

CLiP

15 minute Worksheet



The last hours and days

4: A friend dies.....

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

Dorothy Mathews Macmillan
Nurse for People with Learning
Disability.

Lynn Gibson Manager of
Northumberland Physiotherapy
service (LD)
Northumberland Tyne & Wear NHS
Foundation Trust

Aim of this worksheet

To think about how to support fellow patients during and after the death.

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- If you think any information is wrong or out of date let us know.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

Michael is a 57 year old man with severe learning disability who lives in a community home with three other men with learning disability. Michael was diagnosed with gastric carcinoma some months ago, but presented too late for treatment. He dies peacefully in his bedroom.

Although all the men were aware of Michael's illness, Fred in particular has demonstrated some changes in behaviour and reluctance to participate in his usual activities. The staff are concerned that these changes are related to Michael's death and are unsure how to address these issues.

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INFORMATION PAGE: A friend dies....

Death of a relative or close friend: this can happen during any illness and is an added burden on the patient.

Death of a fellow patient: many patients develop friendships with fellow patients through their shared experiences. This may be a recent friendship with someone in the same bay in hospital or hospice, or may be over months through attending the same day hospice, or over years through living in the same community home. Regardless of the length of the friendship, the death of one patient also can be a loss for fellow patients.

The effect of a death on staff: many staff get to know a patient well, seeing them through crises and listening to their fears and joys. The death of a patient can feel like the loss of a friend.

The consequences of not sharing loss

Every person will experience loss and bereavement at some point in their lives, but many people shy away from discussions involving death and dying. As a consequence these issues can become stigmatised by a team. This tendency to 'hide' death results in several typical practices at the time of death: 'hiding' the body by shutting the door; closing the curtains or putting the body in a box designed to look like a trolley; talking in whispers; not telling children; a determination to continue as normal; moving the body as soon as possible; not telling fellow patients; presenting a 'jolly' manner to cover the sadness.

This reluctance to share the loss results in fellow patients and staff suppressing their grief and having feelings of uncertainty, tension and fear. These problems have occurred because fellow patients and staff failed to view the death holistically from physical, psychological, social and spiritual points of view.

Starting to share to the loss

1. *Unhelpful.* Honesty is the place to start. Every person is an individual in their own right and their specific needs will vary, but more harm will come from hiding fellow patients from the truth.
2. *Unhelpful.* Fellow patients are as likely to suffer from the loss of Michael as anyone else. Taking time to sit and talk can be very beneficial and this includes people with alternative communication.
3. *Unhelpful.* It should be remembered that it is usual to feel sad and hurt during a time of loss, but it is not helpful for carers to try to "jolly" the person along.
4. *Helpful.* For many people, reflecting back on a person's life (life story work) is a useful way to communicate significant life events, and can be seen as a vital element in helping the person bring back memories both good and bad that would otherwise be forgotten. The concept of life story books is also acknowledged in bereavement counselling.
5. *Helpful.* Look for changes in behaviour, which might indicate difficulty in expressing an emotion. Assess Fred's overall condition-don't assume his behaviour changes are a result of his grief since they may be related to something else. Remember that for some people, a grief reaction may take time to manifest itself.
6. *Unhelpful.* If memory is poor, reinforce the loss to assess Fred's understanding/feelings related to Michael's death. Repeat the information to encourage learning.
7. *Unhelpful.* Adjusting to the change can be difficult. It can be tempting for staff to get on with normality. Both Fred and the care staff may need help and support whilst he is adjusting to living in an environment where Michael is missing.
8. *Helpful.* Families may not know how to break the news of the death to their relatives, especially if they are very young or have learning disabilities. They may try to protect the person from the effects of grief, which unintentionally makes matters worse since the person may now wonder why they can no longer visit or see the person who has died. In cases where the mother has died, the child (or adult with a learning disability) has lost the person who understands them most. Informing the person that this important person is ill or dying allows the carer to prepare that person for their loss. They may need help to break this difficult news (see CLiP worksheet on *Breaking Difficult News*)

How do people with learning disabilities experience bereavement?

Historically it was believed that people with learning disabilities were not capable of understanding or expressing grief.

Whether through ignorance or a misguided attempt to protect the person, the death of a relative or friend was often glossed over. Anecdotal evidence indicates that individuals were prevented from attending the chapel of rest or funeral following the loss of a loved one. Sometimes relatives and carers made a conscious effort to hide their true emotions from the person with learning disability.

Carers can test a person's understanding of the concept of death and what it means to that person by using issues raised on television as a starting point. There is evidence to suggest that although a person with learning disabilities uses the words 'death' or 'dead', this does not imply that they understand it as a concept. Keep ideas simple and concrete.

People with learning disability may not suffer all of the recognisable reactions to bereavement. However they may have additional special difficulties due to poor intellect and complex needs, which deny them many of the social, verbal, auditory and visual opportunities of realising the death has occurred.

It is important to remember that people with learning disabilities have the same right to take part in family rituals as anyone else; this should include receiving/sending cards, sending flowers and helping to choose hymns or poems.

So, how should we treat people with learning disabilities following bereavement? The simple answer is easy- like any other person!

Reflect

Think about ways that staff avoid the issues around the death of a patient
Then think about the consequences of these actions and practices

Things staff do to avoid issues about death	Consequences of those actions and practices

Choose

As you read the following list of possible phrases, decide whether they would be helpful or unhelpful when talking to Fred (Michael's friend)

Phrase	Helpful	Unhelpful
1 "Michael's' gone away"	<input type="checkbox"/>	<input type="checkbox"/>
2 "He won't realise that Michael's gone."	<input type="checkbox"/>	<input type="checkbox"/>
3 "Don't worry, everything will be fine"	<input type="checkbox"/>	<input type="checkbox"/>
4 "What do you remember about Michael?"	<input type="checkbox"/>	<input type="checkbox"/>
5 "Fred's been much quieter since Michael died"	<input type="checkbox"/>	<input type="checkbox"/>
6 "It's time to move on- life's for the living"	<input type="checkbox"/>	<input type="checkbox"/>
7 "Let's get the bed filled."	<input type="checkbox"/>	<input type="checkbox"/>
8 "Fred, Michael has died"	<input type="checkbox"/>	<input type="checkbox"/>

Write

What can you do to support a person with learning disability who has just lost a fellow patient?

FURTHER ACTIVITY: A friend dies...

Think about a recent death.

- What did you and the other members of the team do to support fellow patients?

FURTHER READING: A friend dies

Journal articles

- Bonell-Pascual E. *Et al* Bereavement and grief in adults with learning disabilities. A follow-up study. *British Journal of Psychiatry*. 1999; **175**: 348-50.
- Dodd P. *et al* A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research*. 2008; **52**(Pt 5): 415-25.
- Dodd PC. Guerin S. Grief and bereavement in people with intellectual disabilities. *Current Opinion in Psychiatry*. 2009; **22**(5): 442-6.
- Dodd P. Dowling S. Hollins S. A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research*. **49**(Pt 7): 537-43.
- Dowling S. Hubert J. White S. Hollins S. Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research*. 2006; **50**(Pt 4): 277-87.
- Gault J. Bereavement: helping a patient with a learning disability to cope. *Nursing Times*. 2003; **99**(1):26-7.
- Guerin S. *Et al* An initial assessment of the psychometric properties of the Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID). *Research in Developmental Disabilities*. 2009; **30**(6): 1258-67.
- Hollins S. Esterhuyzen A. Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*. 1997; **170**: 497-501.
- Matthews D, Gibson L, Regnard C. One size fits all? Palliative Care for people with learning disabilities: *British Journal of Hospital Medicine*, 2010; **71**(1): 40-43.
- Read S. Elliott D. Exploring a continuum of support for bereaved people with intellectual disabilities: a strategic approach. *Journal of Intellectual Disabilities*. 2007; **11**(2): 167-81.

Further resources

- Blackman N. Todd S., (2005) *Caring for people with learning disabilities who are dying*. Worth Publishing
- Blackman N. (1999) *Helping people with learning disabilities cope with bereavement and loss*. Brighton: Pavilion Publishing,
- Cathcart F. - *Understanding death and dying: Your feelings* Kidderminster: British Institute of Learning Disabilities, 1994.
- 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.
- End of Life Care: A Resource pack for those caring for or supporting people with a learning disability at the end of life* NHS North East (2007)
- Hollins S. Tuffrey Wijne I. *Am I going to Die?* Books Beyond Words: RCPsych Publications/St Georges, University of London (2009)
- Hollins S. Dowling S. Blackman N. (2003) *When Somebody dies*: Books Beyond Words: Gaskell / St George's hospital Medical School London
- The route to success in end of life care – achieving quality for people with learning disabilities. National end of Life Programme, (2011). www.endoflifecareforadults.nhs.uk/publications/route-to-success-people-with-learning-disabilities
- When Someone Dies, An accessible guide to bereavement for people with learning difficulties and their carers*. Speaking up Publications (2006)
- Read S. Morris H. (2008) *Living and dying with dignity: The best practice guide to end of life care for people with a learning disability*. Mencap, London.
- Stedeford A. *Facing death : patients, families and professionals* London : Heinemann Medical Books, 1984. (178p. ISBN 0433315504)



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