CLiP

15 minute Worksheet

15 min

Planning care in advance

2: Issues around capacity

Introductory level

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Aim of this worksheet

To review the issues around capacity and consider when and how to assess capacity.

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- If you think any information is wrong or out of date let us know.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 surgery.

He comes with his wife who explains that he had a major seizure in the early hours of the morning and is still a bit drowsy.

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INFORMATION PAGE: Issues around capacity

The Mental Capacity Act (2005)

The MCA has five key principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Answers: Making an unwise or illogical decision are *not* by themselves indications of a lack of capacity. Drowsiness alone does not affect capacity unless it is severe. Epilepsy is a condition which does not affect capacity, unless a person is having a seizure or recovering from one. Therefore, the only two factors that could suggest a lack of capacity are the presence of an impairment or disturbance of mind (eg. severe depression, psychosis) or brain (eg. dementia).

Assessing capacity

If it is suspected that a person has an impairment or disturbance of mind or brain, capacity must be tested for each key care decision:

1. Can Bill communicate his decision in any way?
   NB. The carers must try every method possible to enable this.
2. Can Bill understand all the relevant information?
   NB. this must be provided in a way he can understand.
3. Can Bill retain the information long enough to make a choice or an effective decision?
   NB. This only needs to be long enough to use and weigh the information.
4. Can Bill use or weigh up that information as part of the process of making the decision?
   NB. He must be able to show that he is able to consider the benefits and burdens to the proposed treatment and the alternatives.

Bill needs to be able to do all four tests to be defined as having capacity. The result of each step of this assessment should be documented, ideally by quoting the Bill.

Answers: cognitive function tests (eg. knowing date and place, or counting backwards) do not test capacity. Being able to have a conversation or speaking clearly tells you nothing about a person's capacity, especially as the MCA is clear that the responsibility is on the carer to enable the patient to communicate their wishes. Only the four tests above can define capacity.

Key points about capacity

1. F Capacity only applies to the decision being made. It is possible to have capacity for one decision, but not for another. For example, few people have the capacity to design a communications satellite, but we have the capacity to decide many aspects of our lives. Similarly, a patient may not have the capacity to decide about a complex treatment, but still have capacity to decide other aspects of their care.

2. T Some conditions can cause capacity to fluctuate. For example, Bill will not have capacity during a major seizure. During his recovery he will have capacity for some decisions (eg. whether he wants to lie in a bed), but as he recovers his capacity will return to the level before his seizure. In patients with delirium, capacity can change from hour to hour.

3. T Testing capacity is not restricted to doctors or psychiatrists. Any carer who has to obtain consent before providing care can test for capacity *if* they suspect an impairment or disturbance of mind or brain, and if they know how to test for capacity.

4. T Even if Bill does not have capacity for the complexity of the decision about surgery, he may still be able to express an opinion about surgery. Although this opinion is not legally binding, it must be taken into account when deciding the best interests of a person lacking capacity (see CLiP worksheet *Best Interests*).

5. F In an emergency that causes a loss of capacity, treatment must take priority if it is clear this is in a patient's best interests *and* that this treatment could be successful. Clinicians can only act on the information they have to hand at the time.

6. F The Mental Capacity Act applies in full to anyone aged 18yrs and over. It also applies to those 16 to 17yrs but they cannot make an Advance Decision to Refuse Treatment (ADRT) or set up a legal proxy. If an individual is aged 16yrs or less they can still have capacity (so-called Gillick competency) and this can be tested in the same way as adults. Young people 16yrs or less can consent to treatment but refusal may require the involvement of the parents.

WORK PAGE: Issues around capacity

Choose

The Mental Capacity Act requires carers to assume a patient has capacity.

Ring those factors that suggest Bill
may not have the capacity to consent to surgery

Making an unwise decision	Disturbance of mind or brain
Epilepsy	Making an illogical decision
Impairment of mind or brain	Drowsiness

Choose

Assessing capacity:
<u>Underline</u> those features that could suggest that Bill
does have the capacity to consent to surgery

Knows today's date and where he is	Can understand the pros & cons of surgery
Remembers current information	Can count from 10 backwards
Able to have a conversation	Can speak clearly
Able to communicate his decision	Can weigh up the pros & cons of surgery

True or false

1. A lack of capacity means Bill cannot make any decisions about his care	True	False
2. Capacity can change from hour to hour	True	False
3. Any carer who knows Bill can assess capacity	True	False
4. If Bill lacks capacity his opinion must still be taken into account	True	False
5. In an emergency causing a loss of capacity, treatment cannot proceed in the absence of consent	True	False
6. A 14yr old child cannot have capacity for decisions	True	False

Think about the last time you met a patient whose capacity had been assessed and documented

Reflect

FURTHER ACTIVITY: Issues around capacity

Have you met patients who did not have their capacity tested despite having an impairment or disturbance of mind or brain?

FURTHER READING: Issues around capacity

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

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