UNIT 305:
Supporting Individuals with Loss and Grief before Death

Tutor’s / Assessor’s Handbook
Acknowledgements

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In the course of developing these materials they have drawn on the resources available through the National End of Life Care Programme, Social Care Institute for Excellence, Help the Hospices, e-ELCA and others.

Skills for Care wishes also to thank all those individuals and organisations that supported the external consultation. All sources have been acknowledged and references have been cited at the point of contribution.

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<td></td>
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</tbody>
</table>
**The purpose of this tutor book**

This book illustrates the learner’s resource and provides you with the answers and the learning points for each activity contained in the learner’s workbook. The answers provided are indicative answers and have been highlighted in red. It is important to note that a lot of questions ask the learners for their own views and opinions therefore in these cases there are no right or wrong answers.

This book also provides a resources guide at the end of each activity. This will signpost you to the various learning resources you will need to support the learner on an individual basis and/or support classroom based activities.

The resource guide will inform you about lesson plans which can be found in the appendices of this document. The resource guide also signposts you to the e-learning resources that are available to support the units learning activities, which are an optional resource. This information can also be found in the appendices. The resources are all in an editable format so that you can amend them as required. The way you deliver this unit is at your discretion and calls upon you to modify the materials in the way that suits your learner’s needs.

These workbooks have been formatted for print and it is therefore advised that you print the PDF version of the Learner Handbook for learners to use as a hard copy. PDF versions should also be available to the learner electronically so they can access the links to various Internet sites directly.

The Word version is available, however, for those who wish to use the workbook electronically, please note that in this instance the formatting of the workbook will be altered.

All the resources to support this learning can be found on the following website:
Table 1: Learning Outcomes and Assessment Methods

**EOL 305: Supporting individuals with loss and grief before death**

**Unit level 3**

**Credit value 2**

**Activity/study hours 15**

**Unit aim** The purpose of this unit is to assess the learner’s knowledge, understanding and skills in supporting individuals with loss and grief before death

<table>
<thead>
<tr>
<th>Learning outcomes</th>
<th>Assessment criteria</th>
<th>Own evidence log (optional)</th>
<th>Assessment Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>The learner will:</td>
<td>The learner can:</td>
<td>Page No</td>
<td>Type of evidence presented</td>
</tr>
<tr>
<td>1. Understand the impact of loss and grief on individuals approaching end of life and others</td>
<td>1.1. Describe what is meant by loss and grief before reaching end of life</td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td>1.2. Explain how the experience of loss and grief is unique to individuals and others</td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td>1.3. Describe stages of loss and grief commonly experienced by individuals with a life-limiting illness</td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td>1.4 Describe the effects of loss and grief on individuals and others</td>
<td></td>
<td>Knowledge</td>
</tr>
</tbody>
</table>
### Table 1 continued

<table>
<thead>
<tr>
<th>Learning outcomes</th>
<th>Assessment criteria</th>
<th>Own evidence log (optional)</th>
<th>Assessment Type</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The learner will:</strong></td>
<td><strong>The learner can:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Be able to support individuals and others through their experience of loss and grief</td>
<td>2.1 Support individuals and others to identify the <strong>losses</strong> they may experience</td>
<td></td>
<td>Competence</td>
</tr>
<tr>
<td></td>
<td>2.2. According to their preferences and wishes support individuals and others to communicate the losses they may experience</td>
<td></td>
<td>Competence</td>
</tr>
<tr>
<td></td>
<td>2.3 Support the individual and others through each stage of grief they experience</td>
<td></td>
<td>Competence</td>
</tr>
<tr>
<td></td>
<td>2.4. Support individuals and others experiencing loss and grief to access support services</td>
<td></td>
<td>Competence</td>
</tr>
<tr>
<td>3. Be able to manage own feelings in relation to loss and grief</td>
<td>3.1 Describe how own feelings about loss and grief can impact on the support provided</td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td>3.2 Use support systems to manage own feelings brought on by loss &amp; grief</td>
<td></td>
<td>Competence</td>
</tr>
</tbody>
</table>
Section 1: Introduction to EOL Unit 305

General Introduction to Unit 305

As a society we are not very good at supporting those who have experienced a loss, to mourn that loss. In reality, many people in our culture grieve but they do not mourn. Instead of being encouraged to express their grief outwardly, they are often greeted with messages such as ‘carry on’, ‘keep your chin up’, and ‘keep busy’. We expect the grieving person to ‘get over it’ and ‘move on’ as quickly as possible, to accepting what is happening to them.

This unit will introduce learners to the concepts of loss and grief. We all experience loss in our lives. However, when someone is faced with a diagnosis of a life limiting illness or a chronic health condition, there is often a huge sense of loss for the person they were, or the life they thought they were going to have.

Loss is not necessarily just about loss of life but many other aspects of a person’s life. It may involve loss of role, loss of self worth, loss of status in family, loss of job. Therefore support, regarding this sense of loss, can be for the individual who is ill as well as their family and friends.

When it does relate to loss of a loved one this again can begin early in an individual’s illness. This is known as pre-bereavement support. This then extends as the individual’s illnesses progresses and can continue for some time after the individual has died.

Sometimes, the way a person expresses their sense of loss and grief appears disproportionate (much greater) than expected in relation to the situation. Although each situation will be unique and we cannot know what it is really feeling like for someone, if this sense of loss has become so overwhelming that it is affecting a person’s ability to carry out their normal routine tasks e.g. eat, drink, wash and dress, and particularly if this is extended over a long period of time then they may require a much greater level of support than we can offer. Individuals may need to be referred to see trained psychologists or bereavement councillors. Therefore, if learners have any concerns these should be reported to their senior carers or doctors.

The unit will help learners understand the impact of loss and grief on individuals. It will provide them with the knowledge of how to support someone through their own unique loss and grief journey.
Learning Support

Due to the sensitive nature of End of Life (EOL) care, topics may be covered that can cause upset to learners, for example asking them to consider their thoughts about their own death, or watch video clips that include the views of people who are actually dying. Tutors / Assessors have a responsibility to ensure that learners are supported to learn safely and at their own pace, through a blended delivery style. It is recommended that at the introductory session with learners you complete a Support Agreement together, which will identify how they wish to be supported if they become upset whilst undertaking any of the following learning activities. You have a template Support Agreement in the appendix of this pack to use if you wish.

- **Lone study** – Identify support networks (these could be friends, family, colleagues) if the learner becomes upset.
- **One to one** – Ask the learner how they would like to be supported if they become upset.
- **Work based learning** - Ask the learner to identify a mentor or supervisor to whom they can go if they became upset at work.
- **Class room based learning** - ask the learner how they would like to be supported should they become upset during classroom sessions. You will not be able to leave the rest of the class so you should encourage learners to nominate a classroom buddy who could leave the classroom with them or identify a quiet place where they can go to be alone and have a cup of tea. This will be their decision and based on the facilities available.

Learner’s workbooks remind them that providing good EOL care can be one of the most rewarding caring experiences they can have. It is a privilege to know that they have cared for someone as they have taken their last breath in the world and that they have been part of their end of life journey. It is often a comfort to know that they have helped someone meet their EOL wishes and they have had a comfortable, dignified death. How they care for someone at end of life can remain with relatives and loved ones for a long time and you only have one chance to get it right. This is a big responsibility and so it is really important that learners take the learning activities seriously and that they also ensure that they learn at their own pace, to fully reflect and absorb the new EOL knowledge and skills they will be developing throughout this unit.
Learning Activities

As everybody has different ways of learning new information, the learner’s workbook contains a range of learning activities which will assist them in meeting the learning outcomes for the unit. Table 2 shows you the type of activities they may be asked to complete.

Table 2: Type of learning activities and symbols

<table>
<thead>
<tr>
<th>Activity Symbol</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>🌐</td>
<td>This symbol means you will need to access the internet *</td>
</tr>
<tr>
<td>📚</td>
<td>This symbol means you will be reading something</td>
</tr>
<tr>
<td>🗣️</td>
<td>This symbol means you will be asked to talk about something with friends, colleagues, your tutor or assessor</td>
</tr>
<tr>
<td>🧠</td>
<td>This symbol means you will be asked to think about something and you may be required to write your thoughts down</td>
</tr>
<tr>
<td>🎥</td>
<td>This symbol means you will be asked to watch a clip from a movie, TV programme or from the Internet e.g. youtube film clip *</td>
</tr>
<tr>
<td>📝</td>
<td>This symbol means you will be asked to write something in a workbook or a worksheet or even provide examples of your work with a service user e.g. a plan you have written</td>
</tr>
<tr>
<td>📚</td>
<td>This symbol means you be asked to research some information. This might be through the internet, books, and articles or from talking to people you know</td>
</tr>
<tr>
<td>🕒</td>
<td>This symbol means your assessor will plan to conduct an observation of your practice or will examine a work product</td>
</tr>
</tbody>
</table>

* Although every effort has been made to ensure video clips are appropriate, as they are often freely available to all, we cannot be held accountable for any inappropriate comments made about the clips. If you should see something offensive please following the offensive reporting guidelines of the web site concerned.

For each activity, learners will see a clock symbol which will provide you and them with a guide to how long the activity could take. Remember this is a guide and the activity may not take as long as it says!
Each activity will signpost learners to a range of resources to support their learning and where appropriate learning materials will be provided e.g. an information leaflet or a section of a website for them to read. If they are not in the learner’s workbook you will find these in the appendices of this handbook for photocopying.

**Here is an example of how each activity works:** The Learner’s Workbook shows each activity in the style below:

### Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

<table>
<thead>
<tr>
<th>1.1</th>
<th>1.2</th>
<th>1.3</th>
<th>1.4</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>2.2</td>
<td>2.3</td>
<td>2.4</td>
</tr>
<tr>
<td>3.1</td>
<td>3.2</td>
<td>3.3</td>
<td>3.4</td>
</tr>
<tr>
<td>4.1</td>
<td>4.2</td>
<td>4.3</td>
<td>4.4</td>
</tr>
</tbody>
</table>

**Assessment Method:** Reflective account  
**Assessment Type:** Knowledge

Learners are provided with space to complete each activity where appropriate. You will be provided with suggested answers. The answers given may not be exhaustive and you will need to draw upon your own knowledge and experience as well as additional research if required.

The appendices relating to this unit will provide you with all the resources you will need to deliver learning and support assessment for this unit. It supports classroom delivery, one to one delivery and distance learning for some aspects. We recommend that a blended delivery approach is most effective.

As learners complete the activities in each section, it is recommended that they log their evidence in table 1 (page 5). The grid at the beginning of each activity will show them assessment criteria they have covered (highlighted green). This will help you to map evidence across to awarding body matrix forms when you are confident that learners have demonstrated knowledge or competence. If learners don’t succeed at first, you can give your further support to get it right!

Table 1 (page 5) shows you and learners what learning outcomes will have to be achieved to pass this unit and what the assessment criteria will be. The table also identifies whether it is a skill or knowledge competency.

Each section will outline the activity and provide guidance on how to do the activity. Look for this symbol to help you with ideas, further learning and suggestions on completing the activity.
Plagiarism and Confidentiality

In their workbooks learners are reminded that plagiarism relates to claiming work to be your own when it is not. All work submitted must be the learners own and not copied from anyone or anywhere else unless the source of the information has been clearly referenced.

Learners are also reminded that confidentiality is essential in all aspects of care and that includes during their learning. They may be asked to reflect upon aspects of their role and people for whom they provide end of life care but it is very important that they do not disclose any personal information about them. They must also be very careful not to include any evidence that relates to individuals in their portfolios e.g. photographs or documents with their details on.

Portfolio of Evidence of Learning

We have recommended that learners keep a portfolio to record all the learning they have collected for this unit. This portfolio will demonstrate their understanding on the subject and will help you assess how the learner is meeting the relevant learning outcomes.
End of Life Care for All (e-ELCA)

End of Life Care for All (e-ELCA) is an e-learning platform from the Department of Health and e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland to support the implementation of the Department of Health's National End of Life Care Strategy (July 2008).

The e-learning platform is aimed at health and social care staff working in end of life care. The e-learning enhances the training and education of these staff, increasing their confidence and competence to ensure well informed, high quality care is delivered to people at the end of their life.

There are over 150 highly interactive sessions of e-learning within e-ELCA. These are arranged in 4 core modules:

- Advance Care Planning
- Assessment
- Communications Skills
- Symptom Management, comfort and wellbeing

Also, there are 3 additional modules in social care, bereavement and spirituality.

All of these sessions are freely available to NHS staff, social care staff who work in an organisation registered with the Skills for Care National Minimum Data Set (NMDS) or staff who work in a hospice. Staff who do not meet these criteria can register at a cost of £199.

There are twelve sessions which are freely available to everyone, including volunteers and clerical and administrative staff on an open access website: [www.endoflifecareforall.org.uk](http://www.endoflifecareforall.org.uk).

For further details see 'Access the e-learning'.

This is an additional resource and not mandatory for this unit as it may not be freely available to every learner.
Providing the right evidence

In their workbooks learners are informed that it is important that they provide the right type of evidence for the outcome they are trying to achieve. Remember there are 2 types of evidence:

a. Competence / Skill – This is where they need to demonstrate something about their practice.

b. Knowledge – This is where they need to demonstrate that they have learned and understood some new information.

Table 3 shows them the type of evidence that is acceptable for the type of outcome.

Table 3: Suitable Evidence

<table>
<thead>
<tr>
<th>Evidence methods</th>
<th>Explanation</th>
<th>Suitable for evidencing Competence</th>
<th>Suitable for evidencing Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct observation of you by assessor</td>
<td>You will be observed by your assessor carrying out your everyday work activities in your learning environment</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Professional discussion</td>
<td>You will take part in a pre-planned and in-depth discussion with your assessor</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Expert Witness evidence</td>
<td>An expert witness, such as a qualified professional, completes a testimony of your competence in the learning environment where it would not be possible for your assessor to observe</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Work products</td>
<td>A work product is evidence used in your work setting and produced, or contributed to, by you. For example, care plans, daily diaries, assessments</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Reflective diary</td>
<td>An on-going record of events produced by you that take place relating to your work, including evaluation and reflection</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Reflective statement</td>
<td>A record of events, produced by you, that relate to an event that happened in your learning environment, including evaluation and reflection</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Written and pictorial information</td>
<td>Written answers and completed activities set by your tutor or assessor</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>A scenario or case study</td>
<td>Written or verbal account of how you would respond to specific events set down by your tutor / assessor</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>
Reflective Practice and Reflective Accounts
Learners have been provided with the following information:

Reflective practice is a process, which enables you to achieve a better understanding of yourself, your skills, knowledge and practice. Although most of us engage in thinking about experiences either before, during or after an event, we need to document our understanding in order to clearly identify our learning, consider the outcomes and evaluate the experience. The aim is to identify what we have learnt in order to find new or different approaches to our future practice, or to recognise when something was best practice.

Learning comes from many different incidents and experiences that we have in life. We can learn much about ourselves, others, our job, our organisation and professional practice, as well as our abilities and skills, if we consciously take the time to reflect on our learning. A popular model of reflection is Gibbs 1988 – The Reflective Cycle. This is shown in the diagram below:

In some of the activities in this workbook, you will be asked to complete reflective accounts. We recommend that you follow the model above to ensure that you include everything.
**Pre and Post Learning Assessment**

We have provided learners with pre and post learning assessments in their workbooks. This will support you and them to assess what they knew before and what they have learned when completed.

The Learner's Workbook has a table asking the learner to rate how confident they feel about understanding and supporting the spiritual needs of those they care for. 1 being not very confident and 5 very confident. There is a second, identical table, at the end of the workbook for them to complete again.

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding loss and grief issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your knowledge of the various models of loss and grief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to support people communicate their loss and grief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to help others identify their losses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How to manage your own feelings of loss</td>
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<tr>
<td>Knowledge about how personal feelings of loss and grief can impact on the care given</td>
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</tbody>
</table>
Section 2: Activities
Introduction to supporting individuals with loss and grief before death

This unit will help you to explore the feelings of loss and grief that an individual will experience before they die. As you work through this unit you will gain a better understanding of the impact of this loss and grief on individuals, their families and others as they approach the end of their life.

We all experience loss in our lives, perhaps the loss of a job or end of a relationship. However, when someone is faced with a diagnosis of a life limiting illness or a chronic health condition, there is often a huge sense of loss for the person they were, or the life they thought they were going to have. This sense of loss causes a grief reaction which can be expressed through a range of feelings, thoughts and behaviours.

This unit will help you understand that people’s experience of loss and grief is unique to them. It will describe some of the stages of loss and grief that individuals may go through and prepare you to support them through their journey of loss and grief.

Through this unit you will also be asked to explore your own feelings about loss and grief and how this can affect the care and support you give to others. In addition, we will discuss how important it is for all health and social care workers working with individuals at end of life care to access support.

This unit will therefore focus on 3 main issues

- Understanding the impact of loss and grief on individuals approaching end of life and how this affects others
- How to support individuals and others through their experience of loss and grief
- How to manage your own feelings in relation to loss and grief

This can be a very emotional and at times upsetting topic, so please ensure that you refer to your support agreement and work through these activities at your own pace.
Activity 1 – Let’s Talk about Loss and Grief

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when you have successfully completed it.

<table>
<thead>
<tr>
<th></th>
<th>1.1</th>
<th>1.2</th>
<th>1.3</th>
<th>1.4</th>
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<tbody>
<tr>
<td>2.1</td>
<td>2.2</td>
<td>2.3</td>
<td>2.4</td>
<td></td>
</tr>
<tr>
<td>3.1</td>
<td>3.2</td>
<td></td>
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</tbody>
</table>

Assessment Method: Scenario question and answer and personal reflection
Assessment Type: Knowledge

These activities will help you define what we mean by loss and grief and the impact of loss and grief on individuals approaching end of life.

We will also explore and how loss and grief can affect others so that you are aware of the needs of families and others at this difficult time.

Tutor/Assessor Guidance:

These activities will assist learners to think about their own experiences of loss and grief. These can be very emotional activities for learners and old feelings of grief and loss may resurface. Ensure the learner support agreement has been completed before the learners start these activities.

Loss and grief is an individual unique experience and people express grief through a range of emotions crying, shouting, becoming angry or withdrawn.

Grief is the emotional response to losing something that is precious; it could be relationship, job, loss of health, loss of a person.

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Activity 1: Let’s Talk about Loss and Grief

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>About 2 hours</td>
</tr>
</tbody>
</table>

Loss has been described as

‘The disappearance of something cherished, such as a person, possession or property.’ (Dyer 2006)

References
Dyer K. 2006 Definition of Loss
http://dying.about.com/od/glossary/g/loss.htm
Think of a time when you have experienced loss, this could be a job, a friendship or the death of a family member or pet or loss of a possession.

- What was your loss?
- How easy or difficult was it for you to talk about your loss to others?
- What emotions were you feeling?
- How did you express these feelings? (e.g. talking, crying, being quiet)
- How did other people respond to what had happened and how you were feeling?
- Do you think your reaction was similar to how others may have responded to the same situation, explain your answer?

These answers will be subjective according to the learner’s experience of loss. It should include feelings of distress, crying, anxiety, fear etc.

People find it hard to talk about loss for fear that emotions of loss will rise to the surface again.
Losses approaching EOL

Society gives people who are dying a different role in life. They are no longer expected to struggle to find a cure and recover, instead they are encouraged to reach a peaceful state with others and offer parting gestures. They are expected to reach some type of peaceful contented conclusion to their life story.

However this transition to becoming someone who is dying is not an easy journey and individuals have to deal with a sense of loss and the emotions that come with that great loss of life.

Let us consider the sense of loss somebody at EOL might be feeling. The following describes all the losses someone at EOL may be experiencing.
As we can see, someone at EOL may face many losses. We will now explore how an individual might respond to these losses through the ‘grief process’.

**Grief and Grief reactions**

Grief can be described as the universal, natural response to loss that is typically expressed through thoughts, feelings and behaviours. Thinking about all the losses identified above, write down how you think somebody at EOL might react to the losses identified in the grief reaction table.

**Grief reaction table**

<table>
<thead>
<tr>
<th></th>
<th>Loss of independence</th>
<th>Frustration, anger, feeling a failure, a burden on others, helpless</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Loss of intimacy</td>
<td>Lonely, frustrated, unattractive to partner, insecure etc.</td>
</tr>
<tr>
<td>2</td>
<td>Loss of self image</td>
<td>Ugly, unattractive, not feeling whole, depressed, anxious, loss of self.</td>
</tr>
<tr>
<td>3</td>
<td>Loss of role</td>
<td>Useless, hopeless, insecure, loss of self, loss of pride, anxious.</td>
</tr>
<tr>
<td>4</td>
<td>Loss of finances</td>
<td>Anxious, worried, lack of feeling secure re finances, effect on others, how will they cope?</td>
</tr>
<tr>
<td>5</td>
<td>Loss of their future</td>
<td>Fear, anxiety, anger, worry, tearful, why me?, disbelief</td>
</tr>
<tr>
<td>6</td>
<td>Loss of privacy</td>
<td>Anger, humiliation, embarrassment, burden, shy</td>
</tr>
</tbody>
</table>

**Grief as a unique business**

Although recognised as a universal natural response to loss, the intensity, timing and the way in which people experience and express their grief is unique to each individual. The way in which someone responds to loss through death can have similarities to the ways in which people respond to other significant losses in their lives such as divorce, redundancy and illness.

Grieving is a personal and highly individual experience. How someone grieves depends on many factors.
The grieving process takes time and healing happens gradually. It can't be forced or hurried and there is no 'normal' timetable for grieving. Some people start to feel better in weeks or months. For others, the grieving process is measured in years.

**Loss and Grief Scenario**

Lucy is a 38 yr old nurse married to John age 36 yrs who is a teacher. They have 2 children Emma aged 8 and Ben who is 6 years old. One year ago Lucy was diagnosed with breast cancer. As a result, she had a mastectomy and was treated with chemotherapy. Lucy and John were recently told that Lucy now has terminal cancer as it has spread throughout her body. Doctors advised Lucy that she has approximately 6 months to live. Lucy wants
the whole family to spend as much time together as possible and John has agreed to give up his job to care for her.

In the boxes below describe:
- Lucy’s loss and grief reactions might be
- John’s loss and grief reactions might be

<table>
<thead>
<tr>
<th>Lucy’s Loss</th>
<th>Lucy’s Grief reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of life</td>
<td>Fear, crying, anger, acceptance she will die, making plans, making wishes.</td>
</tr>
<tr>
<td>Loss of mother role</td>
<td></td>
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<tr>
<td>Loss of wife/lover</td>
<td></td>
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<tr>
<td>Loss of job</td>
<td></td>
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<tr>
<td>Loss of body image</td>
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</table>

<table>
<thead>
<tr>
<th>John’s Loss</th>
<th>John’s Grief reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of wife</td>
<td>Fear, anger, worry, financial security, effect on children, overwhelmed, doubt that he can stay strong for everyone, could drink, leave etc.</td>
</tr>
<tr>
<td>Loss of job</td>
<td></td>
</tr>
<tr>
<td>Loss of role as husband/ lover</td>
<td></td>
</tr>
<tr>
<td>Loss of mother to his children</td>
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</table>

**Emma’s and Bens Loss**

Preparing children for the loss of a parent is an incredibly hard thing to do. Health professionals such as social workers, palliative care nurses, doctors, counsellors and psychologists can help.

It is best to talk openly and honestly with children and to use straightforward language. Talking openly allows children to cope in the future. It also gives the parent the opportunity to show how much they care for their child and allows them to sort out any issues they may have.

**Talking with Children about Dying**

Use straightforward language, which includes saying the words ‘dying’ or ‘died’,
when you tell young children about death. Saying a parent is ‘lost’ or has ‘passed away’ can be confusing. They may wonder why no one is looking for the person who has died.

Saying a person has ‘gone away’ may make a child feel that they’ve been abandoned. Try not to use ‘going to sleep’ to describe dying because young children may then be afraid of going to sleep. Young children often need to be reassured that they’re not responsible for someone’s death, as they can often find reasons to blame themselves.

It’s difficult to describe to a child how someone will die, as no one can ever predict exactly when it will happen. Children need to have gradual explanations about what has happened and why, and what may happen next.

Older children may want to know more about what happens when someone is dying and need more information.

A child’s understanding of death generally depends on how old they are:

**Very young children (aged three and under)**
Children under three can pick up that something very serious is happening. They don’t understand that death is permanent and may confuse it with sleep. However, children as young as three can grieve.

**Young children (aged 3-5)**
Children aged 3-5 may have heard about dying but don’t really understand what it means. They may imagine that a dead person will come back or is living somewhere else. They often need to be reminded the person who has died will not come back again but that they can still remember all the things they did together.

**Older children (aged 6-12)**
Children aged 6-12 know about death but may not always understand the emotions they feel. By about age 9, children begin to understand death more like adults. Their worry is more likely to be that death is frightening or painful.

Emma and Ben have questions
Here are some common questions children ask

**What will happen to me?** Children worry who will look after them

**Am I going to die too?** Children worry they will die next. They need reassurance that they will probably be very old when before they die.

**Will other people I love die too?** Children worry they will be left alone so it is important that they know other people around them are not going to die for some time yet.

**Is it my fault?** It is important that children know it is no-one’s fault that their parent is dying.

Cruse the bereavement charity has a special website for children who are experiencing loss and grief.

[RD4U](http://www.crusebereavementcare.org.uk/CYPResponses.html) is a website that children have created to share to coping strategies with bereaved peers.

### Helping Children to express their Loss and Grief

The death of a parent or sibling is one of the most fundamental losses a child will ever face. Studies show that if childhood grief is not dealt with appropriately it can have a deep and lasting effect on a child’s emotional wellbeing and cause problems later in life.

Look at the following web site and read the common reactions children have to loss and grief

http://www.crusebereavementcare.org.uk/CYPResponses.html
Choose one of the reactions and write down how you might help Emma or Ben through this loss reaction in the box below.

Learners can identify any one of the following grief reactions highlighted by CRUSE

- Shock
- Denial
- Anger
- Bargaining
- Guilt
- Depression/sadness
- Acceptance

Refer to the identified web site for detailed guidance about support for each response.

Below are some suggestions for coping with bereavement put forward by children and young people who have been bereaved.

- Let teachers and school know what is happening
- Get creative - Encourage them to write a poem or draw about their feelings
- Encourage them to make a memory box. Gather together letters, badges, photographs, and keepsakes and put them in to a special memory box that they can reopen and reminisce over when they need to.
• Try to focus on some of the good times – create a DVD
• Encourage them to talk to people; don’t let their hurt grow until they break down.
• It is OK for them to feel sad, angry and scared and to cry.
• It is also OK for them to feel happy and enjoy things.
• It is OK if the loved one they have lost is not in their thoughts all the time.
• Hug those loved ones who are still here.
• Remember that they are not alone and that help is out there if they need it.
• Bereavement can seem to last forever, but it does get easier with time.

The following website is full of helpful tips for parents who have a terminal illness on how to help their children through this difficult time.

http://www.cancer.org/treatment/childrenandcancer/helpingchildrenwhenafamilymemberhascancer/dealingwithaparentsterminalillness/dealing-with-a-parents-terminal-illness-to

Cruse, the bereavement charity, has a special website for children who are experiencing loss and grief

Read some of their stories at the website below.

http://www.rd4u.org.uk/personal/month.html

Resources for further learning
NHS Choices - Dealing with Loss
http://www.nhs.uk/Livewell/emotionalhealth/Pages/Dealingwithloss.aspx
Alzheimer's Society - Grief and Bereavement Factsheet
http://www.alzheimers.org.uk/factsheet/507
Royal College of Psychiatrists - Bereavement leaflet
http://www.rcpsych.ac.uk/expertadvice/problems/bereavement/bereavement.aspx

Winston’s Wish is a charity for child bereavement; to find out more information on how to support bereaved children refer to

http://www.winstonswish.org.uk/
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 1 - Resources

Web resources

NHS Choices - Dealing with Loss
http://www.nhs.uk/Livewell/emotionalhealth/Pages/Dealingwithloss.aspx
Alzheimer’s Society - Grief and Bereavement Factsheet
http://www.alzheimers.org.uk/factsheet/507
Royal College of Psychiatrists - Bereavement leaflet
http://www.rcpsych.ac.uk/expertadvice/problems/bereavement/bereavement.aspx
Dyer .K 2006 Definition of Loss
http://dying.about.com/od/glossary/g/loss.htm
Winston’s Wish is a charity for child bereavement to find out more information on how to support bereaved children refer to
http://www.winstonswish.org.uk/
CRUSE children’s stories about loss and grief
http://www.crusebereavementcare.org.uk/CYPResponses.html
CRUSE site for children
http://www.rd4u.org.uk/personal/month.html

Activity Sheets

Lucy and John Scenario

Power Points/ Lesson Plans

Loss and Grief

E-learning resources

ELCA 305 Refer to ELCA 305 document for e-learning modules that support these activities in the appendices.

Further Reading

Activity 2 – The Common Stages of Grief

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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<td>3.1</td>
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Assessment Method: Reflection
Assessment Type: Knowledge

Tutor/Assessor Guidance:

These activities will introduce the learner to various theories about what stages people go through in their grief journey. As a health or social care worker it is important that they can identify how best to support an individual who is grieving so that they can signpost them to more senior staff or specialist services if required. All resources needed for these activities can be found in the resource guide.

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Activity 2: The Common Stages of Grief

About 2 hours

Theories and Models of the Grieving Process

Theories and models of grief and bereavement attempt to explain the experience of grief and provide useful frameworks for increasing our understanding of what level and type of support individuals might need during their grieving journey.

Kübler-Ross: 5 Stages of Grief Model (1969)

(Denial, Anger, Bargaining, Depression and Acceptance)

This model has 5 stages of grief, although they are not completed one after the other and not everyone goes through all stages.
1. Denial
This first stage of grieving helps individuals to survive the loss. In this stage, the world becomes meaningless and overwhelming. Life makes no sense. The individual is said to be in a state of shock and denial, feeling numb. They wonder how they can go on, if they can go on, why they should go on. They try to find a way to simply get through each day. The authors believe that denial and shock help us to cope and make survival possible. Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature’s way of letting in only as much as we can handle.

2. Anger
The authors consider that anger is a necessary stage of the healing process. Individuals need to feel anger, and the more anger that is felt the less anger the person will feel and the more they will heal.

3. Bargaining
In this stage the author considers before a loss, the individual will do anything if only their loved one would be spared. “Please God, ” they bargain, “I will never be angry at my wife again if you’ll just let her live.” After a loss, bargaining may take the form of a temporary truce. “What if I devote the rest of my life to helping others. Then can I wake up and realize this has all been a bad dream?”

The grieving person wants life returned to what is was; they want our loved one restored. They want to go back in time: find the tumour sooner, recognise the illness more quickly, and stop the accident from happening if only, if only, if only. Guilt is often the bargaining’s companion. The “if only” causes individuals to find fault in themselves and think “if only I could have done differently”.

4. Depression

After bargaining, the grieving individual's attention may move into the present. Empty feelings present themselves and grief enters their lives on a deeper level, deeper than they ever imagined.

This depressive stage feels as though it will last forever. It is important to understand that this depression is not a sign of mental illness. It isn't usually clinical depression, more a deep sense of sadness. It is the appropriate response to a great loss. Individuals withdraw from life, left in a fog of intense sadness, wondering, perhaps, if there is any point in going on alone. Why go on at all? Depression after a loss is too often seen as unnatural: a state to be fixed, something to snap out of.

The loss of a loved one is a very depressing situation, so depression is a normal and appropriate response. To not experience depression after a loved one dies would be unusual. Depression is said to be one of the many necessary steps along the way to healing.

5. Acceptance

Acceptance is often confused with the notion of being ‘all right’ or ‘OK’ with what has happened. This is not the case. Most people don’t ever feel OK or all right about the loss of a loved one. This stage is about accepting the reality that their loved one has physically gone and recognising that this new reality is the permanent reality. Finding acceptance may be just having more good days than bad ones. People at this stage gradually begin to enjoy life again, though some may feel they are betraying their loved ones. People cannot truly live again until they have given themselves time to grieve.
Worden (1989) 4 tasks of Mourning

Rather than seeing grief as a single event that people need to ‘get over’, William J Worden (1989) described grief as a process that people needed to work through and come to terms with. According to Worden the bereaved need to work through four key tasks.

1. To accept the reality of loss
2. To experience and work through the pain of grief
3. To adjust to an environment in which the dead person is missing
4. To withdraw emotional energy and reinvest in new relationship

(Stroebe & Schute, 1999). Dual Process Model of Grief

This model believes that it is too simplistic to think that people grieve in a stage after stage way. Indeed the complex nature of people’s lives means that as well as grieving they have to deal with the everyday business of living.

It is through doing grieving activities such as crying etc, then being distracted with other life issues, that eventually an individual begins to break the bonds and move on.

Dual Process Model of Grief

Everyday life experience
Consider that rather than totally withdrawing all ties with the deceased, it is now considered normal and healthy for the bereaved to maintain a connection or ‘continuing bond’ (Klass et al, 1996) with the person who has died through remembering them. This could mean keeping photographs and marking special dates and anniversaries, whilst also moving on with their life.

With kind permission this section has drawn on materials adapted from McCulloch & Lane (2010) Supporting the Bereaved: An introductory workbook for health & social care staff involved in End of Life Care
Pub NHS Gloucestershire

Available online
www.nhsglos.nhs.uk

The Range of Response to Loss model (RRL)

The Range of Response to Loss (RRL) model of loss and grief suggests that responses to loss can be seen by a range of reactions. At one end is the distressing rise of overwhelming emotions and at the other is the pull to counter this sense of powerlessness, with a desire to regain control.

In the overwhelmed response, feelings dominate – sadness, anger, guilt, helplessness, etc.
In the controlled response, a more thinking reaction dominates. By avoiding dealing with feelings and concentrating on thinking, taking action and focusing on the practical elements of caring; emotions are kept at bay. The management of these competing grief reactions is resolved by various coping factors. An individual is said to have resilience or vulnerability.
**Resilience** is the ability to switch between the emotional, social and practical consequences of loss.

Factors which affect an individual have been identified as:

- **Personal resourcefulness** - flexibility, courage, perseverance, sense of self worth
- **A positive life perspective** - optimism, a capacity to make sense of experience
- **Social embeddedness** - availability of support, capacity to access support

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**Vulnerability** is when there is incapacity to manage the complex emotions of grief, e.g. where there is conflict and tension between the feelings of overwhelming distress and the desire for control, and/or limited sources of social support or social pressures.

This leads to strong and distressing feelings of powerlessness and a very uncomfortable tension between overwhelming emotions and a desire to control.

Risk factors which contribute to vulnerability in bereavement:

- **Circumstantial risk factors** - unexpected death, untimely death, horrific death, multiple losses, stigmatised death etc and concurrent stresses e.g. caring for others, financial problems etc
- **Personal risk factors** - insecure attachment with the deceased, young children, adolescents etc and physical, psychological problems, past history of difficulty in coping with stressful situations etc
- **Interpersonal risk factors** - lack of social support, and/or makes poor use of support, loss of a child etc
There is an uncomfortable tension between the feelings of overwhelming distress and the desire for control.

The process of being able to cope is the capacity to:

1. face the emotional consequences of loss with acceptance
2. achieve a realistic sense of what can be changed/controlled
3. reach a sense of balance, usually as a result of having good support

At times of crisis (such as terminal diagnosis, recurrence, or the stopping of active treatment) some family members may show a tendency to being overwhelmed and others to control.

Many people will feel more comfortable in one mode of response but most will react in both these ways at various times when faced with the terminal illness of a family member.


Choose a grief theory and reflect upon a personal loss or talk to a friend or colleague who has experienced loss such as loss of a job, relationship, person or pet.

Describe the stages of grief you or they went through below:

- Learners should ensure answers reflect the model they are using, highlighting the various stages of their chosen model.
- The emotions and feeling will be subjective but they should demonstrate that they understand their chosen model.
A word about Complicated Grief

An individual’s sadness at loss may never go away completely, but it should not remain centre stage. If the pain of the loss is so constant and severe that it keeps them from resuming their life, they may be suffering from a condition known as complicated grief.

Complicated grief is like being stuck in an intense state of mourning. The person may have trouble accepting the loss long after it has occurred. Their feelings about it disrupts their daily routine and undermines their other relationships as they struggle to manage everyday activities such as going to work, seeing friends etc.

If someone exhibits these signs after 12-18 months then they may need more specialist help and bereavement support.

Cultural Issues in Loss and Grief

The ways in which people of all cultures feel grief personally are similar. This has been found to be true even though different cultures have different mourning ceremonies and traditions to express grief.

Cultural issues that affect people who are dealing with the loss of a loved one include rituals, beliefs, and roles.

Helping family members cope with the death of a loved one includes showing respect for the family’s culture and the ways they honour the death. The following questions may help care and health workers learn what is needed by the person's culture:

- What are the cultural rituals for coping with dying, the deceased person’s body, and honouring the death?
- What are the family’s beliefs about what happens after death?
- What does the family feel is a normal expression of grief and the acceptance of the loss?
- What does the family consider to be the roles of each family member in handling the death?
- Are certain types of death less acceptable (for example, suicide), or are certain types of death especially hard for that culture (for example, the death of a child)?

Death, grief, and mourning are normal life events. All cultures have practices that best meet their needs for dealing with death. Social care workers who understand the ways different cultures respond to death can help the individuals of these cultures work through their own normal grieving process.
Source: National Cancer Institute

http://www.cancer.gov/cancertopics/pdq/supportivecare/bereavement/Patient/page7#Keypoint39

Further resources to support learning
Elizabeth Kübler-Ross Five Stages of Grief

Each culture has its own traditions, rituals and ways of expressing grief and mourning.
http://www.griefspeaks.com/id90.html

Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
**Activity 2 - Resources**

### Web resources


Grief speaks [http://www.griefspeaks.com/id90.html](http://www.griefspeaks.com/id90.html)

### Activity Sheets

Lucy and John Scenario

### Power Points/ Lesson Plans

Loss and Grief slides 11 onwards
Loss and Grief Lesson Plan

### E-learning resources

ELCA 305 Refer to ELCA 305 document for e-learning modules that support these activities in the appendices.

### Further Reading

Relf, Machin and Archer *(2012)* Guidance for bereavement needs assessment in palliative care Second edition pub Help the Hospices
Activity 3 – The Effects of Loss and Grief on Individuals and Others

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Scenario questions and answers
Assessment Type: Knowledge

Tutor/Assessor Guidance:

As we have seen, grief is a natural process. It is that intense fundamental emotion, a universal experience which makes us human. Grief is extremely hard work over a period of many painful months or years. People grieve because they are deprived of a loved one and the sense of loss can feel overwhelming.

The loss of a spouse, child or parent affects our very identities - the way we define ourselves as a husband, wife, parent or offspring. Moreover, grief can arise from the survivor's sudden change in circumstances after a death and the fear of not knowing what lies ahead.

The imminent death of someone close can be a life-changing experience. In the following activities we will explore the effect of loss and grief on carers and others who are facing EOL.

The following activities will ask learners to consider what factors and circumstances may affect the grief of others, in particular

- Anticipatory grief
- Loss of self
- Loss of the caring role
- Loss experienced by health and social care workers and other service users
Activity 3: The Effects of Loss and Grief on Individuals and Others

About 2 hours

**Anticipatory Grief**

If someone has had a prolonged illness or serious memory impairment, family members may begin grieving the loss of the person's 'former self' long before the time of death. This is sometimes referred to as anticipatory grief. Anticipating the loss, knowing what is coming, can be just as painful as losing a life.

Family members may experience guilt or shame for 'wishing it were over' or seeing their loved one as already 'gone' intellectually. This is particularly the case of those who are suffering from Dementia etc.

It is important to reassure family and carers that these feelings are normal, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues and seek out the support of spiritual advisors, family and friends. It is a good opportunity to discuss Advance Care Planning.

It is also an opportunity for the person who is dying and their loved ones to do the things they have always wanted to do.

Listen to Lesley’s and David’s Story in the following video clip:

Ensure you press Ctrl and click on link to make link work

http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness/Topic/4180/

Do you think Lesley is preparing for David’s death? Discuss your answer, why do you think this?

The learner should identify that both have anticipatory grief, they are anticipating his death and planning for it. They are ensuring they get the most of the time left. It is clear that Lesley has already started grieving.
Loss of self

Caring for a person with a terminal illness is not something that we choose to do but it is not something that can easily be avoided when it occurs in someone very close to you. Healthtalk interviewed 40 people about their experiences of caring for someone with a terminal illness. Some were currently caring for a sick friend or relative and others had been bereaved. Watch the interviews to see how carers cope with their new roles.

Ensure you press Ctrl and click on link to make link work

http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness/Topic/4174/

Being a carer often means losing your own identify, giving up your job, having financial loss. Many carers own health suffers as they lose sleep and try and juggle their roles.

Listen to Lynne’s and Maggie’s experiences of juggling their carer’s role.

Ensure you press Ctrl and click on link to make link work

http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness/Topic/4165/

What emotions and feelings come through on the clips you have seen, how are the carers feeling? Do they express any losses?

Lynn and Maggie are both expressing guilt, loss, anger, and some degree of depression/sadness.

Maggie is displaying guilt at letting her work down “I’m sorry I’m going to have to leave”

Lynn is displaying feelings of loss for her mother and some guilt for not coping, not feeling mother had the best care – cue was it’s all about money! )

Loss of the caring role

For many carers, when the person they have been caring for dies, as well as the grief of losing someone close, there is the added difficulty of having to build their lives again almost from scratch.
Carers express a sense of loss of their caring role. Many have had to give up their jobs and social life to care. Their friends often drifted away and interests were put on hold.

This can lead carers feeling isolated and lonely with no sense of purpose in life when they lose the caring role. Many carers describe this as a ‘double loss’

The following film highlights the sense of loss some carers can feel at this time.

View life after being a carer.

Ensure you press Ctrl and click on link to make link work

http://www.nhs.uk/CarersDirect/guide/bereavement/Pages/Overview.aspx

Having viewed this film how did the carers feel about losing their caring role? How are they coping now?

Both carers state they were shocked, depressed, felt useless, did not know what to do with themselves now they were not carers. Both have begun to adapt to a new identity and have taken on others role eg volunteering and one has a new partner.

Loss experienced by social care workers and other residents

In addition to informal carers, health and social care workers can also experience loss when someone they have been caring for dies. In addition other service users can also experience loss, loss of a friend and companion.

This SCIE film focuses on how care homes support their staff after the death of a resident. It starts by showing a memorial service at Amberleigh House, a care home in Liverpool, during an annual event that celebrates the lives of residents who have passed away. The service is one of the ways that helps staff to come to terms with the loss of people that they have cared for. When a resident dies, there is a staff team meeting where people can speak openly about their feelings. Bereavement support is
also a key feature of one-to-one performance reviews. Liz Mumford, the manager of the home says that in the past, the needs of staff were rarely considered following the death of a resident, but by ensuring that they have plenty of support they are much better able to cope with loss.


When you have finished watching the film think about your own role and work setting. Make some notes below about how your own feelings of loss and grief can impact on the way you care for people:

**Notes:**

These answers will be subjective and personal to the learner.
Carers Loss & Grief Scenario

Rose (69) has been looking after Jim (72) for the last 12 years. Jim has Alzheimer’s disease. For the last 12 months Jim has been bed bound, he cannot speak and he no longer recognises Rose.

Before Rose was a carer she was a special events organiser at a large hotel, a job she really enjoyed, it was extremely busy but she loved meeting people.

Rose’s daughter and grandchildren live in Canada and although she Skypes them on a weekly basis, Rose is longing to go out and see them but fears she cannot as Jim is so poorly and at times this makes her feel angry at her situation and her life. At times she wishes Jim were dead. He was just a shell of her husband and what was the point in her being there, he didn’t even recognise her and kept calling her mother!

This morning Rose was very tired, Jim was ill again with another chest infection and he was coughing all night, which had kept Rose awake. Whilst in the kitchen making herself the first cup of tea of the day, Rose had one of her ‘down moments’ and suddenly felt a real sense of loss for her daughter and grandchildren and the life she could be having if Jim was not ill. Rose shed a few tears before going upstairs to check on Jim.

When she got to Jim’s bedroom the room was quiet, she opened the curtains and she could see that Jim had died during the night. Rose immediately rang for an ambulance. Jim was pronounced dead. Rose’s immediate emotion was one of sadness but then she felt relief, she suddenly felt free. This emotion was quickly followed by guilt.

When the paramedic had been and the undertaker had taken Jim away, Rose closed the door and sobbed and sobbed like she had never done before, saying she was sorry she wished he was dead, she didn’t mean it.

Now answer the following questions
1. What losses has Rose experienced in her life as a carer?
   - Loss of job
   - Loss of self
   - Loss of friends
   - Loss of being a wife as Jim does not recognise her anymore

2. What losses has Rose experienced as a mother and grandmother because of Jim's illness?
   Loss of contact with her daughter and grandchildren, loss of watching her family grow up

3. What grief reactions (emotions) do you think Rose has to losing Jim? Explain why she might be feeling this way.
   - Rose feels sadness and loss for Jim. However, she clearly feels very guilty for wishing he was dead, perhaps she blames herself.
   - Rose may also feel guilty as she felt some relief at being free from her ‘caring role’
   - Rose may also feel guilty because she blamed Jim’s illness for her not being able to see the grandchildren and having the life she wanted.
   - Rose may also not grieve that long as she has already lost Jim to dementia, some time ago
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 3 - Resources

Web resources
Social Care Institute of Excellence
http://www.scie.org.uk

Activity Sheets
Rosie & Jim Scenario

Power Points/ Lesson Plans
Effects of loss and grief on others

E-learning resources
ELCA 305 Refer to ELCA 305 document for e-learning modules that support these activities in the appendices.

Further Reading
Activity 4 – Identify the Loss

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Work product, testimony, question and answer
Assessment Type: Competence

Tutor/Assessor Guidance:

Learners will have now discovered that the sense of loss and grief in end of life care can happen at any stage from diagnosis of a terminal illness throughout the individual’s experience of illness and through to after death. Although there are commonly recognised stages of grief there are no rules. They should expect individuals in their care to experience it as it is a natural response but how and when this happens will vary from one situation to another. It is the care worker’s role to anticipate this so that they can help individuals recognise and be prepared for this sense of loss and support them when the loss is felt at its greatest.

Learners are asked to think about a time and where they have been involved in supporting an individual to think about loss particularly before a person has died. This may have included a conversation with them where they wanted to talk about how the illness was causing them to feel that they would be losing their sense of control over family matters or it may have been talking to a relative who was anticipating what it would be like when their loved one died.

If possible they should provide an anonymised care plan / case report or verified expert witness statement to evidence their involvement. Learners may not have been entirely responsible for the conversation but working with a senior carer at the time. If this was the case then a verified statement can be provided as supporting evidence.

Points that should be covered in the discussion:

- Recognising the signs of loss at all stages of illness
- Recognising different types of loss
- Understanding that loss is a subjective emotion and its impact upon an individual
- Picking up on cues
- How loss is expressed – emotionally, verbally and non verbally
- Supporting individuals to talk about the losses they may experience
- Recognising role and scope of role
Activity 4: Identify the Loss

About 2 hours

Provide an anonymised copy of an individual’s care plan that shows where you have been involved in supporting an individual to think about loss particularly before a person has died. This may have included a conversation where they wanted to talk about how the illness was causing them to feel that they would be losing their sense of control over family matters or it may have been talking to a relative who was anticipating what it would be like when their loved one died. (Tip: you may not have been entirely responsible for the conversation but working with a senior member of the team at the time).

Based on that care plan, answer the following points below:

• What was the situation?

• Who did it involve?

• What did they see as a loss?

• What types of things did they say?

• How did they express these words for example, were they sad or angry? How did you know this?

• How did you help them talk about the losses they may experience?

Learners are asked to think about a time where they have been involved in supporting an individual to think about loss particularly before a person has died. This may have included a conversation with them where they wanted to talk about how the illness was causing them to feel that they would be losing their sense of control over family matters or it may have been talking to a relative who was anticipating what it would be like when their loved one died. If possible provide an anonymised care plan / case report or verified expert witness statement to evidence your involvement.

Learners may not have been entirely responsible for the conversation but working with a senior carer at the time. If this was the case then a verified statement can be provided as supporting evidence.
Should include description of:

The situation and people involved will vary according to the learner's experience however they should describe their work setting, the individuals involved, the context and history of the situation and if the situation also involved working with other carers or professionals?

What the individual perceive to be the loss – did it relate to loss due to the affects of illness status or role, position in society and family, functional ability, physical ability, loss of intimacy, privacy, independence, self image, loss of material things?

If it related to the fact that they were ill and were going to die – loss of future. Or if it related to a relative who was talking about the loss they would feel once the individual had died

This will be individualised according to the context but should be along the lines of:

How will I live without …
Look at me I can no longer do…
I’ve lost everything
I haven’t any energy anymore – all I do is sleep
What does all this mean – where is God in all this?

Learners should also describe the ways individuals expressed these words emotionally; they may have been angry, sad, calm, depressed, withdrawn, fearful. They might appear to have felt relief or guilt. They should also describe the ways people showed this and identify that they could tell by what they were saying or the body language they were using.

The learners should describe effective listening skills, empathy, reflection, giving individuals time to express sense of loss. They may have also allowed individuals time to spend with family and friends or worked with other professionals to help individuals make memory boxes to leave for their family and friends. Although the emphasis is to provide psychosocial support, learners may have also provided practical support which enables individuals to have more energy to cope with the emotional side of loss experience.

If you were working with a colleague ask them to verify your involvement and to provide an expert witness statement. Your assessor will support you to do this.
Further resources to support learning

Booklet Supporting individuals cope with Loss and Grief in End of Life Care

Bereavement Advice Centre (free resource)
http://www.bereavementadvice.org/index.php

Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 4 - Resources

Web resources

http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness

http://www.helpguide.org/mental/grief_loss.htm

Bereavement Advice Centre (free resource)

http://www.bereavementadvice.org/index.php

Activity Sheets

Questions in workbook or small group work questions (see facilitator notes)

PowerPoint's/ Lesson Plans

Facilitator Notes – Identify Loss

Lesson Plan & PowerPoint - activity within supporting individuals through loss and grief workshop

E- learning Resources

E:ELCA modules 07 Bereavement

Further Reading

Booklet: Supporting Individuals cope with Loss and Grief in End of Life Care
Activity 5 – Supporting Stan and Rachel

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Scenario role play
Assessment Type: Competence

Tutor/Assessor Guidance:

An individual who is experiencing a sense of loss requires the support to help them to express their emotions and feelings so they can make sense of what they are experiencing and which therefore supports them to cope with the impact of these emotions.

It is important that learners recognise that occasionally someone’s sense of loss or grief can become so overwhelming that they will require professional support to cope. This will need to be provided by an experienced counsellor or psychologist. They may therefore require help to access this care and support workers should seek help from senior carers if they feel this is required.

However in general, as said earlier, the sense of loss and grief in end of life care is a natural process and individuals can often be appropriately supported by an empathetic and effective listener who acknowledges their loss and provides the space, support and permission to allow them to express their emotions.

Therefore having gained some knowledge in earlier activities and thought about how they have helped to support an individual in their care, learners now have the opportunity to practice their skills further by working with a colleague to work through a scenario. This should be a Senior Carer or their Mentor.

They are advised to read the ‘Supporting Stan and Rachel’ scenario and then answer and discuss the questions. This will enable them to gain more competence and insight into what types of loss an individual may experience. The activity also allows learners to practice their skills in responding to an individual’s questions, concerns and emotions regarding their loss.

The scenario allows learners to consider if they can recognise loss for both the individual who is ill and for their close relatives. This will include how losses can change throughout the illness and how carers cope if their loved ones move into a care setting which may change the carer’s role.
The activity will also explore their own response to these types of situation and how they feel if someone should cry. It will also allow them to consider how they deal with their own responses inorder for them to safeguard their own wellbeing.

Learners are advised to refer to the recommended booklet ‘Supporting individuals to cope with loss and grief’ before you start. This will give them pointers of what they should and shouldn’t say or do. They should also consider the knowledge gained in earlier sections to support them with this activity.

The activity can also be delivered as a larger group or classroom activity.

**Points that should be covered in the discussion:**

- Recognising the signs of loss
- Recognising different types of loss
- Understanding that loss is a subjective emotion and its impact upon an individual
- Effective Listening Skills
- Picking up on cues
- How loss is expressed – emotionally, verbally and non verbally
- Supporting individuals to talk about the losses they may experience
- Recognising role and scope of role

Learners need to complete this activity with the support of a senior carer, colleague or their Tutor as it will give them the opportunity to practice their skills in supporting an individual talk about their sense of loss.

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**Part 1 – Scenario & Role Play**

Work with a senior carer, colleague or your tutor.

Both read the following scenario and then together answer the questions to gain more insight into what types of loss an individual may experience, how they may express it and how you can respond to their questions and concerns regarding their loss.
Situation

Stan is 70-year-old gentleman with Stomach Cancer diagnosed 4 years ago. After his last visit to the clinic he has been told that the cancer is continuing to progress despite his treatments and it has now spread into the liver. It was quite difficult to hear but he was given the news that he possibly only has about 10 months to live. He lives with his wife Rachel who is 68; she is generally well at the moment but has always struggled with arthritis which can be at times quite debilitating.

They have three sons Matthew, Martin and Sam and five grandchildren with a great grandchild on the way. Sam is getting married in September and although he isn’t one for big ‘do’s’, Rachel is getting very excited if not a little sad because although he is now 32 Sam has always been her baby and the stay at home bird. She will miss him and all his comings and goings. They thought he would never move out!

Stan has now had to give up work because of the cancer but up until 3 years ago was working in the local boat building yard. Although he had semi-retired he never imagined he would ever give up completely. Besides the extra money it brought in to keep up with the bills, boat building is in his blood. When he was first sick many of this workmates would pop round and even take him down to the local if he was up to it but lately that seems to have gone by the by.

He has always been a keen veggie gardener and DIY-er; he has done much to the house and his children’s houses over the years. He loves watching the rugby and in his day was a keen player in the local club. He is pleased that his grandson seems to have inherited his love for the game and they would often have a family knock about. His grandson is doing well and he likes to go and watch him play when he is playing at home but more particularly when he feels up to it, although it was at least 3 months ago now.

Generally he is having good days and bad days. On his bad days he seems to be feeling sick all the time, can’t really cope with eating and he gets really bad gripping pains which completely exhaust him and he only manages to get out of bed for short periods. Other times he can be well enough to get out into the garden although he never makes it as far as his shed. If only he could get out there and finish that table he was making for Sam’s wedding present. In general he feels pretty useless and what’s the point of that car out there on the drive when he hasn’t been able to drive it since he’s been on those strong painkillers? Perhaps he ought to see if one of the boys needs it or then again perhaps he should sell it so Rachel doesn’t have the worry? It’s just as well they are on a bus route or else Rachel who has never driven would always be relying on someone else. He has lost a lot of weight and he is finding it harder to be tempted by Rachel’s meals. He wishes he could eat more because it might give him a bit more energy to help Rachel when she isn’t feeling so well.

He often thinks what is to become of all this. Is Rachel going to be OK? Will her boys look out for her? He hopes he doesn’t end up having to go into hospital but how will Rachel cope when he’s really sick? Will he get to see that great grandchild or even still be still here for that wedding for that matter?
You are calling to see Stan to help Rachel give him a bath which you do twice a week. Rachel is making a cup of tea after he has had a bath and you are helping him to get comfortable in the sitting room. Stan says that whilst Rachel is out of the room he would like to talk to you about a few worries.

Ask a Senior Carer or your mentor to play Stan.

STAN: I'm glad we have a few minutes because I wanted to talk to you.
YOU: You wanted to talk to me?
STAN: Yes I just can't get all these thoughts out of my head
YOU: Thoughts?
STAN: Yes you know, questions that just go round and round and round?
YOU: What sorts of questions?
STAN: Well (sighs and looks down at himself) just look at me all skin and bone, I'm half the man I was and I'm getting as weak as a sparrow!
YOU: Is it your weakness that is worrying you Stan?
Silence
You sit quietly and let Stan quietly think but after a few seconds you lean forward, gently touch his arm and say

YOU: Can you tell me what is worrying you?
More silence
You make eye contact and nod encouraging Stan to talk
STAN: Well you know...it’s everything... this terrible illness – I can’t be who I want to be, work’s long gone, I haven’t got any energy to do things and I’m certainly no use to Rachel anymore – what sort of husband am I? Just when she really needs me I go and get this. Who is going to look out for her? I can’t go and leave her now. What with Sam moving out an all.
You both sit quietly for while. Stan has tears in his eyes but tries hard not to cry and even gets a little embarrassed.
You lean forward and again just gently touch his arm, offer a tissue and say
YOU: You know it's ok to cry Stan.
After a little while you say to Stan
YOU: There seems to be lots going round in your mind - is there something in particular that worries you more than other things? It sounds like it might be Rachel?
STAN: It is Rachel but...
YOU: (in a gentle and encouraging tone) yes go on ...
STAN: Well because you know she’s not always well herself, will I have to go into hospital you know when I get real bad?
YOU: Would you prefer to go into hospital?
STAN: Not if I can help it but how will Rachel cope?
YOU: We can help you Stan, and the Community nurses and Dr will call in if you need them. Do you think you sons will help Rachel too?
STAN: I guess they will but I don’t really want to be a burden – they’ve got their own families and all.
YOU: Is that what you think that you will be a burden – is that what is worrying you?
STAN: Well yes I’ve always been the one helping them and besides I hate them seeing me like this – it’s only going to get worse isn’t it?
Before you can respond, Rachel returns to the room and says “what are you two chatting about?”
Stan closes the discussion by saying

**STAN:** Ah nothing love we was just putting the world to rights perhaps we can do the same again when you come next week?

**YOU:** If you’re sure Stan but I can always ask to come in again sooner if you want? I’m sure there’s a lot more we can talk about?

**STAN:** (nods, smiles and says) Do you know I’d like that.

THE END

And relax - chat about your home life or your views on something topical.

Now answer the following questions relating to the scenario.

1. Although you were being told what to say in the scenario, how did the conversation feel?

Learners should provide a personal account of how it felt to have the conversation?

2. Why do you think it was suggested that you should respond in these ways?

Learners should describe that they thought it was suggested that they should respond in these ways because the technique used good listening skills:

- The use of non verbal communication - touch, leaning forward, eye contact, reflection - not answering questions but reflecting words back
- Summarising and checking out what Stan was saying
- Asking Stan to clarify which were his most important worries
- Time and empathy
- Tone of voice – gentle, encouraging
- Use of silence
- Acknowledged his sadness and gave him permission to cry.

Stan was allowed to remain in control – he closed the conversation but support worker gave him the opportunity to talk again if he wanted. They respected that Stan did not want to involve Rachel at this time.

3. Did you feel you wanted to respond in other ways? If so give an example.

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This will be subjective but providing a Yes answer will mean they have reflected on the feelings felt and realistically there will always be other responses they could give.

However they should not be considering giving solutions or talking about their own grief or loss experiences. It should remain on Stan’s feelings.

4. Ask your colleague playing Stan what it felt like to be asked these questions?

Again this will be subjective but provides a way to help learners think about the impact of words and the way they express or say these words which they are using on others.

It is hoped that the role player felt that these would have been natural responses that they may have used to express their loss.

5. Which techniques, phrases or ways you said things showed that you were being supportive or that you were listening to Stan?

This answer should be similar to earlier question. As it is a fundamental skill, the learners will benefit by thinking about this again.

- The use of non verbal communication - touch, leaning forward, eye contact, reflection - not answering questions but reflecting words back,
- Summarising and checking out what Stan was saying
- Asking Stan to clarify which were his most important worries
- Time and empathy
- Tone of voice – gentle, encouraging
- Acknowledged his sadness and gave him permission to cry.

6. Ask your colleague playing Stan if it felt like you were being listened to? Were there particular times when it felt more than others?

This will be subjective but will allow learner to appreciate and discuss impact of techniques.

7. What types of losses were you and Stan discussing?
Loss of:

- Self image as a strong man
- Loss of weight
- Self dignity – not wanting sons to see him as he now is, doesn't want to cry
- Physical ability and energy
- Status in family – no longer providing or for or able to help Rachel or sons

8. In truth, the scenario could have run for some time and there is much more that you could have helped Stan with. Although we should never assume what people will consider to be a loss, or something that we think they should be grieving about - look back over the scenario what other losses Stan may have wanted to discuss?

- Future – may not be able to be see grandchild, or go to son’s wedding
- Friends & social life – no longer come and see him or go down to pub
- Role as granddad – not being able to play rugby with grandson, or watch him play.
- Role as Dad – helping family
- Ability to be self – carry out job, hobbies – DIY, make present for son, garden, drive
- Appetite
- Expand on ability to help Rachel
- Dignity and pride – not wanting people to have to do for him or see him as he is or as he becomes more poorly

9. The scenario ended with Stan agreeing he would like to talk again, if this were a real situation what would you do now?

- Advise Stan that you would need to make a note and tell Senior Carer responsible that they had this conversation but that it would remain confidential.
- As soon as able arrange a time to visit Stan as soon as possible.
- Seek support if feel that they are outside their level of experience
- Ask Stan if he would like to talk to someone more experienced

10. How might you start the conversation again? Provide a couple of example opening phrases.
Crying and feeling sad

In the scenario Stan appears embarrassed about crying and tries to stop himself. This is a common response but other individuals may have become completely overwhelmed and cried quite expressively.

By offering tissues like you did in the scenario to someone who is crying does this give a message that they should stop crying? If we don’t offer tissues are we being unsympathetic?

Notes:

There are no right and wrong answers here but learners should be aware of how actions can be interpreted in different ways, particularly if individuals are feeling sensitive. It may be a natural reaction to offer a tissue but it could be perceived differently and learners must be aware of this possible response. Discussion could also involve:

- Words should be used to support their gestures – for example in the scenario the support worker is giving Stan permission to cry.
- It is also important to give individuals the time and space to cry as it is a natural release of emotions.
- On the other hand individuals may have been taught that crying is a sign of weakness and encouraging them to cry may make them feel worse.
- Support workers need to learn how to read non verbal communication and also check out individual’s feelings by asking – do you find it difficult to cry? Do you think it would help if you had a good cry?
- Sensitivity and awareness is the key.

Sometimes when individuals cry it makes us want to cry. What are your and other’s views on crying with individuals we are supporting?

**Notes:**

Learners will find situations sad and it will be a natural response if they do feel the need to cry. Sometimes individuals take comfort if they can see that those caring for them are human and do feel emotion. However they maybe so absorbed with their grief that they may not even notice.

Learners should indicate that they need to learn to control this emotion as empathy and support is remaining focused upon the individual’s needs. Ideally they should take a deep breath and keep focused on what individual is saying or doing which will help them control.

Learners should indicate that they are aware that they should regularly discuss these types of emotions with a trusted colleague or through supervision so they can talk over these feelings.

Sometimes our emotion is triggered because it causes us to identify with the situation and we can relate to it. We may need to resolve other issues to be able to support others.

How do you think you should react if you do feel you might cry when talking to someone like Stan?

**Notes:**

Silences and stillness often give the space to enable you to gain control.

Deep breaths – keep focused on individual using active listening skills to keep focused. Have a hanky at hand for self so can discreetly control own emotion.

If individual notices rather than be embarrassed making comment like – ‘oh I’m crying now’ sometimes helps to reduce the tension felt. The moment though should be steered back to the individual – ‘but this is about you – can you tell me more of what is making you feel so sad?’

If situation became too intense ‘time out’ is ok for all but it might be appropriate to seek support from colleagues to help Stan discuss his situation rather than taking forward independently.
Use reflection to think about how you felt and how you can learn to control emotions.

Sometimes we can feel at a loss or very sad ourselves when we have been supporting people who are distressed. How you would ensure that this does not have a negative impact on your ability to look after someone?

Notes:

Discuss feelings with senior carer. Sometimes it is acceptable and viable to hand over care to others as sometimes the situation is too close to situations or experiences of our own. This puts us in a difficult situation as it becomes very difficult to remain focused on their needs.

Ask for support whilst visiting / supporting others.

Use clinical supervision and reflection.

Find ways to resolve own issues if these are impacting.

Maintain personal and professional support systems ensuring a good work /life balance.

Rachel’s Loss

Another aspect of this situation is how Rachel may be experiencing loss. Again we should not assume losses but from reading the scenario, what losses do you think she might be experiencing?

Future loss of husband and support – Rachel has been dependent on Stan to help her around home, shopping, driving, DIY, gardening etc.

Loss of confidant - sometimes partners do not feel as if they can confide their fears and anxieties with sick partners as they would normally with each other because they do not wish to burden them.

Loss of personal and intimate relationships – Stan’s illness and weakness may be affecting their ability to maintain their normal intimate relationship.

Loss of normal housewife role - she no longer has the task of cooking normal meals as he has no appetite.

Loss of privacy – having carers in home and having others involved in caring for her husband can potentially feel like space is invaded.

Future loss of son when he marries.

Loss of income from Stan.
Think about when Stan becomes more poorly. Rachel is likely to continue to be his main carer. What if Stan has to be transferred into a home or hospice to be cared for over the last few days of his life? This may cause Rachel to feel a further sense of loss i.e. loss of her role as a Carer. Imagine you were working within the home or hospice setting as a support worker how would you find out if she was feeling this?

Carers should be given the opportunity to continue caring and be involved in care decisions if this is what they and the individual wants.

Spend time with Rachel or ask senior colleagues support her to allow her to discuss how she is feeling about the changes. If she has any concerns or worries. Reassuring her that her feelings are natural.

Supporting Rachel and allowing her to express her feelings of loss before Stan dies will help her to prepare for her grief and is an important part of helping carers cope and have a less traumatic bereavement.

What could you to help her cope with this change? What are the pros and cons of carers maintaining this role and how does it affect their ability to cope?

Including her in the first assessment will demonstrate that her views are still respected.

Rachel's involvement should be discussed sensitively and openly with Stan – partners can often be protecting each other.

The ill individual may wish to hand over care to the professionals because having their partners care for them may not be what they want – particularly regarding personal or some nursing tasks. Whereas the carers may feel it is their duty to continue to care for them. Or they also may feel the need to be doing something physical as they do not want the time to think

Some carers though may need the physical break so it is important that they are advised of this to reassure them and prevent them from feeling guilty that they have handed over care.

Sometimes encouraging them to select less physical aspects of care but still key elements will enable them to feel still involved but be able to reserve their energies for giving emotional support to their partner and family. It may be more important that use time with partner and family to discuss worries or practical needs which can be emotionally draining rather than focusing on physical needs.

This is an area where learners recognise the scope of their responsibilities and seek support from senior colleagues as required.
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
# Activity 5 - Resources

**Web resources**


**Activity Sheets**

Scenario Role Play with review questions – Supporting Stan
Observer Sheets

**PowerPoints/ Lesson Plans**

Facilitator Notes – Supporting Stan
Lesson plan and PowerPoint Presentation – activity within Supporting Individuals through loss and grief workshop

**E-learning Resources**

E:ELCA modules 07 Bereavement

**Further Reading**

Booklet Supporting individuals cope with Loss and Grief in End of Life Care
Activity 6 – How did I Support?

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Reflective Account and Professional Discussion
Assessment Type: Competence

Tutor/Assessor Guidance:

Loss and grief can be expressed at any stage and in no standardised order.

Learners are advised to refer back to previous activities to remind themselves of the common stages and how people can move back and forth through these stages as they work through their emotions and learn how to cope with their impact.

In Activity 3 the learners considered how they helped an individual to identify loss but now they are asked to consider how they supported an individual through various stages of loss.

As explained this will not be in any set order so there is no right or wrong answer to how they experienced it but what is important is that they can show that they have the ability to recognise how an individual’s emotions can change and how they can help an individual through these stages.

Therefore learners are asked to provide a reflective account of how they have supported an individual through each stage of grief they experienced.

Points that should be covered in the discussion:

- How individuals emotionally express loss and grief – sadness, anger, withdrawn or denial
- Impact of sense of loss upon individual and people around them
- How does loss impact upon preferences and wishes
- Support strategies
- Multi-professional support
- Reflection of feelings when supporting individuals cope with and express loss
Activity 6: How did I Support?

About 2 hours

Provide a reflective account of how you have supported an individual through each stage of grief they experienced. You need to ensure you have this reflective account signed by a staff member who witnessed your support. Your assessor will advise you about this.

Think about when and how they expressed their sense of loss and grief – were they sad, angry or withdrawn or did they appear to be in denial?

How did they particularly express this emotion?
How did this impact upon them – did it affect their ability to carry out routine tasks or sleep?
How did this impact upon the people around them?
What did you do to support them?
How did they respond to your support?
Did you need to involve other professionals?
How did it concern their preferences and wishes?
How did you feel at the time?
How do you feel you helped – did you support them well?
Do you think how you felt could have had an impact on the support you provided?
On reflection what might you have done differently? What might you do in the future?

When you have completed your reflective account you should plan a professional discussion with your assessor to discuss the account further.

Reflective Account

Learners should provide a reflective account of how they supported an individual through each stage of grief they experienced.

It should therefore show how they helped them identify their sense of loss and then how the individual moved through the stages of grief - this may be sadness through to acceptance or a very varied pattern of moving rapidly back and forth between emotions. They should describe how they recognised these emotions and picked up on cues that they needed support.
Continued
The accounts and hence the stages will vary as there are no rules however the learners should illustrate how the individuals emotions changed and how they helped them to cope through these stages.

Whatever the emotion techniques of support stay consistent that is to say:

• Empathy
• Listening skills
• Time
• Enabling individuals to maintain a sense of control
• Consent to engage
• Confidentiality with regards sharing information
• Practical support and guidance

Reflective Account

They should give attention to what they have learnt and what they would put into place as most of our practice should have room for improvement in some way.

Signed by staff member:

Position:

Date:

Further resources to support learning

The Loss Begins - 15 minute e-learning programme CLIP (Help the Hospices)
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 6 - Resources

Web resources
http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness
http://www.nhs.uk/Livewell/emotionalhealth/Pages/Dealingwithloss.aspx

Activity Sheets
Questions in workbook or small group work questions (see facilitator notes)

PowerPoints/ Lesson Plans
Facilitator Notes – Supporting an individual through loss and grief
Lesson plan and PowerPoint Presentation – activity within Supporting individuals through loss and grief workshop

E- learning Resources
E:ELCA modules 07 Bereavement

Further Reading
Booklet Supporting individuals cope with Loss and Grief in End of Life Care
Activity 7 – Develop a Resource

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Research and written account/professional discussion
Assessment Type: Competence

Tutor/Assessor Guidance:

This final activity for learners to meet Learning Outcome 2 allows them to consider the resources they provide for individuals in their care and how they can signpost them to additional support services if required.

They are asked to develop or update a resource for their work setting which will enable individuals and others experiencing loss and grief to access support services.

They are then asked to write an account or have a professional discussion to show how the competently supported individuals to utilise this resource and access the services they required.

If a situation does not arise where there could use this resource they should write or talk about how they plan to use it.

Points that should be covered in the discussion:

- Organisational Bereavement Guidance Policy
- Signposting to organisational, local and national support services
- Information resources with accessible format versions
- Ability to recognise need to signpost to services or additional support outside the scope of the learners practice.
- Supporting colleagues to use resource
- Role in keeping resource up to date
### Activity 7: Develop a Resource

**Approximately 2 hours**

- Develop or update a resource for your work setting that will enable individuals and others experiencing loss and grief to access support services. You should include any resources you collect in your portfolio.

  It should include:
  
  - Your work setting bereavement guidance policy
  - How to access your local support services – named contact, telephone and internet
  - How to access national support services – named contact, telephone and internet
  - A selection of useful information leaflets

- Provide a written account or have a professional discussion with your assessor to describe how you have supported an individual to use this resource and access support services.

If a situation does not arise where you could use this resource then write or talk about how you plan to use it.

Use the box below to write your response if you choose a written account.
a. Learners need to develop or update a resource from their work setting which will enable individuals and others experiencing loss and grief to access support services.

It should include:

Their work setting bereavement guidance policy

How to access local support services – Named contact, telephone and internet

How to access national support services – Named contact, telephone and internet

A selection of useful information leaflets with coping strategies, financial and practical support.

b. Learners should provide a written account or a record of a professional discussion with their mentor to describe how they have supported an individual to use this resource and access support services.

If a situation does not arise where they could use this resource, they should write or talk about how they plan to use it.

An account should include how they helped an individual understand its content. It should be accessible to all or should include accessible format versions.

They should demonstrate that they understand accessing support is optional and that they followed a person centred approach.

Also, they may include an account of how they helped other staff use the resource.
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 7 - Resources

Web resources

http://www.healthtalkonline.org/Dying_and_bereavement/Caring_for_someone_with_a_terminal_illness

http://www.nhs.uk/CarersDirect/guide/bereavement/Pages/Overview.aspx

http://www.helpguide.org/mental/grief_loss.htm

http://www.bbc.co.uk/health/support/bereavement_usefulcontacts_index.shtml

The Loss Begins - 15 minute e-learning programme CLIP (Help the Hospices)

Activity Sheets

Workbook Exercise

PowerPoints/ Lesson Plans

Lesson plan and PowerPoint Presentation – activity within Supporting Individuals through loss and grief workshop

Handout - Support Services Resource List

E-learning Resources

E:ELCA modules 07 Bereavement

Further Reading

Bereavement support after a death Age UK (January 2012)

When Someone dies – A step-by-step guide to what to do – Money Matters – Age Uk (December 2011)

Bereavement, Loss and Grief Support Resources
Activity 8 – Reflective Account

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Reflective Account
Assessment Type: Knowledge

Tutor/Assessor Guidance:

This activity encourages learners to think about sources of support available in their workplace for loss and grief. They are required to develop or update a resource for their work setting that will enable individuals and others experiencing loss and grief to access support services. They are reminded to include any resources they collect in their portfolios.

<table>
<thead>
<tr>
<th>Activity 8: Reflective Account</th>
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Think of a time when your own experience of loss or grief could have impacted on the support you provided for a service user at the end of life.
- What were your feelings?
- Describe how you think those feelings may have affected your support
- Is there anything you would do differently in the future or have already changed as a result of that experience?
Reflective Account

Learners should cover all of the bullet points above to ensure they have met the learning outcomes. The answers are very subjective but you should look for evidence that the learner has really thought about and reflected on that experience. Learners should be able to identify something that they change as it is rare we deal with anything perfectly.

Further resources for learning

The effect of death on staff - 15 minute e-learning programme CLIP (Help the Hospices)


Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 8 - Resources

Web resources

Activity Sheets

Learner Handbook

PowerPoints/ Lesson Plans

E- learning Resources

E:ELCA modules 07 Bereavement

Further Reading
Activity 9 – Support Systems

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

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Assessment Method: Written tasks and work product
Assessment Type: Competence

Tutor/Assessor Guidance:

For this activity learners are required to think of a time when their own experience of loss or grief could have impacted on the support they provided for a service user at the end of life. They are encouraged to think about whether there was anything they would do differently in the future or have already changed as a result of that experience.

To demonstrate competence for Learning Outcome 3.2 learners will need to provide work products to show that they have accessed support to help them to manage their own personal feelings bought on by loss and grief. Suggested sources could be supervisions and appraisals that the learner has taken part in but this may vary from learner to learner.

Help the Hospices have developed a series of online learning resources (CLIP) that are free to access. It is recommended that learners complete The Effect of Death on Staff module as part of this activity (15 minutes).

Picklist
Activity 9: Support Systems

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Issues in Bereavement for Staff

• Acknowledging staff need
Staff may be so involved in responding to the grief reactions of the remaining service users that their own feelings go unrecognised. Sheer workload in some teams prevents staff exploring what they feel about the death of a service user.

• Permission to cry
Care staff may need ‘permission to cry’. Some care teams understand this and allow staff to show their feelings but other teams cannot cope
with such emotion, viewing it as 'unprofessional', 'letting the team down' or even as seeing it as a weakness. This may lead to feelings being hidden and possible problems not being addressed. Frequently, care staff can take their unresolved feelings home. So, although they may share the reasons with their partners or family, it is more common for them to 'dump the feelings' on the unsuspecting partner or family without being able to explain the reason why. It will be harder if the staff member has recently had their own bereavement.

• **Reassurance**
Care staff may tend to perceive themselves as being able to make things better so they could feel that they have failed in this situation. Guilt may be the result. This in-built desire to ‘fix things’ can prevent staff from realising that, in reality, they made a difference by being with the patient and family, and that this was therapeutic and helpful.

• **Organisational issues**
Organisations should respect the needs of the service user and staff such as remembering to leave an appropriate length of time before reallocating the bed. In a busy setting, stretched at times beyond its ability to cope, this is not always possible. However, a period of bereavement, however brief, should be the aim when possible.

• **Time to reflect on the situation**
Once the rollercoaster of activity has stopped, the staff need time to reflect on the progression of the client’s disease, the nature of the death – whether it was peaceful and expected or unexpected and distressing. It is important to consider how the death has affected both clients and staff.

• **Closure**
This typically North American term describes the completion of a grieving process. Closure is difficult in many health settings and it is not possible to achieve it with every death. Attending the funeral or service of just one patient can act to ‘close the chapter’ on other deaths. Talking to bereaved relatives may also help.

**Complications of staff bereavement**

• **Staff denial**
This works if the feelings are being channelled elsewhere but it may cause that member of staff to remain distant from the next dying individual for fear of exposing unresolved feelings.

• **Team denial**
This can result in a team who are uncomfortable with dying individuals, preferring instead to keep treatments going that are clearly no longer of benefit. Their discomfort will make it very difficult, if not impossible, to share the individual’s fears or distress. Consequently they may miss problems that could be treated such as depression, or may ask for the individual to be moved elsewhere, believing that this is the kindest thing to do.
### Stress and burnout

Some stress is necessary to do our jobs well—it is possible to be too relaxed! However, if this stress builds up because of blocked feelings then the staff member may eventually suffer from an anxiety state, clinical depression, along with physical symptoms of exhaustion, difficulty making decisions and feeling unable to come to work. They feel guilty that they haven’t been ‘stronger’. This is known as ‘burnout’ and usually catches people unawares since the sufferer is often the last to acknowledge that they are suffering from stress.

### How you can help yourself

If there are team difficulties with emotions or death, don’t try to sort this out yourself as it may need organisational change and education, neither of which can occur overnight or without the help of others.

In the meantime:

- Find someone you can talk to about coping with staff deaths, an understanding colleague at work is often better than taking the issue home and dumping it on your family.
- Even if you can’t cry with your team, find somewhere quiet and have a good cry, with a colleague if you can.
- Look back on the things you did that made a difference, keeping the individual comfortable, looking after the relatives. It’s often the small things that make a difference.
- Try to go to one funeral of a service user as it often helps to ‘close the chapters’ of many other deaths. Don’t be ashamed of using a funeral in this way. Funerals are about the dead, but they are meant for the living.

### Support mechanisms

**Colleague:** Ask a colleague to talk over the death. The local palliative care team can help.

**Specialist help:** Persistent or complicated grief will need more specialist help from a bereavement service, counsellor or psychologist. Trusts and health organisations often have support teams but the availability of these can vary.

---

Think about your place of work, what factors do you think help staff to resolve the death of a service user? Write them here:

This will be dependent on the workplace. It may be that there is a staff meeting after the death of a service user where they can talk about that person and remember them or it may be a memorial service. Staff may be asked if they want to attend funerals or they may have a board or book in the office for example where they can write what they
remember about that person. Look for evidence that the learner is aware what support systems may be in place in the workplace to help them.

What factors do you think might hinder staff after the death of a service user? Write them here:

This might include such things as being understaffed or not having the time to stop and remember or grieve for that person. Look to the points in the text above for guidance. The answer is subjective however and learners may identify other factors they feel are a hindrance

Looking after yourself

Recognising that you too may be affected by the death of someone whose care you have been involved in can easily be overlooked or underestimated, sometimes with negative consequences such as depression, stress or professional ‘burnout’. The way in which you might be affected will depend on several things including:

• Your role and relationship in looking after the person who has died.
• The relationship, or not, you have developed with the family and friends of the person who has died including any ongoing role you may have with them.
• The way in which your organisation and colleagues deal with death and bereavement.
• The opportunity to acknowledge the person’s death and express your grief - perhaps by talking about what happened, attending the funeral or sending a condolence card.
• Your own personal experiences of loss and grief, how you deal with them and any other stressors you may have at work or at home.

Understanding your own coping strategies for dealing with difficult and emotional situations and making sure you have a good support system in place is essential for anyone routinely involved in end of life care and bereavement. Having or developing your own personal ‘first aid kit’ is therefore a good way of reminding yourself of what works for you when feeling stressed or overwhelmed.

In the spaces below, write down or draw some pictures or symbols that represent the coping strategies and/or support systems that you have in
place to make sure you look after yourself. This might involve listening to music, going for a walk, talking to friends and colleagues. When you have completed this workbook you might want to copy your personal ‘first aid box’ out to stick on your wall at home or at work as a simple reminder about the importance of looking after yourself.

This is personal to the learner and should be about what works for them

Now complete the following:
Think of a situation recently where you have accessed support systems to help you to manage your own personal feelings bought on by loss and grief. Most commonly this might be during an appraisal or supervision with your line manager. You will need to provide evidence to your assessor of this. Write in the box below what that will be and provide your assessor with a copy. Remember that you must not leave any confidential information about service users or other staff in this documentation.

Two things I am going to change or do to improve my support system for dealing with loss and grief are:

This is subjective but learners may identify they need to find someone to talk to outside of their family or that they are going to take time to go for a walk or visit a certain place.

Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 9 - Resources

Web resources
The effect of death on staff - 15 minute e-learning programme CLIP (Help the Hospices)

Activity Sheets
Learner Handbook

PowerPoints/ Lesson Plans

E-learning Resources
E:ELCA modules 07 Bereavement

Further Reading
Summary

The good news is that you have nearly completed this module! You have had the chance to explore the loss and grief and you have seen that this journey is a unique experience for each individual.

You have:

- Studied communication issues and have had a chance to think about how you might help someone identify their loss and communicate their grief reaction.

- Read about the various models of grief and loss in order to help you understand the loss and grief journey people experience and the tensions this creates for them as they move through grief to accepting their loss.

- Thought about your own feelings of loss and grief and how this may impact on your practice.

As a last task, repeat the assessment you completed at the start of the module to see if your confidence has increased and discuss this with your tutor/assessor. 1 being not very confident and 5 very confident

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<td>Understanding loss and grief issues</td>
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<td>How to support people communicate their loss and grief</td>
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<td>How to help others identify their losses</td>
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<td>How to manage your own feelings of loss.</td>
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<td>Knowledge about how personal feelings of loss and grief can impact on the care given</td>
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CONGRATULATIONS!

You have now undertaken all the activities in this unit.

You now need to meet with your tutor/assessor – to discuss how you might present these completed activities as evidence towards meeting the unit learning outcomes.

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Appendix

• Continuation sheets for photocopying as required
• Glossary of Terms
• Template Support Agreement
• Lesson Plans
## Glossary of terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Advanced terminal illness</td>
<td>When an illness is no longer curable and has moved into its final stages. An individual will be approaching the end of their life.</td>
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<tr>
<td>Anticipatory Grief</td>
<td>Thinking about the loss you may feel before it happens</td>
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<td>Bereavement Support</td>
<td>This is the emotional support that is given to an individual to help them cope with the death of someone important to them. Bereavement support can be given before the individual’s death, whilst they individual is dying or after death.</td>
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<tr>
<td>Culture</td>
<td>The shared knowledge, behavioural norms, values and beliefs that help people to live in families, groups and communities</td>
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<tr>
<td>Factors</td>
<td>The things, events or circumstances which will affect something e.g. what is affecting an individual’s ability to cope with an illness</td>
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<tr>
<td>Grieving</td>
<td>To experience or express a sense of loss</td>
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<tr>
<td>Multi-disciplinary Team</td>
<td>A team of health and social care workers who all have different roles and responsibilities. For example Social Worker, Doctor, Community Nurse, Dietician, Chaplain, Support Workers, Nurses, Occupational Therapists etc.</td>
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<tr>
<td>Picking up cues</td>
<td>Noticing when a person needs or wants to talk about needs, concerns, fears, loss etc. They may do this from the things they say or through non verbal communication.</td>
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<tr>
<td>Psychologist</td>
<td>A professional who studies the mind and behaviour. They teach individuals how to emotionally cope with illness, loss, grief etc</td>
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<tr>
<td>Signposting</td>
<td>Directing people to support services or information they require</td>
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<tr>
<td>Terminal Illness</td>
<td>When an illness is no longer curable</td>
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<tr>
<td>Theories and Models of Grief and bereavement</td>
<td>Through experience, study and research, psychologists develop ways to help us understand and describe how humans think, express emotions and behave.</td>
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# Support Agreement

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Due to the sensitive nature of End of Life (EOL) care, topics may be covered that can cause upset for example you may be asked to consider your thoughts about your own death, or watch video clips that include the views of people who are actually dying. Before you begin learning activities, spend some time with your Tutor / Assessor to complete the boxes below:

**Lone study** – Identify support networks (these could be friends, family, colleagues) if you are upset by topics:

**One to one** – Outline how you would like to be supported if you are upset by topics:

**Work based learning** - Identify a mentor or supervisor to whom you can go if you are upset by topics at work:

**Class room based learning** - Outline how you would like to be supported if you are upset by topics (take into account that your tutor / assessor will not be able to leave the classroom):