



Dying to Understand



ADVANCED DIRECTIVE

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Introduction

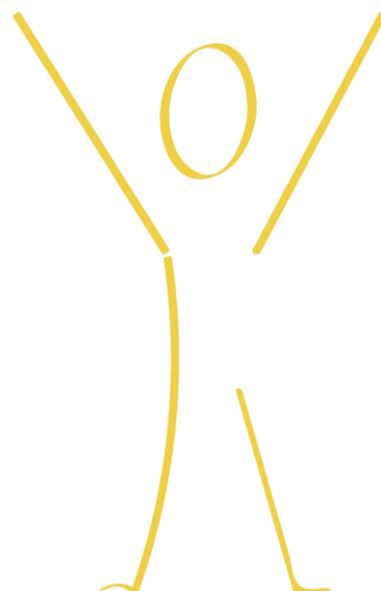
We generally believe that bad things happen to other people - we don't expect them to happen to us. But what happens when they do? Things can suddenly and quite unexpectedly go wrong. A possible outcome of things going wrong is that you will be critically ill and unable to make your wishes known regarding your medical care. In this type of event, an advanced directive can be invaluable.

What is an advanced directive?

Broadly speaking, an advanced directive is a statement or a set of instructions about the care you would expect to be offered if you were no longer competent or able to make decisions about your medical care. Other countries may use different terms for the same idea—tell us now, what we need to know in the future if you won't be able to tell us then.

Advanced directives are not fool proof, but they do make it possible for you to make your wishes clear. This can be helpful in guiding your family about what decisions to make about your medical care (in collaboration with your medical team) in the event you are incapacitated.

The problem with having an advanced directive is that it is an assumption about how you wish to be treated in case of an unknown future event. You can never be sure that you actually *would* react that way at the given time. An advanced directive cannot be an instruction that is contrary to law or to sound medical practice, it has to be reasonable and within the framework of medical care.



Advanced directive scenarios

Typically, the below are some of the scenarios to consider if you choose to develop your advanced directive.

Being in a coma with minimal chance of recovery

Would you want to be intubated (fitted with a breathing tube) and ventilated (dependent on breathing apparatus) when there is no chance of your recovery? Once you are ventilated, the decision to stop ventilation is difficult to make, not only for the friends and family, but also for medical staff. It is easier to allow someone to die than to cause someone to die. The worst outcome is a protracted court case to determine the final outcome of ventilation or coma. Consider the sad case of Terry Schiavo.

Resuscitation

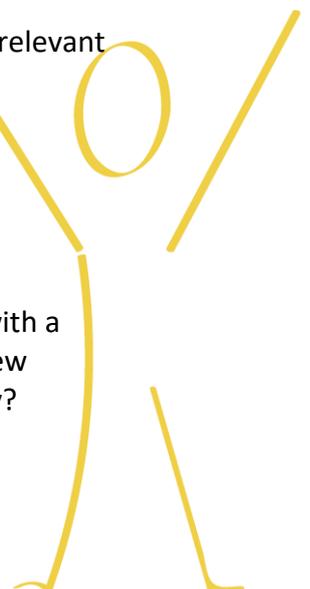
We all want our life to be saved, but what if the life you end up with is a struggle and of little or poor quality? Being resuscitated is no guarantee that things will turn out well for you. The condition that caused you to need resuscitation may permanently debilitate you and resuscitation often results in trauma associated with the event.

A poor prognosis, such as advanced incurable cancer, might influence some people's decision about whether or not they wish to be resuscitated in the event they stop breathing. It is a question that you need to ask if you are planning to have an advanced directive.

Australian hospitals require a N.F.R (Not-For-Resuscitation) decision at admission. They are difficult conversations with a lot of what if's. The reason for this tricky discussion is so you are informed about the implications of a full medical resuscitation, the risks such as permanent brain injury, and whether this is relevant in the medical setting. For advanced incurable illness, resuscitation is not recommended.

Feeding

Food and nutrition are a basic right, but in the setting of advanced illness with a dismal prognosis, should feeding tubes be introduced to prolong life by a few weeks? What extent of feeding should occur if there is no hope of recovery?



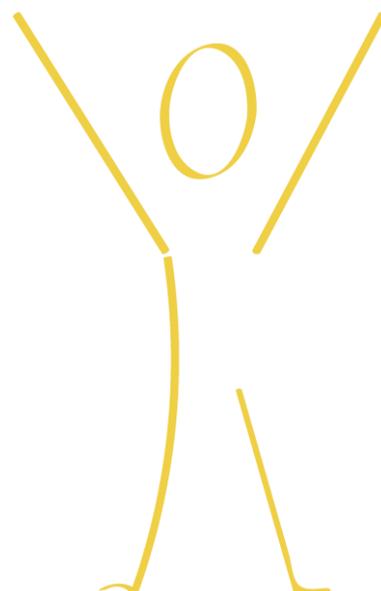
Kidney failure

As the kidneys fail and the blood chemistry changes, the brain lapses into a coma and death is relatively peaceful over a few days. In the setting of advanced incurable illness with a dismal prognosis, is it a good or bad idea to have renal dialysis and delay the inevitable?

Organ donation

Have you given organ donation any thought? If you are suffering from a slowly advancing illness the reality is that it might not be possible to donate all your organs. However, some kinds of donations, such as corneal donations, might still be possible. A decision as to whether you want to donate your organs at death to give others the gift of life is something you can address in an advanced directive. This will require other documentation and it is worth seeking advice from DonateLife.

<https://donatelife.gov.au/register-donor-today>



Developing an advanced directive

Developing an advanced directive takes time and much thought. You need to have an ongoing discussion about the future possible health scenarios, ensuring that you include family members, any proxies, and your medical team in these discussions. It is vitally important to seek advice if you are planning to have an advanced directive.

You need to have a clear understanding of the risks and benefits of choosing one intervention over another. This analysis of the risks and benefits needs to take into account your quality of life in certain scenarios and the costs associated with protracted medical intervention.

You need to regularly review your advanced directive, and again, make sure all relevant parties are included in the discussion. In addition, ensure all interested parties have copies of it. Please discuss this with your doctor and/or your palliative care specialists.

The most common mistake made about advanced directives is to think they are not necessary because you are in such good health today. The ice is very thin on this resonating issue because medical disasters can occur unexpectedly. All it takes is something like a motor vehicle accident to permanently change your situation. Be proactive and get an advanced directive done this week.

There are no perfect solutions. An advanced directive is a bit of a guess about your medical wishes somewhere in the future, but that is much better than being clueless at that time. Everyone needs an advanced directive, I highly recommend getting one done sooner rather than later.

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