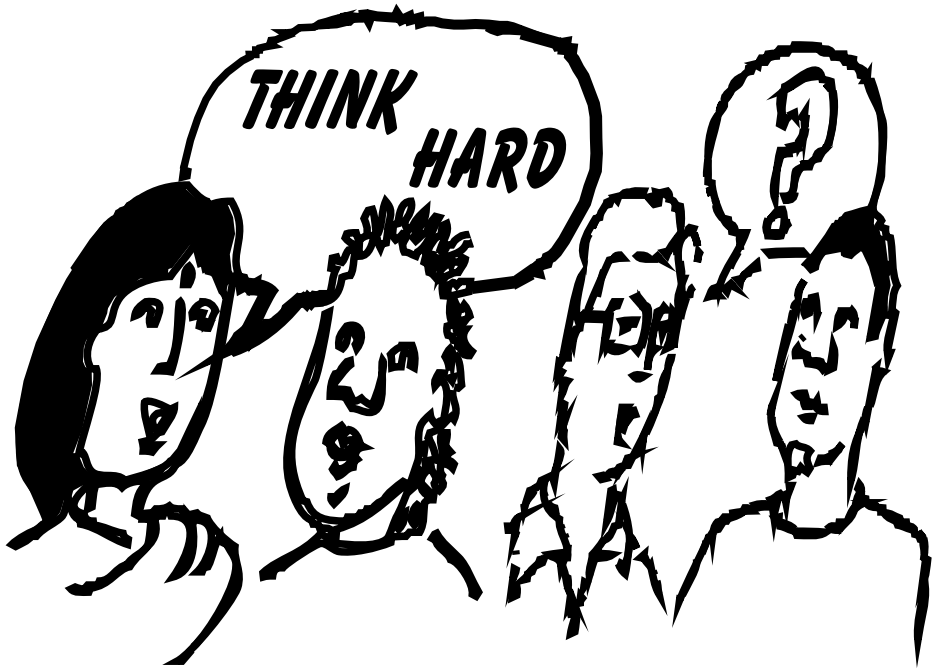

Thinking Clearly

The knowledge and experience of both the patient and clinician are very likely to differ so the only person‘s perception that should count is the patients. If the retail industry are happy to accept that ’the customer is always right‘ why can’t the care sector?

Regards,
Keith.
Admissions Tutor, Mental Health

Written by Mike Stone contact: mhsatstokelib@yahoo.co.uk

Thinking Clearly for End-of-Life Care at Home

ADRTs – Beliefs are Clearly Contradictory: this needs addressing

From Carol (Nurse and University Senior Lecturer):

To refuse CPR you cannot put sanctions on it. You cannot say I refuse CPR if the CPA is caused by a,b,c but will accept CPR if the CPA is caused by x,y,z. Usually we do not know what the cause of a CPA is so it would be difficult to do this and nor should it be done as we would not know where we were and who should have what.

The purpose of being able to refuse is to refuse the proposed treatment regardless of why the treatment is being offered. I do not understand how you can be against a treatment but only in certain circumstances.

The purpose of the MCA is to protect this refusal and stop didactic practices by people who will not be living with the repercussions.

Most solicitors I have spoken to over the years support the above i.e. you can refuse treatment but cannot have a multitude of situations where the refusal applies or not.

My comment: it is technically very difficult to write 'I refuse CPR unless 'X'' because the way 25(4)(b) is written, you can only apparently write on an ADRT 'I refuse CPR if 'X''.

Also, as Carol points out what you often know before a CPA is that the patient is very ill, and perhaps will die soon – you usually don't know exactly why the patient arrests, and knowing that someone is about to die (within a few days perhaps), is the rationale behind 'expected death' but isn't related directly to an ADRT (obviously almost everyone who wrote an ADRT to refuse CPR would be doing so either because they didn't 'like the look of the {loosely predicted} situation post-CPR', or else 'because my life is already intolerable': neither is necessarily connected to the cause of, or probability of, a CPA).

From Rob (Senior Paramedic):

I do agree about the stroke if a pt. is alive as

a clinical assessment including the FAS Test will take place (alongside other clinical assessment)- if a pt. is deceased this would be impossible to perform and therefore determining whether a pt. has died from a stroke, MI or GI bleed is practically impossible and therefore providing treatment or not based upon the identification of a stroke would not be possible

I think I've specifically asked Rob about this, three times – Rob is very clear, that **paramedics cannot work with** 'I refuse CPR if my CPA was caused by 'X'' where 'X' is a clinical cause.

From Claud (Consultant in Palliative Care Medicine):

Alan and Liz (Note: see my Thinking Clearly series no 1 onwards: they are an elderly couple who each wish to refuse CPR if their hearts have stopped beating for any reason) are not required to write in the circumstances, and such a decision will be respected in most situations. But to ensure that their wishes will be followed it is helpful if they can write the circumstances they envisage. Writing circumstances such as severe stroke, non-witnessed cardiac arrest, asystolic arrest etc would all make it much more certain that their advance decision will be followed, *and* that reversible causes will be treated.

My comment: if Rob states that paramedics cannot determine why someone is in CPA (and remember I'm mainly talking about EoL at home – the clinicians will not usually be there to observe things immediately before the arrest, at home {unlike in hospital}) how can Claud suggest 'Writing circumstances such as severe stroke' ?

PLUS MY SURVEY (I carried out 3 short surveys and one covers this 'circumstances on ADRTs' issue – they can be downloaded from http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=667&forumID=45): my survey proved beyond any reasonable doubt (and I only carried it out, because the problem was obvious from things such as CPR/VoD policies) that many or most clinicians believe that an ADRT **has to mention** 'circumstances' – oddly, those same clinicians do not seem to grasp that mentioning circumstances which would leave your refusal unaltered (such as 'whether or not my death could be certified was not a factor in my decision') to restrict the application of section 25(4)(c) {to stop clinicians from considering a circumstance that you yourself consider irrelevant} **does make sense**.

BUT it should be made very clear in clinically-authored ADRT/CPR guidance, so that patients can read it, whether it is sensible to write 'I refuse CPR if I seem to have had a stroke' on an ADRT.

The circumstances issue, could be resolved as I explained on my modified template ADRT last week (modified from the NE NHS ADRT form, by replacing its second and fourth pages) – but ‘the sense of ADRTs’ is as someone said in response to my survey:

Hi Mike,

I am a staff nurse and I work in a national health hospital, I also teach health and social care at the local college.

To me this statement is saying that you need to clarify exactly what it is you want and what the circumstances are that you have based your acceptance or refusal of treatment are.

If it just talks about refusal of treatment on gives no circumstances then it must be taken that the person does not want the treatment whatever the circumstances - but then how do we know that they were fully informed when making that decision if they have not identified any variances.

Linda

Slightly off-topic, another respondent included this – absolutely fundamental, in my view (my added bold):

The knowledge and experience of both the patient and clinician are very likely to differ **so the only person's perception that should count is the patients**. If the retail industry are happy to accept that 'the customer is always right' why can't the care sector?

Regards,
Keith.
Admissions Tutor, Mental Health

Advance Decisions are made by the patient and followed by other people – and this concept of patient self-determination, should take precedence over issues of ‘to whom the decision is expressed’: it should not matter to whom, clinician or layman, a patient explains ‘I am now refusing attempted resuscitation’.

And an ADRT is definitely an instruction – not ‘an expression of wishes’ !

I now show my modified version of the NE NHS ADRT form and then the original, with a linking explanation of my modifications for the ‘treatment’ section – my modification for page 4, is connected to my contention that for EoL at home, it should not matter whether a patient issues an instruction to a relative or to a clinician, and that the fundamental conceptual unit should be a ‘Core Care Team’ of live-with relatives, GP and regularly-attending district nurses (not this concept of MDT, because for EoL at home the communication chain is the principle confounding factor).

Advance decision to refuse treatment (ADRT)

v7 (Adapted from *Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Staff*, 2008)

NHS North East

My name	**If I became unconscious, these are distinguishing features that could identify me:**
Address	**Date of birth:** **NHS no (if known):** **Hospital no (if known):**
	Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in the future.

These are my decisions about my healthcare, **in the event that I have lost mental capacity and cannot consent to or refuse treatment.**

This advance decision replaces any previous decision I have made.

Advice to the carer reading this document: Please check

- **Please do not assume that I have lost mental capacity before any actions are taken.** I might need help and time to communicate when the time comes to need to make a decision.
- If I have lost mental capacity for a particular decision **check that my advance decision is valid, and applicable to the circumstances that exist at the time.**
- If the professionals are satisfied that this advance decision is valid and applicable this decision **becomes legally binding and must be followed, including checking that it is has not been varied or revoked by me either verbally or in writing since it was made.** Please share this information with people who are involved in my treatment and need to know about it.
- Please also check if I have made an advance statement about my preferences, wishes, beliefs, values and feeling that might be relevant to this advance decision.

This advance decision does not refuse the offer or provision of basic care, support and comfort

Note for the person making this advance decision:

If you are refusing a treatment that might be necessary to keep you alive, then you must indicate that you have accepted that the refusal could lead to your death. Clinicians are most used to this being expressed by seeing the phrase '***I am refusing this treatment even if my life is at risk as a result***' written on the advance decision.

It also helps clinicians, although it is not legally necessary, if you re-sign and have re-witnessed your advance decision at appropriate intervals - if you are not in care (if your advance decision is purely in anticipation of a sudden alteration in clinical circumstances - for example, if you are a racing driver and you have considered a serious future crash) then perhaps every 12 months might be 'appropriate'. During care, it would be wise to discuss re-signing with your clinical care team.

Note for the persons reading this advance decision:

Remember that both the treatment and any circumstances intended to restrict the refusal, can be written in the language of lay persons.

My name	

My advance decision(s) to refuse treatment:

I am refusing the treatment(s) I describe below:	If I leave the box below blank, or write 'in all circumstances', then it indicates that I am refusing the treatment in every situation I have been able to envisage. If I would accept the treatment in some circumstances, then I explain these exceptions in the box below.

My signature (or nominated person)	Date of signature

Witness:	
Witness signature	Name of witness
Address of witness	Telephone of witness Date

Person to be contacted to discuss my wishes:	
Name	Relationship
Address	Telephone

I have discussed this with (eg. name of healthcare professional)

Profession / Job title: Date:

Contact details:

I give permission for this document to be discussed with my relatives / carers

Yes **No** (please circle one)

My general practitioner is:

Name: Telephone:

Address:

Optional review

Comment Date/time:

Signature of person named on page 1: Witness signature:

The following are people I have personally discussed this/these advance decision(s) with. They have each signed below to confirm this, and I have signed to also confirm it.

If you are not a person on the list below - for example if you are a 999 paramedic - you are to assume that if there is any doubt about the meaning of my advance decision, **each** of the individuals who have signed below **understands my decision better than you do**.

Name and description (relative, GP, friend, nurse, etc) of the person I have explained my decision to.	The person's signature	My signature

Further information (optional)

I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my advance decision to refuse treatment, but the reader may find it useful, for example to inform any clinical assessment if it becomes necessary to decide what is in my best interests.

The previous template ADRT was a quick modification of the North East one, which now follows, made by replacing the second and fourth pages with my alternatives.

Clearly in a finalised version, there would be space for more than two treatments.

Also, page 3 might need modifications to fit more easily with my new page 4 – however, I would like some feedback about my page 4, before bothering to work out exactly what page 3 looks like.

The rationale or justification for my alterations, are simple:

I am refusing the treatment(s)
I describe below:

That directly matches section 25(4)(a) of the Mental Capacity Act.

If I leave the box below blank, or write 'in all circumstances',
then it indicates that I am refusing
the treatment in every situation I have been
able to envisage.

If I would accept the treatment in some circumstances,
then I explain these exceptions in the
box below.

These directly match section 25(4)(b) and 25(4)(c) of the Act:

(4) An advance decision is not applicable to the treatment in question if—

(a) that treatment is not the treatment specified in the advance decision,

(b) any circumstances specified in the advance decision are absent, or

(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

Currently ADRTs templates being published by clinicians use the less-than-satisfactory:

I wish to refuse the following specific treatments:

and

In these circumstances:

'I wish to refuse the following specific treatments' is okay, **but 'In these circumstances' isn't !**

Advance decision to refuse treatment (ADRT)

v7 (Adapted from *Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Staff*, 2008)

NHS North East

My name	If I became unconscious, these are distinguishing features that could identify me:
Address	Date of birth: NHS no (if known): Hospital no (if known):
	Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in the future.

These are my decisions about my healthcare, **in the event that I have lost mental capacity and cannot consent to or refuse treatment.**

This advance decision replaces any previous decision I have made.

Advice to the carer reading this document: Please check

- **Please do not assume that I have lost mental capacity before any actions are taken.** I might need help and time to communicate when the time comes to need to make a decision.
- If I have lost mental capacity for a particular decision **check that my advance decision is valid, and applicable to the circumstances that exist at the time.**
- If the professionals are satisfied that this advance decision is valid and applicable this decision **becomes legally binding and must be followed, including checking that it is has not been varied or revoked by me either verbally or in writing since it was made.** Please share this information with people who are involved in my treatment and need to know about it.
- Please also check if I have made an advance statement about my preferences, wishes, beliefs, values and feeling that might be relevant to this advance decision.

This advance decision does not refuse the offer or provision of basic care, support and comfort

Important note to the person making this advance decision:

If you wish to refuse a treatment that is (or may be) life-sustaining you must state in the boxes ***"I am refusing this treatment even if my life is at risk as a result."***
Any advance decision that states that you are refusing life-sustaining treatment **must be signed and witnessed on page 3.**

My name	

My advance decision to refuse treatment

I wish to refuse the following specific treatments:	**In these circumstances:**

My signature (or nominated person)	Date of signature

Witness:	
Witness signature	Name of witness
Address of witness	Telephone of witness Date

Person to be contacted to discuss my wishes:	
Name	Relationship
Address	Telephone

I have discussed this with (eg. name of healthcare professional)

Profession / Job title: Date:

Contact details:

I give permission for this document to be discussed with my relatives / carers

Yes **No** (please circle one)

My general practitioner is:

Name: Telephone:

Address:

Optional review

Comment Date/time:

Signature of person named on page 1:

Witness signature:

The following list identifies which people have a copy and have been told about this advance decision to refuse treatment (ADRT)

Name	Relationships	Telephone number

Further information (optional)
I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my advance decision to refuse treatment, but the reader may find it useful, for example to inform any clinical assessment if it becomes necessary to decide what is in my best interests.