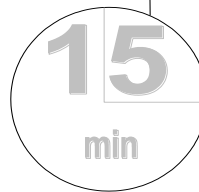


CLiP

15 minute Worksheet



Psychological needs

7: Helping the withdrawn patient

Advanced 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To understand the principles of helping the withdrawn patient.

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- If you think any information is wrong or out of date let us know.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, married with two children. He initially complained of increasing weakness in his legs. Always an anxious man, at first this was put down to stress. When the weakness worsened, however, investigations and examination suggested motor neurone disease, and subsequent progression of the signs and symptoms has confirmed the diagnosis. He wanted to know the diagnosis and was told.

He is normally anxious, but ready to chat and animated. Today he seems distant and speaks to you in brief sentences or single words.

v15

Getting started

- **Acknowledge what is happening.** This first step applies to many situations. Simply reflect back your observations, eg. "You don't seem your usual self today." While this may seem unnecessary, it gives Peter a clear message that you have noticed his withdrawal and that you are taking it seriously.
- **Negotiate further discussion,** eg. "Is there something I can help you with?"
- **Check that Peter can understand:** make sure he's not deaf or distracted by a confusional state.

Reasons for withdrawal

Although depression might be the reason, there are many other possible causes:

- If you have not met Peter before it is important to determine whether this could be usual behaviour.
- His speech and facial expressions may be severely affected by his MND, preventing a conversation.
- Pain might be so distracting that they are preventing him from concentrating.
- A confusional state may be making him suspicious or unwilling to talk.
- Drowsiness caused by drugs, infection or a biochemical disturbance may be preventing a conversation.
- Parkinsonism caused by drugs (eg. haloperidol, metoclopramide) may reduce facial expressions.
- Collusion may be preventing him from talking for fear of upsetting a partner or relative.
- He may be too exhausted to talk.
- He might be too frightened to talk (the 'frozen terror' syndrome).
- Guilt or shame may be present, causing him to withdraw (this may be part of a depression)

Depression

A lowering of mood is natural and expected in individuals with advanced and terminal illness. The differentiation between a normal and appropriate reaction to a life limiting diagnosis and a more serious psychiatric disorder such as clinical depression is challenging. Too often depression is unrecognised and untreated leading to increased suffering for the patient and their family, amplifying other symptoms (such as pain) which in themselves then become more difficult to treat.

Incidence of depression: The proportion of patients with advanced disease who have a clinical depression varies between studies and depends partly on the assessment tools used. It has been suggested that 25% or more of cancer and AIDS patients suffer from depression. It is also prevalent in respiratory disease, heart failure and many other life-threatening and life-limiting diseases.

Diagnosing depression: Screening tools may assist in the diagnosis of depression. The Hospital Anxiety and Depression (HAD) scale is commonly used, but the Edinburgh Postnatal depression Scale is more useful in palliative care. The diagnosis of depression is made on the following characteristics:

- A persistent low mood (>2 weeks for >50% of the time).
- The withdrawal is a change to their usual mood and there is a loss of enjoyment
- There are three or more depressive-related symptoms present: diurnal variation in mood, repeated or early morning wakening, impaired concentration, loss of interest or enjoyment, feelings of hopelessness, guilt, shame or feeling a burden to others, thoughts of self harm, desire for hastened death.

All the features listed opposite *could* indicate a depression, but some are less useful than others in advanced disease. Loss of energy, appetite and sex drive are more likely to be due to the disease itself and cannot be used as diagnostic indicators. Feeling 'fed up' tells you little!

Suicidal thoughts are a less useful indicator in advanced disease, since some patients will express a realistic wish that they would rather be dead, rather than be in pain, a burden, immobile etc. However, if thoughts of self-harm, suicidal planning, and desire for a hastened death are present a thorough risk assessment should be completed with referral to specialist services for further assessment and advice if appropriate.

Helping the withdrawn patient

In Peter's case, the first step is to establish the cause and treat any straightforward causes such as enabling communication using a speech communicator, treating any pain or delirium, reducing drugs that may be causing drowsiness or parkinsonian adverse effects, exploring collusion if this is present (see CLiP worksheet on *Collusion and Denial*), and managing anxiety (see CLiP worksheet on *Anxiety*) or anger (see CLiP worksheet on *Anger*).

If depression is present: inform Peter of the potential benefits of anti-depressant treatment if clinical depression is present. If he is happy to try - start an antidepressant. SSRIs and SNRIs are commonly used eg. sertraline 50mg initially or citalopram 20mg initially. Adverse effects can be a problem including GI bleeds, diarrhoea or constipation, nausea, vomiting and dyspepsia. Note that a) the response to drugs can occur within 2 weeks (so don't delay because of a short prognosis) and b) the patient is the last to notice any improvement.

Other interventions that may be helpful include:

- If possible, increase activity by encouraging participation in activities they previously found pleasurable
- Helping Peter to identify and set goals (that are realistic and achievable). This can foster hope and increase their sense of control.
- Referral for cognitive behavioural therapy (CBT) if there is time for six or more weekly sessions.

Reflect

- How do you start a dialogue with Peter?
- What you need to check first?

Write

List some reasons why Peter might be more withdrawn than usual (you don't have to put depression at the top of the list!)

Choose

How common is depression in advanced disease?

10% 25% 50% 80%

Choose

Which of the following would strongly support a diagnosis of depression in Peter?

Ring your choices

Suicidal thoughts (eg. "I'd rather be dead")

Inappropriate guilt

Loss of appetite

Suicidal plans

Early morning wakening

Feeling fed up

Feeling a burden to others

Reduced sex drive

A change in mood

Diurnal variation (eg. worse on waking)

Persistent, low mood for 1 week

Loss of enjoyment

Feelings of hopelessness

Lack of energy

Reflect

How can you start to help Peter?

FURTHER ACTIVITY: Helping the withdrawn patient

When you next meet a patient who is withdrawn explore:

- Is this a new problem for the patient?
- Is the patient thinking and acting clearly? (ie make sure the patient is not confused)
- Is the patient feeling apathetic and hopeless?

If the answer was yes to these questions, then a depression is possible

- Ask an experienced colleague to review the patient with you and consider whether you should refer the patient for further assessment

FURTHER READING

Journal articles

Candy M, Jones L, Williams R, Tookman A, King M. Psychostimulants for depression. *Cochrane Database of Systematic Reviews*. 2008, (2): CD006722.

Hotopf M, Chidgey J, Addington-Hall J, Ly KL. Depression in advanced disease: a systematic review Part 1. Prevalence and case finding. *Medicine*. 2002; **16**(2): 81-97.

Lloyd-Williams M, Friedman T. Depression in palliative care patients--a prospective study. *European Journal of Cancer Care*. 2001; **10**(4):270-4.

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 & Symptom Management*. 2001; **22**(6): 990-6.

Lloyd-Williams M, Friedman T, Rudd N. Criterion validation of the Edinburgh postnatal depression scale as a screening tool for depression in patients with advanced metastatic cancer. *Journal of Pain and Symptom Management*, 2000; **20**(4): 259-65.

Lloyd-Williams M. Screening for depression in palliative care patients: a review. *European Journal of Cancer Care*. 2001; **10**(1): 31-5.

Lloyd-Williams M. How common are thoughts of self-harm in a UK palliative care population?. *Supportive Care in Cancer*. 2002; **10**(5): 422-4.

Lloyd-Williams M. Screening for depression in palliative care. *American Journal of Hospice & Palliative Care*. 2001; **18**(2): 79-80.

Lloyd-Williams M. The stability of depression scores in patients who are receiving palliative care. *Journal of Pain and Symptom Management*, 2002; **24**(6): 593-7.

Lloyd-Williams M, Shields C, Taylor F, Dennis M. Depression -An independent predictor of early death in patients with advanced cancer. *Journal of Affective Disorders*, 2009, **113** (1-2), 127-132.

Ly KL. *Et al* Depression in palliative care: a systematic review. Part 2. Treatment. *Palliative Medicine*. 2002; **16**(4): 279-84.

Rayner L, Price A, Evans A, Valsraj K, Hotopf M, Higginson IJ. Antidepressants for the treatment of depression in palliative care: systematic review and meta-analysis. *Palliative Medicine*, 2011; **25**(1): 36-51.

Ripamonti C, Filiberti A, Totis A, De Conno F, Tamburini M. Suicide among patients with cancer cared for at home by palliative-care teams. *Lancet*. 1999; **354**(9193): 1877-8.

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.

Wasteson, E., Brenne, E., Higginson, I.J., Hotopf, M., Lloyd-Williams, M., Kaasa, S., Loge, J.H. Depression assessment and classification in palliative cancer patients: a systematic literature review. *Palliative Medicine*, 2009, **23**(8), 739-753.

Watanabe N, Omori IM, Nakagawa A, Cipriani A. *Et al* Multiple Meta-Analyses of New Generation Antidepressants (MANGA) Study Group. Mirtazapine versus other antidepressants in the acute-phase treatment of adults with major depression: systematic review and meta-analysis. *Journal of Clinical Psychiatry*. 2008, **69**(9): 1404-15.

Resource books and websites

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

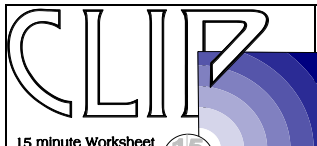
e-lth: e-Learning for Healthcare contains a range of online self-learning programmes, including several relating to end-of-life care (e-ecla). Registration is required but is free.

Introducing Palliative Care 5th ed. Twycross R., Wilcock A. www.palliativedrugs.com 2016

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, Hockley J. 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.



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