

CLiP

15 minute Worksheet



Planning care in advance

1: Principles

Introductory level

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Aim of this worksheet

To understand the principles of planning care in advance

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- If you think any information is wrong or out of date let us know.
- Use the activity on the back page and take this learning into your workplace.

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. At a previous appointment he was clear that he wanted to know the results, and the presence of cancer was discussed.

It was also explained that surgical removal of the tumour is possible, so he has come today to discuss his options.

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Planning care in advance

- The Mental Capacity Act (2005) is central to all plans that require a proactive, coordinated response.
- Individual care planning is a key part of care in all children, young people and adults.
- This is a process of discussion and review in young people and adults to anticipate how their condition may affect them in the future.

Key points about planning care in advance

- 1. F** This is a voluntary process and individuals with capacity have the right to refuse to take part. Some may feel unable to engage in the process or that the time is not right for them. Consequently it is impossible to have a target requiring all patients to plan their care in advance.
- 2. F** Although the decisions of individuals with capacity are paramount, the opinions of individuals who lack capacity must be taken into account.
- 3. F** In people who lack capacity, the decisions must be made using the best interests process of the Mental Capacity Act (see CLiP worksheet *Issues around capacity* and *Best Interests*). This includes taking into account the opinion of the individual.
- 4. F** As long as a patient retains capacity for those care decisions, the patient's decision always take priority. Any decisions made in advance only become active if the patient loses capacity.
- 5. T** Advance care plans have no agreed definition in the UK and are not mentioned in the Mental Capacity Act (MCA). Before they can be used it has to be decided where they fit within the MCA. This is prone to misinterpretation and takes time which may not be available.
- 6. T** Decisions made in advance do not have to be written documents, they can be verbal from conversations with the patient. If the patient agrees, a record of that conversation can be made in their health record.

Prompts for starting care planning discussion

Examples include: an individual's request to discuss future care; a new diagnosis of life-limiting or life-threatening illness; a significant change in treatment, eg. complications of dialysis, failure of second-line chemotherapy; following multiple hospital admissions or crises; a deterioration in health.

Issues that make a care planning discussion difficult or impossible

These include: you have not been trained in initiating an ACP discussion; the individual is reluctant or refusing to discuss the future; the individual is adjusting to a new care environment and carers; the presence of troublesome physical symptoms; the presence of troublesome anxiety, low mood or anger.

Note: none of these are reasons not to have the discussion but should prompt you to ask for help and advice or have a colleague sit in with you.

Possible outcomes of a discussion on planning care in advance

Advance statement: this can be verbal or written and must be made when the individual has capacity for those care decisions. It is a record of an individual's wishes and feelings, beliefs and values. It is not legally binding, but once the individual loses capacity for those care decisions all carers are legally bound to take it into account when making decisions in the patient's best interests.

Making advance decisions for anticipated emergencies: this can be a ReSPECT form which individualises decisions and can be used to limit treatment or ensure that all treatment should be considered. Such a plan can be written with a person who has capacity, or on behalf of a person who lacks capacity using the MCA best interests process (see CLiP worksheets *Issues around capacity*, *Best Interests* and *ReSPECT*).

An *Advance decision to refuse treatment (ADRT)* can be verbal or written, but only an 18yr old with capacity can write a legally binding ADRT (see CLiP worksheet *Advance decision to refuse treatment*). In some situations the individual may wish to discuss cardiopulmonary resuscitation, something that would be important for an individual at risk of respiratory failure.

Lasting Power of Attorney (LPA): this is a legal authority made by a patient when they have capacity to nominate another person to speak on their behalf should the patient lose capacity in the future. A Property and Affairs LPA has no authority to make health care decisions; these can only be made by a personal welfare LPA (also known as a Health & welfare LPA) who must have specific authorisation in the order if the patient wishes them to make life-sustaining decisions.

- True
or
false*
1. All individuals should plan their care in advance True False
 2. Only individuals with capacity can plan their care in advance True False
 3. Individuals who lack capacity cannot have their care planned in advance True False
 4. Decisions resulting from planning care in advance always take priority True False
 5. Advance care plans have no definition or legal status True False
 6. A verbal decision is a valid outcome of planning care in advance True False

Write

Write down some situations and events which could prompt a discussion around planning care in advance

Reflect

Think about what issues could make you hesitate about having an discussion around planning care in advance

Write

Write down some outcomes of a discussion on planning care in advance

FURTHER ACTIVITY: Principles of planning care in advance

What was a patient's reaction the last time you observed their future care being discussed?

FURTHER READING: Principles of planning care in advance

Key documentation

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>

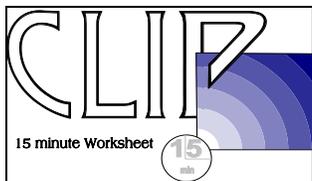
References

- 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.
- Detering, K.M., *et al*. *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*. *BMJ*. 2010; **340**: c1345.
- 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

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>



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