

CLiP

15 minute Workshop



Introduction to palliative care

3: Making sensible decisions

Introductory level

Produced by
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Aim of this worksheet

To understand that most sensible decisions just need common sense

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- If you think any information is wrong or out of date let us know.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

Mary is a 29 year old woman married with 2 young children.

Eight months ago she was found to have an advanced pelvic tumour which was inoperable. She received radiotherapy but the tumour persisted. She has been admitted with severe abdominal pain.

The family are around her bed. Her husband is holding her hand and looks very worried, while the oldest child is clinging to dad. The youngest child is playing with a doll. Mary's sister is standing in a corner, tears streaming down her face.

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Making decisions: dealing with 'The Fog'

In most situations, professional carers make sensitive, sensible and logical decisions, but in complex situations, these decisions can become insensitive, irrational and unhelpful.

This has been described by Robert Twycross as the 'Cancer Fog', but it could equally be the 'AIDS Fog' or the 'Multiple Sclerosis Fog'.

This 'Fog' is caused by too many emotive and unfamiliar demands coming together at one time.

This drives many professionals to rely on automatic behaviour that they learnt last time they were in a frightening or distressing situation. While some will have learnt to cope with compassion and common sense, some professionals use less helpful defence mechanisms:

- being inappropriately jolly (eg. 'We'll soon have you back on your hands and knees!');
- being inappropriately gloomy (eg. 'This is not good. I'm afraid that there's little we can do.');
- showing irritation (eg. 'You all should go home now and leave us to get on treating Mary.');
- being too distressed to function (NB some distress is normal, but you still have to be able to help);
- being inappropriately reassuring (eg. 'It'll be fine.');
- focussing only on the physical aspects;
- avoiding any reference to the obvious distress in the room;
- avoiding difficult questions.

'The Fog' catches everyone out from time to time, so it's worth knowing what makes it worse and what makes it easier.

Things that may make 'The Fog' worse:

- a patient in acute distress
- a distressed or angry relative
- the presence of children, especially if they seem vulnerable
- a tired professional
- training that relies too much on 'surviving'
- using a standard routine to treat an unusual problem
- lack of recognition that when we are stressed we all fall back on routines that are familiar, but that these routines may have been learnt under stress and may not be helpful

Things that may make 'The Fog' clearer:

- using the skills and knowledge you already have
- using common sense
- being sensitive to what the patient and partner are saying to you
- acknowledging the distress of the patient and partner and family
- accepting that there are some situations that need alternative approaches
- gaining the trust of the whole family

Helping the distressed patient

What you need are care and common sense- don't panic!

Psychological things that may help:

- | | |
|---|-------------------------|
| -smile, light touch, introduce yourself | (Be polite) |
| -explain that you're there to help | (Be informative) |
| -acknowledge that she looks distressed | (Be sensitive) |

Other things that may help:

- | | |
|---|---------------------------|
| -get information about her pain eg. Where, Character, Radiation, Precipitating and Relieving factors
(see CLIP worksheet on <i>Diagnosing the Pain</i>) | (Be accurate) |
| -get help if you can't deal with the pain yourself | (Be sensible) |
| -while waiting for help or medication to work, sit with her, and ask how she feels | (Be compassionate) |

Mary is clearly distressed, going pale every few minutes with abdominal pain, whimpering when it is at its most severe.

Write

Give examples of how professionals sometimes react to this situation

By hiding their feelings	
By letting their feelings take over	
By avoiding the problems	

Write

**Why is it difficult to make decisions in this situation?
What would make it easier?**

These make it difficult	These would make it easier

**Don't
panic!**

What can you do to ease Mary's pain and distress?

Psychological help	Physical help

FURTHER ACTIVITY: Making sensible decisions

Think back to the last distressed person you met.

- What made 'the Fog' more difficult?
- What made it easier?

FURTHER READING: Making sensible decisions

Journal articles

Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning interview schedule: a focus group study. *Palliative Medicine*. 2007; **21**(1): 23–8.

Baumrucker SJ. Palliative care, burnout, and the pursuit of happiness. *American Journal of Hospice & Palliative Care*. 2002; **19**(3): 154-6.

Dunne K. The personal cost of caring. *International Journal of Palliative Nursing*. 2003; **9**(6): 232.

Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *European Journal of Cancer*. 1996; **32A**(1): 78-81.

Maguire P. Improving communication with cancer patients. *European Journal of Cancer*. 1999; **35**(14): 2058-65.

Maguire P. Improving communication with cancer patients. *European Journal of Cancer*. 1999; **35**(10): 1415-22.

Maguire P. Barriers to psychological care of the dying. *British Medical Journal Clinical Research Ed.* 1985; **291**(6510): 1711-3.

Parker M, Stewart C, Willmott L, Cartwright C. Two steps forward, one step back: advance care planning, Australian regulatory frameworks and the Australian Medical Association. *Internal Medicine Journal*. 2007; **37**(9): 637–43.

Mental capacity Act Code of Practice.

Available on: www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

Tierney WM. Improving clinical decisions and outcomes with information: a review. *International Journal of Medical Informatics*, 2001; **62**(1):1-9.

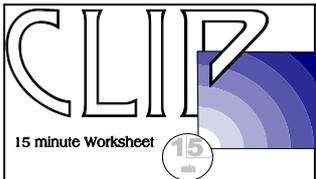
Thorevska N, Tilluckdarry L, Tickoo S, Havasi A, Amoateng-Adjepong Y, Manthous CA. Patients' understanding of advance directives and cardiopulmonary resuscitation *Journal of Critical Care*. 2005; **20**: 26–34.

Vachon ML. Reflections on the history of occupational stress in hospice/palliative care. *Hospice Journal - Physical, Psychosocial, & Pastoral Care of the Dying*. 1999; **14**(3-4): 229-46.

Wright B. Compassion fatigue: how to avoid it. *Palliative Medicine*. 2004; **18**(1): 3-4.

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-elca). Registration is required but is free. <http://www.e-lfh.org.uk/projects/e-elca/index.html>



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