## **Current Learning in Palliative care**



### Bereavement

# 1: The loss begins.....

Introductory level

Produced by

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#### Aim of this worksheet

To outline the responses to grief of patients, partners and professionals

#### 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- If you think any information is wrong or out of date let us know.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 39 year old woman, divorced with a 9 year old son and a 16 year old daughter. She has very advanced breast carcinoma and was admitted to hospital urgently because of rapid deterioration. She is now deteriorating day by day and is insisting on returning home. Her recently widowed mother has been staying at home to look after the children.

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#### **INFORMATION PAGE: The Loss begins....**

Every person will experience loss and bereavement at some point in their lives, but many people shy away from discussions involving death and dying, and as a consequence these issues have become stigmatised by society.

Loss is a common experience with varying degrees of importance, from losing your car keys to losing someone close *Grief* describes the feelings when someone dies.

Bereavement is a term that describes the period of grief around the loss of someone close.

Mourning is the public face of grief in the time immediately following a person's death

#### Responses to loss

People experience grief differently. Grief is a common reaction to loss and can be understood more effectively when it is viewed within the emotional, cultural, social and psychological aspects of a person's life. Bereavement is one of life's most challenging periods. When each family member realised that Mary was gravely ill they will have gone through many different feelings:

Shock at the news is inevitable. Any one of the family may have reacted with <u>numbness</u> or <u>denial</u> at the reality. They may also have reacted with <u>anger</u> or <u>frustration</u> that someone close is going to be taken from them, especially at the meaninglessness of the situation or its unfairness.

Anxiety about this new situation can result in fear with feelings of vulnerability and loss of security.

Any of the family may feel guilt, which may have a good reason or be quite unjustified (children can feel that it is somehow their fault, that if only they'd been good......).

Relief seems odd at first, but <u>relief</u> can result from the ending of any suffering and at release from the burden of caring. Although this relief is understandable, people often feel guilty that they feel such relief.

Sadness is a feeling you would expect, especially one of <u>loss of the future</u> with a <u>yearning</u> that things were different. Pining for normality can occur with a mixture of many of the feelings already described. <u>Despair</u> can intervene and may even lead to depression.

Hyperactivity can occur by 'keeping busy', but irritability and exhaustion can develop.

Mary may be reacting with any of the same feelings. In particular, she will also have feelings of loss. She will grieve for the loss of her future with her family and not being able to see her children grow up.

When Mary dies the family may go through many of these feelings again and again.

After the death, the family may have a few feelings that are different. They may develop a sense of <u>searching</u> for what has been lost, sometimes hearing, smelling or even seeing the person who has died. Paradoxically, this urge is accompanied by a conflicting <u>urge not to search</u> for the lost person (ie a wish to return to normal). Such conflicts are common in bereavement and result in the turmoil so often felt by bereaved people. This turmoil is particularly strong in the early bereavement, but becomes less as the loss and grief begin to resolve.

#### When does bereavement start?

What is clear from peoples' reactions is that they are almost identical before Mary died as after her death. All of these reactions are no different to those that occur after hearing bad or difficult news. This is not surprising as such news usually tells someone about a loss they will suffer. Therefore it could be said that bereavement starts at the time of diagnosis., not just after the death.

It is now becoming clear that loss and grieving are felt by everyone before the death, *including the patient*. This has important implications since it means we can help partners and family in their bereavement in the weeks and months *before* the death. The patient becomes an important part of this bereavement care.

#### The stages of bereavement.....

Kubler Ross described different stages that bereaved people go through (denial, anger, bargaining, depression, acceptance). This was wrongly interpreted by others as a fixed progression. Kubler Ross realised that, although the responses occurred, they often did not occur in any particular order. In addition people oscillate between different 'stages' especially in early bereavement.

In reality, bereavement is a chaotic, disruptive process that makes the individual feel out of control. It has been described as a 'whirlpool of emotions'.

#### **WORK PAGE: The loss begins**



As they all look after and care for Mary, what sort of feelings do you think the family might be having?

Ex-husband:

Mother:

9 year old son:

16 year old daughter:



What sort of feelings do you think Mary is having?

Mary continues to deteriorate and dies peacefully at home.
What <u>new</u> feelings might the family be having?



What feelings are unchanged?

NEW FEELINGS

SAME FEELINGS



Compare the lists you made above.
What do you notice about the different lists?
What does this tell you about the point at which bereavement starts?

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Do you think these reactions develop in any particular order?

#### FURTHER ACTIVITY: The loss begins...

Think of a time you lost a valued or important *material* possession (eg. house keys, credit card): -what were your feelings and thoughts, and how did your behaviour change?

#### FURTHER READING: The loss begins...

#### Journal articles and book resources

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Stajduhar KI, Martin W, Cairns M. What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative & Supportive Care*. 2010; **8**(3): 277-89.

Stedeford A. Facing death: patients, families and professionals London: Heinemann Medical Books, 1984.

Worden JW. Grief counselling and grief therapy: a handbook for the mental health practitioner, 2<sup>nd</sup> ed.. London: Routledge, 1991.

**Further resource: 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. <a href="www.e-lfh.org.uk/projects/e-elca/index.html">www.e-lfh.org.uk/projects/e-elca/index.html</a>



## 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