



**GERIATRIC MEDICINE
SOCIETY OF MALTA**

Promoting excellence in the
care of older adults

Advance Care Planning? A Guide for Clinicians

Advance Care Planning Working Group



ADVANCE CARE PLANNING? A GUIDE FOR CLINICIANS

1. What is an Advance Care Plan?

Advance Care Planning offers patients the opportunity to identify and express their values, beliefs, and preferences for care, to be considered in serious illness situations when they are no longer able to make decisions on their own. These conversations are voluntary and help to discuss a patient's values, wishes, life goals, and acceptable end-of-life treatment outcomes. Furthermore, through an Advance Care Plan, a patient can identify a person whom they trust to act as their representative in future decisions if they are unable to make such decisions for themselves.

2. What an Advance Care Plan is not

An Advance Care Plan in Malta is not legally binding, and a patient cannot impose their preferences on their doctors who should always act in their best interest. At the same time, a patient or relatives cannot, through an Advance Care Plan ask for treatment that is considered by the medical team as futile for their needs. At the same time, a patient can express their preferences through an Advance Care Plan to avoid life prolonging treatment (e.g., a patient can ask to avoid CPR, but he/she cannot ask for CPR if it is futile). In addition, an Advance Care Plan cannot be used as a substitute for a will or testament.

3. When does an Advance Care Plan come into force?

An Advance Care Plan comes into force when a patient is no longer able to make decisions for themselves. In most situations, this happens close to the end-of-life.

4. Is an Advance Care Plan an Advance Directive?

The main difference between an Advance Care Plan and an Advance Directive (sometimes called a living will), is that an advance directive is a formal legal document. To date, Maltese law has provisions to support an advance directive regarding their preferences for organ donation when the patient passes away, but at the same time, Maltese law remains silent with respect to advance directive preferences for end-of-life care. (For Organ Donation see <https://organdonation.gov.mt/>).

5. Is Advance Care Planning euthanasia?

Euthanasia is the intentional termination of life (by a physician) on the explicit request of a patient suffering unbearably from an incurable disease or in an irreversible coma. Under Maltese Law, euthanasia is considered illegal and thus cannot be applied in Maltese medical practice.

Advance care planning is a process that involves discussing and preparing for future decisions about medical care in the event that a person becomes seriously ill or unable to communicate their wishes. Through an Advance Care Plan, a person can express their wish to avoid certain life prolonging extraordinary and burdensome interventions in end-of-life care (e.g., tube feeding at the end-of- life). The fact that such Advance Care Plan instructions in Malta cannot include decisions to terminate life, makes them clearly separate and distinct from euthanasia.

6. Why should an Advance Care Plan be done in writing? Where should copies be kept?

Advance Care Planning (ACP) should be done in writing to help significant others (e.g., relatives, clinicians) know what type of medical care and support the patient wishes for their end-of-life. It is always best for the patient to keep a copy of the ACP Form themselves and give a copy to a family member or significant other whom they trust. Ideally, a copy is given to the caring doctor and another is kept in the patient's Hospital Personal Medical File/Electronic Database. At times giving a copy to the patient's lawyer/notary/spiritual director does help, depending on the circumstances.

7. When should a clinician recommend that the patient is to fill out an Advance Care Plan Form?

It is important to point out that whilst it is the patient's right to be informed about their diagnosis and plan for terminal care, likewise, it is also in the patient's right to be spared from the heartache of knowledge of the existence of a devastating diagnosis. In such cases where the patient prefers to be kept in the dark, it is advisable to refrain from entertaining the patient about advance care planning.

An opportunistic initiation of an Advance Care Plan includes the following:

- a patient or relative generated request to plan ahead
- on or prior to admission to a caring facility
- during routine doctor rounds
- when there is the diagnosis of devastating illness indicating poor prognosis and possible loss of decisional capacity due to the effect of the disease or its treatment (e.g. metastatic cancer, dementia, motor neurone disease, Parkinson's disease, Huntington's disease, organ failure, stroke / TIA's)
- where a patient does not have anyone to act as substitute decision-maker
- where the patient is at a key stage of their illness trajectory that points to a marked worsening of their condition (e.g. repeat hospitalisation)
- where you would not be surprised if the person dies within twelve months (see SURPRISE QUESTION on the GoldStandards Framework PIG website <https://www.goldstandardsframework.org.uk/pig>)

Early intervention when the patient is medically stable, comfortable, and accompanied by family members they trust, does help the patient to better grasp the concepts involved in diagnostic and survival estimates, as well as the benefits and risks of the limited treatment options available as the patient comes closer to the EOL. This early intervention leads to better clarity and serenity in decision-making that leads to appropriate documentation of what they really want for their end-of-life. Such planning is best done over multiple sessions, where the patient is given the chance to take with him back home the ACP Form to ponder its meaning and to discuss it with people they trust.

However, in many instances, ACP is considered quite late in the diagnostic progress of a devastating illness. In such situations, where the survival estimates may be measured in weeks or days, family members are frequently involved, as they provide the necessary support to the patient to better understand the concepts of ACP in the face of impending death. In view of the limited time available, ACP is usually done in one session, and is often quite difficult to address, particularly if there is no pre-existing relationship between the clinician and the patient/relatives. In such cases, involving the patient's GP/other known clinicians does help bridge the gap in issues where trust is seriously challenged.

It is normal for any human being to become emotionally disturbed when faced with the dire reality of one's bleak diagnosis and prognosis. In such situations, the health professional must always manoeuvre an Advance Care Plan at the pace of the patient. In such situations, it is always wise to watch out for the family members' reactions as well as those of the patient.

One must be wary of how to proceed with ACP when relatives object strongly. One ethical issue to be kept in mind in such situations is that patient autonomy in decision-making is a human right to be given precedence over the benevolence expressed by third parties, including relatives. If in doubt, seek psychiatric support to certify the patient's mental capacity and mobilize psychological support. Also communicating in-depth with family members often helps to allay their anxiety.

8. The role of family members in the drawing up of an ACP

Having relatives understand the concept and support their elders in filling out an ACP is always an important asset. Helping relatives appreciate the life course of their elders in care gives them the knowledge to appreciate life's progression, from health to disease, leading to frailty and the inevitable death. Communicating with relatives and patients helps them to appreciate that death and dying are normal processes of all human beings. The benefit of the transmission of the appreciation of the limitations of human life empowers relatives to help doctors /nurses to provide reassurance to the patient that ACP is an expression of their values and wishes for their EOL, in a way to help ensure autonomy, and sustain their voice, till the end.

In light of the Maltese cultural closeness in family ties, it is usually wise to consult also with the family from the very beginning. Such early inclusion of family members in the discussion does wonders to help avoid misinterpretation of what is being proposed through an Advance Care Plan. Always with the proviso that the patient is aware and consents to his/her next of kin's involvement. Such discussions involving family members do help the relatives to better understand the patient's preferences, and this helps them be better prepared when in the EOL, they are asked to make decisions for the patient who has lost decisional capacity.

9. Starting a discussion with the patient/relatives on Advance Care Planning?

A good way to introduce an Advance Care Plan to the patient is to state that this is part of a whole process of ongoing assessment. To decrease the discomfort of talking about end-of-life care, it would also be best to refer to Advance Care Planning as an expression of the patient's preferences for future care. In addition starting with an appreciation of what are the medical conditions that are present and their expected prognosis (where known) does help the patient and relatives focus on the situation at hand, and ultimately better appreciate the plan for future care.

Starting the argument is a tricky issue, one possible first question that could be addressed to the patient to open the discussion could be,

"Have you ever documented or expressed your wishes with someone about what care you want if your medical condition worsens?"

The following are some language prompts that can help doctors and other health professionals raise the topic of advance care planning (Austin Health 2021. Advance Care Planning Australia)

"Introducing the topic - 'I try to talk to all my patients about what they would want if they became more unwell. Have you ever thought about this?'

Speaking for the person - *'Who would you like me to talk to if you were unable to talk to me about important medical treatment decisions?'*

Goals and values - *'What does it mean to you to 'live well'? What are your goals at this time?'*

Care and treatment - *'What do you understand about where things stand right now with your illness?'*

Concluding the conversation - *'Thank you for clarifying your goals, values, and acceptable outcomes. Does your family (or carer or friends) know what you would want?'*

10. Can a patient refuse to fill out an Advance Care Plan? Can he/she cancel or alter an Advance Care Plan?

A patient has the right to refuse to fill out an Advance Care Plan. Patients should be reassured that such refusal will not lead to any consequences on their care or how they are considered as a person in care. Being an expression of their views and preferences for care and support, a patient retains all the right to add to, delete or alter an Advance Care Plan as their medical condition progresses through time. In addition, an Advance Care Plan does not necessarily entail that all questions listed in the ACP Form be filled out by the patient. In fact, some questions asked do not apply to all situations/sites in care.

11. Where the doctor/other health care professionals can opt-out

Ideally, the senior caring doctor should be involved in supporting the patient to fill out an ACP. In this process, the ACP form recommends that the consultant countersigns the ACP form with the patient as a witness. However, whenever the patient is requesting something that goes against the doctor's personal morals or is illegal to endorse (e.g., euthanasia), the doctor may feel uncomfortable signing the form. In such situations, based on conscientious objection, the said clinician should communicate this position to the patient and withdraws from this process.

Likewise, if the attending doctor appreciates that the said patient lacks the cognitive skills necessary to fill out an advance care plan (see section 7 above), in such cases, the said doctor should evaluate if he or she should withdraw from the process. Informing the patient and relatives of one's findings and decision to withdraw, would help to allay any issues of conflict.

In all such circumstances, it would be advisable to write a note in the patient's medical file to document this issue. The Advance Care Planning Working Group can serve as a resource point to help delineate consistency in the implementation of ACP.

12. Follow-up

Progression of the underlying illness often exposes patients to new symptomatology that may require a re-evaluation of the original ACP to meet revised life goals for end-of-life care. In such situations the patient concerned has the right to make changes to their advance care plan.

13. Using an Advance Care Plan Document in the End-of-Life with Profit

The following are some considerations to be kept in mind when at the end-of-life, the medical team becomes aware that the patient had in the past documented their preferences for care on an Advance Care Plan:

- be certain that the patient has truly lost their mental capacity to decide, and thus can't participate actively in decision-making.
- try to identify if the ACP document in hand is truly the last updated version (as there may be multiple such documents running around).
- define what is the actual primary decisional dilemma being faced by the medical team at that point in the life of the patient.
- do remember that the medical team is obliged by law to seek the patient's best interests when cognition is lost. This relates to a re-evaluation of the patient's current needs with respect to their values, beliefs, and consideration of their preferences for care, looking at the pros and cons of treatment options and seeking to uphold their quality of life. Such decisions are best taken by the team and involve the patient's guardians (ideally) / close relatives / significant others, whilst trying to follow a consensus-building approach to respect the patient's dignity at the end-of-life.
- read the ACP form with great care. Usually, there is a clear pattern of what strategy in care the patient would have wanted for their end-of-life.
- at times on reading the ACP form, there is insufficient information, or the message passed is ambiguous to follow. In such cases, it would be difficult to delineate what the patient wanted for themselves. Getting more information from their next of kin and past caring clinicians often helps to clarify this ambiguity. In such cases, 'the patient's best interest' approach to care is a good ethical principle to follow.
- in instituting care decisions, observe the patient closely and see how they respond. Is the patient still comfortable? Is the patient getting more agitated? (e.g., trying to pull out a nasogastric tube). On the basis of these observations, adjust your medical response accordingly.
- family members are usually quite distressed at this point in their relative's life, so ideally, they are kept informed and involved regarding what is happening and why.

14. A step by step guide how to go about performing an Advance Care Plan

At the end of this leaflet guide, is a consensus-based algorithm, which the ACPWG has set up to guide the process of advance care planning.

15. Support

Additional leaflet support for patients and clinicians, or soft copies of the ACP Form (in English or Maltese language), can all be accessed on the GMS website <https://gmsmalta.com>.

If you wish to make contact with the Working Group behind this initiative, please use the email acpwg.mt@gmail.com.

Flow Chart to follow in the process of building up an Advance Care Planning ACPWG (2023)

