CLiP

15 minute Worksheet

15 min

Psychological needs

1: Fostering hope

Introductory 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, St. Oswald's Hospice

Veronica Oliver-Jenkins
Consultant Clinical Psychologist Newcastle Specialist Palliative Care Service, Newcastle Hospitals NHS Trust

Aim of this worksheet

To consider ways of fostering hope in advanced disease

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- If you think any information is wrong or out of date let us know.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

Peter is a 46 year old man who initially complained of increasing weakness in his legs. As he was always an anxious man, this was at first put down to stress. When the weakness worsens, however, the clinicians suspect motor neurone disease. He is married with two teenage children.

He suspects he has a serious illness and comes to see you for reassurance.

v15

INFORMATION PAGE: Fostering hope

What is hope?

Hope of realistically achieving something good in the future is at the heart of coping with advanced illness and enabling a good quality of life. Unlike denial or optimism, hope needs people to be realistic, since one can only successfully hope for something that is possible, not something that can never be achieved. It is about being open to possibilities.

It is not about being unrealistic or being in denial, it is different to optimism (which needs some denial and perhaps avoidance of reality), and it is not about finding the meaning of life.

It is a realistic desire for good in the face of uncertainty, and it helps a person cope with tragedy and loss

What Peter needs to foster hope

- Nurturing relationships and a sense of connection with others.
- Support that Peter can trust, allowing him to feel safe to express his distress.
- A willingness to confront uncertainties and consider possibilities at an appropriate pace.
- Professionals willing to offer information at Peter's pace, not at the professional's pace.
- Professionals willing to allow and help Peter adapt his hope as his illness progresses.
- The ability to imagine his hope by seeing it as a realistic possibility, not just fantasising or wishing that something may happen.

True or false 1) F 2) F 3) T 4) F 5) T

How does hope show itself?

Hope shows itself in different ways at different stages of illness:

Early in the disease there is hope of cure.
As the illness progresses there is hope of control and hope for comfort.
At the end of life the hope often changes to one of peace and hope of a pain-free death.

Hope shows itself in different ways in different people:

Some people are practical in their hope, eg. hoping to avoid pain, tie up loose ends, or going home to die.
Others are more generalised in their hope, eg. the hope to be at peace, to take 'each day as it comes', hope that they are valued, and a hope of 'letting go' at the end.

The realignment of hope as events warrant rather than relinquishment of hope is key.

How can I use this information to help?

- Professionals can positively and negatively influence hope.
  Action: Hope is fostered by being receptive, honest and genuine; affirming the individual's worth and value; demonstrating caring behaviours (e.g. touch) .
- As an illness progresses Peter needs to be allowed to change the focus of his hope, eg from cure to comfort.
  Action: Allowing Peter to talk freely about his fears and hopes will help.
- Keep a look out for patients whose pace of change has been abrupt, eg. being told their illness cannot be cured or treated.
  Action: These people will need extra time to mull over this new information, with a trusting ear to listen.
- Peter may make it clear he does not want more information at present, eg. 'I don't want to hear any more bad news'. This shows he is in 'reality overload' and cannot take any more information right now.
  Action: Make sure the team knows of Peter 's wishes. Avoid misinterpreting his 'reality overload' as a lack of knowledge- this can push professionals into loading even more information onto Peter when he is already struggling with the knowledge he has already!
- Hope is soon damaged by persistent physical symptoms, eg. pain, nausea, vomiting.
  Action: Make sure the team knows about the problem and deals promptly with the symptom.
- Hope is very difficult to keep going in the presence of persistent psychological symptoms. eg. anxiety, anger or a clinical depression.
  Action: Let the team know if Peter seems anxious, angry, frightened or withdrawn so these symptoms can be eased.
- Hope is difficult to foster if a person's life has been one of neglect, rejection or abuse.
  Action: These people will need time to talk to mull over future possibilities. They may need specialist help.

Key points

- Hope is a realistic desire for something good in the face of uncertainty.
- Hope is not about denial or optimism.
- Hope changes as the illness progresses.
- A trusted, listening ear is the most helpful support, not someone who offers false reassurance.

Reflect

What do you think hope means for people with incurable illness?

True or false?

Consider the following about hope

1. Hope is about being optimistic — True False
2. You cannot be realistic and hopeful in the face of death — True False
3. Hope is greater if information is given at the patient's pace — True False
4. Wishing is the same as hope — True False
5. Hope is easier to foster if the person feels safe to express their distress — True False

Reflect

Think of ways in which patients adapt their hope

Early in the disease

As the illness advances

Write

How could you help foster Peter 's hope in these situations

Situation	How you can help
Recently told bad news	
Peter says he wants no more information	
Peter is nauseated	

FURTHER ACTIVITY: Fostering hope

Think back to the last person you met with an advanced illness

- Did they show any signs of hope?
- How did you, or might you have, helped them foster hope?

FURTHER READING: Fostering hope

Journal articles and chapters

Alidina K. Tettero I. Exploring the therapeutic value of hope in palliative nursing. *Palliative & Supportive Care.* **8**(3): 353-8, 2010

Benzein E. Norberg A. Saveman BI. The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine.* 2001; **15**(2):117-26.

Choi YK. The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients. *Journal of Music Therapy*. **47**(1): 53-69, 2010

Cutcliffe JR. Herth K. The concept of hope in nursing 1: its origins, background and nature. *British Journal of Nursing.* 2002; **11**(12): 832-40.

Kennedy V, Lloyd-Williams M. Maintaining hope: communication in palliative care. *Recent Results in Cancer Research,* 2006, **168:** 47-60.

Kylma, J. Duggleby, W. Cooper, D. Molander, G. Hope in palliative care: An integrative review. *Palliative and Supportive Care*. 2009. **7**, 365-377

Lloyd-Williams M. Friedman T. Rudd N. An analysis of the validity of the Hospital Anxiety and Depression Scale as a screening tool in patients with advanced metastatic cancer. *Journal of Pain and Symptom Management,*; 2001, **22**(6): 990-6.

McClement SE, Chochinov HM. Spiritual issues in palliative medicine. In, Hanks G, Cherney NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. *The Oxford Textbook of Palliative Medicine, 4th ed.* Oxford University Press, 2009, pp 1403-9.

Mok E. *Et al* Healthcare professionals' perceptions of existential distress in patients with advanced cancer. *Journal of Advanced Nursing.* **66**(7): 1510-22, 2010

Panke JT, Ferrell BR. The family perspective. In, Hanks G, Cherney NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. *The Oxford Textbook of Palliative Medicine, 4th ed.* Oxford University Press, 2009, pp 1437-44.

Penson J. A hope is not a promise: fostering hope within palliative care. *International Journal of Palliative Nursing.* 2000; **6**(2): 94-8.

Selman L. Beynon T. Higginson IJ. Harding R. Psychological, social and spiritual distress at the end of life in heart failure patients. *Current Opinion in Supportive & Palliative Care.* 2007, **1**(4): 260-6.

Vachon M. The emotional problems of the patient in palliative medicine. In, Hanks G, Cherney NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. *The Oxford Textbook of Palliative Medicine, 4th ed.* Oxford University Press, 2009, pp 1410-36.

Vivat B. Members of the Quality of Life Group of the European Organisation for Research and Treatment of Cancer. Measures of spiritual issues for palliative care patients: a literature review. *Palliative Medicine*. 2008, **22**(7): 859-68.

Wagner GJ. *Et al* Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *Journal of Pain & Symptom Management.* **39**(3):527-34, 2010

Further resources

Effective Interaction with Patients, 2nd ed Faulkner A. New York : Churchill Livingstone, 1998.

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. http://www.e-lfh.org.uk/projects/e-elca/index.html

Introducing Palliative Care 3rd ed. Twycross R. Abingdon : Radcliffe Medical Press, 1999.

Talking to Cancer Patients and their relatives. Faulkner, A. Oxford: Oxford University Press, 1994.

A Guide to Symptom Relief in Palliative Care, 6th ed. Regnard C, Dean M. Oxford: Radcliffe Medical Press, 2010

Oxford Textbook of Palliative Medicine, 4th ed. Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK. eds. Oxford : Oxford University Press, 2010.

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