

The Death Plan

Article

You have the greatest stake in the numerous decisions made regarding your dying and death care. Therefore, you are the one who should be making informed decisions on behalf of your body, mind and spirit with consideration for your friends and family. The professionals involved in the care of a dying person are your consultants helping you make the best decisions possible.

The purpose of this pamphlet is to provide information on the choices available in death and dying care, to assist you in discussing your plan with your doctor, death midwife and family and to help you plan your death with the goals of a supportive environment.

What is a Death Plan?

A Death Plan is a written plan for the procedures and atmosphere for your death and dying process, which has been agreed upon by you and your support team. It is not a contract; rather a guide for caregivers to follow. The idea of a Death Plan may be new to your doctor or other caregivers.

Although written Death Plans are a novel idea, they are really only another step in the improvement in cooperation between patients and physicians that has been improving in the last few years. For ages, people have discussed their preferences around death and dying, forming verbal agreements or even writing certain points in a patient's chart. Problems have often happened when a colleague substituted for the doctor and/or if the caregivers were not informed of the patient's wishes. Under such circumstances the patient would be left to restate and possibly renegotiate their options, or more likely, would simply bear their disappointment silently.

Often the most important aspects of a Death Plan are stating the things you do not want. Things that make you uncomfortable and things that will take away from your ability to have the quality of life and death you are seeking.

With a written Death Plan, one copy is placed in the medical chart with the patient's signature and the other is kept with the patient and support team members, to be referred to, in case of misunderstanding. One concern frequently expressed by doctors is that the Death Plan not be rigid, but that it reflects awareness that deaths sometimes do not go as expected. The Death Plan should not tie your support team's hands and prevent them from intervening if it is necessary for your welfare. Therefore, a Death Plan is based on the assumption that a death will go with some predictability; it also contains options which apply in cases when the death deviates from the expected course. Before finalizing your Death Plan, it is good to review it with your Health Care Agent, your primary health care provider, your Death Midwife and any other pertinent caregivers or support people. Once finalized, have it signed and consider having it notarized. Then be sure to give a copy to your primary care givers, Health Care Agent, loved ones as appropriate, and include with all copies of your Advanced Directives, POLST, DNR orders or wills.

When used in this way, the Death Plan enhances communication, takes the surprise out for both; patients caregivers, family and loved ones to ensure that all are working together as a team towards the same goals.

Getting Started

Most people find the idea of planning their deaths somewhat disturbing and/or overwhelming at first, not having realized how much choice they have. *"How am I supposed to know about these things? I'm not a doctor. I'm happy to let my doctor decide for me."* Is not as difficult as one may think to, make a Death Plan. Much of the necessary information is already possessed by patients; a knowledge of themselves, what makes them comfortable, which philosophy of care is most appealing to them, etc. Other information is available in books, Advanced Directives classes, medical facility tours, and a consultation with a Death Midwife.

Choosing Place of Death and Support Team

If possible, before you choose a place for your dying process, it is good to tour the local facilities where you may find yourself being taken care of. It's good to find out what level of care you might receive at these facilities and what is the common level of training or certification of the staff and caregivers. Another thing to keep in mind is what are the facility's rules or protocols around visitors and their duration and frequency of stay.

Communication

Start the conversation early. Tell your health care providers that you want to write a Death Plan with his/her help, and that you'd like it to become the guidelines for your care during your death and dying process. It's good to write questions down to talk with your caregivers about so you won't forget them. Be sure to bring a support team member with you to all medical appointments. It's very helpful to have your Health Care Agent meet and talk with your health care providers prior to your latter stages of dying so they can become familiar with each other.

Some caregivers are very uncomfortable with Death Plans and do not care for patients having such a strong part in their own dying process. If you run into a caregiver with a particularly strong reaction to your ideas or plans, you may want to consider choosing a different caregiver who can support your conscious decision making process for death and is more attuned to your wishes.

A flexible Death Plan is the best kind. It is a good idea to think about the options you desire in terms of priority. Which options are the most important to you? Which are the least? The language you choose in writing your death plan can have a profound effect on the medical staff, Death Midwife, funeral staff and other caregivers. Language which reflects an attitude of cooperation and flexibility on your part is greeted with more respectability. You may want to consider an opening statement like this: *"I realize that flexibility and a willingness to make changes in my plan may be necessary. Following are my preferred options for a predictable death."* Phrases like "would prefer", "if possible", "as long as I can" convey a cooperative spirit. Wording such as "no intervenious fluids", "no medications" etc., indicate rigidity and unwillingness to accept the possibility that these interventions may be useful in the right situation.

Being informed

Your Death Plan should consist of options which reflect your philosophy and attitude towards death. If you believe that a death is a normal, physiologic event in the life cycle of a living being, your choices will be along those lines of little or no medications, minimal intervention and more participation on your part and that of your support team. If on the other hand, you are worried about pain during death, or worried that something will go wrong unexpectedly, or feel that you may not have the ability to make decisions on your own care; your choices might be towards the use

of maximal pain relief, technological interventions and decision-making by medical personnel. These choices are complex and require knowledge as well as discussion with medical providers. You should learn about benefits and risks associated with each type of care. It is important to seek out caregivers in your area in advance who will be able to support you in the types of care and support you would like. It's good to interview different personnel to be sure you can make an educated choice.

Some interventions and care practices in effect today are there for provider comfort and not for patient comfort or ease. Many are still in place from a time when we kept death hidden away in a sterilized hospital room away from friends and loved ones. Many facilities have protocols they follow that have little to do with patient needs or wants. It's good to know in advance what these protocols or procedures might be in the hospitals, nursing homes, and assisted living facilities in your area. Otherwise you may find yourself swept away in a protocol that has nothing to do with your Death Plan.

The Unexpected

Everyone knows that Death has little to do with convenience or planning. It comes exactly when it chooses (most of the time) and we are in the position of finding our own path through a very unknown territory. It is good to consider the potential rougher more difficult course in the dying process. The more variation you have given thought to the more comprehensive and flexible your Death Plan will be. Be sure to have a place in your plan for the unexpected. If you are planning to die at home, be sure to include a section about what kind of care you want if you do end up being transferred to a hospital or other facility.

It's good to consider what support your support givers might need at the end of the process.

Personal Preferences

Your favorite music

Presence of partner relatives, friends, siblings

Absence of nonessential personnel (e.g. observers)

Assistance with death by clergy

A comfortable room with pleasing furnishings

Double bed with room for partner

Personal items for focal points (pictures, flowers, objects)

Translator, if necessary

Camera (photographer) taper recorder to record stories, thoughts, ideas.

Comfort items: toothbrush, lip balm, cold packs, heat packs, glasses, ice, food and drinks of choice, massage, warm socks and blankets.

Candles, scents (aromatherapy)

Creating sacred space

Notebook/journal for support team and guests

Dim lights, low noise, gentle handling of your body.

Religious personnel, ritual, ceremony