HPCSA
Health Professions Council of South Africa

HEALTH PROFESSIONS COUNCIL OF SOUTH AFRICA

GUIDELINES FOR THE WITHHOLDING AND WITHDRAWING OF TREATMENT

BOOKLET 7

REVISED: MARCH 2023

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THE SPIRIT OF PROFESSIONAL GUIDELINES

High quality clinical outcomes are only achieved if patients and health professionals trust each other explicitly. Practice in the health profession is therefore a moral enterprise and demands that health practitioners have a life-long commitment to sound, ethical professional practice and an unstinting dedication to the interests and wellbeing of society and their fellow human beings.

It is in this spirit, that the HPCSA formulates these ethical guidelines, to guide and direct the practice of health practitioners. They apply to all persons registered with the HPCSA and are the standard against which professional conduct is evaluated.

[In these guidelines, “health practitioner” and “health professional”, refers specifically to persons registered with the HPCSA].

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GUIDELINES FOR THE WITHHOLDING AND WITHDRAWING OF TREATMENT

1 DEFINITIONS AND INTERPRETATIONS

“Withholding life sustaining treatment” - processes by which medical interventions are refused or denied being provided often with the understanding that the patient will most probably experience natural death from the underlying disease or related complications.

“Withdrawal of life sustaining treatment” – processes by which medical interventions are ceased or discontinued often with the understanding that the patient will most probably experience natural death from the underlying disease or related complications.

“Patient-selected proxy” (PSP) – When a patient is no longer competent to make health care decisions, then an appropriate substitute decision maker should be identified and afforded the same opportunity to fully discuss the patient’s care plan. This representative should be chosen based upon the willingness and ability to make decisions that reflect the patient’s most recent wishes if explicitly stated, or their likely wishes if not.

“Respect for autonomy” - asserts the right of competent patients to accept or refuse medical treatments.

“Directive” - a document executed by a competent individual concerning health care decisions to be made in the event that the individual becomes incompetent to make such decisions.

“Closest Relative/Close family member” - the individual’s spouse, individual’s and the spouse’s grandparents, parents, siblings, children, nieces, nephews, aunts, uncles, and first cousins, any other person who shares the same household with the individual.

‘’Guardian’’ - means a parent or other person who has guardianship of a child or patient

‘’Caregiver’’ – means a person other than a parent or guardian who factualy cares for the patient.

‘’Child/Children’’- means a person under the age of 18 years

‘’Authorised Representative’’ – means a person chosen to act on behalf of the patinet. The authorised representative can be given specific authority to act on behalf of the patient or a more general authority to act.

‘’**Best Interests of the Patient**’’ – means that the health practitioner take certain steps or follow certain rules so that the patient and is prevented from unnecessary harm, and unduly suffering.

2 INTRODUCTIONS

2.1 Health practitioners have a responsibility to make the care of their patients their first concern. This is essential when considering any of the growing range of lifesaving or life-prolonging treatments which make it possible to extend the lives of patients who, through organ or system failure, might otherwise die. The benefits of modern techniques such as cardiopulmonary resuscitation, renal dialysis, artificial ventilation, and artificial nutrition and hydration are considerable. However, life has a natural end and the existence of such techniques of life support may, in certain cases, sustain life artificially for many years for patients for whom there is little hope of recovery. The quality of life which may follow some treatments might raise questions as to whether it is in the best interests of the patient to start or continue treatment.

2.2 The guidance which follows is intended to provide an ethical framework of good practice for health practitioners in circumstances where they are faced with making a decision on whether to withhold or withdraw life-prolonging treatment. It is based on those areas of broad consensus so far established and recognises the need to ensure that patients can die with dignity and that their families and others close to them are appropriately involved in their care. It takes account of existing law in this area, that allowing for withholding and withdrawing of life sustaining treatments and that which prohibits killing, active euthanasia, and assisted suicide. It is, therefore, based on the premise that any medical intervention where the health practitioner's primary intention is to end the patient's life is both contrary to the ethics of health care and unlawful.

2.3 The health practitioner may alleviate the suffering of a terminally ill patient by withholding treatment, i.e. allowing the natural process of death to follow its course, provided there is consultation with another health practitioner who is an expert in the field, and where available, discussions with the closest relatives. Withholding of treatment does not exempt the health practitioner from the duty to assist the dying person by providing him or her with the necessary medication in order to alleviate the terminal phase of illness. The health practitioner shall refrain from employing unusual methods of treatment which are of no benefit to the patient.

2.4 The Health Professions Council of South Africa (HPCSA) also expects health practitioner to observe the provisions of the World Medical Association Declaration on Terminal Illness, see annexure 1 below.

2.5 Health practitioner has a duty to give priority to patient on the basis of clinical need, while seeking to make the best use of resources and using up to date evidence about the clinical efficacy of treatments. Health practitioner must not allow their views about, for example, a patient's age, disability, race, colour, culture, beliefs, sexuality, gender, lifestyle, social or economic status or other irrational grounds to prejudice the choices of treatment offered or the general standard of care provided.

2.6 At an inquiry, the board concerned shall be guided by the ethical rules, its annexures, ethical rulings or these guidelines and policy statements of the board concerned, or council makes from time to time.

3. GOOD PRACTICE FRAMEWORK: PROCEDURES TO BE FOLLOWED

3.1 The National Health Act (Act No. 61 of 2003) allows patients, in writing to mandate a person to act on their behalf when they are no longer able to do so. Therefore, patients should be encouraged to appoint in writing a person to make decisions on their behalf when they are no longer capable of doing so. The patient-selected proxy decision-maker must then be regarded as the substitute for the patient whenever reference is made to the patient in these provisions, and proof should be made available when required.

3.2 Patients and their families, unless a contrary wish is expressed, must be kept informed of treatment, treatment alternatives and outcome probabilities.

3.3 Discussions should be calm, honest, respectful, and compassionate. Medical jargon should be avoided so that everyone can understand the terms being used.

3.3 Patient should be given the opportunity and be encouraged to indicate their wishes regarding further treatment and to place in writing their directives for future care in possible critical circumstances (e.g., permanent coma or terminal illness). An appropriately drafted "living will" may be used for this purpose. These instructions can also be set out in the mandate to a third party mentioned in para 3.1 above. Patients should also be given the opportunity to reconsider their directives from time to time and to alter instructions, should they wish to do so.

3.4 When the patient is incapable of being involved in making a decision related to treatment and no advance directive or other information regarding the patient's wishes is available, close family must be consulted and a decision taken in what are considered to be the patient's best interests.

3.5 Before taking definitive action, the responsible health team should carefully consider and discuss the issues, obtain advice of other health practitioners, the family, patient (if possible). Health practitioner should always involve the family and patient (where practicable) in the discussions, and should never act in haste.

3.6 When the patient or the family request continued treatment against health advice that considers such treatment to be futile, the patient or the family must be given guidance and advice why such decision was taken and be advised regarding their choice of transferring to another institution where such treatment is available. If this option is refused and the health team considers treatment to be futile, and this is confirmed by independent health practitioner(s), may nevertheless, implement the decision to withhold or withdraw treatment?

3.7 All decisions should be fully and clearly documented in the notes, including the reasons for the decision and the procedure adopted in the decision-making process. Where significant disagreement arises about a patient's best interests, health practitioner should seek a clinical and / or ethical review, independent of the health care team. If this fails to resolve the disagreement, they must seek legal advice on whether it is necessary to apply to the court for a ruling.

4 CLINICAL RESPONSIBILITY FOR DECISIONS

4.1 A decision to withhold or withdraw life-prolonging treatment should ideally be made by a senior health practitioner responsible for the care of the patient, preferably after consultation with other health care practitioners involved in the care of the patient taking into account the views of the patient or those close to the patient.

4.2 it is not the health practitioner's duty to prolong life at all cost. However, it is their responsibility to know when to initiate and when to cease attempts at prolonging life, while ensuring that patients receive appropriate relief from distress.

4.3 when a patient dies, a health practitioner shall be willing to explain, to the best of their knowledge, the circumstances of death to appropriate family members.

4.4 cultural practices related to death and dying, where known, should be respected. Communicating to patients and their families in the most appropriate way is necessary and providing support for them while they deal with this information.

5 DIAGNOSIS AND PROGNOSIS

5.1 Before a decision is made to withhold or withdraw treatment, the treating health practitioner must carry out a thorough assessment of the patient's condition and the likely prognosis, taking account of up to date guidance on good clinical practice.

5.2 The health practitioner should always consider seeking a second opinion. Health practitioners must seek a second opinion in cases where they are not sufficiently experienced or knowledgeable. Patient and family members also have the right to seek second opinion on the matter.

6 OPTIONS FOR TREATMENT

6.1 Health practitioner should only identify treatment options as being appropriate if based on up-to-date clinical evidence about efficacy, side-effects and other risks, while also referring to any relevant clinical guidelines on the treatment and management of the patient's condition, or of patients with similar underlying risk factors.

6.2 Health practitioner must reach a considered judgment on the likely benefits, burdens and risks (including non-clinical ones) for the particular patient of each of the treatment (or non-treatment) options identified. They should always consult a practitioner with relevant experience in cases where:

6.2.1 The health practitioner and the health care team have limited experience of a condition; or

6.2.2 The health practitioner is in doubt about the range of options or the benefits, burdens and risks of a particular option for the individual patient; or

6.2.3 The health practitioner is considering withholding or withdrawing artificial nutrition and hydration.

6.2.4 There is a serious difference of opinion between the health practitioner and the patient, within the healthcare team, or between the team and those close to a patient who lacks capacity, about the preferred option for a patient's treatment and care.

7 EMERGENCIES

7.1 In an acute life-threatening emergency, where any delay might prejudice the outcome and where it is impossible to obtain all relevant information or hold any consultations required or where there is uncertainty about the diagnosis or the likelihood of recovery, health practitioners should start treatment which may be of some benefit to the patient until a clearer assessment can be made.

7.2 If the treatment referred to in para 7.1 above, was done without the consent of the patient the health practitioner should inform the patient about the procedure that were done as soon as the patient is mentally capable of understanding such information.

8 CHOOSING BETWEEN OPTIONS: PATIENTS WHO CAN DECIDE FOR THEMSELVES

8.1 SEEKING THE PATIENT'S VIEWS

8.1.1 Where a patient is competent to participate in decision-making, health practitioners must discuss with the patient their conclusions about diagnosis, prognosis and which options they consider may be in the patient's best interests (setting out the potential benefits, burdens, and risks of each option). It is for the patient to judge what might be acceptable; what weight or priority to give to any burden or risks; and to decide which of the options would be in his or her best interests.

8.1.2 Health practitioner should bear in mind that the decisions of competent adult patient to refuse a particular medical intervention must be respected, even where this would result in serious harm to them or in their own death unless the patient's state of mind is such that he/she is incapable of taking or participating in the decision.

8.1.3 Where the possibility of withholding or withdrawing of life-prolonging treatment is being considered as an option, health practitioners should discuss with the patient how his or her care would be managed if such a decision were made. This should include arrangements for providing basic care and other appropriate treatment; and what might be his or her palliative or terminal care needs and how these would be met. In addition, the patient's preferences about who should be involved in decision making or in providing additional support if he or she becomes incapacitated should also be discussed.

8.1.4 Discussions in the above paragraph will allow patient the opportunity they need to decide what arrangements should be made to manage the final stages of their illness; and to attend to personal and other concerns which are important in ensuring that patients can die with dignity.

8.1.5 Discussions about the possibility of withholding or withdrawing a potentially life-prolonging treatment may be difficult and distressing. However, this does not mean that such discussions should be avoided. Instead, the discussions should be handled sensitively and with appropriate support being provided to the patient. Health practitioner should also consult with those close to the patient about the best means of withholding or withdrawing treatment where this is appropriate.

8.1.6 Where patient clearly indicate that they do not wish to know or discuss the details, health practitioner should still provide the patient with sufficient information about his or her condition and its treatment to enable the patient to make an informed decision.

8.1.7 A linguistic or cultural barrier may exist between health practitioner and their patient. Under these circumstances, an interpreter who is cultural sensitised and fluent in the language used by the patient should be present in order to facilitate communication when discussions are held and decisions regarding the treatment of the patient are to be made.

8.2 TIMING OF DISCUSSIONS WITH THE PATIENT

8.2.1 Health practitioner should hold discussions at a time when the patient is best able to understand and retain information. They should allow the patient sufficient time to reflect and ask questions before deciding.

8.2.2 Health practitioner should also discuss the patient’s right to change his or her mind about the decision. Where a patient has an existing condition and the likely progression of the disorder is known, the health practitioner should consider formulating an advance management plan with the patient and the clinical team.

9 CHOOSING BETWEEN OPTIONS: PATIENTS WHO CANNOT DECIDE FOR THEMSELVES

9.1 ASSESSING CAPACITY TO DECIDE

9.1.1 In most cases where the dying process itself affects the patient's mental capacity, the correct course of action for the patient should have been decided previously. Where no such advance management plan had been agreed, or the plan has not been reviewed recently, or is not relevant to the patient's current condition, health practitioner are advised as follows: -

9.1.1.1 Where patient have difficulty retaining information, communicating their views, or are only intermittently competent, health practitioner should provide any assistance a patient might need to enable him or her to reach and communicate a decision.

9.1.1.2 Where there are doubts about a patient's capacity at making a decision, health practitioners should consult with other relevant health practitioners in order to formulate ethical way forward.

9.1.4 Where a directive exists, this should be taken into consideration. The purpose of the directive is to maintain the autonomy of the patient even when he/she loses decisional capacity. A Directive usually specifies an individual, patient-selected-proxy, whom the patient has chosen to make health care decisions in the event that he/she loses decisional capacity. It may also specify the patient's values or instructions that should be used to guide health care decisions or indicate specific treatments that the patient would or would not want to receive. A Directive cannot compel the healthcare team to provide treatments that lie outside acceptable standards of care, nor may it direct a proxy to do so.

9.2 DECISIONS ON BEHALF OF THE PATIENT

9.2.1 Where a patient lacks the capacity to decide, health practitioner must respect any valid advance refusal of treatment.

9.2.2 Where there is no advance refusal of treatment the senior health practitioner responsible for the patient's care must make the decision about what course of action would be in the patient's best interests: -

9.2.2.1 The senior health practitioner should consult the patient’s authorised representative if such a person was appointed.

9.2.2.2 The health practitioner should also consult the healthcare team and the patient’s authorised representative and, wherever possible, those close to the patient. The latter may be able to provide insights into the patient’s preferences and be able to offer an opinion on what would be in the patient’s best interests.

9.2.2.3 Health practitioner should pay due regard to any previous wishes of the patient about not disclosing information to particular individuals.

9.2.2.4 If the patient is new to the health practitioner at the time decisions are needed, the health practitioner must satisfy himself or herself whether or not such consultations have previously been carried out and if so, find out what had been agreed.

9.2.3 The health practitioner should consider what support could be provided to family members and others close to the patient.

9.3 REACHING CONSENSUS

The consultations between the health practitioner and the healthcare team and those close to the patient should aim to achieve consensus on what course of action would be in the best interests of the patient. The factors considered in assessing best interests should take into account guidance from the HPCSA, pertinent ethical principles and relevant statutory requirements.

10 WITHHOLDING TREATMENT DUE TO SCARCITY OF RESOURCES AND ALLOCATION OF SCARCE RESOURCES

10.1 There are circumstances when withholding treatment, even if it is not in the best interest of the patient, is permissible. This will apply to continued care in special units such as critical care and chronic dialysis units for end stage kidney failure.

10.2 A healthcare institution has the right to limit life-sustaining interventions without the consent of a patient or surrogate by restricting admission to these units. However, such restriction must be based on national admission criteria agreed upon by the expert professional bodies in the relevant speciality, as well as the HPCSA.

10.3 A healthcare institution is, however, obliged to provide the appropriate palliative care and follow up when specialised care is withheld.

10.4 If, however, the patient does satisfy all the criteria for admission, but cannot be admitted because of limited resources at a particular institution, the health practitioner must transfer the patient to another institution where such resources exist. However, this should be done only after the necessary emergency treatment has been instituted.

10.5 The HPCSA considers it unethical to continue with life-prolonging treatment for the sole purpose of financial gain. Moreover, it is unacceptable that patients are transferred to state institutions after all their funding has been exhausted as a result of prolonging futile treatments.

10.6 The health practitioner should take suitable and prompt action when needed and refer the patient to another practitioner or service when this is in the patient's best interests.

11 COMMUNICATING DECISIONS

11.1 Whatever decision is made, health practitioners must ensure that all those consulted, and especially those responsible for delivering care, are informed of the decision and are clear about the goals and the agreed management plan.

11.2 It is particularly important where treatment is to be withheld or withdrawn that everyone involved is clear about the arrangements for providing appropriate palliative or terminal care and about their own roles.

11.3 Health practitioner should discuss what the role of the family or other carers will be and what support they will receive from the health care team.

12 RECORDING DECISIONS

12.1 Health practitioner must ensure that decisions are properly recorded, including but not limited to: -

- the relevant clinical findings;
- relevant Medical history;

- options discussed and those consulted, if applicable;
- details of discussions with the patient, health care team or others involved in decision-making;
- details of treatment, available treatment options and associated risks or other significant factors which may affect future care;
- details of consent provided including the names of people involved in the discussions;
- any request or concern expressed;
- any decisions made and the reasons for them; and
- the proposed management plan.

12.2 Health practitioner should record the information at the time of the events described or soon thereafter. The record should be legible, clear, accurate and unambiguous. It should, for example, avoid abbreviations or other terminology that may cause confusion to those providing care.

12.3 Health practitioner should ensure that the records are securely kept and appropriately accessible to team members and others involved in providing care to the patient.

12.4. In the management of medical record or any other information, the health practioner must adhere to the provision of the Protection of Personal Information Act 2013 (Act 4 of 2013) and other relevant provisons on managing information.

13 REVIEWING DECISIONS AND CHANGING DECISIONS

13.1 Health practitioner must review their decisions at appropriate intervals during the agreed treatment or the period of palliative or terminal care to determine whether the goals of treatment or the management plan remain appropriate.

13.2 Health practitioner should seek a second opinion or peer review where, for example the patient’s condition is not progressing as expected or their views about the benefits, burdens and risks of treatment have changed.

13.3 Based on opinion sought, the health practitioner may change to the appropriate decision that is in the best interest of the patient including withholding or withdrawing treatment.

13.4 A patient’s or close family member’s change of mind on previously taken or consented decision must be respected, however, upon the advise to the patient or close family member who is changing the decision.

14 AUDIT

14.1 As in other areas of decision making, health practitioner must carry out clinical audits of the process which can improve their own and others’ knowledge about the outcomes of different treatment and non-treatment decisions.

15 CHILDREN

15.1 The general principles of good practice set out in this framework also apply to decision-making in cases involving children - including premature babies - where the decisions may be particularly difficult for everyone involved.

15.2 Health practitioner should respect the decisions of children who have the legal capacity to make decisions about refusing health care – except in cases where the practitioners believe that it is not in the child’s best interests – in which case they should approach the parents or guardians or caregiver, person in charge of the healthcare establishment, minister, high court or children’s court for a decision.

15.3 In all cases, health practitioner and others who make decisions on behalf of a child have to consider only those options that are in the best interest of the child.

15.4 If the child does not have the legal capacity to make a decision, but has sufficient mental maturity to understand the procedures to be adopted, he or she should be consulted during the decision-making process.

ANNEXURE 1

World Medical Association Declaration on Terminal Illness

Adopted by the 35th World Medical Assembly Venice, Italy, October 1983 and Revised by the WMA General Assembly, Pilanesberg, South Africa, October 2006

Preface

1. When addressing the ethical issues associated with end-of-life care, questions regarding euthanasia and physician-assisted suicide inevitably arise. The World Medical Association condemns as unethical both euthanasia and physician-assisted suicide. It should be understood that WMA policy on these issues is fully applicable in the context of this Statement on Terminal Illness.

Preamble

2. When a patient's medical diagnosis precludes the hope of health being restored or maintained, and the death of the patient is inevitable, the physician and the patient are often faced with a complex set of decisions regarding medical interventions. Advances in medical science have improved the ability of physicians to address many issues associated with end-of-life care. However, it is an area of medicine that historically has not received the attention it deserves. While the priority of research to cure disease should not be compromised, more attention must be paid to developing palliative treatments and improving the ability of physicians to assess and address the medical and psychological components of symptoms in terminal illness. The dying phase must be recognized and respected as an important part of a person's life. As public pressure increases in many countries to consider physician assisted suicide and euthanasia as acceptable options to end suffering in terminal patients, the ethical imperative to improve palliative treatment in the terminal phase of life comes into sharp focus.

3. The World Medical Association recognizes that attitudes and beliefs toward death and dying vary widely from culture to culture and among different religions. In addition, many palliative and life-sustaining measures require technologies and/or financial resources that are simply not available in many places. The approach to medical care of the terminally ill will be influenced significantly by these factors, and thus attempting to developing detailed guidelines on terminal care that can be universally applied is neither practical nor wise. Therefore, the World Medical Association articulates the following core principles to assist physicians and National Medical Associations with decision-making related to terminal care.

Principles

4. The duty of physicians is to heal, where possible, to relieve suffering and to protect the best interests of their patients. There shall be no exception to this principle even in the case of incurable disease.

5. In the care of terminal patients, the primary responsibilities of the physician are to assist the patient in maintaining an optimal quality of life through controlling symptoms and addressing psychosocial needs, and to enable the patient to die with dignity and in comfort. Physicians should inform patients of the availability, benefits and other potential effects of palliative care.

6. The patient's right to autonomy in decision-making must be respected with regard to decisions in the terminal phase of life. This includes the right to refuse treatment and to request palliative measures to relieve suffering but which may have the additional effect of accelerating the dying process. However, physicians are ethically prohibited from actively assisting patients in suicide. This includes administering any treatments whose palliative benefits, in the opinion of the physician, do not justify the additional effects.

7. The physician must not employ any means that would provide no benefit for the patient.

8. Physicians should recognise the right of patients to develop written advance directives that describe their wishes regarding care in the event that they are unable to communicate and that designate a substitute decision-maker to make decisions that are not expressed in the advance directive. In particular, physicians should discuss the patient's wishes regarding the approach to life-sustaining interventions as well as palliative measures that might have the additional effect of accelerating death. Whenever possible, the patient's substitute decision-maker should be included in these conversations.

9. Physicians should endeavour to understand and address the psychosocial needs of their patients, especially as they relate to patients' physical symptoms. Physicians should try to ensure that psychological and spiritual resources are available to patients and their families to help them deal with the anxiety, fear and grief associated with terminal illness.

10. The clinical management of pain in terminal patients is of paramount importance in terms of alleviating suffering. Physicians and National Medical Associations should promote the dissemination and sharing of information regarding pain management to ensure that all physicians involved in terminal care have access to best practice

guidelines and the most current treatments and methods available. Physicians should be able to pursue clinically appropriate aggressive pain management without undue fear of regulatory or legal repercussions.

11. National Medical Associations should encourage governments and research institutions to invest additional resources in developing treatments to improve end-of-life care. Medical school curricula should include the teaching of palliative medical care. Where it does not exist, the establishment of palliative medicine as a medical specialty should be considered.

12. National Medical Associations should advocate for the development of networks among institutions and organizations involved in palliative care in order to foster communication and collaboration

13. Physicians may, when the patient cannot reverse the final process of cessation of vital functions, apply such artificial means as are necessary to keep organs active for transplantation provided that they act in accordance with the ethical guidelines established in the World Medical Association Declaration of Sydney on the Determination of Death and the Recovery of Organs.

Ethical guidelines for good practice in the health care professions

The following Booklets are separately available:

Booklet 1: ***General ethical guidelines for health care professions***
Booklet 2: ***Ethical and professional rules of the health professions council of South Africa as promulgated in government gazette R717/2006***
Booklet 3: ***National Patients' Rights Charter***
Booklet 4: ***Seeking patients' informed consent: The ethical considerations***
Booklet 5: ***Confidentiality: Protecting and providing information***
Booklet 6: ***Guidelines for the management of patients with HIV infection or AIDS***
Booklet 7: ***Guidelines withholding and withdrawing treatment***
Booklet 8: ***Guidelines on Reproductive Health management***
Booklet 9: ***Guidelines on Patient Records***
Booklet 10: ***Guidelines for the practice of Telehealth***
Booklet 11: ***Guidelines on over servicing, perverse incentives and related matters***
Booklet 12: ***Guidelines for the management of health care waste***
Booklet 13: ***General ethical guidelines for health researchers***
Booklet 14: ***Ethical Guidelines for Biotechnology Research in South Africa***
Booklet 15: ***Research, development and the use of the chemical, biological and nuclear weapons***
Booklet 16: ***Ethical Guidelines on Social Media***
Booklet 17: ***Ethical Guidelines on Palliative Care***