Advance Decisions to Refuse Treatment: Explaining Low Uptake in England & Wales

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Structure of talk

1. The national context: ADRTs in England & Wales

2. Factors influencing low uptake in England & Wales

3. Some suggestions for change

What is an ADRT in England & Wales?

“Living will”

Mental Capacity Act (2005) Ss. 24-26

“Advance decision” means **a decision** made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—

(a) **at a later time and in such circumstances as he may specify,** a specified treatment is proposed to be carried out or continued by a person providing health care for him, and

(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, **the specified treatment is not to be carried out or continued.** (24(1))

Format

* No standard form
* Does not require a solicitor
* If it refuses LSTs, it must be in writing & signed
* Signature must be witnessed (no restrictions on who can witness)
* Must also include statement (to the effect that) “I maintain this refusal even if my life is shortened/at risk”
* Does not require a declaration of mental capacity

Key distinctive features

* Covers treatment *refusal* only (not treatment requests)
* Does *not* include possibility of nominating an alternative decision-maker (proxy, surrogate, substitute) – this requires separate legal provision (Lasting Power of Attorney for Health & Welfare)
* Next-of-kin have no automatic decision-making rights (and cannot overrule an ADRT)
* Absent an ADRT, decisions must be in patient's 'best interests' (not substituted judgement)
* No provision for assisted dying

Status

* An ADRT is legally-binding (not just advisory) – advance refusal treated as equivalent to contemporaneous refusal

* Important in context where the default situation is to give/continue medical treatment, and where treatment is free at the point of delivery (NHS)

* Also in context where ‘over-treatment’ is a contemporary issue (e.g. BMJ ‘Too much medicine’ campaign; concerns about non-beneficial treatment at end-of-life)

Uptake of ADRTs in England & Wales

* Only 4% of people in England & Wales have an ADRT or LPA (YouGov polls 2013 & 2014 for *Compasssion in Dying.* Latest report (2015) available at: https://compassionindying.org.uk/library/plan-well-die-well/)

* Compares with 10-20% in other Western European countries (Evans et al, 2012) & 20-30% in USA (Hickman et al, 2005)

* Current uptake: strongly-motivated individuals who know what they want (my work with *Compassion in Dying* & *Advance Decisions Assistance*)

Explaining low uptake: 7 key factors

1. Psychological barriers
2. Lack of public knowledge
3. Confusion with other types of end-of-life provision
4. Ignorance of health & care professionals
5. Lack of support for making ADRTs
6. Misleading media representations
7. Lack of belief that that an ADRT will ‘work’

1. Psychological barriers

* Reluctance to talk about death: avoidance & procrastination widely-documented (e.g. Hirschman et al, 2008; Sachs et al, 1992); also: superstition, 'too soon'/'not ill' (Pollack et al, 2010; van Wijmen et al, 2010)

* Reasons for *not* wanting an ADRT:
  - - religious or ideological objections: leave it to god/fate (Douglas & Brown, 2002; Schickedanz et al, 2009)
  - - happy to let someone else decide: doctors/proxy (Volker & Wu, 2011)
  - - don't want to make decisions now for future incapacitated self (prioritise 'experiential' over 'critical' interests: Dworkin's (1994) 'happy dementia patient')

ADRTs not for everyone – but particularly useful for:

People who want to refuse specific medical treatments:

- e.g. blood products (Jehovah's Witnesses)
- e.g. CPR (e.g. frail elderly)

People who want to avoid specific medical conditions:

- e.g. a prolonged disorder of consciousness:
  - 82% of people would not want to be kept alive in a PVS – yet up to 16,000 are (YouGov, 2013; PostNote 489, 2015)
- e.g. advanced dementia
  - condition which most-commonly prompts an ADRT (Schiff et al, 2000; also Albers et al, 2011 in Netherlands)

People who especially value autonomy & independence at end-of-life:

- e.g. callers to *Compassion in Dying* helpline (Wilkinson, 2013); ADA clients

ADRT also alternative to appointing a proxy (LPA):

* When person has nobody they know or trust to make decisions on their behalf
* When person believes that family members would not respect their treatment-refusal wishes (e.g. ‘not ready to let me go’)
* When person wants to protect loved ones from ‘burden’ of involvement in medical decision-making on their behalf

[NB ADRT need not be an alternative – can have both ADRT & LPA]

Example of ‘simple’ ADRT (for disorders of consciousness 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 I am in a prolonged disorder of consciousness and have been so for at least 4 weeks.

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

Valid if signed, witnessed & has accompanying statement (to the effect of) “I maintain this refusal even if my life is shortened/at risk”

Applicable under circumstances specified

2. Lack of public knowledge

* No government promotion or public education in England & Wales

* People simply don't know that making an ADRT is a possibility

* Many people believe myth that next-of-kin have decision-making power (enough that 'they know what I want')

3. Confusion with other types of end-of-life provision

People may think they already have an ADRT (or equivalent) because:

* Advance Care Planning occurs across England & Wales
  - (typical tools: ‘Advance Statement/Wishes’, ’The Pony Book’)
* Have completed a DNACPR form (or TEP, or – more recently – a ReSPECT form)

NONE OF THESE IS LEGALLY-BINDING

Typical ACP tools

Advance Statement / Wishes

"What I would like to happen to me if I become unwell"

Guidelines for people over 18 wishing to make an ADVANCE STATEMENT or WISHES relating to their future Mental Health care.

Plymouth Community HEALTHCARE

NHS
Northern, Eastern and Western Devon Clinical Commissioning Group

NHS
Devon, Plymouth and Torbay

Planning for Your Future Care

Advance Care Planning

Preparing for the future

Assisting with practical arrangements

Enabling the right care to be given at the right time

Adapted from the Weston Hospicecare Advance Care Plan and National Preferred Priorities for Care Guidelines

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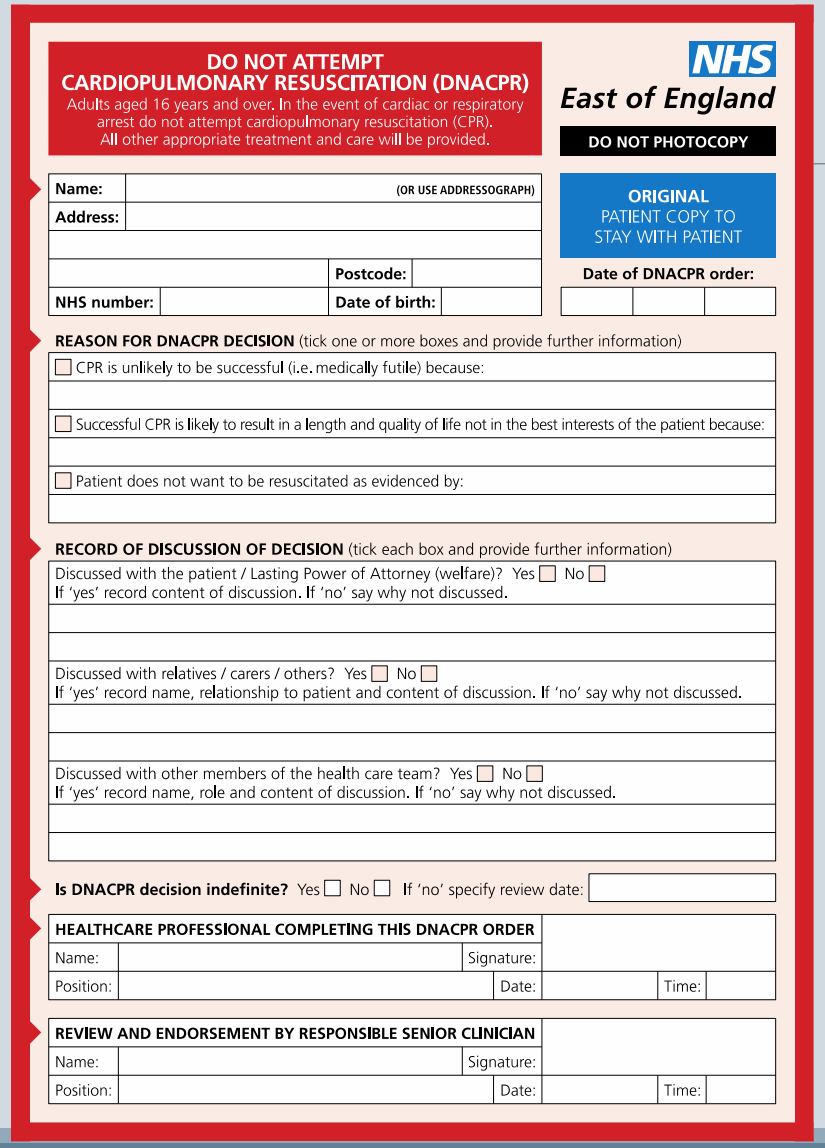
ADA
Advance Decisions Assistance

Other forms



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

Adults aged 16 years and over. In the event of cardiac or respiratory arrest do not attempt cardiopulmonary resuscitation (CPR). All other appropriate treatment and care will be provided.

NHS East of England

DO NOT PHOTOCOPY

Name:	(OR USE ADDRESSOGRAPH)
Address:	
Postcode:	
NHS number:	Date of birth:

ORIGINAL
PATIENT COPY TO STAY WITH PATIENT

Date of DNACPR order:

REASON FOR DNACPR DECISION (tick one or more boxes and provide further information)

- ☐ CPR is unlikely to be successful (i.e. medically futile) because:
- ☐ Successful CPR is likely to result in a length and quality of life not in the best interests of the patient because:
- ☐ Patient does not want to be resuscitated as evidenced by:

RECORD OF DISCUSSION OF DECISION (tick each box and provide further information)

Discussed with the patient / Lasting Power of Attorney (welfare)? Yes ☐ No ☐
If 'yes' record content of discussion. If 'no' say why not discussed.

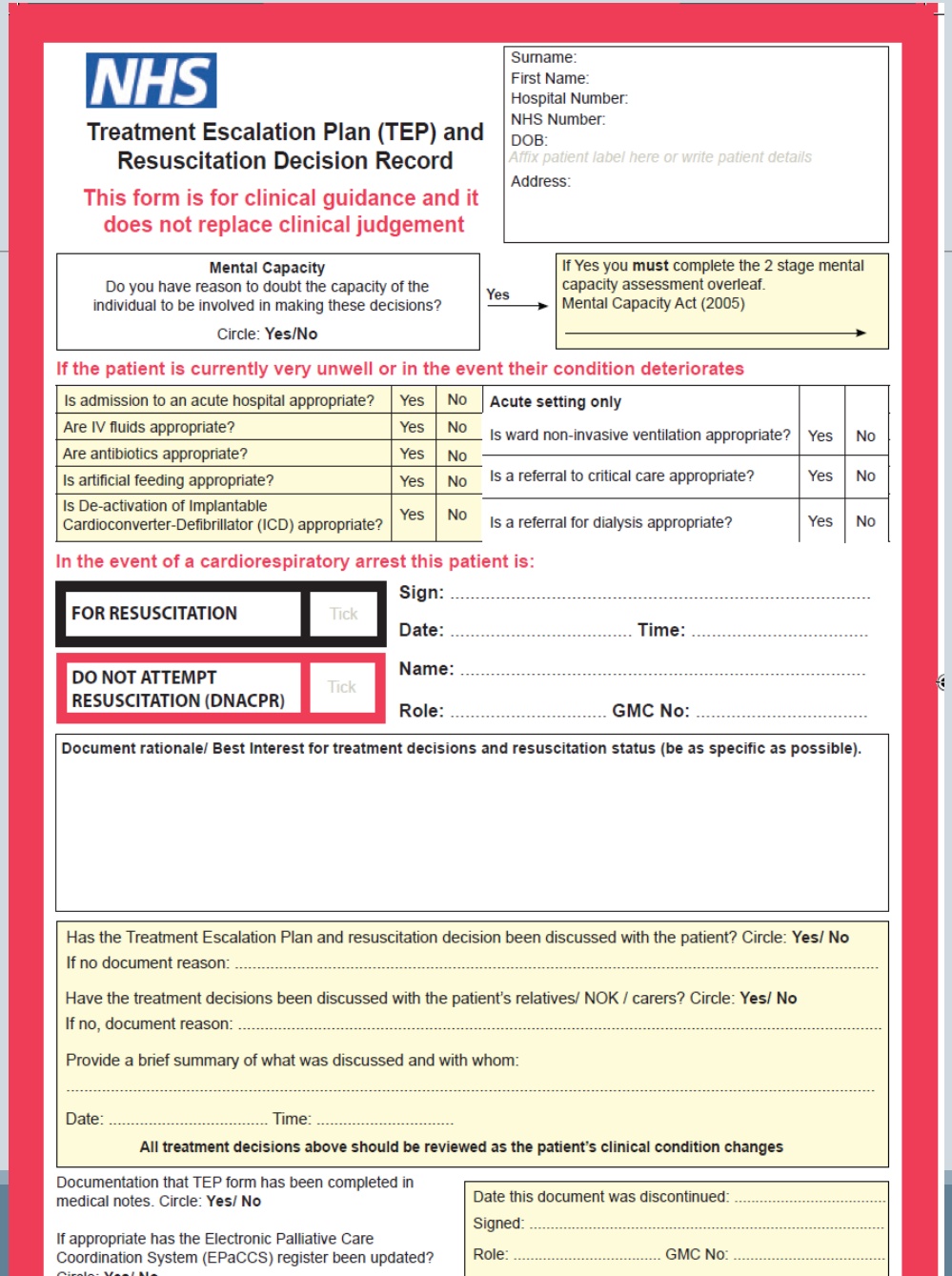
Discussed with relatives / carers / others? Yes ☐ No ☐
If 'yes' record name, relationship to patient and content of discussion. If 'no' say why not discussed.

Discussed with other members of the health care team? Yes ☐ No ☐
If 'yes' record name, role and content of discussion. If 'no' say why not discussed.

Is DNACPR decision indefinite? Yes ☐ No ☐ If 'no' specify review date:

HEALTHCARE PROFESSIONAL COMPLETING THIS DNACPR ORDER					
Name:		Signature:			
Position:		Date:		Time:	

REVIEW AND ENDORSEMENT BY RESPONSIBLE SENIOR CLINICIAN					
Name:		Signature:			
Position:		Date:		Time:	



NHS

Treatment Escalation Plan (TEP) and Resuscitation Decision Record

This form is for clinical guidance and it does not replace clinical judgement

Surname:
First Name:
Hospital Number:
NHS Number:
DOB:
Affix patient label here or write patient details
Address:

Mental Capacity
Do you have reason to doubt the capacity of the individual to be involved in making these decisions?
Circle: **Yes/No**

Yes → If Yes you **must** complete the 2 stage mental capacity assessment overleaf. Mental Capacity Act (2005)

If the patient is currently very unwell or in the event their condition deteriorates

Is admission to an acute hospital appropriate?	Yes	No	**Acute setting only**		
Are IV fluids appropriate?	Yes	No	Is ward non-invasive ventilation appropriate?	Yes	No
Are antibiotics appropriate?	Yes	No	Is a referral to critical care appropriate?	Yes	No
Is artificial feeding appropriate?	Yes	No	Is a referral for dialysis appropriate?	Yes	No
Is De-activation of Implantable Cardioconverter-Defibrillator (ICD) appropriate?	Yes	No			

In the event of a cardiorespiratory arrest this patient is:

FOR RESUSCITATION	Tick
DO NOT ATTEMPT RESUSCITATION (DNACPR)	Tick

Sign: .....
Date: ..... **Time:** .....
Name: .....
Role: ..... **GMC No:** .....

Document rationale/ Best Interest for treatment decisions and resuscitation status (be as specific as possible).

Has the Treatment Escalation Plan and resuscitation decision been discussed with the patient? Circle: **Yes/ No**
If no document reason: .....

Have the treatment decisions been discussed with the patient's relatives/ NOK / carers? Circle: **Yes/ No**
If no, document reason: .....

Provide a brief summary of what was discussed and with whom:
.....
Date: ..... Time: .....

All treatment decisions above should be reviewed as the patient's clinical condition changes

Documentation that TEP form has been completed in medical notes. Circle: **Yes/ No**

If appropriate has the Electronic Palliative Care Coordination System (EPaCCS) register been updated? Circle: **Yes/ No**

Date this document was discontinued: .....
Signed: .....
Role: ..... GMC No: .....

Advance Decisions Assistance

4. Ignorance of health & care professionals

* ADRTs not routinely included in training

* Knowledge of ADRTs of relevance to very wide range of health & care professionals

* ADA has trained:

  GPs, intensivists, clinical psychologists, ambulance services, nurses, hospice and care home staff, advocates …

Examples of misconceptions

Common misconceptions about scope of ADRTs & who can make them:

* Must refuse all treatments, or none (can't be selective)
* Can't refuse treatments unless terminally ill
* Can't make an ADRT if have mental health problems (esp. depression)

Common misconceptions about process of creating an ADRT & its subsequent validity:

* Must include a declaration of mental capacity
* Witnesses can't be relatives
* An ADRT is no longer valid after 1/2/5 ... years
* Health professionals don't need to comply with an ADRT if not in patient's best interests

5. Lack of support for making ADRTs

* Not integrated into the healthcare system (nobody's job)

* Occasionally done (badly) by solicitors

* Largely left to charities:
  - *Compassion in Dying*
  - *Advance Decisions Assistance*

Compassion in Dying - online tool: https://mydecisions.org.uk

MY DECISIONS

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

ADA - 'case studies' & 1-to-1s: http://adassistance.org.uk

Ann

Ann is a physically active 25-year-old, with no major health problems. She is concerned about what would happen if she suffered serious brain damage in a sporting accident.

Read Ann's Advance Decision

Make an Advance Decision similar to Ann's (Form A)

Brian

Brian is 50 and generally healthy, although he has Type 1 diabetes and is prone to bouts of depression. His parents both died after many years in long-term care homes and Brian wants to try and avoid this fate.

Read Brian's Advance Decision

Make an Advance Decision similar to Brian's (Form B)

Mental capacity statement similar to Brian's

Chris

Chris is in her late 60s and has a range of health problems which mean she experiences substantial pain on a daily basis. She is also a breast cancer survivor. She does not want life-prolonging treatments in the future. She has strong religious beliefs.

Read Chris's Advance Decision

Make an Advance Decision similar to Chris's (Form C)

Dawn

Dawn is 82 and has just been diagnosed with Alzheimer's disease. She also has heart and circulatory problems. She hopes to avoid years of decline and eventual death with late-stage dementia, preferring to die sooner. Her adult daughter is very distressed by this.

Read Dawn's Advance Decision

Make an Advance Decision similar to Dawn's (Form D)'

Mental capacity statement similar to Dawn's

Other key features

* Move away from ‘tick box’ forms
* Facilitated conversation about values, wishes, feelings & beliefs
* Raise ‘future self’ issues if appropriate
* Accompany ADRT with an ‘advance values statement’ (+ve feedback from heathcare providers)
* Attempt to ‘future proof’ (going well beyond law)

6. Misleading media representations

A recent example:

Mr. Justice Jonathan Baker's lecture at the University of Oxford, October 2016

COURTS AND TRIBUNALS JUDICIARY

A MATTER OF LIFE AND DEATH

Mr. Justice Baker

Oxford Shrieval Lecture 11th October 2016

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Don't obey orders in a living will, judge orders doctors: Ruling means patients in an unconscious state cannot die without the case going before a court

- **Judges have ordered that living wills must no longer be obeyed by doctors**
- **No one in a coma should be allowed to die without the case going to court**
- **The new rules set out by judges strike down the 2005 Mental Capacity Act**

By STEVE DOUGHTY, SOCIAL AFFAIRS CORRESPONDENT FOR THE DAILY MAIL
PUBLISHED: 23:07 BST, 24 October 2016 | **UPDATED:** 23:20 BST, 24 October 2016

Living wills – the documents by which desperately sick patients can give advance orders to doctors to end their lives – must no longer be obeyed by the medical profession, judges have ordered.

They have declared that no one who is in a coma or an unconscious state should be

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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.

Consequences

Anxious phone calls and emails from ADA clients – e.g.

“I wondered if what is said here [in Daily Mail] really does ‘strike down the Mental Capacity Act’? If this article is accurate … or has any sway it is a bad day for Advance Decisions.”

Correcting media misrepresentations: via Twitter

THE TIMES JOIN NOW LOG IN

End-of-life cases must go to court

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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
Compassion in Dying @AGoodDeath · 1h
There's been some misleading coverage of Advance Decisions
recently, please RT this explanation compassionindying.org.uk/advance
14 4

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
Misleading a
@thetimes This artic
correcting

Celia Kitzinger
@KitzingerCelia
Helpful corrections to legal errors @thetimes + @DailyMailUK
on #EOL rights @AGoodDeath
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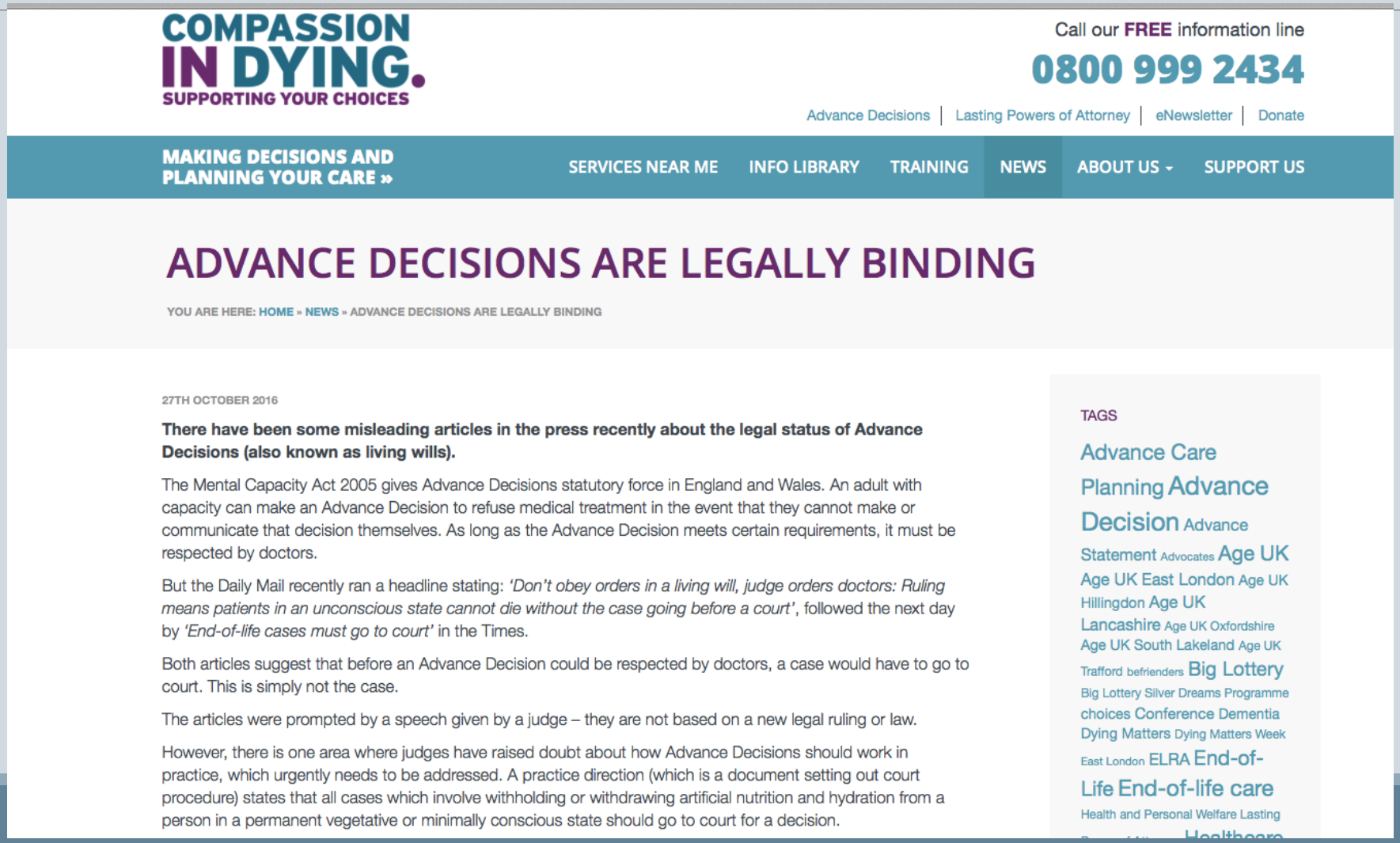
Correcting media misrepresentations: *Compassion in Dying* statement



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27TH OCTOBER 2016

There have been some misleading articles in the press recently about the legal status of Advance Decisions (also known as living wills).

The Mental Capacity Act 2005 gives Advance Decisions statutory force in England and Wales. An adult with capacity can make an Advance Decision to refuse medical treatment in the event that they cannot make or communicate that decision themselves. As long as the Advance Decision meets certain requirements, it must be respected by doctors.

But the Daily Mail recently ran a headline stating: *'Don't obey orders in a living will, judge orders doctors: Ruling means patients in an unconscious state cannot die without the case going before a court'*, followed the next day by *'End-of-life cases must go to court'* in the Times.

Both articles suggest that before an Advance Decision could be respected by doctors, a case would have to go to court. This is simply not the case.

The articles were prompted by a speech given by a judge – they are not based on a new legal ruling or law.

However, there is one area where judges have raised doubt about how Advance Decisions should work in practice, which urgently needs to be addressed. A practice direction (which is a document setting out court procedure) states that all cases which involve withholding or withdrawing artificial nutrition and hydration from a person in a permanent vegetative or minimally conscious state should go to court for a decision.

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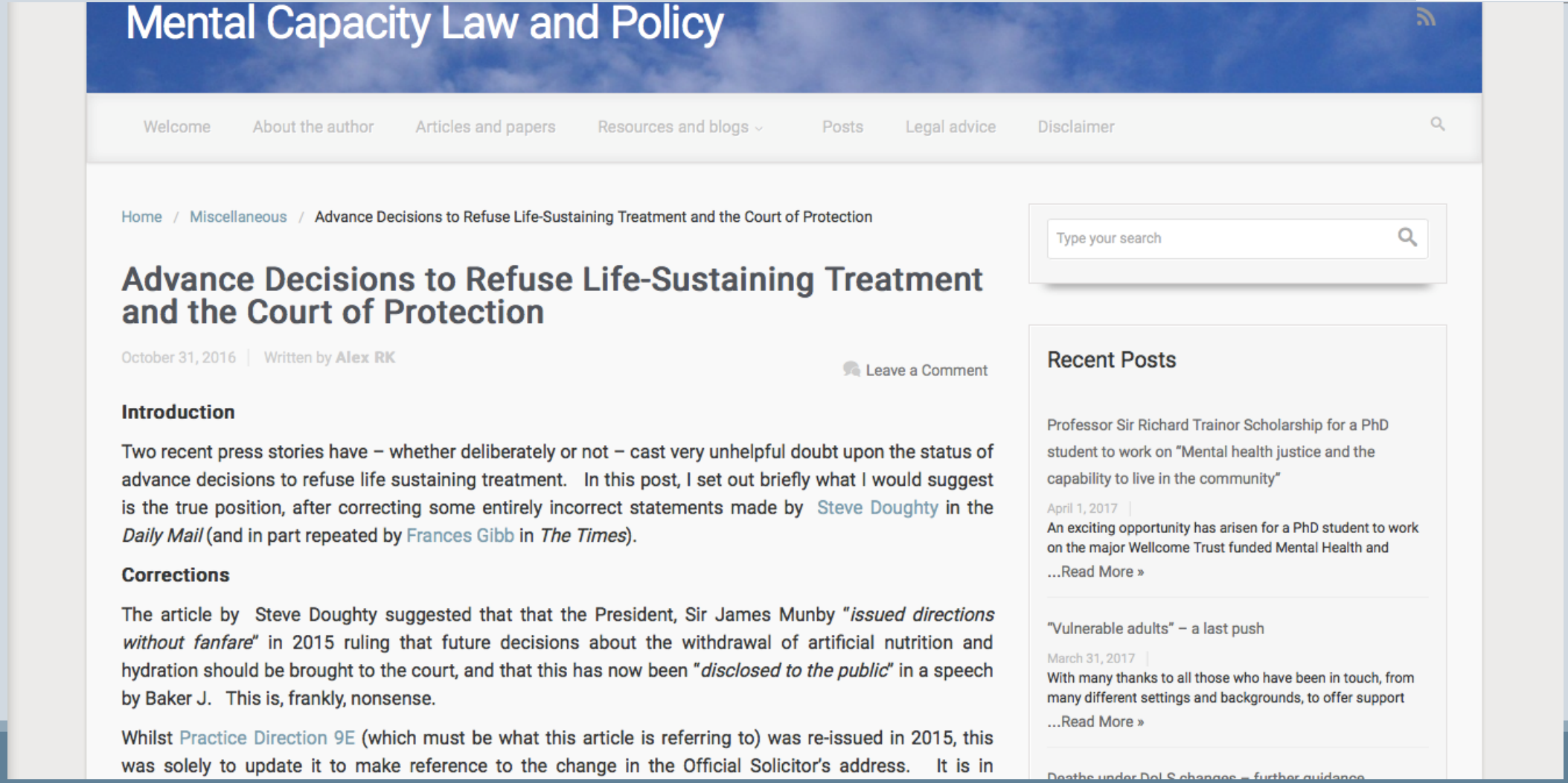
Correcting media misrepresentations: Alex Ruck Keene blog



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Advance Decisions to Refuse Life-Sustaining Treatment and the Court of Protection

October 31, 2016 | Written by **Alex RK**

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Introduction

Two recent press stories have – whether deliberately or not – cast very unhelpful doubt upon the status of advance decisions to refuse life sustaining treatment. In this post, I set out briefly what I would suggest is the true position, after correcting some entirely incorrect statements made by Steve Doughty in the *Daily Mail* (and in part repeated by Frances Gibb in *The Times*).

Corrections

The article by Steve Doughty suggested that that the President, Sir James Munby "*issued directions without fanfare*" in 2015 ruling that future decisions about the withdrawal of artificial nutrition and hydration should be brought to the court, and that this has now been "*disclosed to the public*" in a speech by Baker J. This is, frankly, nonsense.

Whilst Practice Direction 9E (which must be what this article is referring to) was re-issued in 2015, this was solely to update it to make reference to the change in the Official Solicitor's address. It is in

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7. Lack of belief that an ADRT will ‘work’

* Confusion between treatment-refusal & euthanasia (worry treatment-refusal might be illegal)

* Lack of trust that doctors will respect treatment-refusal (sometimes: ‘counter to Hippocratic Oath’)

* How will anyone know I’ve got one?
  - Get placed on medical records
  - Other ad hoc solutions (e.g. multiple copies; Lions’ ‘Message in a bottle’ scheme; MedicAlert & SOS jewellery)

Suggestions for change

* More public awareness-raising
* More – and systematic - professional training
* Focus on supporting those who *do* want ADRTs to write them (rather than a blanket attempt to increase uptake)
* Normalisation of ADRTs (so not just end-of-life)
* Create central registry for ADRTs
* Harmonise legal provision across UK - & across Europe (see *Council of Europe* Recommendation (2009) 11)
* Court judgements on assault following treatment-provision counter to an ADRT (preferably with damages)

Questions/discussion

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