



L-Università ta' Malta
Faculty of Medicine & Surgery

CONSENSUS DOCUMENT

FACULTY OF MEDICINE & SURGERY, FACULTY OF LAWS, FACULTY OF THEOLOGY

BIOETHICS RESEARCH PROGRAMME AND MEDICINE & LAW PROGRAMME

As part of an Erasmus+ project of the Bioethics Research Programme of the Medical School, on Harmonisation of end of life care (EndCare)

UNIVERSITY OF MALTA

Endorsed by: THE NATIONAL BIOETHICS CONSULTATIVE COMMITTEE

Professor Pierre Mallia

Coordinator



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Foreword by the Dean of the Faculty of Medicine & Surgery

The Bioethics Research Programme (BRP) has recognised the importance of End of Life care and the problems this has brought with it both locally and internationally. Medicalisation of death has indeed become an issue as many medical journals are now attesting. The concept of the study in fact started with a seminar on End of Life organised by the same Programme which took place during the controversy of the Liverpool Care Pathway. At the same time many of our medical staff were contacting the BRP coordinator for advice. EndCare is an Erasmus+ project which was awarded almost half a million euros and is coordinated by our Faculty.

Outcomes have included guidance for health care professionals, especially doctors. The three summer schools held in Malta, L'Aquila, Italy and Dublin, Ireland were very informative. These have laid the basis for the next planned summer school in Malta.

It is hoped that with this guidance, our medical staff will find comfort in the support and advice it provides. The BRP has followed, in the main, Maltese Law, however, the General Medical Council guidelines of the UK were assimilated and adapted to our local needs. Guidance of experts from UNESCO, UK, France, and indeed the Pontifical Academy for Life have also been solicited.

I commend the Bioethics Research Programme for the work and energy it has put into End of Life care and this project. This was done in collaboration with the Faculty of Laws and the Faculty of Theology. We would like to thank the Dean of the respective Faculties, Professor Kevin Aquilina and Professor Emmanuel Agius for their support and help in reviewing the general guidance for legal and moral issues.

Professor Godfrey LaFerla
Dean, Faculty of Medicine and Surgery
University of Malta
Msida, 6th April 2018

Foreword by the Dean of the Faculty of Laws

As Dean of the Faculty of Laws at the University of Malta it gives me pleasure to write a short Foreword to this Consensus Statement. The latter has been drawn up by the Faculties of Medicine and Surgery, Laws and Theology, with the active participation of the Bioethics Research Programme and the Medicine and the Law Programmes of the University of Malta. I remain indebted to the collaboration received from the Government of Malta's National Bioethics Consultative Committee and the Medical Council of Malta.

This Consensus Statement is the result of an Erasmus+ project of the Bioethics Research Programme of the Medical School on *Harmonisation of end of life care (EndCare)* which has brought together representatives from the entities listed in the first paragraph and international scholars who have produced a much needed document intended to fill in a lacuna in Malta in relation of end of life care. Malta is indeed being affected by the discussion on end of life issues but the main problem in this field is the lack of an elaborate legislative framework to regulate end of life issues. But the problem is not only legal. Guidance is required also both at a moral and religious perspective in so far as end of life issues raise serious moral and religious considerations which cannot be dismissed. On the contrary, all these issues need to be brought together, discussed and a way forward proposed. This is essentially what this Consensus Statement does in so far as end of life care is concerned. It is also good to note that the principal actors in this field have come together to rack their brains and produce a document agreeable to all discussing the main areas needing direction in the realm of end of life care.

The Consensus Statement is of course not a law but a set of guidelines. Currently, there is a dearth of such guidance and the Consensus Statement is the first step in providing clear guidance to health care professionals who, in the exercise of their profession, are faced with apparently complex and irresolvable dilemmas which need instantaneous settlement. Hopefully it will be worked out, at a later stage, into an enactment to provide more certainty to stakeholders involved which include not only the legal and healthcare professions but also bioethicists, hospital administrators, patients and the latter's relatives. All should know where they stand on these issues and the State should provide such definitiveness. It is augured that the Medical Council will discuss in depth these guidelines and, if need be, pass on to improve them and that, perhaps, at a later stage, when these guidelines have been tried and tested, they are enacted into law which such modifications required following the appraisal of the implementation of these guidelines.

Professor Kevin Aquilina

Dean, Faculty of Laws,

University of Malta

Msida, 19th December 2017

Foreword by Dean of Faculty of Theology

Recent surveys carried out by the Council of Europe in its Member States reveal that end-of-life issues are gaining more and more prominence in social media debates and in public policies. As medical knowledge and technology increase, people from all walks of life are becoming more conscious and conscientious of the complex ethical dilemmas in the end-of-life decision-making process. People want an open and transparent discussion on how to resolve the psychological, spiritual, legal, existential, and medical issues surrounding end-of-life care.

Among the European institutions, the Council of Europe has been the leading fora promoting on-going debates, reports, resolution and recommendations on the dignity and rights of the terminally ill and dying patients. The Parliamentary Assembly, in its Recommendation 1418 (1999) on *Protection of the human rights and dignity of the terminally ill and the dying*, declares that the vocation of the Council of Europe is the protection of the dignity of all human beings and the rights which stem therefrom. Therefore, for the Council of Europe, it is undisputed that dealing with the concerns of the terminally ill or dying is to be guided by the notion of human dignity and the concept of human rights founded therein.

The fundamental rights of the terminally ill or dying person are threatened today by a variety of factors. Insufficient access to palliative care and good pain management; artificial prolongation of the dying process by either using disproportionate medical measures or by continuing treatment without a patient's consent; as well as the patients' fear of losing their autonomy and becoming a burden to, and totally dependent upon, their relatives or institutions are serious threats to patient's dignity and the right to be treated as a living human being until death.

The Council of Europe recommends to all member states to recognise palliative medicine and care as a legal entitlement of the individual and to ensure that relatives and friends are encouraged to accompany the terminally ill or dying and to support professionally their endeavours. Moreover, a terminally ill or dying person should receive adequate pain relief and palliative care, even if this treatment as a side-effect may contribute to the shortening of the individual's life. Furthermore, the terminally ill or dying person's expressed wishes with regard to particular forms of treatment should be taken into account, provided they do not violate human dignity.

Recommendation 1418 (1999) of the Council of Europe states unequivocally that the fundamental right to life and the prohibition of intentionally taking human life are to be upheld also under the special conditions of the terminal phase of an individual's life. Dying is a phase of life. Thus, the right to die in dignity corresponds with the right to a life in dignity. Article 2 of the *European Convention on Human Rights* declares that "no one shall be deprived of his life intentionally".

A terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person. In other words, a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death. Taking a patient's life is no therapeutic option, since it is not directed towards terminating the patient's suffering but rather at terminating the patient himself.

Rev Professor Emmanuel Agius
Dean, Faculty of Theology,
University of Malta
Msida, 2nd March, 2018

Preface from coordinator of the project

The End Care Project started with the realisation that end of life care is not homogenous notwithstanding that we have ample moral sources to harmonise it. End of life care has become medicalised. Many have come to expect nothing less than miraculous cures even when people suddenly approach an unexpected death. A consultant recently told me that when faced with a patient who was dying a discussion arose with one of his registrars who had come from the UK and who had suggested the Liverpool Care Pathway, which was intended to be nothing more than a Palliative Care pathway for the dying and accepted in the NICE guidelines. The consultant replied that in Malta Euthanasia is not accepted. One cannot blame him as the LCP turned out not to be applied with proper training and became a tick-box where all people who were put on the pathways suddenly had all treatment, hydration and nutrition stopped. This of course was a misapplication, as all know, of the pathway and led to the 'One chance to get it right' document. It was a learning experience. People were simply abandoned on a 'pathway' which was meant to provide them with proper end of life care as was done in Hospices throughout the UK. The pathway was developed for those people who did not have access to hospices. It turned out not to have been practiced as a *pathway*.

Countless books written by doctors exist on the discontent the profession feels about the incoherent way we treat dying people. Ought we to keep them alive as much as possible? When ought we to stop nutrition and even hydration? When is it a discomfort? Many have the conviction that we should at least provide hydration. And indeed most people dying in hospital do so with a drip attached to them. Yet when someone dies at home it is accepted that this is not always possible. Is hydration a part of dying naturally? Does it really provide the comfort we think it does? Are we convinced that a doctor on call who is asked to change a drip on a dying patient ought to puncture the patient a number of times trying to find a vein which is not collapsed? Are we convinced that these patients do not feel that pain? Who makes the call to stop hydration nowadays? Even when we stop nutrition, doctors and nurses may disagree with other health care professionals who may insist on nutrition via a PEG. These people will eventually need to evacuate their bowel. But do dying people need nutrition in their last days? Most people who die naturally do so without food. It is appropriate in conscious or semiconscious, no doubt. But it is a fact that we may not be preparing patients and relatives and indeed ourselves that dying people do not need nutrition and that this may simply be prolonging the agony. As the GMC guidelines recommend, we need to recognise the imminence of death and move towards a plan so as not to come towards the end with doubts on whether to increase morphine due to the fear of respiratory suppression to even whether re-inserting an intravenous line to provide fluids is necessary when we are expecting the patient to die very soon.

This document is a result of the EndCare Erasmus+ project of the Bioethics Research Programme in the Faculty of Medicine & Surgery, Mater Dei Hospital. Preliminary studies we carried out did show that many doctors are concerned about legal issues and lack of understanding of relatives of what *ought* to be done. Therefore we resort to what *can* be done. It is with this understanding that this project involved not only the Faculty of Medicine & Surgery of the University of Malta but also the Faculties of Laws and of Theology; the former to give us the legal guidance, the lack of which was complained about and the latter to remind us of the accepted moral practice. The EndCare (Erasmus+) project also partnered with Dublin City University and the University of L'Aquila, besides experts from law, philosophy, theology, bioethics and institutions like UNESCO and the Pontifical Academy for Life of the Vatican.

There is a sea between theoretical bioethics, which gives us the necessary grounding of our moral actions, and clinical ethics when one is faced with a real patient and real relative; and not least a team which not only wants to do well by the patient but want to *be seen* to be doing what is just.

It is hoped that this document will be accepted by the Medical Council. It has been highly commended by the Minister for health who is concerned about legal issues as much as all doctors are. It is fine to follow moral guidance which is even found in sections of death and dying in the Catholic Catechism; but it is another thing not to be sure that the law is behind you and that you are not in danger of stopping treatment which is futile or which the patient considered to be extraordinary. The document has to ideally also be read by the other material of the project which includes a detailed curriculum for retreats and summer schools and recommendations of Advanced Care Planning (to be distinguished from legally-binding documents such as Advanced Directives which can sometimes cause more dilemmas).

Advanced Care Planning already happens to a certain extent by GPs when people decide to die at home. We discuss what is available and what is not. Family doctors know when to stop treatment because they explain its futility in the presence of relatives and at a time convenient to them. They speak with relatives and explain when 'time has come'. *But they are at an advantage*. The GP has known the family for quite some time; there is a fiduciary relationship built over years. It is not the same in a hospital where personnel change according to a time table and decision made perhaps only during ward rounds and where ideas can vary on whether we should keep that drip, even at least subcutaneously.

The frustration of many health professionals and the input of many of them has led to this local document which one hopes will be followed by the necessary retreats/summer schools necessary. The summer school we help in 2016 was a success and attended by nurses, doctors (not least consultants working with dying patients), and paramedical professionals. The recent debate on euthanasia showed that those who agreed with made statements like, 'why should one die in pain' or 'why should one be put on a machine that she/he does not want'. One of our Master's thesis in Clinical Ethics & Law brought out the important finding that nurses do not see as morally equivalent withholding treatment and withdrawing of treatment. The latter is more emotionally charged, indeed, but it should not be feared. We hope that this document alleviates these concerns and brings people together to discuss end of life.

Last but not least we tackle Spirituality – a subject which should not be left to the priest alone. We all need to contribute. Spirituality is finding meaning in one's existence towards the end of life. It is a conversation with people. I thank therefore the Faculty of Theology and the Faculty of Laws and those involved who have helped with this document. Just as philosophy is driven by scientific knowledge, so should science be driven by philosophical and ethical reflection and guidance. This has led to proper laws and amendments. Medicine is the field which brings all life experience, from science to philosophy and law together. No wonder it has been called an art. To this art at the end of life we must reflect so as to move away from what has become a medicalization of death, simply because home deaths have decreased because of changing family dynamics and social life.

I sincerely hope that this is only the beginning of the process and that the document can serve as a comfort to those who know what they ought to do but find the necessary framework insufficient. It is with pleasure that the Hon. Deputy Prime Minister and Minister for Health, Mr. Chris Fearn has

invited me to present this document to officials in the Ministry and the Department of Health and he is to invite me to address parliamentarians to effect any necessary changes in the law. I can only conclude by thanking him for the interest he has taken not only in this project but in clinical ethics in hospital and in general.

Professor Pierre Mallia

Coordinator, EndCare Erasmus+

Coordinator, Bioethics Research Programme, Faculty of Medicine & Surgery.

University of Malta,

Msida, 26th February 2018

ABBREVIATIONS

EoL	End of Life
DH-BIO	(refers to) The Council of Europe Bioethics Committee
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
GMC	General Medical Council (UK)
HCP	Health Care Professional
ACP	Advanced Care Plan
ANH	Artificial Nutrition and Hydration
PEG	Percutaneous Endoscopic Gastrostomy
RCP	Royal College of Physicians
RCGP	Royal College of General Practitioners
MCFD	Malta College of Family Doctors
MAM	Medical Association of Malta
BCC	Bioethics Consultative Committee
CoE	Council of Europe

CONSULTATION DOCUMENTS

Treatment and Care towards the end of life: good practice in decision making. General Medical Council Guidelines for Doctors, UK. 2010

“Spiritual care for the dying”, from “*End of Life. Ethical Challenges and Problems*”, The Danish council on Ethics, Copenhagen, 2004.

Draft guides concerning the decision-making process regarding medical treatment in end-of-life situations, Council of Europe. DH-BIO (2103), Strasbourg.

LAWS

The Constitution of Malta.

European Convention Act, Chapter 319 of the Laws of Malta.

Health Care Professions Act, Chapter 464 of the Laws of Malta.

Mental Health Act, Chapter 525 of the Laws of Malta.

DEFINITIONS

Advanced Care Plan: This is a *plan* which is described in detail in this document and here is *not* to be confused with Advance Directives. It is a plan which can change as the situation changes and requires only the *Capacity* (taken as defined under the Mental Health Act of Malta) and not Competence, which can be affected by one's illness.

Advance Directive: This is a legal document which a person signs before one has an illness or when an illness is diagnosed. It is drawn up by legal practitioner and must be signed by a competent person.

Disproportionate treatment: This is treatment which is not proportional to the normal standard of care in a given situation. It may be given however if there seems to be some benefit, albeit psychological or social.

Doctor: Unless otherwise stated the term refers to the consultant or physician in charge of the patient.

End Of Life: The term 'end of life' is used in the context of an imminence of death. The latter, as explained in the text, is taken to mean a spectrum of recognition that death will be imminent within one year up to the point where death is imminent within a few days or a few hours.

Euthanasia is taken to mean the deliberate intention to terminate the life of an individual by an act of commission (Active Euthanasia) or omission (passive Euthanasia). In this document any form of licit removal of futile treatment, treatment which is disproportionate or considered by the patient to be extraordinary are not, as in some definitions, considered as passive euthanasia. Neither is pain relief which, when provided according to a standard of due care, considered as active euthanasia if it hastens death in any way. These measures are morally acceptable in many traditions and are considered charitable towards dying patients.

Extraordinary treatment: This is *not* futile treatment but simply treatment which may be prolonged with some benefit, albeit sometimes at some cost to the patient.

Futile treatment: Futile treatment is that treatment which is not considered by the doctor to be in any way beneficial to the patient. It is ultimately a clinical decision and is not to be confused with extraordinary or disproportionate care, which in and of themselves can provide some benefit and in which the patient ought to participate. Doctors have thus been known to stop treatment, such as inotropic agents, whilst speaking in general terms to patients and relatives that treatment will be tailed down or stopped. **Health Care**

Professional: (HCP) This is taken to be any professional working within the team dealing with the dying person. It includes doctors, nurses, physiotherapists, health care workers and other recognized paramedical personnel working together towards the care of patients.

Ordinary treatment or care: This is considered as the basic care required to keep a patient comfortable. One has to emphasise that the patient has to be involved as something which usually is considered as ordinary care, such as hydration, may at times be considered uncomfortable, or even disproportionate and extraordinary.

Patients' Rights: Whenever this term is used, it is to be considered as applicable under Maltese law unless otherwise stated.

Recognition of death: This is taken to mean when one arrives to a conclusion that the patient is now dying and is expected to die within the next few hours or at most days. It is a clinical diagnosis with specified signs and symptoms.

UK: In view of developing political situations, UK is taken to mean the United Kingdom as constituted on the date of publication of this document.

Vegetative States: Although this document does not enter into a discussion of vegetative states, this term is taken to mean a neurological state which is duly diagnosed by modern equipment and is not to be confused with a Coma, or with patients who are still entering into a vegetative state. Vegetative states may be persistent or permanent.

INTRODUCTION

The recent debate on Euthanasia and end of life issues on the media and in public life have given rise to concern about the end of life processes in our homes and hospitals and indeed as to whether our traditional moral values on end of life are protected under Maltese law. By traditional moral values one has generally understood that one ought not to treat patients without their consent, that the patients have a right to refuse treatment and that they can choose between what they deem as ordinary care and extraordinary or disproportionate care. Conversely doctors are not obliged to give futile treatment and they can give pain relief, as long as it follows a standard of care, even if it may hasten death.

However this does not seem to be the whole picture. Health Care Professionals still find it difficult to initiate discussion on end of life as the system seems to be geared towards cure. End of life is therefore not recognized when imminent and it may be difficult at that stage to discuss decisions which people may find hard to understand. Much depends on the individual carer but often there may be no coherent understanding and opinions may vary. On the media one often hears complaints that it was the pain relief that killed a loved one, especially if the death occurred only a few minutes after the morphine was given. Conversely others complain of pain.

Recent surveys carried out (Abela & Mallia, 2010; Mallia & Abela, 2011) have shown that doctors are concerned that there may not be enough protection of the law when deciding about futile treatment, that it is not clear that the patients decide about what is extraordinary care for them and indeed whether they have clear rights to refuse life-prolonging treatment. Also there is a general concern that the public does not understand the moral issues at the end of life, even though many follow a Christian (more often Catholic) faith. There is also a rise in people of Islamic faith. Many are not sure about the coherence and agreement about end of life care between these two faiths. In general it is felt that authorities should be teaching more about end of life rather than discuss the issue of euthanasia only. Indeed recent surveys done on local televised popular programmes which questioned people about whether euthanasia ought to be a right found that amongst those who favoured euthanasia, the main reasons were that people ought not to die in pain or to suffer. Indeed that people need not die in pain and that even if pain relief hastens death, once death is recognised as the inevitable outcome, is morally acceptable by all religions seems generally not to be understood.

This consensus document is aimed therefore at providing health care professionals with clear guidance on the moral, legal and religious perspectives on end-of-life decision making within the local context, keeping in mind normative values whilst avoiding controversial areas. Many health professionals, patients and their relatives fear making the right decisions at the end of life of a patient because of fear of litigation or lack of awareness of accepted

moral values. This guidance, which borrows also from the General Medical Council (UK) guidance on End of Life (General Medical Council, 2010) in areas which are of common normative value within the Maltese context, aims to clarify the following:

1. The necessity of consent on the part of the patient before any treatment is started and the right to refuse life-prolonging treatment once death is an inevitable outcome or there is danger of unduly prolonging life which results in suffering or pushes patients into the dangerous zone of persistent or permanent vegetative states.
2. What to do if a patient lacks capacity.
3. Explain the difference between killing and allowing to die
4. Explain the difference between providing ordinary as opposed to extraordinary or disproportionate care
5. Clarify what is meant by passive euthanasia and the acceptance of avoiding futile treatment
6. Reassurance on pain relief and sedation when appropriate, following a standard of care, even if this is thought to hasten death.
7. To recognise when death is imminent and to accept death as an inevitable outcome so as to provide the proper dignity and attention that patients deserve without putting them through undue hardship.

These guidelines do not intend to re-invent the wheel, as it were, but follow accepted international documents and guidelines listed in the bibliography. Following the British General Medical Council guidelines, 'you must' is used for an over-riding duty or principle, and, 'you should' is when an explanation is provided of how one will meet this over-riding duty, or when the duty or principle will not apply in all situations or where there are factors beyond one's control.

This document is meant to be presented to the Medical Council of Malta which will be asked to approve it as guidance for doctors and health care professionals dealing with patients who are approaching the end of life. By definition this means when patients are likely to die within the next 12 months. This includes those whose death is imminent (expected within hours), and, following GMC guidelines, those with:

- a. Advanced, progressive, incurable conditions
- b. General frailty and co-existing conditions that mean they are expected to die within 12 months
- c. Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- d. Life-threatening acute conditions caused by sudden catastrophic events.

PRINCIPLES

The principles used here are to help professionals in their work in end of life and in explaining to patients and relatives the medical, moral, religious and legal obligations and to promote the values of team work and working with patients and those close to them. In particular:

1. One must give patient approaching the end of life the same quality of care as all other patients. Patients must be treated with dignity, respect and compassion, as must those close to them, especially when facing difficult questions about decision-making in the care of the dying person.
2. Privacy and rights to confidentiality must be respected and also the right to spiritual care.
3. There must be no discrimination based on the patient being older, having a disability or those who understandably may be referred to as 'social cases'. It is recognised that internationally as well as perhaps locally, some of these groups have experienced inequality in getting access to health services.
4. People in the care of dying people must be aware of Chapter IV of the Constitution of Malta setting out fundamental rights and freedoms and the European Convention Act, Chapter 319 of the Laws of Malta, and its main provisions on basic rights and principles.
5. There is a presumption in favour of prolonging life following established ethical and legal principles but that however there is no absolute obligation to prolong life irrespective of the consequences to the patient and irrespective of the patient's views, if they are known.
6. One must assume that every adult patient has the capacity to make decisions about their care and treatment. The difference, which can be subtle, between obtaining a proper informed choice, which includes determining competence, and making sure that the patient has capacity will be explained, as this can lead to wrongful decision, especially in groups mentioned in '3' above – for example, it can be deduced that an elderly person may not be competent and therefore unable to give proper informed consent. Yet such a patient may still have the capacity to make a decision on the care and treatment, including the capacity to refuse life-prolonging measures.
7. If a patient's capacity is limited, one must provide all the necessary support and help to maximise their ability to understand and weigh information. When capacity is impaired the one must see who is making a decision on the patient's behalf. Decisions doctors and relatives make must ensure the overall benefit of the patient, including options not to treat. Doctors must consult closely with relatives, especially where wishes by the patient have been expressed or even documented.
8. Under Maltese law the patient has the right to refuse treatment, whether ordinary or extraordinary. This however should be discussed clearly and with respect for information and understanding and making sure it is a voluntary choice. Competence

cannot be put into question if the patient has the capacity to assimilate, retrain and give consistent feedback on information.

DECISION-MAKING MODELS (adopted from GMC-UK)

1. In patients who have capacity
 - a. Doctor and patient make assessment of the patient's condition taking into account the medical history, views, experiences and knowledge.
 - b. Doctor uses specialised knowledge, clinical judgement and patient's views to identify the treatment and any investigations which are appropriate and likely to be of benefit. Doctors must be aware not to put pressure or in any way coerce or thwart in any way information which will lead patients not to make a voluntary choice.
 - c. The Patient decides whether to accept the options or refuse them
 - d. If the patient asks for treatment with which the doctor, after appropriate discussion, disagrees, then explanation why it is thought not to be the clinically appropriate path must be offered. Other options may be offered including the seeking of a second opinion or legal representation.
2. In patients who lack capacity
 - a. Doctors must be clear on the decision they think are clinically appropriate
 - b. Check if there are any legally binding documents which express the patient's wishes
 - c. Check whether there is a power of attorney who can discuss further care and treatment with the patient and check whether the legal scope of the power of attorney actually covers medical decision-making
 - d. Take responsibility for the treatment which will provide overall benefit to the patient when no power of attorney exists and after consulting those close to the patient and the health care team.
 - e. One must judge the validity of any documents which the patient has made.
 - f. If the patient has granted a power of attorney, then the doctor must give the same information which would have been given to the patient and explain the benefits, burdens, and risks of the options available. Doctors must help attorneys come to decisions which overall benefit the patient, offer support and in the same way as dealing with patients with capacity, must not put pressure on the attorney.
 - g. As well as advising the attorney the doctor must involve those close to the patient and the health care team involved as they may be able to contribute information which is relevant.
 - h. If no attorney is available the doctors is responsible for decisions after consulting with the health care team and those close to the patient.
 - i. If disagreement arises one must follow the procedure for conflict resolution explained in this document.

USING THE PRINCIPLES AND MODELS

Role of Relatives, partners and those close to the patient

- a. People close to the patient play an important role in ensuring the patient receives high quality care in both home care and the hospital setting. These people are involved in speaking and discussing with the patient helping them to come to decisions and enabling them to communicate their wishes.
- b. In some cases they may have legal power to make decisions
- c. It is important to acknowledge the roles and responsibilities of people close to the patient and to ensure that their needs for making decisions, whilst at the same time their need for support in this difficult time, are met.
- d. They may need or want information about the patient's diagnosis and the likely progression of the illness in order to help them to provide the necessary support and care. One should check that the patient agrees with this if they have capacity; if they do not one may assume it reasonable to share relevant information and to keep them informed of progress.
- e. One should explain clinical issues in a way the person understands and approach distressing issues with tact.
- f. In considering those close to the patient who do not have legal capacity, one must be clear that their role is to advise the health care team about the patient's known or likely preferences, feelings, beliefs and values. One must be clear that they are not being asked to make decisions on behalf of the patient.

Clinical Decision-Making and judgements

- a. The bio-psycho-social needs of the patient must guide decision making
- b. Where appropriate proper guidelines must be followed (e.g. the stepping up and stepping down of pain relief)
- c. Early consideration to palliative care must be given
- d. A second opinion on management must be sought if the doctor has limited experience of the condition, there is uncertainty on how to manage symptoms effectively, and if one is in doubt about the range of options.

Emotional Difficulties

- a. It may be more difficult to withdraw a life-prolonging treatment than it is to withhold starting such treatment, notwithstanding the principle of moral equivalence involved. This may be the cause of emotional distress but one must not

allow this to hinder one's clinical judgement and the best interests of the patient or to continue with treatment which does not have overall benefit.

- b. Keeping a treatment going for the sake of the family is incorrect clinical practice and judgement. Conversely emotional difficulties can lead one not to start treatment which would have some benefit. This includes, but is not limited to, pain relief, which can indeed hasten death. (One must assess, for example, what benefit one is obtaining from a hydration drip which needs replacement when knowing it will be difficult to find a vein and that the likelihood of dehydration is small. One must not assume that without a drip a patient is left dehydrated).
- c. One should make sure that the patient does not feel pressured into accepting or refusing particular investigations and treatments, and that they are given the time and information necessary to help them reach their own decisions.
- d. In this regard all the support, counselling and spiritual services must be offered, including any ethics consultations.
- e. One must never withdraw or not start treatment because of resource constraints. This also (and especially) includes sending people to die at home because of lack of beds notwithstanding the prerogatives that the beds can be used for other patients. It is inappropriate to breach the fiduciary relationship that exists between patients and health professionals at the end of one's life because of reasons outside the scope of the best interests of the patient.
- f. One must weigh the benefits and risks of treatment options. Treatment which can prolong life can also increase risks and burdens on patients. Such extraordinary or disproportionate treatment need not be given. In the end it is the patient who decides whether a treatment is extraordinary as this takes into account the patient's circumstances.
- g. One should explain all the options available to patients and avoid bias by withholding information because of certain circumstances, such as the difficulty a patient may find in communicating. All reasonable steps to maximise the patients' capacity must be taken.

Conflict Resolution

“By its very nature the arena of medical ethics is replete with conflict. Here principle meets practical: the burden of allotting limited resources challenges what may be a morally correct course of action; personal encounters policy; a hospital-wide procedure may not fit the unique circumstances of a particular patient; and a mixed multitude, sometimes a whole committee, ponders a question ultimately in the domain of the individual. In a health care setting, doctrines of justice and patients' rights translate into concrete decisions based on immediate reality. Although an action may directly affect one particular patient, many

people affect and are affected by it, and this may claim a secondary stake in what happens. Herein lies the ingredients of conflict” (Neveloff Dubler, N. 2005)

The principles recommended are:

1. Legal advice should be the last option
2. It is important to distinguish between a conflict and a dispute. Both involve disagreement but a conflict involves values, whereas a dispute involves disagreements which can be more easily understood.
3. One should aim to reach a consensus through mediation (see below)
4. Patients may feel that certain treatments, or mission of treatment, may go against their religious beliefs. Whilst this shows the importance of discussing options ahead of time, it also raises the issue that many may not be aware what their religion, for example, allows or disallows. This has led to misconceptions about such issues as pain relief and removal of futile treatment. Having an advanced care plan can help in resolving these issues ahead of time.
5. It is important to realise that
 - a. One cannot treat without the patient’s consent
 - b. There is a difference between killing and allowing someone to die when death is the inevitable outcome
 - c. One can give appropriate pain relief and if necessary even sedation, even if these shorten life.
 - d. One need not give disproportionate or futile treatment, or treatment which is considered extraordinary, especially by the patient.
6. People may be afraid that high doses of pain relief which may shorten life are active euthanasia, or, that removing a treatment which is extraordinary, disproportionate or even futile, is a form of passive euthanasia. In this case one needs to explain that there is no conflict of values about deliberately bringing about, directly or indirectly, the death of the patient.
7. One should make an effort to understand whether patients or those close to them are asking for, or refusing, a treatment or procedure because they feel it goes against their religious beliefs or that one is offering a deliberate intention to shorten life. If one is convinced that there is no clear understanding of points in 5(a-d) then one has a disagreement which is not based on value of life. One should explain that the issue may be clarified by offering the person to speak with a spiritual or ethics counsellor.
8. Families may conversely request measures which go beyond normal medical wisdom, or even make requests which are unreasonable, such as keeping someone on a life support system when there is not hope for improvement or when there is already a diagnosis of brain death.

9. Some patients or relatives may feel that certain treatment is not being provided because of cost containment or because of scarce resources. This indeed will amount to a conflict as it involves a value.
10. Clear communication is the key to effective conflict resolution

It is important to keep in mind the following myths (Marshall, P., Robson, R. forthcoming 2018):

- Conflict can be avoided
- Conflict is bad
- Conflict is impossible to resolve
- A lawyer is always needed
- All disagreements can escalate into conflict

The origin of conflict is often due to:

- Unmet needs (including emotional)
- Lack of effective communication
- Emotional and moral distress
- Disparity of knowledge, power and control

11. Mediation is the most important and efficient route to resolving conflict, especially where there are differences in the cultures of patients, families, and health providers. One has to keep in mind that bioethical analysis favour the academic positions which often favour the medical culture. Mediation strives to dissociate itself from closed systems of analysis and intelligence for unarticulated values and preferences of the particular patient (Neveroff Dubler, 2005).

12. Mediation may have to involve an ethicist who will:
- a. Identify the parties to the conflict
 - b. Understand the stated and latent interests of the parties
 - c. Level the playing field to minimise disparities of power, knowledge, skill, and experience
 - d. Search for common ground, especially one that is time-sensitive
 - e. Ensure that the consensus reached is a 'principled resolution' in light of legal rights and ethical scholarship
 - f. Follow up to be sure that the agreement reached has sufficient structural support to become the reality of care (Neveroff Dubler, 2005).

Advanced Care Plans

The concept of a legally binding 'Advance Directive' has caused concern with theoretical issues that they may be binding even if the patient or the person with legitimate power of attorney, may not make decisions which even the health professionals taking care of the patient would agree with and which they will be bound not to be able to implement.

This consensus statement therefore does not discuss Advance Directives in the contemporary traditional meaning as this would require legal implementation. It does however support the concept of an 'Advanced Care Plan'. Although some people may use the two terms interchangeably and an Advance Care Plan will still need legal support, this can be done with existing legislation. An Advance Care Plan is decided in advance with the health care team for such a time when the patient cannot make informed choices but still has capacity (as defined in this document) or when the patient loses consciousness, allows those close to the patient to be able to discuss medical care. Although not legally binding it will provide a guide as to the patient's wishes.

It must be understood that:

1. The limits and contents of an advanced plan should remain within the law and within the contents of this document. It does not allow requests which are illegal or verge into dangerous areas. It is therefore debateable whether a patient can refuse artificial nutrition and hydration when this is not providing discomfort and when death is not yet imminent. Although one can make a case for this right to refusal, especially if invasive methods are used, this has to satisfy all concerned that the reason is not to deliberately shorten life but because the patient has been recognised to be dying and the nutrition and hydration are being refused on a basis of discomfort and that they will not provide appropriate care.
2. Conversely patients can refuse life-prolonging treatment in terminal diseases, such as motor neuron disease and if he or she considers this treatment to be extraordinary and although prolongs life, will provide a life of discomfort, pain and dependency which are unacceptable to the dignity of the patient. There have been enough international cases, decided even within religious contexts, of this possibility.
3. Doctors and health professional cannot provide any form of treatment without the patient's consent, especially if they have expressed this wish repeatedly beforehand, knowing that there will come a time when a treatment considered extraordinary would not be wanted.
4. In this circumstance the consultant must have the final say but must take into consideration the rights of the patient. Over-riding these right will be verging also into dangerous legal and moral territory which will require over-riding justifications, sometimes difficult to prove, especially when family disagree.

5. In this circumstance the consultant, when such a time as the considered extraordinary or disproportionate treatment need to be provided in order to prolong life, must:
 - a. Consult with the patient once again
 - b. Consults the family about the wish of the family
 - c. Has a right to make a consultation with another consultant or hospital ethicist
 - d. Must provide the patient with the necessary medical treatment so as not to allow suffering (such as sedation) or physiological distress, and accept that the patient dies a natural death whilst continuing to provide ordinary care and comfort.
 - e. Everyone concerned must accept that what is being omitted is disproportionate and extraordinary care, which although may prolong life indefinitely, is not being given to respect the rights of the patient.
 - f. In the absence of legal protection the consultant can have a right to an objection of conscience.
 - g. In this case the consultant should ideally discuss this early and not when the time for the said treatment arrives, in order to find another consultant who is willing to undertake such care.
6. There is a need to formalise such requests on a document or in the patient's file. Patients should also be handed a copy which can be shown to doctors in the future.
7. It is recommended that if the refusal of treatment is controversial, such as refusing to be put on a respirator when still conscious, then the document should be countersigned by the legal representative of the patient (an attorney).
8. It should be understood that the moral is that doctors have the necessary knowledge to appraise the patient's situation from a medical point of view. They have a prime role in decision-making; but it is recognised that rights and social issues must be balanced from case to case.
9. Refusal of a particular treatment means ONLY removal of that treatment. As with a DNACPR order, it refers only to that procedure and NOT to other treatments.
10. This should be communicated well among the team looking after the patient and the patient should not be labelled as having had all treatment stopped. With proper care and comfort, and if necessary treatment not yet considered futile, patients may continue to live for a number of days comfortably. One is simply respecting the right to refuse a procedure which is considered disproportionate and extraordinary, albeit not futile, by the patient.
11. Ultimately, the decision making process should be the result of:

- a. **Information.** The patients and relatives have to understand the concepts well and social institutions, both legal and religious, can help in alleviating fears and concerns about the right to refuse treatment.
- b. **Training.** This is important so that health care professionals can deal with the increasing requests of patients who may be displeased with certain advance care available.

Nutrition and Hydration

There has been considerable concern over the issue of nutrition and hydration and this therefore merits separate attention.

It is accepted that when patients choose to die at home, they may not receive the same amount of medical treatment and attention that they receive in hospital. Once in hospital hydration drips are set up and almost invariably remain there until a patient dies. When veins become thrombosis and it is difficult to find an appropriate site, the use of subcutaneous drips have become commonplace. Whilst there are difficulties in understanding whether this actually provides any benefit, and indeed it may provide discomfort when the underlying skin becomes swollen, it does provide a sense of security.

All patients are entitled to food and drink of adequate quantity and quality and to the help necessary that they need to eat and drink. If a patient refuses to eat and drink or has problems with eating or drinking, one must address the underlying physiological and psychological problems (such as mouth ulcers or depression). If a patient needs assistance, this should be provided. *If one is convinced* that a patient is not receiving adequate nutrition or hydration by mouth, even with support, one must assess their condition and consider clinically assisted nutrition and hydration.

The following points are important in this consideration (Jones, 2010):

1. A futile treatment is unethical and not in the patient's best interest
2. This treatment frequently ignores the respect to the autonomy of patients and moreover breaches the other three principles which today are considered very relevant in health care. It causes harm, it provides no good (beneficence) and it consumes resources which may otherwise benefit other patients (Justice). It should be stressed that the last consideration in the previous sentence, although important is not the focus of end of life care however.
3. This challenge is especially relevant in the nutritional support and hydration of patients toward the end of life.
 - a. *For example, "the natural history of advanced dementia is commonly for cognitive decline with deterioration in swallowing, leading to malnutrition and finally death from pneumonia. Until only 30 years ago, such patients*

were treated permissively without artificial nutrition and hydration (ANH). However the introduction of the fine-bore nasogastric feeding tube (NGT) and percutaneous endoscopic gastrostomy (PEG) in the early 1980s meant that many demented patients could be fed artificially – frequently without proper consent. This inevitably led to considerable debate. It is now clear that the use of PEG feeding in dementia achieves no discernible benefit in most patients but often causes mortality and morbidity (Ref 2-5).

4. In other words this treatment breaches all four principles
5. The dilemma is between those who espouse the preservation of life at all costs as opposed to those who at the other extreme espouse euthanasia or assisted suicide.
6. IT should be noted that non-provision of futile treatment is not in any form an assisted suicide.
7. Futile treatment should be based on evidence and scientific knowledge and not on anecdotal or opinion, especially of lay persons. Whilst communication may be difficult it is essential to explain that what one aims to achieve is the comfort of the patient and that preserving life at all costs not only does not benefit the patient but it causes considerable suffering. That religions agree on this may help health care professionals explain the rationale behind omitting futile treatment.
8. Conversely when there is disagreement, the decision should be based on a proper informed choice. Under law patients are able to refuse or consent to treatment through a proper informed consent process, requiring:
 - a. Information which a 'reasonable person standard' requires
 - b. Making sure that there is adequate understanding of goals, and outcomes.
 - c. A voluntary choice on the part of the patient
 - d. Capacity to consent
 - e. A Decision to consent or refuse a treatment.
9. Conversely patients are not able, under law, to request treatment which is proved to be futile for that particular patient – ranging from keeping people on life support systems to ANH.
10. Under normal circumstances doctors should consider nutritional support and hydration. It should be clearly understood however that such provision when death is imminent and recognised to be near, can be disproportionate and cause morbidity and suffering, especially if one has to re-insert needles, etc. In this circumstance, even if it is doubtful whether it is futile, the overall well-being of the patient should be considered. Removing an intravenous line at the end, for example, is *not* passive euthanasia. It simply acknowledges that death is the inevitable outcome and one seeks the charitable removal of disproportionate treatment or treatment which has now become extraordinary, as one seeks when administering pain relief.
11. The following quotation is put as an important guideline:
 - a. The concept of a distressing death by starvation or dehydration as a result of a fatal condition leads understandable to the commonly held belief that

nutrition must be achieved by all means possible. This is a valid belief if the patient is able to perceive ANH as beneficial. On the other hand, *if cognitive capacity is seriously impaired and likely to be progressive, and if there is no potential for achieving the objective of improving duration or quality of life, no benefit can accrue from imposing ANH which would be unethical.* This is particularly true for a potentially dangerous invasive procedure such as PEG. The possibility that ANH might prolong dying must always be considered. *A decision not to provide nutritional support while continuing intravenous (i.v.) hydration should also be recognised as irrational since this practice also prolongs the dying process without benefit.* However, if ANH might provide support during an acute episode, such as a post-cerebrovascular accident (CVA) or head injury, it is justified even if the patient is unaware.”

Defined outcomes in helping overcome difficulties (Jones, 2010):

1. In most cases decisions on ANH and consent are settled without dissent but consensus cannot always be achieved.
2. In these circumstances, a ‘trial of treatment’ with specified and agreed objectives over a finite period of time may help clarify the correct decision regarding ANH.
3. *It should be emphasized that withdrawal of treatment is held to be identical to withholding treatment morally, ethically and legally, despite the greater emotional burden on the relatives and care team associated with withdrawal of treatment.*
 - a. This is a principle of ‘moral equivalence’.
 - b. It should be explained clearly before and ‘trial of treatment’.
 - c. Starting treatment never means that a treatment ought to be continued, especially if it is considered futile, extraordinary or in any way disproportionate.
4. Defining the outcomes:
 - a. One should actively ask, “does this patient need nutritional support?, or “does this patient need a PEG?” or even, “do we need to re-insert a needle to provide an i.v. line?”
 - b. These are pertinent questions and should be answered *clinically* before any discussion. Such decision should not be taken empirically.
 - c. In case of an advanced care plan, nutritional support is never an emergency and one can provide hydration to allow time to determine any prior decision by the patient.
 - d. If ANH is considered potentially futile, then its provision is unethical. It simply prolongs morbidity and even suffering.
 - e. Defined outcomes should include:
 - i. Prevention of malnutrition

- ii. Pneumonia and bed sores
 - iii. Improvement in quality of life
 - iv. Length of survival.
- f. In regard to ii and iv, one should consider pain relief without actually providing a support which would simply prolong a natural process.
- g. In cases of dementia, since there is little or no evidence to support the achievement of any of these objectives using artificial nutritional support, ANH is potentially futile and therefore unethical treatment which is capable of greater harm. Instead, it is recommended that careful feeding be offered despite the risk of aspiration pneumonia (Jones, 2010)

The following are relevant points in a clinical decision process regarding ANH:

1. In many laws nutrition and hydration provided by a drip or tube are regarded in law as medical treatment, and should therefore be treated in the same way as other medical interventions.
2. However many consider this treatment as basic and it is important to listen to the patients and those close to them, including their cultural and religious beliefs, whilst explaining the issues including benefits, risks and burdens, as described above.
3. If you consider ANH to be inappropriate and there is no consensus, you have a right to objection of conscience and follow the guidelines provided in this document in this regard.
4. If a patient lacks capacity but you judge, notwithstanding the patient is in the end stage of the disease, that death is not bound to occur within hours or days, then you must provide clinically assisted nutrition or hydration if it would be of overall benefit to them.
5. One should continue to monitor and assess and not hesitate to withdraw treatment if it is not considered to provide overall benefit. The patient's interests must be thoroughly considered.
6. If there is consensus that ANH need not be started or ought to be withdrawn, one must still make sure that the patient is comfortable and any distressing symptoms addressed.
7. Recognition of death:
 - a. If a patient is expected to die within hours or days, and you consider that the burdens and risks outweigh any benefits which treatment may provide, then it is unethical to start or continue with this treatment. ANH must be considered *separately*, but in the same manner.
 - b. The patient's condition must be kept under review especially if they live longer than you expected. In this case the benefits and risks must be reassessed again.

DNACPR – Do Not Attempt Cardio-Pulmonary Resuscitation

This document does not attempt to re-write the document on DNACPR at Mater Dei Hospital. The intention is to emphasise some points, some of which are already mentioned in said document.

1. Every person who is not approaching death has a right to CPR. When death is imminent one has to define whether by imminence one is meaning over the next few months or is in hospital and expecting to die. In the former case CPR can be considered unless there is a clinical reason or a directive not to.
2. DNACPR documents have to be re-visited during each ward round as the situation of the patient may change
3. They should be discussed with the patient and relatives if possible but when death is considered imminent, it is the medical team which should make the final decision.
4. It should be kept in mind that a futile CPR will keep the person alive and in agony simply to wait for another similar episode.
5. CPR may be successful by restarting a heartbeat, breathing and restoring circulation. These benefits must be weighed against the burdens and risks and should be discussed sensitively if patients and relatives are prepared to talk. Discussion should not be forced as people may understand that one has given up on them or on their loved one. One must provide accurate assessment of the burdens including the risk that one CPR may lead to another in a short while.
6. In patients who lack capacity, CPR must be discussed with the legal proxy. If there is no legal proxy one must discuss with those who are close to the patient and give them the same details as described in point 5.
7. If relatives or the proxy insist on CPR and as the responsible physician you still consider it would not be for the overall benefit of the patient, you should explain your reasoning (for example that it will burden the patient and cause futile distress) and explain to them their right for a second opinion.
8. DNACPR applies only to CPR and in no way should it imply that the patient does not receive other treatments, including other extraordinary treatment which at the time is being given. Such statements as 'this patient is on a DNACPR order' which is meant to imply to a visiting on-call doctor not to give some other form of treatment is to be avoided. Clinical information provided must be factual and non-directive.
9. Until such time as Advance Care Plans are in place, a person re-admitted to hospital who was formerly on a DNACPR order, should be re-evaluated and the decision must include any improvement the patient has made.

Spiritual Care

The following points are taken from the 'Statement from the Danish Council of Ethics', Spiritual Care for the Dying (The Danish Council of Ethics, 2004):

1. Spiritual care is often used synonymously with spiritual and existential care; it includes care which is both specifically religious and regard for the existential issues and concerns that a dying person may go through.
2. On the verge of death a person may be confronted with great existential issues such as the meaning of the life lived, the loss of life and the relationship with the next-of-kin, about faith in God, and faith in life after death.
3. A person also experiences a series of agonising losses; as a result of impairment of health a person may not continue to preserve social relations and activities which before could be done.
4. Faith and religiousness are a significant aspect of many people's outlook on life. It is important to acknowledge this and not in any way diminish their outlook at these final stages as it can increase existential suffering.
5. The scope of religious care is not to triumph over death but rather to acknowledge the impotence one feels and that this is outside the power vested in any human being. Religious care helps the dying person to recognize the limits of his or her own power and to come to terms that God is taking over.
6. The Danish Council gives four examples which conclude that:
 - a. From a theological point of view, patients can be helped to direct the anger that life is the way it is towards God (and that He acknowledges this) as otherwise it could be directed towards the people around them and this compounds loneliness. They may be comforted in knowing that death does bring with it a loneliness that no one can reach into. This is regarded as a 'vertical' approach of the person with God.
 - b. From a psychological point of view it may be fear of death, desperation, anger or difficult relations with next-of-kin which may need to be addressed. The help psychologists or counsellors can provide may need to be directed not only to the dying person but also to relations which may be involved. This is a horizontal work which is complementary to the vertical described above.
 - c. Experienced nurses have acknowledged that there may be an avoidance of contact with the dying person. Some acknowledge that this is due to the fact that nurses are trained to 'fix' things. To overcome this nurses acknowledge that it is important to establish contact and enter into a dialogue with the dying, during which the latter does not have to hold back their need to share their thoughts. This requires the nurse to show a genuine interest and that she is taking time to enter into this dialogue. Whilst they should recognise that the patient may express frustration about living and dying, one should be opportunistic and recognise points where they can offer some assistance, such as communion, or speaking with a spiritual person. The nurse can also be a means of conveying messages such as that of a mother who is disappointed that she will not see her child grow into a teenager; the nurse can convey this worry to the person concerned.

d. Finally the doctor should not think of themselves only as a 'medical technician' but a 'medical humanist'. Although doctor's contacts with patients are relatively short, they can be very intense and have a special role to play in spiritual and existential suffering. Every word the doctor utters remains in the patient's recollection, being turned over and over. It is primarily the doctor who speaks about the progression of the disease. It is important to build trust in order to foster confidence. The doctor can encourage the patient to do certain things now rather than postpone if he or she feels that the time is short. Conversely the patient must give meaning to the time ahead, if one is envisaging a longer period. This helps the patient talk about 'the whole point of being here'. Indirectly these messages point to the patient the length of time left. Pointing out a sort holiday or getting important things done is quite different than encouraging one to take long holidays and doing all the things that they always wanted to do. Although the doctor may not be the right person to provide specialised spiritual care, one should show willingness and ability to take spiritual care seriously. Experience shows that both the patient and the next-of-kin often request a talk with the doctor despite having been thoroughly informed about the disease.

7. Ethical considerations

- a. There should be respect for the patient's self determination.
- b. One should explain that pain can be relieved by pain relief and explain that ethically this is permissible.
- c. Spiritual care should be offered if the patient feels the illness is a punishment from God.
- d. It is important for the health professional to be versant with the main spiritual declarations of different religions, and especially the Catholic religion in the Maltese context, with regard to end of life. One can point out specific paragraphs of the Catechism which speak about the difference between passive euthanasia and not having to give futile, extraordinary or disproportionate treatment, and also, knowledge that providing pain relief which may hasten death follows the principle of double effect and is morally allowed.
- e. The monotheistic religions (Judaism, Christianity, and Islam) all agree on these basic principles.

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