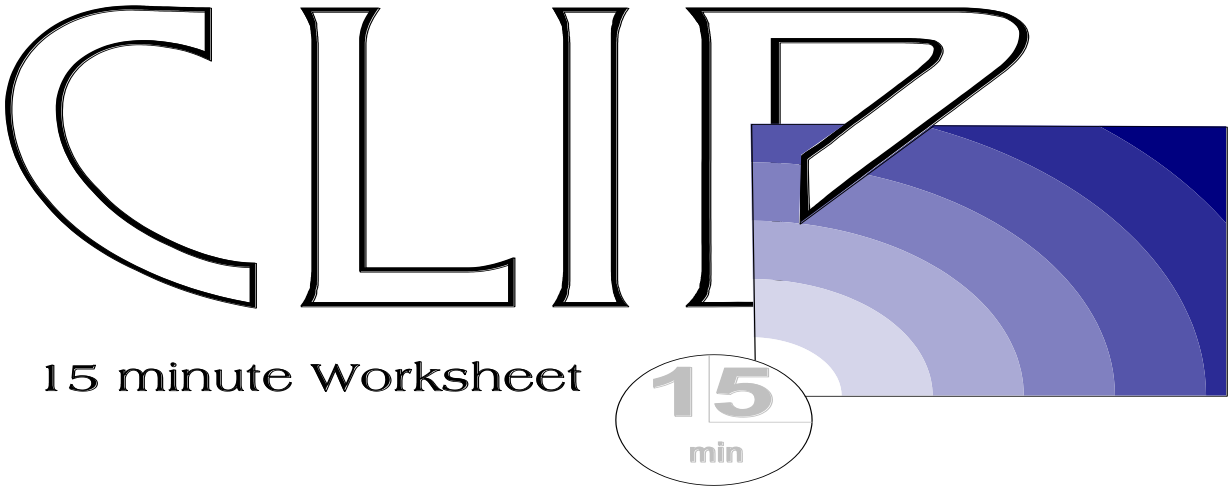

Planning care in advance

6: Advance Decisions to Refuse Treatment (ADRTs)

Intermediate level

Produced by
St. Oswald's Hospice
Regent Avenue
Gosforth
Newcastle-upon-Tyne
NE3 1EE

Tel: 0191 285 0063
Fax: 0191 284 8004

This version written and edited by:

Claud Regnard Honorary consultant in Palliative Care Medicine at St. Oswald's Hospice

Tricia Wilson Social Worker St. Oswald's Hospice

Aim of this worksheet

To review the issues around making decision in advance to refuse treatment.

How to use this worksheet

- You can work through this worksheet by yourself, or with a tutor.
- Read the case study below, and then turn to the Work page overleaf.
- Work any way you want. You can start with the exercises on the Work page using your own knowledge. The answers are on the Information page - this is not cheating since you learn as you find the information. Alternatively you may prefer to start by reading the Information page before moving to the exercises on the Work page.
- This CLiP worksheet should take about 15 minutes to complete, but will take longer if you are working with colleagues or in a group. If anything is unclear, discuss it with a colleague.
- If you think any information is wrong or out of date let us know.
- Take this learning into your workplace using the activity on the back page.

Case study

Bill is a 54 year old man with epilepsy who developed weight loss and intermittent diarrhoea. Investigations showed a carcinoma of the colon with liver metastases. A bowel obstruction was treated surgically by forming a colostomy. He had a difficult time with a prolonged hospital stay, including a few days in intensive care. He is now at home, and making clear that he does not want further treatment. He wants to make sure his wishes are followed.

v15

INFORMATION PAGE: Advance Decisions to Refuse Treatment (ADRTs)

What is legal?

The terms *Living Will* and *Advance Directive* no longer have meaning in law in England and Wales. The terms are still widely used and at the very least they can be considered as Advance Statements (see below). If an Advance Directive was written in the right way, it could count as an ADRT (see below) if it fulfils the requirements of the Mental Capacity Act (see below).

An *Advance Statement* is a statement of a patient's wishes, preferences, beliefs and values. It is not a legal document, but must be taken into account as part of the best interests process of the Mental Capacity Act (MCA).

An *Advance Decision to Refuse Treatment (ADRT)* is the only one of these options which can be legally binding. It can be verbal, but if it refuses life-sustaining treatment it must be written, signed, witnessed and contain the phrase explain the treatment should be withheld *'..even if my life is at risk."*

A *DNACPR* and a ReSPECT document are advisory documents only since clinical judgement should take priority.

Advance Care Planning is a process of ongoing dialogue about a patient's future care. It may lead to an Advance Statement and/or an ADRT. A care plan is an advisory document only.

True or False answers

1. F Treatments can only be refused under the MCA. A patient can express wishes and preferences in an Advance Statement, but carers are not bound by this.

2. F An ADRT can only be made by a patient while they have capacity to make that decision.

3. T An ADRT is inactive while a patient retains capacity since their decision overrides any decision made in the past. However, when the patient loses capacity the ADRT becomes active and now represents the patient's decision- it has the same authority as if patients themselves were making the decision now.

4. F An ADRT can be verbal, but for a refusal of life-sustaining treatment it must be written and signed by the patient. The MCA does not prescribe any particular format, but an excellent example exists (see resources).

5. F An ADRT can be invalid or inapplicable in some circumstances (see below).

6. T An ADRT that is valid and applicable must be followed, regardless of the opinion of the carers.

7. F The patient has full control over who sees the ADRT. Most patients will want it distributed, but patients must be asked. For example, patients may not want it to be seen by a partner or family, so a patient may ask for the ADRT to be kept in their clinical records elsewhere.

Validity and applicability of an ADRT

An ADRT is invalid if any of the following apply:

- the person withdrew the decision while they still had capacity to do so
- the person drew up a later ADRT which now takes precedence
- after making the advance decision, the person made a Personal Welfare Lasting Power of Attorney (also known as a Health & welfare LPA) giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision
- the person has done something that clearly goes against the advance decision which suggests that they have changed their mind

An ADRT is not applicable if any of the following apply:

- the proposed treatment is not the treatment specified in the advance decision
- the circumstances are different from those that may have been set out in the advance decision
- there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision
- the patient has been detained under the Mental Health Act and requires emergency psychiatric treatment

Giving advice on an ADRT

Bill's ADRT could run into problems at the end of life for two reasons:

1. Bill has epilepsy and as he approaches his last days he may be swallowing very little and would have to stop his anticonvulsants. This risks him having a seizure which needs an anticonvulsant.
2. He may be troubled with nausea or vomiting which needs an antiemetic, or agitation which may need a sedative. All these can be treated, but the ADRT only allows for analgesics which would either be ineffective or make some problems worse. This can cause conflicts between carers, partner and family.

Fortunately there is a solution. If any of these problems arise it is reasonable to assume that Bill would have allowed treatment, had he realised that they were a risk and had he known that their treatment would not prolong his life. Therefore the ADRT is not applicable for a seizure, vomiting or agitation, allowing treatment to go ahead. However, the ADRT will still be valid and applicable for other treatments such as refusing CPR or admission to intensive care.

This example demonstrates the importance of having the right person to advise the patient when making an ADRT.

WORK PAGE: Advance Decisions to Refuse Treatment (ADRTs)

Choose

Which of the following can be legally binding?

Living will	Advance statement	Advance directive
ADRT	DNACPR (Do Not Attempt CPR) ReSPECT document	Advance care plan

True or false

1. Under the MCA, Bill can refuse or demand treatments	True	False
2. Bill's ADRT can be written on his behalf if he lacks capacity	True	False
3. Bill's ADRT only becomes active when he loses capacity	True	False
4. A verbal refusal of life sustaining treatment is legally binding	True	False
5. A signed ADRT is always legally binding	True	False
6. If Bill's ADRT is valid and applicable, carers must follow it even if they disagree with its content	True	False
7. An ADRT must be distributed to all relevant carers	True	False

Write

Think of situations in which an ADRT may be invalid or not applicable

Circumstances making an ADRT invalid	Circumstances making an ADRT inapplicable

Reflect

In the event that Bill is seriously ill and loses capacity, Bill's GP advises him to write an ADRT that refuses all drugs and treatment (even if his life is at risk), with the exception of analgesics.

Can you foresee any problems with this ADRT at the end of life?

FURTHER ACTIVITY: Advance Decisions to Refuse Treatment (ADRTs)

Have you recently met patients who would have welcomed making an ADRT?

FURTHER READING: Advance Decisions to Refuse Treatment (ADRTs)

Key documentation

ADRTs, including an example form: http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Advance-Decisions.pdf

Mental Capacity Act: https://www.legislation.gov.uk/id/ukpga/2005/9

MCA Code of Practice: https://assets.publishing.service.gov.uk/.../Mental-capacity-act-code-of-practice.pdf

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff. NHS End of Life Care Programme, 2011: http://www.ncpc.org.uk/publication/advance-care-planning-guide-health-and-social-care-staff

References

Amjad H. Towle V. Fried T. Association of experience with illness and end-of-life care with advance care planning in older adults. *Journal of the American Geriatrics Society.* 62(7):1304-9, 2014

Burge AT. Lee A. Nicholes M. Purcell S. *et al* Advance care planning education in pulmonary rehabilitation: A qualitative study exploring participant perspectives. *Palliative Medicine.* 27(6):508-15, 2013

Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *British Medical Journal,* 2006. **333**: 886-889.

Dickinson C. Bamford C. Exley C. *et al.* Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics.* 25(12):2011-21, 2013

Khan SA. Gomes B. Higginson IJ. End-of-life care--what do cancer patients want? *Nature Reviews Clinical Oncology.* 11(2):100-8, 2014

McMahan RD. Knight SJ. Fried TR. Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *Journal of Pain & Symptom Management.* 46(3):355-65, 2013

Mitchell S. Plunkett A. Dale J. Use of formal advance care planning documents: a national survey of UK Paediatric Intensive Care Units. *Archives of Disease in Childhood.* 99(4):327-30, 2014

Ridley S. Fisher M. Uncertainty in end-of-life care. *Current Opinion in Critical Care.* 19(6):642-7, 2013

Sharp T. Moran E. Kuhn I. Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *British Journal of General Practice.* 63(615):e657-68, 2013

Singer PA, Thiel EC, Naylor CD *et al*. Life-sustaining treatment preferences of hemodialysis patients: implications for advance directives. *J Am Soc Nephrol* 1995;6(5):1410–7.

Stone L. Kinley J. Hockley J. Advance care planning in care homes: the experience of staff, residents, and family members. *International Journal of Palliative Nursing.* 19(11):550-7, 2013

Thorevska N, Tilluckdharry L, Tickoo S *et al*. Patients' understanding of advance directives and cardiopulmonary resuscitation. *J Crit Care* 2005;20(1):26–34.

Further resources

ADRTs, including an example form: http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Advance-Decisions.pdf

e-lfh: e-Learning for Healthcare contains a range of online self-learning programmes, including several relating to end-of-life care (e-ecla). Registration is required but is free.

IMCA service: https://www.scie.org.uk/mca/imca

CLiP 15 minute Worksheet

Current Learning in Palliative care

An accessible learning programme for health care professionals

15 minute worksheets are available on:

- An introduction to palliative care
- Helping the patient with pain
- Helping the patient with symptoms other than pain
- Moving the ill patient
- Psychological and spiritual needs
- Helping patients with reduced hydration and nutrition
- Procedures in palliative care
- Planning care in advance
- Understanding and helping the person with learning disabilities
- The last hours and days
- Bereavement

Available online on

www.clip.org.uk