Writing an Advance Decision

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When you are ill, you can usually make your *own* decisions based on discussing treatment options with your health care team. But if you develop a severe mental illness or suffer serious brain damage (e.g. from a car accident or stroke) the medical team will make the decisions for you. Such decisions may take little account of what **you** would have wanted in the situation.

In 2007 a new Mental Capacity Act came into force. The Act is designed to protect people who 'lack capacity' (i.e. are judged unable to make decisions for themselves). It states that any treatment should take into account what an individual might have wanted. The Act also allows anyone to make legally binding 'Advance Decisions'- statements setting out any refusal of treatments in given situations. You do NOT need a lawyer for this.

My sister Polly championed the rights that are enshrined in the Mental Capacity Act. Indeed, she helped others to write Advance Decisions. Ironically, however, she never got around to writing one herself. She suffered very severe brain injuries in a car accident on 30 March 2009 and has been kept alive artificially since then in a coma, vegetative state and minimally conscious state. Because she lacks capacity, she is unable now make her own decisions about treatment. We were shocked to discover that 'next of kin' have no automatic legal rights to make decisions about her care: all decisions are the responsibility of the clinical team treating her.

Please consider taking action **now** to ensure that **your** health care choices will be respected. You could write an Advance Decision. Alternatively (or in addition) you can appoint someone to represent you by setting up a Lasting Power of Attorney now. Visit the sites below for step-by-step, guides of what to do.

Compassion in Dying: www.compassionindying.org.uk Info about advance decisions; sample advance decision forms

Court of Protection: 'Making Arrangements for Yourself'
http://www.publicguardian.gov.uk/arrangements/arrangements.htm about appointing someone to represent you

This information (and more) is available on www.welovepolly.org/ad.htm along with links to the associated websites.

I am attaching a copy of my own Advance Decision. This is almost identical to the one I have signed and placed on my medical records: as you can see, I have removed all names, dates etc. (and a few personal observations relating to Polly). The decisions I have made might offer a useful starting point for thinking about the decisions *you* might want to make. Note however that these are my own personal decisions and would not be right for everyone - in particular I have refused a broad range of treatments, some of which you might prefer to accept. Please feel free to get in touch if you have any questions or observations: celia@welovepolly.org (NB I have been asked about how my AD might impact on organ donation and am currently checking this out & will post information soon.)

ADVANCE DECISION

To Health Care Professionals: This document should be used in the event of loss of capacity of YOUR NAME HERE. To treat YOUR NAME HERE contrary to the clearly expressed advance decision is likely to be civil trespass and/or a criminal assault.

I, YOUR NAME HERE, of YOUR ADDRESS HERE, have the capacity to make the decisions set out in this document. I have carefully considered how I wish to be treated if, in the future, I lose the capacity to consent to medical treatment, or the ability effectively to communicate my refusal or consent.

Date of birth: YOUR DOB HERE
NHS number: YOUR NHS NUMBER HERE

Review dates **(Leave this blank now, but it is advisable to revisit your AD every year or so to check you are still happy with it, as your circumstances may change.)**
I have reviewed my advance decision and reaffirm that the wishes stated in this document are my own.

Signed : ____________ Dated ___________________

Signed : ____________ Dated ___________________

Signed : ____________ Dated ___________________

REFUSAL OF TREATMENT
To avoid any doubt, and unless stated to the contrary below, I confirm that the following refusals of treatment are to apply even if my life is at risk or may be shortened by virtue of such refusal.

In the event that I am no longer competent to make decisions on my own behalf, these are the decisions I have made in advance. If I lack mental capacity and also have an advanced disseminated malignant disease, advanced degenerative disease of the nervous system (including MS, motor neurone disease and Parkinson's disease), moderate or severe brain damage due to injury, stroke, disease or other cause, senile or pre-senile dementia, severe difficulty in breathing (dyspnoea) that cannot be cured, or any other condition of comparable gravity, I refuse any medical intervention aimed at prolonging or sustaining my life.

In the event of any of the above conditions applying, I refuse all life-prolonging treatments, including but not limited to: cardio-pulmonary resuscitation, artificial ventilation, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial hydration and nutrition. I also refuse all life-sustaining treatments including but not limited to therapies whose purpose is to maintain or replace a vital bodily function and without which death would most likely occur as a result of organ or system failure.

I recognise that I am unlikely specifically to have included all possible current or future treatments for whatever health condition may lead to the applicability of this AD. Nonetheless I wish to refuse them. Furthermore I am unable to anticipate all possible circumstances under which this AD might become applicable but believe that any such circumstances would be extremely unlikely to alter my decision had I anticipated them. I am very anxious that new treatments or unpredictable circumstances might be used by my

healthcare team to argue that this AD is not applicable and not binding. I wish so far as I can to pre-empt any such arguments.

I also wish to refuse (if the grave conditions outlined above apply) the following treatments: surgery for bladder or bowel incontinence, investigation of episodes of sepsis, anticoagulant medication, and immunisation of any kind.

CONSENT TO TREATMENT

I do consent to any medical treatment to alleviate pain or distress (including any caused by lack of food or fluid) aimed at my comfort. I do consent to palliative treatment for incurable vomiting or feeling sick (but not for treating any underlying condition causing these symptoms). I maintain this request even in the event that it may shorten my life.

HEALTH CARE PROXY

My health care proxy is GIVE NAME AND RELATIONSHIP TO YOU HERE – this is someone you trust to advise on your best interests – their advice is not legally binding and they cannot over-ride the decisions made in the rest of this document:
GIVE THEIR ADDRESS, PHONE NUMBER & EMAIL HERE
I have full confidence in XXX's ability to make decisions in my best interests.

I have deposited this advance decision with:

1. My health care proxy: NAME, ADDRESS, PHONE NUMBER, EMAIL
2. My GP: NAME, ADDRESS, PHONE NUMBER
3. Anyone else you want…

VALUE STATEMENT AND ADDITIONAL DIRECTION

(PERSONALISE AS REQUIRED - NB THIS PART IS *NOT* LEGALLY BINDING)
Independence, autonomy, personal privacy and full intellectual competence are very important to me. I do not wish to be kept alive if my independence, autonomy or mental competence were seriously compromised. I do not wish to be kept alive if I am unable to live outside of institutional care.

I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask my medical attendants and any person consulted by them to bear this statement in mind when considering what my intentions would be in any uncertain situation. **If there is any reasonable doubt as to what I would choose in a particular situation, then I request that the decision should be made not to keep me alive since it would be less distressing to me to be 'wrongly' allowed to die than to be 'wrongly' kept alive.**

I strongly prefer to be allowed to die at home - or, if this is impracticable for any reason, in a hospice. I refuse permission for transfer to hospital under circumstances where it is apparent that my death is imminent. I do not wish to be rushed to hospital in my final hours.

I have had extensive (ongoing) discussions with XXX (INSERT NAME OF YOUR HEALTH CARE PROXY HERE). I ask for XXX to be consulted about all aspects of my care and for her/his views to be taken as seriously as if they were my own. In the event of any disagreements or disputes between XXX and other members of my family (or friends), I wish XXX's views to prevail. Please do not allow delays to be occasioned by attempts to achieve a consensus: XXX knows me and my values better than anyone else and I have absolute confidence in her/his ability to represent my views.

Everything contained in this advance decision is true and correct at the time of writing.

Signed: ______________________ Date: __________________
YOUR NAME

[Your witnesses can sign before taking this to your GP, or you might wish to revise the statement after discussing it with your GP]

Witness 1 (Witness can NOT be partner/family member)

Witness Name : _________________________

Address: __________________________

I witness that this advance decision was signed or acknowledged in my presence.

Signature: _________________ Dated: _________________

Witness 2 (Witness can NOT be partner/family member)

Witness Name : _________________________

Address: __________________________

I witness that this advance decision was signed or acknowledged in my presence.

Signature: _________________ Dated: _________________

GP DETAILS
My GP is: GIVE NAME, ADDRESS, AND PHONE NUMBER HERE

GP's DECLARATION
I have discussed the matters contained in this document with YOUR NAME HERE. I am satisfied that s/he has the capacity to make the decisions in this document and that s/he understands the consequences of these decisions.

Name: YOUR DOCTOR'S NAME HERE

Signature: __________________ Date: ____________________