

Advance Decisions, Advance Statements, and Policies around Assisted Dying in England + Wales

Professor Celia Kitinger & Professor Sue Wilkinson
University of York
Advance Decisions Assistance

MDMD Meeting
Conway Hall London
29 Oct 2016

Professor Celia Kitinger

- Chartered Psychologist
- Co-Director of the Coma & Disorders of Consciousness Research Centre
- British Psychological Society Working Party on End of Life Care
- Government-funded research on Advance Decisions (including commissioned public policy report on “Improving Understanding and Uptake of Advance Decisions in Wales”)

working with Professor Sue Wilkinson – Psychologist, founder of Advance Decisions Assistance

Advance Decisions Assistance (ADA): helps people write
ADs+ education, training & research

<http://ADassistance.org.uk>



Our activities

- Helped 300+ people write Advance Decisions; reviewed many more ADs
- Training for GPs, intensivists, clinical psychologists, ambulance staff, hospice & care home staff, advocates
- Talks & public education events: e.g. to faith groups, right-to-die organisations, hospice & care homes; U3A, Before-I-Die Festivals
- Public policy contributions: e.g. PPIW, Law Commission consultation; BPS End-of-life Care WP
- Collaborations with Compassion in Dying; CDoC etc.

Correcting media misrepresentations

A spate of these in Oct/Nov 2016

THE  TIMES

JOIN NOW LOG IN

End-of-life cases must go to court

Frances Gibb, Legal Editor

October 26 2016, 12:01am, The Times



Under a living will, people can instruct doctors to withdraw medical treatment. GETTY IMAGES

People's instructions in "living wills" for doctors to end their lives should be brought before the courts for approval before treatment is withdrawn, judges have said.

They advise that no one who is in a coma or an unconscious state should be allowed to die without the case first being considered by a court.

Tor Butler-Cole Retweeted @AGoodDeath · 1h
... some misleading coverage of Advance Decisions (Living Wills) ... this explanation compassionindying.org.uk/advance-decisi...

Sue Wilkinson @sue_wilkinson · Oct 26
What a mess! Valid & applicable Advance Decisions do NOT need to go to Court
AGoodDeath.mydecisions.org.uk ADassistance.org.uk

Celia Kitzinger @KitzingerCelia
Misleading article - inaccurate factual reporting @thetimes This article is legal nonsense + needs correcting

Celia Kitzinger @KitzingerCelia
Helpful corrections to legal errors @thetimes + @DailyMailUK on #EOL rights @AGoodDeath compassionindying.org.uk/advance-decisi...

See this article correcting misrepresentations by leading barrister: click [here](#)

STRUCTURE

1. What is an Advance Decision?
2. The right to refuse treatment
3. Why an Advance (Values) Statement is important too
4. Making your Advance Decision effective
5. Can I use my Advance Decision (or Statement) to request an assisted death?
6. Developing policy concerning Advance Decisions
+ assisted dying

1. WHAT IS AN ADVANCE DECISION?

What is an Advance Decision?

- A legally-binding way of making decisions about future health care, in the event of losing the mental capacity to do so at the time
- Specifically, refusing (life-prolonging) medical treatments
- Mental Capacity Act 2005 (England & Wales)

‘Advance Directive’ in Scotland (& USA);
old term = ‘living will’

- Advance Decisions are **individual** to you. You decide what treatments you want to refuse and under what conditions – and that's what you use an advance decision to communicate
- You might only want to refuse treatment to keep you alive in PVS; or if you have a known condition (MS, Parkinson's, MND, dementia) you might make specific refusals related to your diagnosis + prognosis.
- Three examples....

Advance Decision refusing treatments in case of profound disabilities only

“I refuse all medical treatments aimed at prolonging or artificially sustaining my life (including - but not limited to - clinically-assisted nutrition and hydration) if:

- (a) I am persistently unconscious and have been so for at least 4 weeks; &
- (b) There is little prospect of **recovery** to a quality of life that I would consider worthwhile (see ‘values statement’ below) in the opinion of two appropriately qualified doctors.

I maintain this request even if my life is shortened as a result.”

Valid if signed, witnessed & has ‘magic sentence’: “I maintain this request even if my life is shortened as a result”

Applicable in circumstances specified

Advance Decision refusing treatments with known medical condition

AD to apply

“in the event that my disease progresses to a stage where I am unable to communicate my needs and lose the ability to have any control over my decisions of my care and management. I fully understand the implication of the advance decision, and appreciate the consequences and it would put my life at risk. I consent to have relevant treatment before and after NIV removal to prevent me from becoming distressed or experiencing pain. However, apart from the above, I would not wish to have any life prolonging treatment, including my PEG feed”.
(Extract)

XB & YB [2012] EWHC 1390 (Fam)

67 year old man with motor neurone disease

Tracheotomy – used communication board

Requested removal of ventilation 2 weeks after loss of ability to communicate

Advance Decision from ‘frail’ older person with no life-limiting illnesses: total refusal of treatment – hoping to hasten death

- “I refuse ALL medical treatment or procedures/interventions aimed at prolonging or artificially sustaining my life. I maintain this refusal of treatment in the hope that my life will be shortened as a result.”

(Extract from
Avril Henry’s
Advance Decision)



Advance Decisions are NOT the same as:

- DNR/DNACPR (Do Not Resuscitate/Do Not Attempt Cardio-Pulmonary Resuscitation) form
- Treatment Escalation Plan or ResPECT (Recommended Summary Plan for End of Life Care and Treatment)
- Advance Statement
- Advance Care Plan (20 Questions, My Little Pony Book.....etc)
- Lasting Power of Attorney [or Enduring Power of Attorney]
- Overseas documents (e.g. from LifeCircle and Dignitas) which may be labelled 'Advance Directive' or 'Power of Attorney'

ONLY Advance Decisions (and Powers of Attorney) drawn up according to laws of England & Wales are legally binding

Requirements for writing an AD

- Over 18 (England & Wales)
- With mental capacity to make these decisions (can include people with depression/mental illness/early-stage dementia/ some learning disabilities etc) – with appropriate support if needed
- Don't need a solicitor
- Can simply write out what you want to refuse + 'magic sentence', sign it and get it witnessed
- Or you can use a template: e.g. Compassion in Dying's online tool 'My Decisions' (see <https://mydecisions.org.uk>)
- Or you can use ADA's 'case histories' as a starting point (see <http://ADassistance.org.uk>)

Excellent tool for making ADs

<https://mydecisions.org.uk>



This free and simple website will help you do an important thing:

PLANNING AHEAD FOR **YOUR** FUTURE TREATMENT AND CARE



IT FELT EMPOWERING.
LIKE I HAD TAKEN CONTROL. IT ALLOWED
ME TO GET ON WITH LIVING WELL NOW.

You might not like to think about it but there might come a time when you're too unwell to tell those caring for you - like your family or a doctor - what you do and don't want to happen.

WE KNOW THAT PLANNING FOR
THE FUTURE ISN'T ALWAYS
EASY AND YOU MIGHT NOT
KNOW WHERE TO START...

THIS **WEBSITE** WILL TAKE YOU
THROUGH SOME QUESTIONS AND
SCENARIOS TO GET YOU THINKING ABOUT
WHAT'S IMPORTANT TO YOU.

At the end it will generate a legal document about your wishes for treatment and care for you to print, sign, witness and share.

What might you want to refuse? (Examples)

- **‘Emergency’ treatments**, e.g. cardio-pulmonary resuscitation (CPR); ventilator
- **Long-term treatments you don’t currently need** and would not want to start after losing capacity. You can refuse any medical treatments you want, including ventilator, tube-feeding, physiotherapy designed to clear your lungs, blood transfusion
- **Treatments you are currently using but would not want to continue after losing capacity**, e.g. any of the long-term treatments above, but also (for example) insulin if you have Type 1 diabetes; dialysis; implantable cardioverter defibrillator (ICD) ; medication for coronary heart disease; medication for hypertension; anticoagulants

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2. THE RIGHT TO REFUSE TREATMENT

Refusal rights depend on your mental capacity

- 1. If you have 'mental capacity' to make the decision you have an absolute right to refuse treatment
- 2. If you do NOT have 'mental capacity to make the decision then (absent an Advance Decision) the decision is made by others in your 'best interests'

1. If you have “mental capacity” ...

- **You** are the decision-maker.
- You have the legal right to refuse treatment for any reason or for no reason at all
- You have the legal right to make “unwise decisions”
- You can refuse treatment that would have kept you alive (so that you die)
- You have the legal right to kill yourself (although anyone who assists you commits a criminal offence)

What is 'mental capacity'?

- Defined in Mental Capacity Act 2005
- The ability to understand, retain and weigh information relevant to the decision
- Decision-specific
- Can be lost permanently (e.g. vegetative state, advanced dementia) or temporarily (e.g. unconscious - fainting or anaesthetised)
- Can be fluctuating (e.g. dementia; mental illnesses)

- Mental capacity to make decisions should be PRESUMED
- It is possible to have mental capacity for serious medical decisions even with: schizophrenia; alcoholism; anorexia; other mental illnesses; early stages of dementia
- You are entitled to support to make your own decision if capacity is borderline/fluctuating
- If your capacity may return in future and the decision can wait, medics should wait until you can make the decision for yourself.

Court support for the right to refuse treatment (with capacity)

- Ms B [2002] – 43 year old paralyzed from neck down; refused ventilator. Court established absolute right of patient with capacity to refuse treatment, irrespective of consequences of decision - click [here](#)
- Ms C [2015] - Woman who refused treatment after losing her 'sparkle': she was entitled to make her own decision even if 'unwise' and 'immoral': click [here](#)

BPS Consultation Exercise (Kitzinger): Why are EOL psychologists involved?

- Capacity assessment – either for treatment refusal or for assisted dying
- Helping P think through decision, assess costs + benefits
- Working with multi-disciplinary team (MDT) to improve quality of life/palliative care
- Managing relationship between P and MDT and distress/anger of MDT

Psychologists' Views + Experience

- Psychologists working in EOL care have very little experience with Advance Decisions
- More than two-thirds had been referred patients re. assisted dying for capacity assessments

“Dignitas is an issue that comes up fairly frequently in our palliative care team. It’s something I’ve been asked about maybe 4 or 5 times in the last couple of years – to support the team when a patient has been thinking of well, it’s not always as formal as Dignitas, but ending their own life. We currently have a couple who are both poorly and want to die together....” (Clinical Psychologist, Palliative Care)

- “Working with older adults I’m very aware that the generational cohort has changed over the last ten years. The previous generation was the World War II generation and they had learnt to put up, shut up, and get on with it. Older adults now are people who grew up in a very different kind of society and they have expectations about their end of life care and they want to meet them – and if they can’t then they want to do something about it.” (Principal Psychologist, Acute Care)

- ‘Certainly I see people who want it to be over, but they’re not actively suicidal. It’s more like, “I know I’m dying and it’s getting a bit drawn out”. I hear things like, “You wouldn’t treat a dog like this”. [...] When people are coming to end of life and make a comment about Dignitas that’s often their way of drawing attention to the fact that the current situation they’re in is intolerable for some reason.’ (Principal Clinical Psychologist)
- ‘People say “this life is intolerable” and adding “so I’m pursuing the idea of Dignitas” is a way of conveying how badly they are feeling. If you shut it down right away that would be unhelpful.’ (Consultant Clinical Psychologist, Acute Care and Hospice Care)

- “I don’t feel that expressing an interest in Dignitas is the same as sharing a plan or intent to commit suicide because, rather than being from a place of fear and hopelessness for the future, for some at least, it’s more about the kind of death they have and having some sense of control in a point in their life when they feel very powerless.” (Clinical Psychologist, Oncology and Palliative Care)
- “I do feel there’s a significant difference between suicide and assisted dying. It’s not that she’s not wanting to live. It’s that she’s not wanting the death she’s going to have with this illness.” (Clinical Psychologist, Hospice)

- ‘I didn’t find the safeguarding stuff very helpful in my work with him. He didn’t fit comfortably into the role of a “vulnerable adult”. I felt he had full capacity to reflect on his choices and understand what was on offer, and he’d weighed it and decided “not now but later” and that was his informed choice.’
(Clinical Psychologist in Oncology and Palliative Care)


- For the medical team, the most painful thing about [a patient who planned to go to Dignitas] was that they were devastated that after all their input and support he still wanted to go. They felt that they'd done their best and he was telling them it wasn't good enough. It was experienced as a failure on *their* part. They were saying, "but we will look after him; we will be there for him; we will do our very best". We had to talk about how it wasn't a failure of the palliative medical team – it was just that some people want the control to be with them and certainty is very important to them. (Clinical Psychologist, Palliative Care)

2. If you do NOT have 'mental capacity'

- to make decision at time it needs to be made
- Unless you have an Advance Decision a 'best interests' decision will be made by someone else
- Default: doctor/ clinical team (**not** family or 'next of kin')
- Can be someone you choose (Lasting Power of Attorney **for Health and Welfare**)

LPA (Health & Welfare)



EU Referendum On Thursday 23 June there will be a vote on the UK's membership of the European Union. [More information](#) 

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1. Overview

A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf.

Advance Decision gives you the right to refuse treatment PROSPECTIVELY - i.e. in advance of losing mental capacity

Retains personal autonomy + personal decision-making

(Not for everyone – no crystal ball; may prefer someone else to make contemporaneous decision for you)

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3. WHY AN ADVANCE (VALUES) STATEMENT IS IMPORTANT TOO

Advance (Values) Statement

- Can include your personal definition of **recovery**
- Provides an opportunity to express your values and beliefs – to say what you value about life, what you fear, what matters to you as a person
- Can be used to explain why you have made the decisions you have
- Opportunity to be **persuasive** to professionals: doctors, lawyers
- Opportunity to acknowledge that others may not share your views (maybe thank them!): e.g. “I offer the healthcare team my heartfelt thanks for respecting my sincerely held wishes as expressed here”

Some personal definitions of “recovery”

“Recovery to a quality of life that I would consider worthwhile”

- “By ‘a quality of life that I would consider worthwhile’ I mean a return to normal independent living.”
- “The quality of life I would want is being able to recognize my family and friends and to take pleasure from their company.”

Example of Advance (Values)

Statement 1

“I don’t want to be left without what I call quality of life. I can’t imagine anything worse than not being able to do what I do now. I hate even being stuck indoors. I do the lunches, I do stroke club, I do befriending. I see a lot of people with disabilities and I could imagine living with a certain level of disability, but if I’d also lost capacity to make my own decisions, then I would be impaired in a way I wouldn’t want.”

Example of Advance (Values) Statement 2

“Independence, autonomy and intellectual competence and making my own choices are very important to me. I fear pain, confusion and powerlessness far more than I fear death. I do not wish those I love to become full-time carers if I cannot meet them with emotional and mental engagement and recognition. I would want them to go forward with their lives with joy.”

Example of Advance (Values)

Statement 3 – Avril Henry

“ My long, happy, productive life is more than ‘complete’. Aged 80, I now live alone in incurable, unbearable pain (which cannot be relieved by opiates which render me dangerously dopey and incapable) and with crippling and progressive disabilities. My registration for Assisted Dying at a Swiss cent has been in lengthy, difficult progress for more than 10 months. However, my death in UK is vastly preferable and would be welcome, enabling me to avoid:- ((continued))



Avril Henry: Advance (Values)

Statement **Contd.**

- further unavoidable physical deterioration, I can barely care for myself already
- a long, painful, difficult, very expensive journey ...
- Swiss cremation, of which I do not approve on ecological grounds.

Also, my Green Burial in my own orchard is all legally arranged and prepaid with my undertaker.”

(Extract)

Why being 'persuasive' matters

- Explaining your reasons and your views enables doctors to deliver patient-centered care (which most want to do) + reduces their fear about allowing death
- Saying 'please' + 'thank you' encourages compliance with the law – so does acknowledging their pain in not being allowed to deliver treatment
- If an AD is not legally binding or applicable to the situation you are in, your advance (values) statement is a very persuasive contribution to 'best interests' decisions about you.

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4. MAKING YOUR ADVANCE DECISION EFFECTIVE

Advice for making an AD effective (1)

- Ensure it is valid and likely to be applicable
- Consider relationship between AD and LPA (Health & Welfare), if you have both
- Ensure that you are refusing what you want to refuse – many ADs do not in fact reflect person's wishes (e.g. “permanent vegetative state” - means up to 1 year and excludes MCS)
- If you change your mind, change or update your AD
- If you change your circumstances (e.g. pregnancy, religious affiliation), update your AD

Advice for making an AD effective (2)

- Discuss with GP and/or medical specialists
- If there is any possible doubt about your capacity at the point that you are making your AD - e.g. early dementia, mental illness, depression - get a statement of 'capacity' (ideally a formal capacity assessment)
- Review (possibly update) it every year – more often if your medical circumstances change
- NOTE: Pre-2005 'living wills' may well no longer be valid and are definitely not 'persuasive'

Advice for making an AD effective (3): Ensure that people know about it

No central register so...

- Get it on your GP notes and lodged with specialists at hospital etc.
- Give copies to family, friends, neighbours
- Carry it with you; keep in car
- [MedicAlert](#) or [S.O.S. Talisman jewellery](#); [Lions 'message in a bottle' scheme](#)
- Revisit it before elective surgery – give it to hospital
- If you are DNACPR ensure you are on the local Ambulance Service EOL register (or equivalent)

Internationally recognised symbol to alert medics to your health conditions



Emergency phone number that's available 24/7

Tel. +44 (0)1908 776111

Type 2 Diabetes
Allergic:
Penicillin
Organ Donor
GB137623

Your conditions will be engraved here

Your individual number that allows access to your full medical records, as well as next-of-kin emergency contact details



Tattoos don't work: not legally binding



Variant ways of expressing your Advance (Values) Statement

- You can make a video/audio recording rather than a written statement (maybe in conversation)
- Show through the way you live your life what your values are (e.g. faith communities, political activism)

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**5. CAN I USE MY ADVANCE DECISION
(OR STATEMENT) TO REQUEST AN
ASSISTED DEATH?**

NO.

No.

- An assisted death is not lawful in UK
- Even if it were, an Advance Decision (MCA 2005) is about **refusing treatment**
- You cannot use Advance Decision to **demand** specific treatments
- You cannot use an Advance Decision to compel doctors actively to **give a treatment** (e.g. a lethal injection)...
- ... to someone who cannot **at the time request** it (this goes well beyond proposed assisted dying legislation)

However....

- You can indicate in your **Advance (Values) Statement** that this is something you might want....
- “I would like to record my wish for an assisted death if this is lawful at the point that my Advance Decision comes into effect. I would rather die swiftly from treatment that is given to end my life than die more slowly from withdrawal of life-sustaining treatments.”

- You can also indicate that you are willing (and eager) to accept sedation and pain relief at the end of life – even at the risk of shortening your life, e.g. “I want to receive whatever quantity of drugs will keep me free from pain and distress even if death is hastened.”

And you can state that your AD covers suicide attempts

- “This Advance Decision to Refuse Treatment is intended to apply even if the condition that makes it relevant is a suicide attempt on my part. To be clear, I specifically refuse the treatments specified if I lack capacity to make my own decisions following an attempt to end my own life.”

Pros and Cons of indicating preference for an assisted death (etc) in AD/AS

- Makes values and beliefs very clear
- May alleviate concerns about 'double effect' + help health care professionals (HCPs) to feel protected from law
- May cause concern/alarm among HCPs about how their actions may be interpreted (esp. in relation to sedation/pain relief)
- May leaves HCPs feeling implicated in suicide/assisted suicide (they need support!)

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6. DEVELOPING POLICY CONCERNING ADVANCE DECISIONS + ASSISTED DYING

Concerns about Advance Decisions (**lawful** means of hastening death)

- May discourage quality palliative care &/or rehabilitation
- Uncertainties of diagnosis and prognosis
- May not reflect P's wishes at time Advance Decision was written (e.g. lack of mental capacity, coercion, illegitimate concerns about being a 'burden')
- May not reflect P's wishes at time of implementation (changing mind with experience)
- ADs and suicide
- Role of doctors/Hippocratic Oath/ conscientious objection

Concerns about Assisted Dying (unlawful means of hastening death)

- May discourage quality palliative care &/or rehabilitation
- Uncertainties of diagnosis and prognosis (six months)
- May not reflect P's wishes (e.g. lack of mental capacity, coercion, illegitimate concerns about being a 'burden')
- May not reflect P's wishes at time of implementation (changing mind with experience)
- ADs and suicide
- Role of doctors/Hippocratic Oath/ conscientious objection

Protecting the 'vulnerable': Key issue in defeat of Assisted Dying Bill

Sept 2015

- Research by Age UK has shown that about 500,000 elderly people are abused each year in the UK and there is a very real danger that if this Bill were to pass, many of these people could be put at further risk. As the Care Not Killing campaign has said: “The right to die can so easily become the duty to die.”
(Caroline Spelman)

From the Commons Assisted Dying Debate September 2015

- the elderly and infirm will be pressured. (John Pugh, opposing)
- people will feel under pressure to take their own life if they feel they are becoming a burden to their family or society. (Barbara Keeley, opposing)
- It is naive to believe that we can prevent an elderly, expensive or asset-rich relative being encouraged, coerced or emotionally blackmailed into taking their own life. (Lyn Brown, opposing)
- People will feel pressurised into ending their life early so as not to be a financial or care burden on their loved ones. (Jim Shannon, opposing)

From the Commons Assisted Dying Debate September 2015

- It was noted earlier that people feeling that they are a burden when making a decision to end their lives prematurely is only one factor, but that is one reason too many. The answer is not to make it easier to kill people; we need societal change to prevent people from feeling a burden in their elderly years. (Liam Fox, opposing)

From the Commons Assisted Dying Debate September 2015

- On coercion, I do not doubt that perhaps there are evil relatives out there who will seek to coerce their elderly mother. However, that elderly mother will then have to persuade two doctors and a judge that this is her choice. I do not think that someone who is vulnerable enough to be coerced by their evil relatives could persuade a judge that they are taking such action from their own choice. (Sarah Champion, supporting)

Serious Medical Decisions + Vulnerable Adults

- Decades of experience in health and social care
- Right of adults with capacity to make 'unwise choices' v. protecting people who lack capacity (Mental Capacity Act 2005) and the 'vulnerable' (Care Act 2014)

Who is 'vulnerable'

- Definition of “vulnerable adult” from the 1997 Consultation “Who Decides?” issued by the Lord Chancellor’s Department, is a person: **“Who is or may be in need of community care services by reason of disability, age or illness; and is or may be unable to take care of unable to protect him or herself against significant harm or exploitation.”**

Care Act 2014

- Gives social workers + others access to ‘vulnerable adults’ defined as people who are or may be....
- “under constraint” or “subject to coercion or undue influence” + therefore unable to exercise free choice. or “giving or expressing a real and genuine consent”
- Idea is not to overrule wishes of adult with capacity but to ensure that adult is making decisions freely

Using + developing existing expertise on mental capacity + vulnerability

- It's not up to individuals to have to prove capacity or autonomous decision-making – burden is on others to prove we DON'T have it
- And to facilitate it where possible
- ... including 'unwise decision-making'

Safeguards

Psychologists, independent mental capacity advocates, social workers, judges etc have experience of:

- assessing decisional capacity
- assessing volition v coercion
- facilitating decision-making
- balancing 'risk' and 'harm' associated with maximising right to autonomous decision-making.

Let's build on what already exists to ensure safeguarding!

QUESTIONS AND DISCUSSION