

ADVANCED DIRECTIVES

INTRODUCTION

There are a multitude of terms being used, often interchangeably, to describe Advanced Directives. Terms like Advanced Statements; Living Wills; Proxy Decision Makers; Durable Power of Attorney; Healthcare Advocates; Welfare Power of Attorney; Advanced Healthcare Directives; Continuing Power of Attorney; Medical Directives; Advanced Decisions; Healthcare Proxies; Biological Wills and Advanced Healthcare Directives. These are just some of the terms used in English speaking countries.

All of these terms are being used to talk about Advanced Directives, so what exactly is meant by the term 'Advanced Directive'.

It is simply a way of telling others what type of care you would like to have if you become unable to make decisions for yourself or unable to communicate your decisions to others.

This is not something that is unique to the ALS/MND community but it does have considerable relevance to it.

So why bother with such a thing?

The World Medical Association's Declaration of Lisbon on the Rights of the Patient states that "if the patient is unconscious or cannot communicate and if a legally entitled representative is not available but a medical intervention is urgently needed, consent of the patient may be presumed unless it is obvious and beyond any reasonable doubt on the basis of the patient's previous firm expression or conviction that he/she would refuse consent to the intervention in that situation".

ADVANTAGES OF ADVANCED DIRECTIVES

There are a number of advantages to having an advanced directive. Firstly it informs others of your wishes. It gives you the opportunity to ensure that everyone is aware of your feelings on medical interventions and future care requirements, thus trying to ensure that you will not have any treatment that you do not want if at any time you cannot tell the doctor your wishes. It can take some of the pressure off family and friends because they are fully aware of your wishes and any decisions that they may have to make is done from an informed position. Similarly, knowing what you want in advance will help the doctors make the right decision in difficult circumstances. It also provides a legitimate excuse to talk about death and end of life issues which otherwise you may never get around to discussing. Most importantly, particularly with ALS/MND, it allows you to stay in control.

Generally Advanced directives are used to refuse particular treatments and interventions such as if a treatment has unwanted side effects or does not improve quality of life but they can also be used to express the persons wish to be considered for any appropriate new drugs that may be developed etc.

LIMITATIONS OF ADVANCED DIRECTIVES

They cannot be used to request anything which is illegal;

They cannot be used to request euthanasia

They cannot be used to demand particular or inappropriate treatments or interventions;

Generally they cannot be used to refuse basic care such as hygiene and food and drink by mouth.

TYPES OF ADVANCED DIRECTIVES

Most of the popular terms currently being used can be grouped into three main types of advanced directives; Living Will type; Healthcare proxy/attorney type and Medical directives.

Living Will

The Living Will type is usually a written plan that states your wishes regarding future health care, whether in general terms or relating only to specific situations and circumstances. In some countries this would include the term advanced statements where your wishes are not written down but you have expressed your feelings verbally. Generally, whether written or verbal, the statement you have made needs to have been witnessed by someone else. Whether this type of advanced directive is recognised legally within your country or not, it does serve the purpose of giving a clear intention as to your wishes and as such can assist the doctors in their decision making about your care.

Healthcare Proxy/Attorney

This Advanced directive is where you appoint someone else to be responsible for expressing your wishes and making decisions on your future care. Because you are handing over a large degree of your power and control to someone else, this form of advanced directive, which would include the terms Durable Power of Attorney, Welfare Power of Attorney, Health Care proxies etc usually require some form of legal proceedings to be followed, with the form being notarised and lodged with the appropriate authorities.

Medical Directive

The third type of Advanced Directive is that of the Medical Directive, such as DNR or Do Not Resuscitate orders, which will be recorded on your medical records.

GENERAL POINTS

An advanced directive can only reflect a person's wishes at the time at which it was created, and many circumstances, including improvements in medical science and available treatments can change as time passes. For this reason people are encouraged to ensure that they review their directives regularly and to destroy any previous versions.

When initially creating an advanced directive, you should discuss the issues with your family and your doctor and keep these discussions ongoing. The more people that know about your wishes the better so that they can speak up for you when the time arises.

In most cases advanced directives do not need to involve complicated documents. In many countries a hand written document stating your wishes is enough. In some countries and states there are some specific forms that need to be completed in order for the directive to be recognised legally.

The legal standing and enforcement of advanced directives varies from country to country and state to state, so you need to check the situation within your own country. Because of this, no definitive statement on the terms and legal standing of Advanced Directives can be issued here.