enough. Pellegrino and Thomasma advocate that in order to promote patients' best interest physicians should facilitate and enhance patients' capacity for self determination in accordance to the patients' perspective. Thus healthcare professionals need to know the values, beliefs, concerns of the patients and to nurture a partnership with the patients. This partnership model entails mutual respect and trust, an ongoing dialogue as well as for health care professionals to possess appropriate character traits and attitudes which effect the nature of the healthcare professional-patient relationship<sup>6</sup>.

In accordance to this partnership model, healthcare care professionals must build trust and an alliance with the patients and their families. Through an ongoing dialogue they help patients and their families make difficult decisions by:

- elucidating patients' preferences, fears, hopes, beliefs, values, and needs and expectations;
- drawing, discussing and updating goals of treatment and care;
- anticipating and laying out clearly the decisions that will have to be made at each step in the process;
- clarifying misunderstanding, explaining in greater depth certain aspects which might be of concern to the patients, avoiding confrontation, conflicts with patients and family members, and promote understanding;
- enabling patient, family members and carers to come to terms with the situation;
- fulfilling patient, family members 'needs (physical, psychological and spiritual), by tailoring interventions to patients' needs taking into consideration their preferences and values.

It is within such a relationship with health care professionals that patients can realise their right to self determination and be able to take a decision which is in line with their healthcare needs, values and in accordance to the current state of scientific knowledge and treatment.

### **Patients not legally competent to make choices**

There can be situations when the person may no longer be competent to make choices about his or her health. These include patients who are not in a position to take a decision because they are unconscious.

Capacity might be temporary impaired in patients in an emergency situation or in a reanimation room and in these case the appropriate consent cannot be obtained.

Considerations needs to be given in situations were patients' mental capacity can be diminished or impaired as for example in neurodegenerative disorders, mental illness and Parkinson disease.

Special considerations need to be given to children, who although minors are mature enough to understand what is happening to them and who can express their specific wishes and opinions.

Patients has a right to make informed decisions about their health, which include the right to refuse a treatment even if such refusal might shorten their life. The questions that arises are: how can patients continue to exercise this right when their capacity to take decisions is impaired?; and what effect does their previously expressed wishes have on medical decisions?

## **Advance Directives**

Patients can express their wishes or preferences on what type of decisions about future treatment are to be taken in such situations when they are no longer competent to take such decisions. In many countries these can be expressed through advance directives, and are based on the principle of autonomy and respect for persons.

Advance directives can be in the form of a living will or in the form of special (durable) power of attorney or a combination of both. Oral statements made by patients either instead of written advance directives or to supplement them may be useful guidance to determine what type of treatment they wish or do not wish.<sup>7</sup>

### **Living wills**

A living will, is a legal document, which lays out a patient's written direction to healthcare professionals about the course of treatment the patient would or would not approve in situations when the patient is unable to give informed consent or refusal due to incapacity.

### **Special (durable) powers of attorney for health care**

The special (durable) power of attorney for health care is a legal document which enables persons to appoint someone as a 'health care proxy' to make health care decisions in their behalf when they are no longer capable of making their own decisions. The appointed person has, in essence, the same rights to request or refuse treatment that the patient would have if still capable of making and communicating health care decisions.

### **Combination of living will and special power of attorney**

The special (durable) power of attorney for health care and the living will can be combined into one document whereby the patient can also give specific instruction about treatments they want or do not want and other issues that concern them.

## **The Oviedo Convention and Advance Directives**

The Oviedo Convention on Human Rights and Biomedicine provides a European legal framework on advance directives. Article 9 of the Oviedo Convention states that "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."

This is the first European legal framework relating to advance directives which is binding for those countries which ratified the Convention. This article is of significant importance as it recognises previously expressed wishes. However, it is not without shortcomings. Andorno et al<sup>8</sup> states that it focuses on living wills and does not refer to the possibility of appointing a health care proxy. Furthermore, several scholars have pointed out that the legal implications of this article are vague. The statement that the previously expressed wishes 'shall be taken into account' seems to indicate that one should consider them but not necessarily follow them. Andorno et al questions the

utility of this article if healthcare professionals can take a decision, without a clear reason, not to comply with patients' wishes. The article does not contain a basic proviso, "nor is there any indication of what reasons can be given by health care professions for not complying with patients previously expressed wishes". A number of countries have addressed this fundamental issue in their legislation on advance directives.

### **Council of Europe -Recommendation on Advance Directives**

The Recommendation of the Council of Europe's Committee of Ministers, 2009(11), on Principles concerning continuing powers of attorney and advance directives for incapacity<sup>9</sup>, aims to "promote self determination for capable adults in event of future incapacity by means of continuing powers of attorney and advance directives". It is based on the principles of self determination and subsidiary and has as its objectives to promote coherence as regards to the basic principles in the legislation of European countries on this matter. It builds on Article 9 of the Oviedo Convention by addressing continuing powers of attorney. Principle 15 of the Recommendation stipulates that patients wishes should be given due respect, and leaves it up to the individual country to address changes in circumstances in order to determine the validity of the living wills.

### **Principles and aims of advance directives**

Advance directives serve to preserve patients' right to self determination. In this way the benefit and burden of end of life will be chosen by the patient rather than being simply decided by others.

Everybody has hopes and values that lead to integrity and meaning to their lives. These values, beliefs, religious convictions, and hopes also shape how they would wish their life to end. According to Dworkin most people would like their death to reflect their lives and the values they cherished. The choices made in an advance directive can later safeguard patients' interests when they can no longer do so because of incapacity.<sup>10</sup>

Advance directives may also contribute to promote the good of the patients<sup>11</sup> as it enables them to refuse treatments in end of life care which they would consider to be more harmful than helpful, or which will unnecessarily prolong their life and their agony. They also protect against under treatment, and from the premature cessation of interventions.

Advance directives protect and respect patients' dignity. Many people are concerned that life sustaining treatments will be pursued aggressively and that they will end up without dignity.

Advance directives are a useful way to enable people to start thinking and talking about end of life treatment preferences. The preparation and execution of advance directives will enable patients to communicate and discuss foreseeable treatment decisions with others, including health care professionals, relatives and friends. Some patients might not wish to end up in a hospital bed surrounded by instruments, and

tubes, while others might not wish to be a burden on their family. Other wishes might focus on treatment and quality of life. Communicating one's hopes and concern, increases understanding and the likelihood for these wishes be respected.

Advance directives will facilitate choice and decrease the stress on family members in making decisions for the patient. Thus the burden of end of life decision does not fall heavily on the shoulders of family members and or friends. There can be situations where family members regret certain decisions taken as they feel that they hastened or prolonged death unnecessarily.

Advance directives can offer comfort to patients knowing that their wishes will be followed. They can also offer them relief knowing that the family's financial resources are not going to be spent on costly treatments of limited value.<sup>12</sup>

Advance directives can act as an instrument between health care professionals and patients not capable of making decisions, and link the solitude of healthcare professionals to that of the patients.<sup>13</sup> They enable healthcare professionals in difficult situations to take a decision which is in line and compatible with the patients' wishes. They can will also protect health care professionals from future litigation by family members.

## **Limitations of Advance Directives**

Advance directives are not sufficient in themselves to address the needs of all patients in end of life situations. The explanatory report of Article 9 of the Oviedo Convention provides two circumstances when physicians can have '*good reason*' not to follow patients' wishes as they no longer apply. These relate to situations when the wishes have been expressed a long time before and when there has been significant advances in medical technology since the advance directive was signed which one could reasonably assume would have influenced the wishes of the patient had he known about them.

Studies have identified a number of limitations. These relate to the application of advance directives in practice and to ethical considerations.

### **Living wills – inadequate guidance**

It is difficult to predict what choice a patient might want to make in the absence of a diagnosis or a specific condition, and without knowing the particular circumstances in which he or she will be. Even if patients know that they are suffering from a particular condition their wishes cannot possible cover all eventual clinical situations.

Living wills might be too general and vague or too specific to give guidance to the real clinical situation that needs to be addressed. The later can be problematic especially if the actual situation does not directly parallel the situation covered by the directive. Living wills rarely dictate the care that needs to be given to a patient when he lacks decision making capacity<sup>14, 15</sup> and are not sufficient to guide the complex issues and obligations of care giving.

Living wills range from short questionnaires to more elaborate ones. However, it is unlikely that any of the scenarios would reflect the one the patient ends up in. Furthermore studies suggest that people are confused when asked to fill advance directives and might be misinformed about medical interventions they are asked to choose from.<sup>16</sup>

### **Conflict with good quality care**

While patients may be capable to make decisions, they may be incapable of reasoning about their personal impact. Patients' expressed wishes might be in conflict with good quality medical practice<sup>17</sup>. Advance directives reduce the patient-health care professional relationship to a contract whereby the healthcare professional is bound to respect the wishes of a patient expressed years before. In this situation the healthcare professional is reduced to a technical role, as he cannot provide his expertise in the form of a recommendation after assimilating medical facts, prior experience of similar situations and his knowledge of patients' preferences.<sup>18</sup> There can also be situations which constrain health care professions from promoting the wellbeing of their patients and from their responsibilities. Strict instructions in advance directives might deny patients good quality care, in a situation the patient had not predicted, because of the limits imposed by the directive. Patients' living will might forbid some interventions, when patients might not have known or understood how short term use of these interventions might restore their basic/normal function. A living will forbidding resuscitation in dementia could mean that a patient with mild to moderate dementia, still capable of happiness and of giving the family the opportunity to care for him or her, would be left to die. These situations can create trauma for the family knowing that the death was premature. In addition the morale of health care professionals would be undermined, since they might feel that they failed in their duty to care for their patients.<sup>19</sup>

### **Advances in treatment and medical sciences**

Decisions taken years before may no longer be relevant due to advances in treatment and in medical science. Prognoses of a number of conditions have improved these past years. In addition there have been advances in diagnosis, treatments and palliative care. Advances in palliative care are enabling many patients with terminal illness to live their last years or days serenely and enjoying a good quality of life. A life very different from what one would have perceived in similar circumstances years back with patients spending their last days in pure suffering and without any dignity. Indeed one could reasonably assume that had the patients known about such advances their wishes might have been different.

### **The question of '*Informed consent*'**

There are doubts whether the preparation and execution of a living will is really an exercise of informed consent at all, and how informed consent can occur so far away from the real clinical situation. The possibility that a living will was executed without full knowledge of the situation and options available means it lacks the moral weight of an autonomous and contemporaneous choice.<sup>20</sup> Many people fear illness, have misconceptions about diseases and do not understand the nature of illness until they actually experience it. It is impossible to make projections for treatments and care for

a particular disorder when one has misconception about a disease and without knowing the reality of living with the disease. This situation is highly inconsistent with the procedure of informed consent.

### **Wishes and values over time**

Patients' wishes and values change over time. People have the capacity to reflect on their wishes, to revise their desires and preferences and to adopt to new circumstances they encounter in life. Even though changes or deterioration in health can have profound effect on patients' lives, wishes and desires, through self reflection and consideration many patients do adopt to the new circumstances. Studies show that individual preferences often are not stable over time and that patients poorly predict their own preferences and desires regarding choices far off in the future<sup>21</sup> The wishes expressed by patients years before in an living will might be incompatible with the wishes and desires of these same patients, who can no longer change instructions and who have adopted to the new circumstances. This means they are stuck with instructions in advance directives that they made years before.

A person's body and mind develop, change and deteriorate over time. It is a continuous process of the evolvement of the person both physically and mentally. Dworkin states that we do less than justice to people when we designate one moment as the decisive moment of end of life decisions as if a living will enacted years before could be adequate expression of a person's needs and desires now in the present.

### **Family and healthcare professionals values**

There can be situations whereby patients tell healthcare professional what they want after being given a number of options for a given situation, or after being given information. Robert Burt argues that decision making should be more complex than that, and that family members and health care professionals need to be invited to express their views about what is in the patients' best interest, other than leaving the patient on his own.<sup>22</sup> Otherwise the healthcare professional-patient relationship would be reduced to what is referred to as the information model characterized by lack of interaction and discussion. Self-determination according to Burt is that one is not by oneself, as there are others who voice their values to enable patients after in an ongoing dialogue to take a decision specific for themselves within a clinical context<sup>23</sup>

### **Inadequate or no communication with proxy decision maker**

The proxy decision maker, the appointed trusted person does not always have a good idea of the patient's wishes. Studies revealed that what proxy decision makers have been told was too vague and not meaningful when faced with a clinical decision.<sup>24</sup> In situations whereby patients fail to express their wishes to the proxy decision maker, then decisions are taken on patients' presumed wishes, on what Brudney calls 'authenticity' or else what they think would be in the patient's best interest.<sup>25</sup> Daniel Brudney argues that unlike decisions expressed in living wills, decisions based on what the patient might want in a given situation fails to promote self determination.



## **Oral declarations**

Oral declarations may give rise to particular serious problems of interpretation and falsification.

## **Living will – unavailable when decisions are taken**

The living will or information in the living will might not be available when decisions are to be taken, either because healthcare professionals treating the patient did not know about it as it was not available or not recorded in their file, or because the family members who know about it were not available at the time decisions had to be taken. Other possibilities could be that a living will signed years before might have been misplaced or forgotten, or the family members who know about it were deceased.

## **Bureaucratic**

Another limitation is the fact that legal requirements for witnessing or notarizing advance directives may be counterproductive as it makes it difficult to complete a written directive during a visit to a healthcare professional<sup>26</sup>.

## **Competence to do an advance directive**

For advance directives to be legally valid persons need to have the necessary competence. Competency to do an advance directive entail that patients are able to understand the terms and consequences of an advance directive, and are free from abnormal state of mind that might distort feelings or judgment relevant to making an advance directive.<sup>27</sup> They need to gain an insight about the essential nature, significance and scope of an intervention, and after weighing the pro and cons be able to take a decision.

## **Special Considerations**

### **Children**

Special considerations need to be given to children, whose role in determining what their interests are, and their preferences in relation to treatment increases with maturity and experience. There is a substantial body of research indicating that children are capable of making mature decisions when faced with terminal illness.

With a view of preserving the autonomy of children with regards to treatment interventions, Article 6 (2) of the Oviedo Convention states that 'the opinion of the minor shall be taken into consideration as an increasing determining factor in proportion to his or her age and degree of maturity.' and article 12 of the of the United Nations Convention on the Rights of the Child, stipulates that "States Parties shall assure the child, who is capable of forming his or her own views, the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child".

Due importance is given in these two articles to the rights of children to be involved in the decisions which are going to affect them in accordance to their maturity.

Children should be given the right to participate in end-of-life decision making at a level appropriate for their maturity, if they are willing to do so. A child who demonstrates cognitive, abstract and thinking abilities to comprehend the terms of the living will, is to be jointly involved with the parent/guardian to develop a living will. The healthcare professionals need to handle these cases with sensitivity, compassion and in partnership with the child and parent/guardian, and aim to achieve consensus with them about the best course of action. Living wills are to be created with the child's best interest in mind and jointly signed by the parent/legal guardian and the child.<sup>28</sup>

Children who complete living wills benefit in multiple ways. Adopting this approach could benefit patients by demonstrating respect for their autonomy, informing parents/guardians and health care providers that the child may be ready to have treatment withdrawn,<sup>29</sup> and making suffering less painful. Thus they will be able to live their last days with dignity, as comfortable as possible, surrounded by their loved ones and receiving individualised care depending on their needs and values.

## **Patients with neurodegenerative disorders and mental illness**

### **Dementia**

Consideration needs to be given to patients with dementia and with other neurodegenerative disorders. Studies indicate that there are a number of ethical issues related to the end of life care of demented patients. These include the administration of disproportionate treatment which negatively affect patients' quality of life in the terminal stage of their illness.<sup>30</sup> Patients with dementia suffer from progressive neurodegenerative decline towards incompetence and physical vulnerability. Depending on their cognitive status, patients with dementia can prepare an advance directive. As in the case of making a will, there is prior assessment by a medical practitioner to certify that the patient has the mental capacity to make informed decisions about medical care.

Dementia can disturb the interests of the patient and psychological continuity of personal identity to the extent that the patient might no longer seem to be the same person. In situations whereby a patient with dementia had made a living will it is debatable whether the living will should have ethical and legal force in connection with the treatment of a severely demented patient. According to Parfit<sup>31</sup>, continuity between the former and the current self is a matter of degree in that there can be strong, weak or no connection between the different selves. In line with Parfit's theory of personal identity there is no moral ground to respect living wills in advanced dementia because of severe memory loss and marked psychological changes. Rebecca Dresser<sup>32</sup> argues that living wills are both theoretically and ethically dangerous. The best interest standard provides a better way to make treatment decisions for demented patients. Helge Kuhse argues that acceptance of the psychological view of personal identity does not entail that refusal of life sustaining treatment in advance directives should be overridden<sup>33</sup>. Compromising on these two

positions Martin Harvey<sup>34</sup> states that advance directives and best interest standards have a role to play in guiding the treatment in patients with advanced dementia.

## Mental disorders

Patients with mental disorders who are not legally competent to do a living will need to be given the right to contribute to decisions about end of life care and have their wishes respected. These wishes should be taken into consideration by their legally appointed guardian or representative.

## **Conflicts with patients' right to self determination**

### **Futility**

Patient autonomy and right to self determination enable patients to consent or refuse a treatment which is medically indicated for their condition. Patients cannot demand to receive a treatment that the responsible health care professionals regard as being not clinically indicated for them or futile. Health care professionals' decision to withhold or withdraw futile treatment is supported by scientific evidence that it is not clinically indicated and after an assessment of the benefits and burdens of the treatment on an individual patient in a specific situation Key determinants of futility are patients' best interest and length and quality of life.

Wishes expressed in an advance directives to receive a treatment which is considered futile are not binding on healthcare professionals. The decision of the court of appeal in the UK in the case General Medical Council v Burke (2005) overturned the judge's sentence which permitted Burke to make an advance directive with the specific request that he would not want nutrition and hydration to be stopped. Burke's lawyer had argued in court that the General Medical Council's guidelines that allowed withdrawal of life support in a patient with spinocerebellar ataxia were contrary to his human rights.<sup>35</sup> The withdrawal of life sustaining treatment from an incompetent patient is based on the best interest model. It is questionable whether the model should be more subjectively based and gives more consideration to the previously expressed wishes of the patient.<sup>36</sup>

### **Conscience**

A health care professional can refuse, on grounds of conscience, to withhold or withdraw a treatment which can lead to the death of a patient. Every person has a right to follow his conscience. This is enshrined in the European Convention of Human Rights and Charter of Fundamental Rights of the EU. A Health care professionals cannot be forced to do something which is inconsistent with their beliefs and values especially in situations dealing with the life of human beings.

Codes of conduct make it clear that members of a profession have a right to conscience objection and have no obligation to render a professional service in ways which conflict with their own moral or religious beliefs, however, they do have an

obligation to respect the moral, religious and cultural beliefs of those requesting a professional service. In such situations another professional colleague has to be called to execute the patient's wishes.

## **Precautions**

### **Undue pressure**

Patients live as part of a complex network of relationships. They live within families, friends and within a community. There are arguments of the importance of taking into account the interest of close family members when planning and making advance directives. Decisions to forbid a treatment thereby shortening one's life can have repercussions on one's child who is still a minor, and on denying the spouse to take care of him or her. Bioethicists reject them as valid considerations unless the patient chooses to take them into account. There can be situations when the patient can be persuaded to take them into account.<sup>37</sup>

Any decision about future wishes expressed in an advance directive has to be voluntary. There can be situations where undue pressure is made on patients to sign an advance directive. The elderly and patients with neurodegenerative disorders require a lot of care in the long term. Their care can be expensive, stressful and a burden on human and financial resources and family members. Situations can arise whereby family members might want to try to reduce health care costs not to exhaust their inheritance, or are under stress and want to continue with their life.

Similarly nursing homes and insurance companies might abuse of advance directive to reduce their health care costs. Nursing homes and insurance companies should not oblige patients to do advance directives as part of their contract.

### **Conflict between expressed wishes and current wishes**

Situations can arise where by a patient had made an advance directives. She or he currently does not have decision making capacity and her or his current wishes for a proposed treatment are clear and consistent, however they are not in line with the wishes expressed in the advance directive. This creates a dilemma for health care professionals and opinions differ. (see limitations of advance directives and dementia)

### **Health care proxy decision makers**

Health care proxy decision makers appointed by the patients might not act in their best interest and can take decisions to overtreat or undertreat a patient. Overtreatment is possible to avoid responsibility, in acceptance of the critical status, unaware of poor functional status and unwillingness to let go when the time comes to do so. Undertreatment is also a concern as proxy makers can underestimate the patients' quality of life and functional status. There is the risk that health care proxy decision makers will act according to their convictions and attitudes and not in line with the wishes and values of the patients.

In the case of health care proxies who are family members there can also be conflict of interests. These concerns support the need to restrict family's discretion.<sup>38</sup>

Health care proxy decision makers are supposed to respect patients' wishes when acting on their behalf. In the case of a combined living will and appointment of a health care proxy, they can elaborate instructions recorded in a living will. However to what extent they can revise or depart from the patients' explicit instructions is questionable. These persons can face a dilemma on whether to take a decision on what seems right and in the best interest of the patient in that given situation and that same decision goes against a wish the patient had previously communicated.

There can also be differences in opinion on interpretation of a living will between the healthcare proxy, family members and healthcare professionals.

### **Legally binding in different countries**

Countries has different legislation regarding advance directives, or no legislation at all. Patient who makes an advance directive in one country and takes up residence in another country has to make sure that it is legally binding in that country.

## **Advance Care Planning**

### **Information and empowerment**

Individuals and patients' existential maturity

Individuals are invited to face up to dependencies in the future and to death and start thinking on what treatment they would wish to receive in a given situation and how they would like their life to end. Individuals are vulnerable, have difficulty in determining what they themselves would wish and need the solidarity of their family, friends and healthcare professionals.

Through dialogue with family members, friends and healthcare professionals in a relationship based on trust, patients and individuals can start to discuss their views and values on what would be in their best interest in case they are in a situation whereby they are incapable of taking decisions about their health and treatment. As the wishes of individuals change, due to experiences in life including the effect of illness itself, it is necessary to revise ones wishes through an on going dialogue. It is thorough a network of interactive and intertwined models of communication in trust and cooperation in trust that the wishes of individuals and patients about future decisions are formulated and respected.<sup>39</sup>

Health care professionals, family and friends need to respect patients' values and beliefs and respect patients' autonomous decisions. Respect for patients' self determination and responsibilities entails respect for patients' conscience, values and goals which are different among individual adults.

## Dialogue with doctors

During visits to their clinic, doctors can dedicate time to initiate discussion with patients about advance directives, and encourage them to think about what treatment they might want for themselves and to discuss their wishes and concerns. These discussions, which should be handled with great attention and sensitivity, can enhance the doctor-patient relationship, increase patient's satisfaction with their care and help overcome communication barriers.<sup>40</sup> Discussions about advance directives enable doctors to learn about patients' preferences for healthcare proxy decision makers.

For advance directives to better reflect patients' wishes, discussions with patients and their families should include a range of care options that can arise in hypothetical settings, which include settings related to patients' prognosis so as to enable them to think through options. The place where they would like to receive care towards their end needs to be covered as it can have implications on the type of treatment they can receive. These discussions should also cover interventions that can be considered in an emergency situation. Taking place over a number of visits, these discussions can help elicit goals and can enable patients to articulate their wishes taking into consideration their beliefs, values, fears and hopes.

In situations where there is either a change in the health status of the patients, or advances in treatment, or a change in views, doctors shall take up the discussion so that patients' wishes of treatment preferences would reflect the current situation. Through this ongoing dialogue advance directives could be made and reviewed thereby reflecting the current state of health of the individual, and advances in medical sciences and palliative care. Patients should be given advice on how to formalise their wishes.

## Awareness

In the United States of America, patients on entering a hospital are informed of their right to do an advance directive. Moreover patients' rights organizations and NGOs provide information and facilitate the making of advance directives. It is important to disseminate information among the public and patients about the possibility of making advance directives. Patients on being admitted to hospital need to be informed about their rights including the right to make advance directives.

## **Health care professionals**

Health care professionals need to be informed about advance directives and their limitations and thus be in a position to guide their patients and their families.

Healthcare professionals need to have updated knowledge on end of life care and palliative care so as to be able to be in a position to empower and guide patients and their families to face up to dependencies and dying and to assist them to plan appropriately for the end of life.

## **Living Wills**

Individuals and patients can express their wishes or preferences on treatment/s and other decisions about their care towards the end of life in a living will. Living wills serve to preserve individuals and patients' right to self determination at a time when they are no longer capable of being involved in decisions about their care. Living wills have however, as seen above, a number of limitations.

Individuals can for example request that extensive suffering be avoided and for a treatment to be withheld or withdrawn because it is unduly burdensome or futile and which would otherwise prolong their death and their suffering. However individuals cannot request restriction of their basic care, pain management and palliative care. Health care professionals are legally and ethically bound by their duty of care. While healthcare professionals need to respect patients' rights to refuse a particular treatment they cannot abandon the patients, but have an obligation to render due care and to protect their dignity. This obligation to protect and respect the dignity of a dying or a terminally ill person stems from the inviolability of human dignity.<sup>41</sup> This protection and respect can be expressed in the provision of adequate pain control and in enabling them to be as comfortable as possible.

A right to express one's wishes does not mean that an individual or patient can request for euthanasia or for assisted suicide. In Maltese legislation euthanasia or helping a person to commit suicide is a criminal offence. A patient's right to life is protected by legislation<sup>42</sup>. This is reflected in the decision of the European Court of Justice in the case *Pretty vs UK* which upheld the prohibition against intentionally taking the life of a terminally patient.

## **Health care Proxy**

Individuals and patients can face up to future dependencies without necessarily laying down all possible preferences in case of eventualities that can arise and they are incompetent to take decisions by making a special power of attorney for healthcare and nominating a health care proxy. This requires the presence of people whom they can trust and who are willing to care for them and take prudent decisions in their best interest. This approach places less emphasis on self determination and highlights trust, dialogue, solidarity and interdependence.<sup>43</sup>

Patients and individuals entrust end of life decisions to a person who could be a family member or a friend who has their best interest at heart. Ideally it should be a person who is close to them who knows their values and has no vested interest in a particular outcome.

Rather than making written detailed instructions about end of life care this approach centers on dialogue with the health care proxy. It is precisely this dialogue that enhances the interaction between the patients and their health care proxy and motivates and encourage healthcare proxies to seek the best possible care for their patients.

Through an open dialogue with the health care proxy, individuals and patients can think ahead and discuss some circumstances that can arise when their capacities are impaired. During these dialogues patients express their values, fears and wishes and it is precisely these feelings and concerns which will be able to guide the health care proxy in taking decisions for them, including withholding and withdrawing of treatment. These dialogues should be ongoing to reflect the current situation of the patient.

The Healthcare proxy should act in the interest of the wellbeing of the patient he or she represents and in accordance to that patient's wishes. Healthcare proxies will be able to discuss with the healthcare providers about the various options available taking into account the circumstances in which the patient is and participate in decisions on behalf of their patient. Health care proxies can make real-time decisions on the spot as opposed to wishes expressed in 'hypothetical situations' and recorded in living wills.

### **Combination of living will and health care proxy**

The role of a health care proxies are enhanced and facilitated by having living wills, and the living wills are enhanced by nominating health care proxies.<sup>44</sup> Health care proxies have a difficult and responsible role and are assisted by having living wills. Similarly living wills contain written directions, which are time bound, but cannot engage in deliberations with health care professionals who are making decisions.

In the case of a combination of living will and the nomination of a health care proxy, the health care proxy will serve as an advocate for the patient, and a point of reference for the healthcare team in the treatment of the patient. He or she will be able to discuss care and address questions to the healthcare team. In this relationship with health care professionals, the health care proxy will be able to clarify patient's preferences as well as deal with unexpected developments that have not been addressed in the living will. Emanuel<sup>45</sup> argues that, health care proxies' role is to apply living wills as to what decisions should be taken in real time and to recognise that there can be situations, whereby health care proxies can override them by the use of substituted judgment, if necessary.

The health care proxy also ensures that the patient is receiving due care and attention

### **Recommendations**

- A patient who is capable of consenting should be able to express his wishes on treatment he would or would not like to receive in the eventuality that he or she ceases to be legally competent at some future date. This is within his right to self determination.
- Advance directives can specify withholding or withdrawal of treatment which is medically indicated to preserve life. Ideally for living wills to be able to guide decisions, they should not be vague as to create doubt. The wishes expressed should correspond to clinical situations the patient might possible



find himself in and should be updated in case of changes in the medical condition or the views of the patient and in case of advances or treatment. However, they should not restrict basic care, pain management and palliative care. Living wills are to be revised on a regular basis or they lapse.

- Advance directives should not contain requests for euthanasia or assisted suicides which are against the law and in conflict with the code of ethics of health care professionals.
- Living wills are to be drawn after consultation with health care professionals.
- Children should be involved in drawing of living wills in accordance to their maturity.
- A combination of living will and special power of attorney can be more useful to address a specific clinical situation and define the limits proposed by the patient.
- The conditions and scope of advance directives should be regulated by law. This legislation should define health care proxy decision maker and define his or her powers to enforce compliance with patients' wishes.
- Legislation should oblige health care professionals to take into consideration the expressed wishes of the patients. An advance directive in which the patient has made specific wishes which correspond to the situation he finds him in should be binding on health care professionals.
- A person should be free to draw up an advance directive and to nominate a health care proxy decision maker. Advance directives should not be a precondition to nursing homes or insurance policies or misused for economic purposes.
- There should be adequate provisions about storage and on who should have access to advance directives to safeguard confidentiality.

## **Conclusions**

Advance directives can be important instruments to enable patients to receive care at the end of their life in line with their wishes and consistent with their values and beliefs. A combination of living will and appointment of a health care proxy is more useful to address the complexities in end of life care. It is through relationships with health care professionals and family members, dialogue, trust and solidarity that patients and individuals can realise their wishes and part this life in a manner which is consistent with their values.

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