My wishes...?

Let’s Talk about it!

My WISHES for my health care
Communication tool for advance care planning

If you stop and think about what you consider important with respect to your health care, you may well realise how difficult you find it to express your feelings. Your needs and preferences in terms of treatment may vary considerably, depending on the disease and context, and may change over time. Nevertheless, it is definitely meaningful to be able to talk to those around you and your care providers early on, whilst you are still healthy or in the event of serious illness. On the one hand it will give you and those around you clarity and peace of mind and on the other hand it will give your doctor(s) and other care providers guidance to enable them to adapt your health care to your personal wishes as much as possible.

Advance care planning does not just cover potential treatments and medical decisions. It is equally important to have an idea of your outlook on life and to take specific practical matters into account such as your need for information, physical care, comfort, emotional support, practical assistance, care for your family, etc.

This document covers a number of areas and stages of care about which you can make your wishes known. It can act as a guide when discussing your health care with your relatives and care providers. At the back it provides information on the medical possibilities and limitations applicable to the various stages of disease and on legislation pertaining to patient rights and euthanasia.
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ADVANCE CARE PLANNING

You have various options to express your wishes concerning your health care. If you are healthy you can discuss this with your relatives/confidants and your general practitioner (GP). If you are suffering from a serious medical condition, you can talk about your wishes concerning your current and future treatment in more detail with your care providers. Your physicians can then set up treatment agreements in line with your wishes and medical condition. You can also indicate in advance what your wishes are, should situations occur in which you lose your decision-making capacity, for example in the event of severe dementia or brain damage. We refer to this as a situation in which you are no longer mentally competent. To this end an advance directive can be prepared and a representative appointed. (see On Patient Rights)

‘MY WISHES for my health care’ was developed as a tool to manage all these aspects of advance care planning: as an aid in conversations with your relatives and your care providers, to document your current and future care needs and treatment preferences, and if desired also as an advance directive. It will ensure that your health care is tailored as far as possible to your wishes.

Obviously, your preferences may change over time, which means that they will have to be reviewed at regular intervals. As long as you are capable of decision-making, your written preferences will merely be a starting point for further dialogue.

HOW TO USE THIS DOCUMENT

- Use this document primarily as a guide during conversations about your health care.
- Ask for explanation where desired and be guided by your relatives and your care providers (in particular your general practitioner (GP) and your consultant specialist).
- There’s no need to complete everything. You can limit it to what is currently relevant to you.
- Multiple choice questions sometimes show circles and sometimes squares:
  - Circles are meant for exclusive options: you only tick one.
  - Squares are meant for multiple options: you can tick several at the same time.
- Consider it a ‘living’ document: as long as you are of sound mind and judgement the content must always be verified in dialogue and if necessary updated.
- You retain the original and give a copy to your relatives, your GP and your consultant specialist. Keep an accurate record of who has been issued with a copy to ensure that their copies are also updated should changes be made.
- The section entitled ‘MY WISHES in case I lose my decision-making capacity’ can act as an advance directive if desired, providing item 12 is completed and signed by your representative(s) and you sign for consent at the bottom. In that case this advance directive is legally valid for an indefinite period. You can always update or void it. This will obviously then be discussed with the relevant physicians and relatives.
With this document I, ................................., born on ... / ... / ... in ................................., wish to stipulate that my health care, now and in the future, must be in accordance with the following:

**MY WISHES as a mentally competent patient**

1) I regularly want to receive clarification about my:  
   - Diagnosis: **YES / NO** (circle)  
   - Life expectancy (prognosis): **YES / NO** (circle)  
   - Disease progress (expected symptoms): **YES / NO** (circle)  
   - Treatment options (+ chances and risks): **YES / NO** (circle)

2) I want to **continue to play an active part** in the evaluation of treatment options.  
   **YES / NO** (circle)

3) I want information about my health care to be shared with my **confidants**.  
   **YES / NO** (circle)

To this end I am appointing:  
Name, tel., kinship where applicable, signature  
I also want to be supported by this person during planned discussions about my illness

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4) What is **important** to me in my life:  
   *For example: What is my reason for living? What is meaningful for me now? Who or what adds significance and purpose to my life?*

5) What would constitute **lack of quality of life** for me:  
   *For example: Which living conditions, limitations, burdens, prospects, etc. do I consider intolerable?*

6) What are significant **values and standards** for me that have an impact on my view of good health care:  
   *For example: values and standards governed by my beliefs and convictions, religion, culture, etc.*

7) I would like particular **support** with my health care in the following areas:  
   *For example: physical limitations and burdens, emotional ability to cope, social situation (partner, children, family, work, leisure time, etc.), financial situation, practical support, legal issues, existential questions, etc.*
### MY WISHES as a mentally competent patient

#### 8) If my disease **can be cured** *(curative stage)*, I want to:

- Give the treatment every chance of success even if my quality of life is permanently affected.
- Give the treatment every chance of success providing my quality of life remains acceptable afterwards (see item 5).
- Only have treatments that have minor or no burdensome side effects.
- Avoid treatments focused on a cure, I only want care to make me comfortable where necessary.

**Clarification:**

#### 9) If my disease **can no longer be fully cured**, but can be controlled or slowed down *(chronic stage)*, I want my health care to focus on the following **treatment objectives**, insofar as this is feasible:

- **A)** Life prolonging, improving my self-reliance and improving my general level of comfort.
- **B)** Mainly retaining my self-reliance/independence and improving my general level of comfort.
- **C)** Only treatment to improve my general level of comfort.

**Clarification:**

#### 10) If my disease progression can no longer be controlled or slowed down, and **only pain and symptom management** is possible *(palliative stage)*, I want to:

- Be cared for as long as possible with life-sustaining and quality of life enhancing treatments.
- Cease all life-sustaining treatments, only comfort care in support of a natural end of life process.
- Explore the possibility of receiving euthanasia.

At this stage, I preferably want to be cared for *(insofar as it is feasible)*:

- In my home environment with support from, for example, my relatives, GP, home nursing staff, palliative home care, etc.
- In a professional care environment such as a hospital ward, residential care facility or palliative care unit.

**Clarification:**

#### 11) During the final stage of life when the end is expected within days or weeks *(terminal stage)*, I want the **end of life care**, within the limits of good pain and symptom management, to ensure that:

- I can remain alert for as long as possible.
- I am not conscious when the end comes.
- My relatives have the opportunity, and are given the necessary support, to watch over me.
- A ritual is made available, religious or non-religious.
- I can preferably die at home.
- The possibilities of euthanasia are explored.

**Clarification:**
MY WISHES in case I lose my decision-making capacity

12) I hereby appoint the following individuals as representatives to carry out my wishes in case I lose my decision-making capacity:

NOTE: a representative will act on your behalf should you no longer be mentally competent (see ON PATIENT RIGHTS).

NOTE: the 2nd representative will only act if the 1st representative is unavailable.

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13) In the event of an acute critical condition (e.g. heart failure, brain seizure), I want:

- A) Life saving interventions, providing they are medically justified, even if the prognosis is not good.
- B) Life saving interventions, as long as there is a real chance of recovery of my self reliance/independence.
- C) No life saving interventions, only comfort care and a natural end of life process.

☐ An assessment to be made at that time as to what would be best for me, where possible in consultation with my representative.

14) In the event of temporary absence of mental competence (e.g. temporary confusion, temporary coma), I want:

- A) Life prolonging treatments, providing they are medically justified.
- B) Only treatments to improve my self reliance/independence and level of comfort.
- C) Only treatments to improve my level of comfort.

☐ An assessment to be made at that time as to what would be best for me, in consultation with my representative.

15) Should I permanently lose my mental competence, but still be able to have emotional contact (e.g. advanced dementia, permanent brain damage), I want:

- A) Life prolonging treatments, providing they are medically justified.
- B) Only treatments that will support my self reliance/independence and level of comfort.
- C) Only comfort care in support of a natural end of life process.

☐ An assessment to be made at that time as to what would be best for me, in consultation with my representative and in line with the signals I am giving.

16) Should I permanently lose my mental competence, without any form of consciousness or emotional contact (irreversible coma, permanent vegetative state), I want:

- A) Life prolonging treatments, providing they are medically justified.
- B) Only treatments that will support my functionality and level of comfort.
- C) Only comfort care in support of a natural end of life process.

☐ An assessment to be made at that time as to what would be best for me, in consultation with my representative.

☐ To have access to euthanasia because of the irreversible loss of consciousness.

To make this legal I shall prepare an official ‘declaration of intent for euthanasia in the event of irreversible loss of consciousness’ and renew it every 5 years (see EUTHANASIA).

17) Moreover, I also want the following concerns, reservations, important matters, etc. to be taken into account:

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MY WISHES in the event of my death

18) If I die, I want:

☐ My organs to be donated for transplantation.  
   NOTE: if you DO NOT want this to happen, contact the registry office in your town/city (see OTHER DOCUMENTS)

☐ To donate my body to science. To this end I will contact the following university ..........................................................
   NOTE: this will result in the funeral being postponed for an indefinite period.

☐ That my body is taken to ..........................................................

☐ That my body is taken care of in accordance with the customs of my religion, i.e.:

19) I also wish/ prefer:

☐ to be buried, preferably at the following location: ..........................................................

☐ to be cremated and my ashes: buried/ stored /scattered (circle) preferably at the following location: ..........................................................

☐ That the preferences expressed by my relatives be respected.

20) I would like the following wishes to be taken into account for my funeral:

(e.g. in terms of service, music, text, message or other requests)

21) I want my relatives to know this of me:


Reviewing MY WISHES

22) The following circumstances may compel me to review my wishes for my health care:

For example: changes in your medical condition (i.e. admission to hospital, additional diagnosis, changes in therapy, complications, etc.) or your perception of your illness (e.g. as a result of altering possibilities, significant events in your life, changes affecting your ability to cope, etc.).
On MEDICAL POSSIBILITIES AND LIMITATIONS

The physician and care team will regularly provide you with details about your disease, geared to your need for information, to enable you to properly formulate your care and treatment preferences. It is advisable to attend these discussions in the presence of a confidant (see ON PATIENT RIGHTS), to ensure that you can review together what has been said. This may, for example, relate to: What is the diagnosis? What stage is my disease at? What is my life expectancy in the best and worst case scenario? What is the likely development of my disease? What are the treatment options? What are the chances, burdens and risks of specific options? What happens if the treatments are no longer effective or become too burdensome?

It is useful to describe the various stages of disease in terms of feasible treatment objectives:

- **Curative stage:** At an early stage the treatment of disease often focuses on a complete cure / recovery.
- **Chronic stage:** When full recovery is no longer an option the objective of the treatment will be more limited, for example, to:
  - **A)** Stabilise or slow down the disease progression: active extension of life.
  - **B)** Improve functionality and mobility: maintain self reliance/independence.
  - **C)** Improve the general level of comfort.

During this stage there is often a need for additional support for patients and those around them.

- **Palliative stage:** When treatments are no longer effective the symptoms can still be managed with palliative comfort care. In such cases the objective is to enhance the quality of life and level of comfort.
- **Terminal stage:** During the final stage of the disease, when death is expected to be imminent, terminal care will offer support to bring about a serene and comfortable dying process. In exceptional cases, in which the desired level of comfort cannot be achieved with normal pain and symptom management, palliative sedation can be initiated. This will lower the level of consciousness (temporarily or permanently) to ensure that the patient no longer consciously experiences the symptoms.

Within the limits of what is medically possible, your wishes are taken into account in order to implement agreed treatment arrangements. Your own limits with respect to treatment must always be observed. Moreover, a medical limit can sometimes apply, for which the physician will assign a therapy limitation code (often referred to as a “DNR code”):

- **No code:** If no code has been assigned it is assumed that every possible measure should be taken as part of your health care. Where necessary resuscitation or other life extending interventions must be initiated.
- **Do not resuscitate:** This restriction is usually appropriate if the expected outcome of a potential resuscitation is too limited. In the event of breathing or heart failure no resuscitation measures will be taken (no CPR, artificial ventilation, no paramedics or ambulance, no medication). In any other situation you will receive the necessary therapy. Your dignity and comfort shall always be paramount.
- **Withholding life-sustaining therapy** (unless strictly necessary to enhance the level of comfort): This limitation is advisable when certain treatments are no longer effective, have become too burdensome or are causing serious complications. The physician in charge of the treatment can decide which treatments should no longer be initiated. For example: no admission to the intensive care unit, no breathing apparatus, no artificial administration of fluids and/or nutrition, no antibiotics, no surgical interventions, no chemotherapy or radiation, no dialysis, transplantation or transfusions, etc.
- **Withdrawing life-sustaining therapy:** During the terminal stage it is often necessary to gradually withdraw already initiated treatments in order to maintain the right level of comfort. For example, it may become necessary to cease the artificial administration of fluids and nutrition because the body can no longer process them, which would then become burdensome and cause more complications (e.g. pulmonary oedema). Terminal comfort care will in that case prevent you from feeling thirsty.
On EUTHANASIA

Euthanasia is the act of deliberately ending a person’s life by someone other than the person in question, at the latter’s specific request. In such cases medication is administered resulting in the immediate death of the patient. The Belgian Act on Euthanasia, which was introduced in 2002, allows physicians to practise euthanasia providing the patient has made an unwavering, repeated, voluntary and well-advised request and is suffering unbearably and without any hope of improvement from the physical or psychological consequences of an incurable medical condition:

http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&table_name=wet&cn=2002052837

If a patient is considering euthanasia we recommend that they talk to the attending physician(s) in a timely manner. A request for euthanasia must be heard and carefully considered, but no one is obliged to collaborate with, or carry out, euthanasia. A physician who doesn’t want to, or cannot, proceed with a request for euthanasia has to explain why and discuss what kind of care is available in a timely manner. In such cases the patient reserves the right to obtain information elsewhere and have their medical file transferred. Requests for euthanasia are frequently abandoned as a result of good (information on) palliative care being available. For some patients, however, it remains the only conceivable option.

If a physician is prepared to carry out euthanasia two procedures are possible: a current request for euthanasia and an advance directive for euthanasia in the event of irreversible loss of consciousness:

• When a competent patient submits a current request for euthanasia to a physician, a written request must be drawn up, dated and signed by the patient. The following statement can be written on a blank sheet of paper “I, the undersigned, …, want to proceed with euthanasia.” If the patient is no longer able to write the request, it can be done on their behalf by an adult who has no material interest in the patient’s death, in the presence of the attending physician, who must indicate the medical reason why the patient could not write it. A reasonable period of time must then be observed, during which a second independent physician must assess whether the request complies with the relevant legal stipulations. If a natural death is not expected on short notice, the minimum period is one month, and a third independent physician will be consulted. It is particularly important that every effort should be made to improve the patient’s physical and emotional comfort, that the underlying reasons and needs are explored, that the question as to whether euthanasia is the only and best answer to these needs is fully investigated and that possible alternatives are discussed in detail (e.g. the palliative comfort care options). The involvement of the patient’s relatives in the handling of/guidance with the request is not legally binding but definitely recommended.

• If you want to stipulate in advance that you want to resort to euthanasia in the event of you ending up in an irreversible coma or permanent vegetative state, you can draw up an advance directive for euthanasia in the event of irreversible loss of consciousness. This living will is a pre-printed official document that can be downloaded from, for example: http://www.health.belgium.be/nl/gezondheid/zorg-voor-jezelf/levensbegin-en-einde/euthanasie. The document has to be signed and dated by the patient as well as two adult witnesses (at least one of whom has no material interest in the patient’s death), who must confirm that the living will is drawn up voluntarily. It is advisable to appoint one or more ‘trusted representatives with respect to the living will for euthanasia’ (they can be heirs): they will retain the living will and hand it over to the relevant physician at the appropriate time. A copy of the document should also be retained by the attending physician. In order to remain valid, the document must be reviewed and re-issued every 5 years. This living will cannot be used as a current request for euthanasia, nor in other situations in which the person is mentally incompetent. This document consequently only applies in the specific instance of irreversible loss of consciousness, i.e. an irreversible coma or permanent vegetative state.
On PATIENT RIGHTS

Since 2002 Belgium has also introduced more wide ranging legislation pertaining to patients’ rights, which stipulates the following with respect to any kind of care provision:

- As a patient you are entitled to meticulous quality care, in terms of both disease control and pain/symptom treatment. Social class, sexual orientation, religious beliefs etc. shall not play a part in this.
- You are free to choose your care provider. You can review that choice at any time. You are also entitled to a second opinion about your health if you feel that is necessary.
- As a patient you are entitled to receive clear information about the diagnosis, prognosis, disease progress, treatment options, cost, etc., which must be provided in comprehensible language to ensure that you fully understand it all. If you indicate that you don’t want to be informed your physician must respect this decision.
- You can ask for support from a confidant at all times (see item 3). This person can assist you during a consultation, when perusing your medical file, when submitting a complaint, etc.
- Your care provider will require your consent in order to treat you. They must provide you with information in good time to enable you to make well informed and entirely voluntary decisions. The information they provide must be unambiguous and complete. In the event of an emergency your care provider shall be entitled to start treatment immediately if your instructions cannot be verified at that time.
- Your care provider will maintain a medical file for you. This file will be stored in a safe location. You can ask your care provider to add specific documents to your file. You are entitled to consult and ask for a copy of the file upon request.
- The care provider must respect your privacy. During your treatment only individuals with relevant professional skills shall be entitled to attend. Information about your condition must not be revealed to others without your consent.
- If you have complaints that are not being addressed you can contact the Ombudsman. Depending on the person or department to which the complaint relates, you can contact a local Ombudsman in the hospital or the federal Ombudsman. If you cannot settle a dispute with your care provider yourself the Ombudsman can mediate.
- To exercise your rights in the event that you are no longer able to do so yourself (i.e. in case you lose your decision-making capacity, for example, due to dementia, coma, etc.), you can appoint a representative (see item 12), who will represent your wishes if you are no longer able to express them. If no official representative was appointed the following legally binding sequence shall apply: the individual’s trustee (if one has been appointed, by the justice of the peace), actual co-habiting partner, adult children, parents, siblings.

Remember: a legal representative does not have the same powers as an appointed representative.

Do not confuse the various phrases!

✔ Confidant: assists a mentally competent patient.
✔ Representative: represents the wishes of a patient who has lost his/her decision-making capacity.
✔ Witness: witnesses that the advance directive has been drawn up voluntarily.
✔ Trusted representative with respect to an advance directive for euthanasia: retains the advance directive and hands it over to the relevant physician at the appropriate time.
On OTHER DOCUMENTS

The following wishes can be officially registered at the civil registry office of your town/city:

- **An advance directive for euthanasia in the event of irreversible loss of consciousness:** For the time being there’s not much point to have this document registered with your local council, in view of the fact that there is no guarantee that it will be requested or forwarded to your care providers. What’s more important is that you give a copy of this advance directive to your GP or attending physician(s) and your relatives, and to discuss your reasons for this decision with them. If you still want to register this advance directive at your local registry office use the documents provided via the following link:

- **Organ donation refusal:** If you DO NOT want to donate your organs for transplantation after your death, you can only do so by submitting an organ donation refusal to your local registry office. This requires official registration. For further information visit:

It is also possible to draw up a ‘negative advance directive’ in which you can refuse a number of specifically described medical interventions in the event you are no longer mentally competent.

The websites www.delaatstereis.be and www.leif.be provide a number of examples. These forms tend to focus more on the patient’s autonomy and less on exchanges with relatives and care providers.

This is where ‘MY WISHES for my health care’ wants to make a difference and invite you to reflect on all aspects of your health care together with your relatives and care providers on time.
Notes