



Supporting carers
in end of life care:
An introductory
programme

Facilitator
Handbook

contents

Facilitator handbook

Introduction for facilitators

Acknowledgments	2
Introduction	3
Programme objectives	4
Terminology	5
What is the training programme about?	6
Who might be interested in running the programme?	7
What skills do I need to be a facilitator?	7
Programme structure	8
Training pack structure	9
Practicalities	10

Session one –introduction and welcome

Objectives	17
Suggested timetable	18
Part 1a welcome and introduction	20
Part 1b introduction to the programme	21
Part 1c introduction to trainees	22
Part 1d setting ground rules	23
Part 1e introductory film	24
Additional facilitator information	25

Session two – Caring and being cared for at the end of life

Objectives	27
Suggested timetable	28
Part 2a overview of session	29
Part 2b exploring terminology	30
Additional facilitator information	32
Extra activity suggestion	33
Part 2c the need for support in end of life care	34
Additional facilitator information	37
Extra activity suggestions	39
Part 2d being with carers	41
Additional facilitator information	44
Extra activity suggestions	44

Session three – supporting in practice

Objectives	50
Suggested timetable	51
Part 3a overview of session	52
Part 3b case study group work and feedback	53
Additional facilitator information	55
Extra activity suggestion	55

Session four – being a safe supporter

Objectives	57
Suggested timetable	58
Part 4a recap of morning session	60
Part 4b introduction	61
Part 4c grief: assumptions and understandings	62
Additional facilitator information	63
Extra activity suggestion	63
Part 4d grief, personal biography and wellbeing	66
Additional facilitator information	67
Extra activity suggestion	68
Part 4e putting it into practice	70
Part 4f identifying support for trainees	71

Session five – The principles of supporting in end of life care

Objectives	73
Suggested timetable	74
Part 5a introduction to the principles	75
Additional facilitator information	76
Part 5b putting it into practice	77
Part 5c feedback on putting it into practice	78
Additional facilitator information	79

Session six – boundaries and exit strategies

Objectives	81
Suggested timetable	82
Part 6a introduction	83
Additional facilitator information	84
Part 6b considering boundaries and exit strategies	85
Part 6c feeding back responses	86
Extra activity suggestion	88
Part 6d summary	88

Session seven – Ongoing learning and personal development

Objectives	91
Suggested timetable	92
Part 7a introduction	94
Part 7b introducing the resource pack	95
Part 7c planning to support carers in an end of life context	96
Part 7d individual planning	97
Part 7e 'top tips for supporters' film.	98
Part 7f summing up	99
Evaluation form	100

Handbook for Facilitators

Acknowledgements

This training programme and resource pack was developed out of work undertaken as part of an action research project, 'Cascading knowledge about end of life care at home: the development and piloting of a training programme for those who help carers and a carer resource pack'. Funded by the Dimbleby Marie Curie Cancer Care Research Fund.

Research team: Research partners⁶: Advisory group members:

Jane Seymour ¹	George Wood	Gill Horne ⁷
Beth Hardy ¹	Deborah Tanner	Kathryn Almack ¹
Gail Ewing ²	Donald Robertson	Roz Lynch ⁵
Glenys Caswell ¹	Heather Redshaw	Tess Hullet ⁵
Gunn Grande ³		
Sheila Kennedy ⁴		
Julia Tabreham ⁵		
Andy Perrey ⁵		

1. The Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, University of Nottingham.
2. Centre for Family Research, University of Cambridge.
3. School of Nursing, Midwifery and Social Work, University of Manchester.
4. University of Sheffield.
5. Carers Federation Ltd, Nottingham.
6. Volunteer bereaved carers.
7. Rowcroft Hospice, Devon.

This work draws on insights from a previous project, which was a volunteer training programme about Advance Care Planning (Let's Talk now and Prepare for the Future) developed by Jane Seymour, Kathryn Almack (University of Nottingham) and Katherine Froggatt (Lancaster University). This was supported and funded by the National End of Life Care Programme and the Dying Matters Coalition.

Introduction

Thank you for using the training programme 'Supporting carers in end of life care: an introductory programme'. All the information you need to run the programme is contained in the training pack. In this introductory chapter we will explain what the training programme is about, provide guidance about facilitating the programme, provide advice on pre-course preparation and consider support that the facilitator and trainees may need during and following the programme. We hope that this information will enable you to decide whether the programme will meet the needs of you and your organisation.

The programme is intended to offer basic knowledge and skills for those who provide support for informal carers (usually family members or friends) who are providing home-based end of life care. This support may be given either as a paid worker or as a volunteer. The programme assumes no prior knowledge of end of life care on the part of trainees and is thus introductory in nature. The programme objectives are outlined on the following page.

Detailed facilitator's notes are included with the programme. Facilitators do not need any prior knowledge of the end of life care field, but it will be necessary to spend time preparing to deliver the programme. Although the facilitator's notes are detailed they do assume some prior experience as a trainer.

The programme is designed as a one day course. However, it is also intended to be flexible and there are extra activities included so that you can run the programme at a pace which suits your local requirements. Although the sessions are intended to flow in order to make a coherent whole programme, each session can stand alone. Therefore, depending on your needs and preferences you could run the programme on two separate occasions, or you could use just those sessions which are relevant to your trainees' needs.

We hope you will find the training programme interesting and useful.

Programme objectives

- To equip support workers and volunteers with confidence and skills to be able to support carers safely in home based end of life contexts.

- For trainees to understand that there are a number of principles that underpin the supporting role:
 - The supporter is someone who will listen.
 - The supporter will have an awareness of the palliative approach to care.
 - The supporter appreciates the wider context of 'caring' and recognises that carers may have a variety of responsibilities.
 - The supporter understands that they are part of a larger team of people involved in supporting the carer and the person being cared for.
 - The supporter will be self-aware of their knowledge and skills.
 - The supporter and carer are clear about the supporter's role and that the relationship is constrained by professional boundaries and contractual obligations.
 - Supporters work within the scope of their own organisation's policies and procedures.

Terminology

In this training programme we use the following definitions of words and phrases. You may need to clarify these words and phrases throughout the training.

Carer: A relative or friend who provides care and support for someone who is approaching the end of life.

Facilitator: The person delivering the course

Trainees: The course participants.

Volunteer: People who are involved in supporting carers in a voluntary capacity. This may be with an organisation or independently.

Support worker: People who work in a paid capacity to support carers. They may work directly with carers, or with both patients and carers.

Supporter: A support worker or volunteer who supports carers.

Discussion of palliative and end of life care terminology is contained within the facilitator notes on page 30.

What is the training programme about?

This programme is designed for support workers and volunteers who support carers providing home-based end of life care. It gives volunteers and support workers an introduction to the support needs of carers in end of life contexts. The training programme is used in conjunction with a comprehensive resource pack about caring at the end of life. We know that carers frequently report they feel very isolated in their caring role, and that they often have many unmet needs for support. Those who care for relatives and friends approaching the end of life often assume a great responsibility in ensuring that their friend or relative receives appropriate care, often carrying out many aspects of this care themselves. It is also the case that carers often experience substantial difficulties. There are many reasons for these difficulties; not least because the experience of caring for someone at the end of life is likely to be unknown territory.

During this training programme trainees will gain knowledge about the support needs of carers and themselves in end of life situations. They will gain confidence to work safely with carers of people who are approaching the end of life. There is a workbook provided for trainees, which is intended for them to use as they wish and includes space for them to make notes if they want to. The workbook contains the timetable, learning objectives, activities and copies of the power point slides.

Who might be interested in running the programme?

This course might appeal to you and your organisation if:

- You are a health or social care organisation with a role in carer support
- You work with community based volunteer carer supporters
- You recognise a need to improve skills and knowledge in end of life carer support
- You are looking to run an introductory end of life carer support programme

What skills do I need to be a facilitator?

The programme has been designed so that it can be facilitated by anyone with some previous teaching or training experience, and experience of carer support issues. More experienced facilitators may wish to adapt the mode of delivery of the programme to suit their personal style.

You do not need to be an expert in palliative and end of life care as all the information you require for this introductory course is contained within the teaching pack.

However, you will need to have a strong interest in palliative and end of life care, as we anticipate that you will probably need to go through the materials three or four times before running the programme. It may also be helpful to work through some of the trainees' exercises.

Normally, we would suggest that facilitators for this course work in pairs when delivering the course to more than eight trainees. This is to ensure that there is someone to support trainees if they become upset or affected by the subject matter. If you have been a carer in end of life contexts or suffered bereavement, you need to be able to use your experiences constructively and not become too upset when thinking back to your loss. You are likely to have to listen to the stories of others' losses, so do bear this in mind.

The role of the facilitators is to:

- Organise the day and deliver the training.
- Keep the group focussed on the task.
- Remain as neutral as possible, treating each person and their contribution with respect.
- Manage a group of people in a sensitive manner and help them to gain confidence.
- Involve and encourage everyone in the group.
- Listen and contribute.
- Remind the group what has been discussed.

Programme structure

There are seven sessions in the programme. These sessions can be facilitated over a one-day course. If you have more time available, each session contains extra content and exercises that you can use to expand the programme.

Session one: Introduction and welcome

Session two: Caring and being cared for

Session three: Supporting in practice

Session four: Being a safe supporter

Session five: The principles of supporting

Session six: Boundaries and exit strategies

Session seven: Ongoing learning and development

Facilitator notes for each session contain all of the information you will need to deliver this training.

A suggested one-day timetable

09.30 - 10.00	Session one Introduction and welcome
10.00 - 11.00	Session two Caring and being cared for
11.00-11.15	<i>Coffee</i>
11.15 - 12.00	Session three Supporting in practice
12.00 - 12.45	<i>Lunch</i>
12.45 - 13.45	Session four Being a safe supporter
13. 45 - 13.50	<i>Comfort break</i>
13.50 – 14.20	Session five The principles of supporting in end of life contexts
14.20 – 14.50	Session six Boundaries and exit strategies
14.50- 15.00	<i>Comfort break</i>
15.00- 15.50	Session seven Ongoing learning and development
15.50-16.00	Evaluation

This timetable includes several short coffee and comfort breaks. We have found that it is helpful to have regular breaks to allow people to have a short rest from the subject matter, with time to use the facilities and refresh their coffee cups. You may wish to adapt this, based on the trainees that you have on your course.

Training pack structure

This training pack includes all of the information you need to deliver this introductory course, including a facilitator handbook, a trainee workbook, Power point slides and a resource pack.

The facilitator handbook contains a detailed breakdown of the contents of each of the seven sessions, background information about the session topic, and extra activities so that sessions can be extended to suit you and the needs of your group. The sessions contain a mixture of facilitator led discussions, individual and small group exercises,

case studies (fictional cases based on real life scenarios), and film and audio clips of carers talking about their experiences for the group to consider and discuss.

The trainee workbook contains all the information that trainees need during the course. As a facilitator you may find it helpful to work with both the facilitator handbook and the trainee workbook in front of you.

The resource pack is a list of resources that you will find helpful. These resources contain a wealth of information about supporting carers and other end of life care information. You may find it useful to use these resources to expand your own knowledge about this area, as well as signposting the trainees to read these resources, and to advise the carers that they support that these resources are available. You may wish to print a copy of the resource list for each of your trainees. All of the resources are free to access. Please note: we cannot guarantee that all the resources will continue to be available in their current formats. You may also find it helpful to identify some of your local resources to share with trainees before running the course.

Practicalities

You will find a checklist to work through on pages 13 to 15 which covers all the practicalities of running the programme. On page 15 you will find a materials and resources section which provides a checklist of materials which go with each session.

Location

It is important that the venue is large enough to accommodate all of the trainees comfortably and that it is easily accessible. Ideally, you will have a main meeting room as well as small spaces where trainees can do group work. Having somewhere to get a hot drink will be welcome.

Equipment and resources needed to help you

- You may find it easier to facilitate the programme in pairs. This is useful to help manage group work, and also to support any trainees who need extra support or time-out if they become upset by the discussions.
- You will need some equipment: ideally, facilities to project power point slides, flip charts and pens. Some of the exercises need particular resources so you will need to check this carefully beforehand. If power point slides are unavailable you will need to provide printed copies of the slides.
- You will have to make copies of some of the hand-outs and the pre-course leaflet to send to trainees, so bear this in mind as it will add to the costs of running your programme. See page 15 for a list of resources required for each session.
- As a separate document attached to the programme you will find the resource list that accompanies this programme. All of these resources are free to access. Some of these can be ordered, and others can be obtained via the internet. You may find it helpful to obtain copies of some of these to give to your trainees on the day, in addition to checking out some of your local resources.
- If your organisation has some resources to assist you and you agree to reimburse attendees' expenses, you will need to enclose expense forms (with an explanation of what can be claimed) with the pre-course materials. You may also need to send directions to attendees so that they can find the venue.
- You may also wish to give trainees a phone number in case they need to make contact at the last minute, for example if they are having trouble finding the venue.

Support

Throughout the course sensitive issues and topics will be discussed, therefore it is important to ensure both facilitators and trainees taking part are provided with support if needed. Because of the subject matter, there may be times when trainees recall stories or experiences of their own losses: make sure you have tissues available just in case.

It is important to factor in breaks and time to reflect during the programme. Some timings have been suggested in the timetable, but you will need to be guided by your own group.

Before running the programme it is essential that you consider who you can go to for some support. As the facilitator you may be offering support to trainees who become upset, and you will be leading discussions about some sensitive topics.

An integral part of the programme consists of helping trainees think about accessing support for themselves. In addition to this, you may want to provide some information about opportunities for support within your locality.

Evaluation

Evaluation is an important aspect of training. You will find an evaluation sheet for trainees to complete at the end of the materials for session 7 in this handbook. It contains space for you to adapt it to your local needs, should you wish to do so and it can be copied and handed out to trainees.

Pre-course preparation checklist

Action	Action by	Target date
Programme dates and attendance		
<ul style="list-style-type: none"> Recruitment. Start recruitment through existing contacts. A simple poster is provided for you to modify but you may want to develop your own. Decide when, where and how the programme will be run. Trainee selection. Discuss the programme with people who are interested. Ensure they are aware that this is an introductory level course. List of trainees. Produce a list of people who are enrolled on the course with basic biographical information for the facilitators. 		
Budget		
<ul style="list-style-type: none"> Check the budget available for running the programme as there are a number of materials and resources which will require printing or photocopying. You may wish to consider whether you can offer to reimburse trainees' travel expenses and whether or not you will provide lunch and refreshments. 		
Facilitators		
<ul style="list-style-type: none"> Decide on facilitators and co-facilitators (if using). Check availability and possible budget approval for external facilitators (this may not be applicable to you/your organisation). 		
Timetables		
<ul style="list-style-type: none"> Decide the length of your course, and whether you will use only the core material or also use the additional exercises. Create a course timetable to meet your local requirements - we have included a suggestion for a one day course but you may want to modify this. 		
Bookings (as required)		
<ul style="list-style-type: none"> Rooms – book room(s) for the course delivery and additional rooms as needed. Remember to check that access to the room 		

<p>and facilities is possible for everyone who wishes to attend.</p> <ul style="list-style-type: none"> • Presentation facilities – book the necessary computer and computer driven presentation facilities to project power point slides. Make sure flip charts and pens are also available. • Furniture – book furniture (seating/tables) for rooms (if required). • Environment – check room is suitable for group work e.g. noise, temperature etc. 		
Catering		
<ul style="list-style-type: none"> • Organise catering and refreshments as required (this might be as simple as asking people to bring their own lunch). Be aware of any food allergies or dietary requirements if you are providing food. 		
Obtaining resources		
<ul style="list-style-type: none"> • Ensure you have up to date copies of all programme resources and presentations (see page 15). • Obtain enough copies of one of the resources for each trainee to have one to take away (see session 7b ‘The Resource Pack’). • Check out local resources and ensure you have the details for sharing. 		
Reproducing resources		
<ul style="list-style-type: none"> • Copy and send, or e-mail, the pre-course leaflet to all trainees. Have extra copies available at the beginning of the course in case needed. • Have enough copies of all hand-out materials, including the resource list and the workbook, required through-out the course. 		
Administration		
<ul style="list-style-type: none"> • Create attendance instructions for trainees (if required). • Send attendance instructions to trainees. • Create an attendance list 		
Evaluation		
<ul style="list-style-type: none"> • Make copies of the evaluation form for participants 		

Materials and resources required

Session		Resources required
1	Introduction and welcome	Power point slides 1 to 5 Spare copies of pre-course reading Copies of the workbook for all trainees Workbook page 3 Flip chart and Pens
2	Caring and being cared for at the end of life	Power point slides 6 to 12 Workbook pages 5 to 9 Flip chart and pens
3	Supporting in practice	Power point slides 13 & 14 Workbook pages 11 to 18 Flip chart and Pens
4	Being a safe supporter	Power point slides 15 to 20 Workbook pages 20 to 24 Flipchart and pens
5	The principles of supporting in end of life contexts	Power point slides 21 to 23 Post it notes Workbook pages 26 to 28 Flip chart and pens
6	Boundaries and exit strategies	Power point slides 24 to 27 Workbook pages 30 to 32 Flipchart and pens
7	Ongoing learning and personal development	Power point slides 28 to 34 Resource list Internet connection Workbook pages 34 to 43 Evaluation forms Facilitator Handbook pages 100 and 101

Session 1: introduction and welcome

Objectives

At the end of this session, trainees will have:

- Met the facilitators and other trainees
- Been introduced to the day's programme
- Set ground rules for the day

Suggested timetable: 30 minutes

Part	Time needed	Content	Activity	Resources required	Outcomes
1a Welcome and introduction to facilitators	5 minutes	Welcome trainees Facilitator/s introduce themselves Housekeeping information	Facilitator presentation about the day	Power point slide 1	Trainees feel welcome Trainees have been introduced to facilitators Housekeeping information relevant to venue has been shared
1b Introduction to programme	5 minutes	Ethos of training introduced Timetable of day introduced	Facilitator presentation Opportunity for trainee questions about day	Pre-programme reading Power point slide 2 Timetable in workbook (page 3)	Trainees understand what the training is about They have been introduced to the timetable Trainees have had the opportunity to ask questions
1c Introduction to trainees	10 minutes	Introductions among trainees	In pairs trainees introduce themselves to someone they do not know Trainees then introduce their partner to the group	Power point slide 3 showing details to be shared	Trainees have introduced themselves to each other
Section	Time needed	Content	Activity	Resources required	Outcomes

<p>1d Setting the ground rules</p>	<p>8 minutes</p>	<p>Ground rules established</p>	<p>Facilitator led discussion of ground rules</p> <p>Use suggestions on slide if wish</p>	<p>Power point slide 4</p> <p>Flip chart paper and pens</p> <p>Blue tac if wish to pin to wall</p>	<p>Ground rules for day are established</p> <p>Comfortable and safe environment for trainees and facilitators</p>
<p>1e Introductory film</p>	<p>2 minutes</p>	<p>Short film introducing palliative care and carer support.</p>	<p>Trainees watch film</p>	<p>Power point slide 5</p>	<p>Trainees are given an initial insight into palliative care and carer support and are welcomed to the training.</p>

Part 1a: Welcome and introduction to facilitator

Activity: facilitator presentation

Time: 5 minutes

Materials: power point slide no. 1

Facilitator actions:

- Facilitator welcomes trainees to the day.
- If there is more than one facilitator, each introduces herself or himself in turn.
- Any necessary housekeeping information for location explained, e.g. fire exits/tests; location of toilets; arrangements for breaks etc.
- Facilitator reminds trainees that they are dealing with an emotional topic and that some of the material may remind them of their personal experiences. Support is available if someone becomes distressed.

Outcomes of part 1a
Trainees feel welcome on the training.
Trainees understand the purpose and timing of the session and have opportunity to ask questions.

Part 1b: Introduction to the programme

Activity: facilitator presentation

Time: 5 minutes

Materials: pre-programme reading; timetable for day in workbook (page 3) and on power point slide no. 2.

Facilitator actions:

Check all trainees have their copy of the workbook.

Introduce timetable for the day, as shown in workbook and on power point slide (you may want to include times on the slide).

Give a brief description of the day:

- As described in pre-programme reading, training programme is intended as an introduction to supporting carers in a domestic setting who are looking after someone who is approaching the end of life.
- No prior knowledge of end of life care or supporting in this context is assumed.
- Some trainees will have lots of experience in supporting carers in other contexts and so will have transferable knowledge and skills that they can use.
- This is a one day programme intended to introduce trainees to providing support to carers at end of life in a safe, non-threatening environment.

Ask trainees whether they have any questions relating to the programme.

Outcomes of part 1b:

Trainees understand who the training is intended for.
Trainees have been introduced to the timetable.
Trainees have had the opportunity to ask questions relating to the programme.

Part 1c: Introduction to trainees

Activity: Group exercise

Time: 10 minutes

Materials: power point slide no. 3

Facilitator actions:

- Trainees work in pairs, ideally with someone they have not met before.
- Each person tells their partner their name; organisation they work for; role within the organisation; whether they have personal and/or professional experience of supporting carers in an end of life context.
- Each participant introduces their partner to the group.

Ten minutes have been allowed for this, but depending on numbers attending it could take less time or longer: facilitators should adjust timings as appropriate.

Outcomes of part 1c:

Trainees have introduced themselves to each other.
Trainees have practiced speaking out loud in front of the group.

Part 1d: Setting ground rules

Activity: facilitator led discussion

Time: 8 minutes

Materials: flip chart and pens; blue-tac if the list is to be pinned to the wall

Facilitator activity:

If appropriate for the group, facilitator leads a discussion about ground rules for the day.

Take suggestions from trainees and write on flipchart.

Ideas offered may include (these are on slide 4):

- Respect for each other's opinions.
- Respect confidentiality of what other participants say.
- Allow other people to speak.
- Do not talk over each other.
- Keeping to time.
- Share only what people feel comfortable sharing.
- Remember it's okay to leave if you are becoming upset.
- Look after selves and others.

Conclude session by reminding trainees that the topic is an emotional one and the material included may prompt memories of trainees' own experiences.

Remind trainees that it is important to take care of oneself, so if anyone feels upset or if the material has become too personal, it is okay to take time out and leave the room at any point.

Outcomes of part 1d:

Trainees have agreed the ground rules for the day.
A comfortable and safe environment has been established for the day's training.

Part 1e: Introductory film

Activity: watch film

Time: 2 minutes

Materials: Power point slide no. 5

Facilitator activity:

Advise trainees that this is a short film of Bill Noble discussing palliative care and carer support. Bill Noble is a palliative care consultant and the Medical Director of Marie Curie Cancer Care.

Purpose of part 1e:

Trainees understand that this is a topic of significance and that their participation in the training is valued.

Part 1: Additional trainer information

We have suggested here that you may want to attach the flip chart paper to the walls of the room you are in. We suggest that you do this throughout the day with all the activities involving flip chart paper. This provides a reference point for trainees of the discussions that have taken place and gives trainees a sense of the quantity of learning that they have undertaken. At the end of the day, trainees can be encouraged to take pictures of the walls of the room on their smart phones – this provides them with an ongoing reference of the contents of the day that can be referred to in conjunction with their workbooks. You may wish to bring a camera along and take pictures of the walls which you can offer to email to trainees who do not have smart phones.



Photographs taken of group flip chart work on a training day

Session two: caring and being cared for at the end of life

Objectives

At the end of this session, trainees will:

- Understand that 'end of life' is described in a variety of ways and be familiar with the different terms.
- Identify that carers may have a range of relationships with the person who is ill.
- Recognise that carers have a range of support needs, including help for themselves, and help to support the person who is ill.
- Understand the importance of actively listening to carers talk about their experiences.
- Be given the chance to think about strategies for dealing with carers who are upset.

Suggested Timetable: 1 hour

Part	Time needed	Content	Activity	Resources required	Outcome
2a Overview of session	2 minutes	Brief presentation of objectives of the session and summary of content	Presentation by facilitator	Power point slide 6 and Workbook page 5	Trainees are aware of objectives of the session and have insight into content that will be covered.
2b Exploring terms	10 minutes	Trainees have an opportunity to discuss and consider the meaning of the terms used in end of life care.	Facilitated whole group discussion	Flip chart and pens Power point slide 7 Workbook page 6	Understand that end of life is described in a variety of ways and be aware of the terminology.
2c The need for support in end of life care	28 minutes	Trainees explore a variety of issues related to the identification of carers and the range of carer needs.	Watch film clip Facilitated group discussion	Film clip on power point slide 8, power point slide 9, and Workbook pages 7/8 Flip chart and pens	Identify that carers may have a range of relationships with the person who is ill. Recognise that carers have a range of support needs, including help for themselves, and help to support the person who is ill.
2d Being with carers	20 minutes	Trainees have opportunity to consider what to do when a carer becomes upset.	Watch film clip Paired activity Group feedback	Power point slide 11 and workbook page 9 Flip chart and Pens	Be given the chance to practise strategies for dealing with carers who are upset.

Part 2a: Overview of session

Activity: Short introductory presentation

Time: 2 minutes

Materials: Power point header slide number no. 6. Trainee workbook page 5

Facilitator actions:

Explain to trainees that the overall goals for this session are to:

- Explore the variety of terms used to describe end of life and end of life care.
- Consider who carers are and the range of relationships they might have with the person who is dying.
- Explore carer support needs.
- Reflect on how to support carers who become distressed.

Direct trainees to page 5 in their workbooks.

Advise trainees that the session will last about an hour, following which there will be a break.

Give trainees the opportunity to ask questions.

Outcomes of part 2a:

Trainees understand the purpose and timing of the session and have opportunity to ask questions.

Part 2b: Exploring terminology

Activity: small group exercise

Time: 10 minutes

Materials: workbook page 6 (exercise 1), flip chart paper and pens, power point slide no. 7

Facilitator actions:

Explain that the purpose of this activity is to consider the range of terminology used when discussing end of life care. Remember that while it is important for trainees to be aware of the terminology they may encounter when supporting carers, it is also important to remember that there is no consensus about what terminology should be used.

- Ask trainees to work in groups of 3 to 4 people.
- Give each group a piece of flip chart paper and a pen.
- Ask the group to spend 5 minutes sharing all the different words and terms they have heard in relation to death, dying, palliative and end of life care. Direct the trainees to write these on the flip chart.
- Encourage them to discuss what the words might mean.
- Watch the time!
- Ask each group to feedback one of the terms that they have identified and tell the rest of the group what they think it means.
- If you are able, hang the flip charts on the wall for the remainder of the day.

Clarify key points:

- 'End of life' means different things to different people, and professional groups. In this course we use the term to mean people who are likely to die within the next twelve months. Sometimes the phrase is used specifically to refer to the last days and weeks of life.
- 'End of Life Care' is the care that people are given at the end of life, including care given to carers. This care does not end when the patient dies, and will continue

into bereavement for carers and family members, although the individuals providing that care may change.

- 'Palliative care' is an approach to care that aims to improve quality of life of patients and families who are living with life threatening illness. This includes managing pain, and other problems including physical, psychosocial and spiritual issues. Sometimes patients and carers misunderstand this term to mean that the patient is imminently dying.
- It is important when using these terms with carers that there is a common understanding of how the term is being used to aid effective communication.

Outcomes of part 2b:

Trainees understand that a variety of terms are used in end of life care.

Trainees have chance to discuss the meanings of these terms and consider the implications of a range of terms for clear communication with carers.

Trainees have the opportunity to say these words out loud, and familiarise themselves with them to set a grounding for the rest of the day.

Part 2b: Additional facilitator information

There are a number of terms that are used in relation to the end of life, and end of life care. Some of these are listed below, but you may also have others that are used within your local communities.

- End of life
- End of life care
- Death
- Dying
- Pegging out/ pegged out
- Kick the bucket
- Dead
- Palliative care
- Supportive care
- Terminal/ terminally ill
- Life-limiting illness
- Life threatening illness
- End-stage
- Hospice
- Passing/has passed/passed away/passed on
- With the angels
- Died
- Near the end
- Bereavement

Many of these terms have multiple meanings attached to them and can be scary to use, as well as to hear as a patient and carer. Further information about the meanings of some of these words can be found in the resource pack.

Extra activity suggestion:

Extend the amount of time for feedback relating to the discussion of words used. You might use prompts such as 'what do we mean by end of life', 'when does end of life start', 'when does end of life end', 'how might we know someone is at the end of life'? Have a group discussion about these words and how meaning can be misunderstood without clear communication.

Part 2c: The need for support in end of life care

Activity: Watching a film clip and interactive group discussion

Time: 25 minutes

Resources: Power point slides nos. 8 and 9. Flip charts and pens. Workbook pages 7 and 8 (exercise 2).

Facilitator actions:

Explain that having considered what end of life care is, the purpose of this activity is to consider who carers are in the 'end of life care' context, and the type of issues that they may need support with.

There are three sections to Part 2c:

- 1) A clip of a carer talking about their experiences (5 minutes).
- 2) Interactive group discussion (20 minutes).
- 3) Trainer led slide presentation (5 minutes).

1. Film clip

- Advise the group that you are going to play them a film of a carer 'Jacqui'. Jacqui will be talking about her experiences of caring for her husband, Terry. Terry had Chronic Obstructive Pulmonary Disease (an illness affecting the lungs) for 16 years, and towards the end of Terry's life Jacqui was his full time carer. Jacqui is a retired cleaner and has 3 adult children.
- Ask the group to think about the issues that Jacqui highlights while they are watching.

2. Interactive discussion

- Split the whole group into smaller groups of around 4 people.

- Ask the groups to discuss what they have seen and consider what types of issues Jacqui raised in relation to her caring role. The trainees can make notes of these in their workbooks if they wish (10 minutes).
- Pull the groups back together and facilitate the sharing of ideas amongst the group about the range of issues that the carer might need support with. You might choose to do this by going around the small groups and asking them to contribute one or two suggestions that they came up with. These can then be written by the facilitator on a flip chart at the front.
- You might want to use some prompts to develop the discussions, such as:
 - What is really important to the carer? (A partner relationship as well as being a carer, being in control in her own home, try and cheer Terry up etc.)
 - What else did you hear? (Changed roles within their marriage, nurses took over, tried to protect children etc.)
- If you are able, hang the flip charts on the wall for the remainder of the day.

3. Facilitator led discussion and presentation

- Using Power point slide no. 8 explain that (as the group has identified), carers are known to have a variety of issues and range of needs for support.
- These needs can be understood as need for help for themselves (column two), and also help for the carer to 'care' effectively. Make links between the items highlighted in the table, and the items that the group have identified in Jacqui's experience.
- Explain that not all people will have all of these support needs at any one time, but that they are common amongst carers in end of life situations.
- Explain that since the implementation of the Care Act 2014, carers have the right to an assessment of their support needs to be carried out by the local authority.

Outcomes of part 2c:

Trainees understand that a carer has a range of support needs.

Trainees appreciate that a carer might have multiple roles, such as providing physical or personal care, being a wife or a partner, and being a family member to others.

Trainees practise listening to a carer talking about their experiences and identifying needs.

Part 2c: Additional trainer information

Carers Support Needs Assessment Tool

The table shown in power point slide 9 has been developed from information contained in the Carers Support Needs Assessment Tool (CSNAT ©). The CSNAT © is an evidence based assessment tool that is used by nurses working with carers in end of life situations. The tool was developed by researchers who systematically identified the range of needs that carers identify in end of life situations, and further research has shown that the CSNAT© is a valid and comprehensive tool for covering the range of support needs discussed by carers. This means that each of the fourteen 'domains' (or broad areas) covered in the CSNAT © and shown on the slide, covers a range of support needs that individual carers may experience.

It is not expected that the trainees on this course would use the CSNAT © to assess carers' needs. However, the tool is an important framework for understanding the range of needs a carer may experience, and to demonstrate that carers have practical and emotional support needs. Trainees may use this framework to guide their thinking in terms of the range of carer needs, and the type of knowledge they may wish to develop in terms of their ongoing learning in relation to carer support.

For example: The CSNAT © domain 'talking with your relative about his or her illness' may be expressed in a number of ways, such as:

'I don't know what to say to him'

'I'm scared about the future, and think she is too, but we don't seem to be able to share this'

'He just won't talk to me'

Trainees would not be expected to know immediately how to respond to these types of comments – they can be hard concerns to address with carers. However, once the trainee has done their own reading (ways to address these types of concerns can be

found in the resource pack), they will find that they have increasing knowledge and confidence to discuss these issues with carers.

If you would like to know more about the CSNAT © tool, further information can be found in the following papers:

Ewing, G., Brundle, C., Payne, S. & Grande, G. (2013) The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home. *Journal of Pain and Symptom Management*. 46 (3) 395-405.

Ewing, G. & Grande, G. (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine*. 27 (3) 244-256.

For further information about the CSNAT © please contact:

Gail Ewing: ge200@cam.ac.uk

Gunn Grande: gunn.grande@manchester.ac.uk

Care Act 2014

The Care Act 2014 came into effect in April 2015. This Act gives carers a number of rights, including the right to an assessment of their support needs by the local authority. This assessment can, if both agree, be carried out at the same time as an assessment of the needs of the person who is receiving care. Once the carer's assessment is complete the local authority has a duty to decide if the carer is eligible for support from the authority. If you would like to read more about the Act and its implications for carers, a series of short factsheets can be found here:

<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>

Part 2c: Extra activity suggestions

Activity one:

Repeat the activities contained in part 2c, but watch the film of Heather (power point slide no. 10)

Activity two:

After you have shown the carer support needs power point slide (no. 9), and completed the activities you could ask the group to consider how carers might express these needs in a conversation with the supporter.

- Ask the group to split into pairs.
- Give each of the pairs one or two of the domains to discuss.
- Ask the pairs to come up with three different ways that the carer might express the support need. Some suggestions are given below but there are many different possibilities.
- Encourage the pair to write their suggestions on flip chart paper.

Understanding your relative's illness	<ul style="list-style-type: none">• 'The hospital told us the cancer has metastasized (spread) but I don't know what this means.'• 'He doesn't have any pain – we think this might mean he is getting better, what do you think?'• 'The doctors use all these words I don't understand when they are talking about her illness, it is very confusing.'
Having time for yourself during the day	<ul style="list-style-type: none">• 'I don't like to leave him in case he needs me.'• 'It is like a full time job sometimes.'• 'I sometimes wish I could see more of my other friends.'

<p>Providing personal care for your relative</p>	<ul style="list-style-type: none"> • 'I am embarrassed to wash my dad – it seems so personal.' • 'She has always been very proud of her appearance, but she hasn't got the energy to get to the hairdressers anymore, I wish I could help more.' • 'Yesterday I didn't manage to help him to the toilet in time and he had an accident. It was terrible for us both – I don't know what to do'. • 'I have care assistants who come in to wash him each day but sometimes I would like to help them a little but they always seem to be in such a hurry.'
<p>Financial, legal or work issues</p>	<ul style="list-style-type: none"> • 'Parking at the hospital is so expensive.' • 'I am worried I am going to lose my job because I am taking so much time off work.' • 'Someone at the support group said I might be able to get some government benefits.'
<p>Looking after your own health</p>	<ul style="list-style-type: none"> • 'I cancelled my own annual medical review, it just didn't seem important.' • 'I've been losing weight.' • 'I'm not well myself you know.' • 'I'm just a bit tired, but I will be fine. He's the one you need to concentrate on.'

Draw the group back together and ask each pair to feedback their suggestions. This will encourage the trainees to consider in real life terms how carers may discuss their support needs.

Part 2d: Being with carers

Activity: Watching a carer speaking about their experiences and discussion

Time: 20 minutes

Resources: Power point slide no. 11. Flip charts and pens. Workbook page 9.

Facilitator actions:

Introduce this section by explaining that we have considered that carers have a variety of roles, and a range of support needs. In this section, we focus on the challenges of being with carers as they are discussing their experiences and how to manage a situation when carers become upset or distressed.

There are two parts to this section:

- 1) A video of a carer talking about their experiences (6 minutes).
- 2) Managing distress exercise (14 minutes).

1. Video clip

- Ask the group to watch George talking about his experience. George was the main carer for his wife who had a brain tumour.
- Ask the group to think about what George is saying, and to make some notes about George's possible support needs.

2. Managing distress

George has demonstrated that giving the carer the chance to talk about how they feel can be a very valuable type of support. However, sometimes when people talk about hard experiences in their life they can become upset. Sometimes we might avoid awkward conversations, or change the subject when someone brings up a conversation that we are uncomfortable with, such as fear of death and dying. We can also be concerned about what might happen if the person we are talking with becomes upset.

The following exercise is intended to help trainees reflect on this and consider what they might do in this situation.

- Ask the group to work in their smaller groups again.
- Ask the trainees to imagine that they were supporting George, who had been talking to them about his wife's illness. George starts crying while he is talking. Ask the group to discuss what they might do. Ask the groups to write their thoughts on a flip chart. Prompts to help the discussion can include:
 - *How do you think you would feel in this situation?*
 - *What could you do to manage your own emotions?*
 - *How might George know you were listening to him?*
 - *How might you respond to George crying?*
- Draw the group back together. Ask each group to take it in turns to present their thoughts briefly on how they might manage this situation.
- Possibilities include:
 - Listening well, such as being respectful, honest and being engaged with your body language, listening closely.
 - Putting your own thoughts to one side.
 - Not offering false reassurances.
 - Offering nonverbal encouragement.
 - Touch can help but read the situation carefully.
 - Offer a tissue.
 - Ask the carer if they would like to continue talking.
 - You also need to manage your own emotional response – activities that can help include breathing slowly to calm yourself and grounding yourself by placing both feet on the floor.

Outcomes of part 2d:

Trainees consider the role of listening in providing good support to carers.

Trainees have opportunity to discuss and reflect on the challenges of supporting carers who become upset or distressed, and have considered some practical ways to manage these situations.

Part 2d: Additional facilitator information

The organisation 'Dying Matters' publishes a number of resources designed to 'help people to talk more openly about dying, death and bereavement'. These resources can be accessed on their website <http://dyingmatters.org/page/resources-talking-about-death-and-dying> and can be good background reading for facilitators on the issues that trainees might raise. You may also want to direct the trainees to these resources for further reading.

Part 2d: extra activity suggestions

Activity one:

Listening skills exercise (25 minutes)

This exercise might be particularly useful with groups who have not received much previous training in supporting carers, and could be used prior to the managing distress exercise. The exercise does require a little preparation, as you will need to photocopy the 'cards' to be distributed prior to the session.

Ask the group to split the group into pairs, and ask the pair to decide who is person A, and who is person B.

- Distribute the cards for exercise one and ask the pairs not to reveal to their partner what the card says.
- Ask the pairs to start the activity, and then after three minutes, stop the conversations and ask the individuals to spend one minute writing down what it felt like as person A or B in the activity. They should not discuss this at this point.
- While they are making their notes, distribute the cards for exercise 2.
- Repeat the activity, and again give the group one minute to write down their initial reactions.

Once both exercises have been completed draw the group back together as a whole to discuss the experience of 'listening' and being 'listened to'.

You could use prompts such as:

- How did it feel to be listened to closely?
 - Good, unusual, uncomfortable, special, unfamiliar
- How did it feel when your partner was not paying attention to what you were saying?
 - Horrible, 3 minutes a long time, difficult to keep talking
- How did it feel to be a good listener?
 - Takes effort, tiring, worth it, good, interesting
- How did it feel to be a poor listener?
 - Uncomfortable, out of character, hard, easy
- What kind of verbal prompts did you use to show you were listening?
 - Para-phrasing (summarising) what the speaker has said, using prompts such as 'uh-huh', and 'mmm'
- What type of non-verbal language did you use to show you were listening?
 - Eye contact, open body posture, arms and legs uncrossed, mirroring the speakers body language, looking at the speaker, not interrupting
- How did poor listeners show that they were not paying attention?
 - Interrupting, not making eye contact, looking elsewhere in the room, arms/legs crossed, playing with phone, not facing speaker

As the group is discussing good and bad listening you should highlight that good listening is a central component of good communication and has a huge number of benefits for carers and for supporters. In end of life care, it is very important to communicate clearly, but without being brutal or coarse in the use of language. Good communication helps to build and maintain relationships between carers and supporters. Carers will not be comfortable in the relationship if they do not feel listened to.

Listening effectively helps the carer to share their thoughts and experiences, and the supporter to gather information. It can reduce feelings of isolation and uncertainty, and by being a good listener you show the other person that they are valued.

Materials required for exercise:

Photocopy the cards on the following page and cut them so you have four different stacks of cards (Person A exercise 1, Person A exercise 2, Person B exercise 1, Person B exercise 2).

Resource: Cards required for the listening skills exercise.

Person A - exercise one.

Think of an event in your life that you have enjoyed, and that you do not mind sharing with your partner.

Spend 3 minutes telling your partner about event, and why it stands out so much in your memory.

Person A - exercise two.

Your partner is going to tell you about the town or village that they lived in as a child.

You begin by listening to what your partner is saying, but lose interest very quickly. Show by your behaviour and body language that you are not paying attention.

Person B - exercise two.

Think of the town or village that you lived in as a child.

Spend 3 minutes describing this place your partner.

Person B – exercise one.

Your partner is going to talk to you about an event in their life that they have enjoyed.

You will listen with great attention to what your partner says for three minutes. Make use of non-verbal skills, and verbal prompts to show that you are listening carefully.

Person A - exercise one.

Think of an event in your life that you have enjoyed, and that you do not mind sharing with your partner.

Spend 3 minutes telling your partner about event, and why it stands out so much in your memory.

Person A - exercise two.

Your partner is going to tell you about the town or village that they lived in as a child.

You begin by listening to what your partner is saying, but lose interest very quickly. Show by your behaviour and body language that you are not paying attention.

Person B - exercise two.

Think of the town or village that you lived in as a child.

Spend 3 minutes describing this place your partner.

Person B – exercise one.

Your partner is going to talk to you about an event in their life that they have enjoyed.

You will listen with great attention to what your partner says for three minutes. Make use of non-verbal skills, and verbal prompts to show that you are listening carefully.

Activity two:

Speaking with bereaved carers:

This exercise may be helpful for trainees who have not worked with people during end of life or into bereavement. People often worry about what to say to someone who has been recently bereaved, and worry about saying the wrong thing, or causing the bereaved person further distress.

Ask the group to work on their own and spend a few minutes writing a personal list of any concerns that they may have about working with or speaking with bereaved carers. Then ask them to spend a few minutes speaking about their concerns with a partner, and coming up with suggestions about how they might manage these concerns.

Once trainees have completed this activity, ask them to watch the film 'Heather – Speaking with bereaved carers' (power point slide no. 12). In this clip Heather is giving her advice about how you might approach a carer who has been recently bereaved. When the clip has finished, have a discussion amongst the group about Heather's thoughts, and whether they are similar/different to those of the trainees.

If you would like to know more about carer bereavement, Marie Curie Cancer Care has some useful information on their website www.mariecurie.org.uk/help/bereaved-family-friends/coping-grief. There is also information on bereavement within the leaflets in the Resource Pack.

Session three: Supporting in practice

Objectives

At the end of this session, trainees will:

- Have applied learning from session two to case study examples.
- Have engaged in reflective discussion about carer needs at the end of life, and reflected on the supporting role.
- Recognise that there are a range of activities that can be used to support carers.
- Understand that there are a range of agencies involved in end of life care and recognise the importance of signposting.
- Appreciate that supporters will already have many skills that are transferable to this context.

Suggested timetable: 45 minutes

Part	Time needed	Content	Activity	Resources required	Outcome
3a Overview of session	2 minutes	Brief presentation of objectives of the session and summary of content	Presentation by facilitator	Power point slide 13 and Workbook page number 11.	Trainees are aware of the objectives of the session and have insight into content that will be covered.
3b	43 minutes	Trainees work in small groups on a 'real world' case study and then feedback their discussion to the rest of the group	Group work	Power point slide 14 and Workbook page number 12 to 18. Flip chart paper and pens	Trainees have engaged in discussion about the possible support needs of a carer and considered what could be offered to support them.

Part 3a: Overview of session

Activity: Short introductory presentation

Time: 2 minutes

Materials: Power point slide no. 13. Workbook page 11

Facilitator actions:

Explain to the group that the overall goals for this session are to:

- Apply learning from session two to case study examples.
- Work through 'real life' cases to identify carer needs and discuss possibilities for support.
- Practise applying a range of activities that can be undertaken to support carers.
- Consider the range of agencies involved in palliative and end of life care with whom the carer may be in contact.
- Recognise that supporters have many transferable skills.

Briefly go over this information and direct trainees to page 11 in their workbook.

Advise trainees that the session will last about 45 minutes, following which there will be a lunch break.

Give trainees the opportunity to ask questions.

Outcomes of part 3a

Trainees understand the purpose and timing of the session and have opportunity to ask questions.

Part 3b: Case study group work and feedback

Activity: Small group work and feedback.

Time: 25 minutes

Materials: Workbook pages 12 - 18. Flip chart paper and pens. Power point slide no. 14

Facilitator actions:

Ask the group to work in small groups of 3 to 4 people. You may want to split the groups so that they are working with different people from the earlier session.

This part is in two sections:

- 1) Small group discussion (25 minutes)
- 2) Whole group feedback (20 minutes)

1. Small group discussion

- Direct the groups to the case studies in the workbooks.
- Allocate each group one of the case studies to work on (If you have limited time available it may be useful to only use one or two case studies as this reduces the amount of time required for whole group discussion).
- Ask the groups to read, or listen to, their case study before working through the questions on pages 12, 13 and 14 of their workbooks. Encourage them to discuss the answers amongst their small group.
- Advise the groups that they have 25 minutes for the activity. At the end of this time, they will be asked to feedback their answers to the rest of the group.

2. Whole group discussion

- Ask each group to nominate someone to present their case study.
- Play the audio file of the case study that the group has worked on.
- The nominated people will feedback on the group's discussion (if more than one group has worked on each case study then ask them to feedback on one or two questions each).
- Where possible, link the group's feedback to the earlier session and the support needs identified in the CSNAT ©.

Outcomes of part 3b

Trainees have engaged in discussion about the possible support needs of a carer, and considered what could be offered to support them.
Trainees have an opportunity to share their ideas with the wider group.
Links are made between theories about carer support needs to 'real world' case studies.

Part 3b: Additional facilitator information

As the groups are working on the case studies you may want to join them for a few minutes to ensure their conversations are focussing in the right areas. If the group is struggling with the task then it might be helpful to use some verbal prompts to get them talking.

Possible prompts include:

- Have you come across a case like this before?
- How do you feel about this case?
- Are you clear about the questions asked in the workbook?

Extra activity suggestion:

If you have more time for this activity you could extend the amount of time available for small group discussions and feedback. You may also repeat the activity but give the groups a different case study to consider.

Session 4: Being a safe supporter

Objectives

At the end of this session, trainees will have learned that:

- Supporting in end of life situations can be emotionally challenging.
- Being a safe supporter means looking after your own wellbeing.
- There are strategies available to assist supporters in looking after their own wellbeing.
- Ongoing support is important to enable you to maintain the quality of support you provide.

Suggested timetable: one hour

Section	Time needed	Content	Activity	Resources required	Outcomes
4a Recap of morning sessions	5 minutes	Recap of morning sessions	Facilitator presentation		Trainees have been reminded of main issues covered in morning sessions
4b Introduction	5 minutes	What is meant by being a safe supporter Session outline	Facilitator presentation	Power point slide 15 – title of session Workbook page 20	Trainees have been introduced to the session and its contents
4c Grief: assumptions and understandings	10 minutes	Quiz Discussion	Individual work on quiz Facilitator led discussion of answers to quiz	Workbook page 21 Power point slide 16 and 17 with quiz questions	Trainees have thought about grief and the assumptions that are made about it
4d Grief: personal biography and wellbeing	20 minutes	Personal and professional grief Impact of personal biography Strategies to support personal wellbeing	Facilitator led discussion	Power point slides 18 and 19. Flipchart and pens	Trainees have been introduced to some strategies to help promote their wellbeing Trainees understand how personal biography can impact upon their work/volunteering

<p>4e Putting it into practice</p>	<p>10 minutes</p>	<p>Case study</p>	<p>Trainees read/listen to case study</p> <p>Facilitator led group discussion of answers to questions</p>	<p>Power point slide 20 with questions</p> <p>Workbook pages 22 to 23</p>	<p>Trainees have applied the learning from this part to a real world scenario</p>
<p>4f Identifying support for trainees</p>	<p>10 minutes</p>	<p>Consideration of support through trainees' organisations</p> <p>Accessing support</p>	<p>Paired discussion</p> <p>Facilitator led discussion of what to do if there is no organisational support available</p>	<p>Workbook page 24</p>	<p>Trainees have identified sources of support that are available to them</p> <p>If support is not readily available trainees have begun to develop ideas of where they can access some support</p>

Part 4a: Recap of morning sessions

Activity: facilitator led discussion

Time: 5 minutes

Materials: none required.

Facilitator actions:

- Remind trainees of some of the ground covered in the morning sessions.
- Remind them that the topic can be emotional, and that it is okay to leave if they feel they need to.
- Ask them if they have any questions.
- There may be particular aspects which seemed significant to the group you are working with and which you wish to highlight.
- Alternatively, you may wish to remind trainees that during the morning you discussed the following:
 - What it means to say that someone is at the end of life.
 - Some of the terminology that supporters might come across, e.g. terminal, palliative, dying, end stage etc.
 - Who carers are, their varied needs and experiences.
 - The importance of listening and being there.
 - The impact that it can have on a home and family when a member of that family is dying at home.

Outcomes of part 4a

Trainees have been reminded of main issues covered in morning sessions.

Part 4b: Introduction

Activity: facilitator led presentation

Time: 5 minutes

Materials: Power point slide no. 15 with session title. Workbook page 20.

Facilitator actions:

Introduce the idea of being a safe supporter to the trainees. Being a safe supporter includes the following aspects:

- Managing one's own wellbeing.
- Not doing harm to self.
- Not doing harm to others.

These elements are important in all supporting, but especially so in end of life contexts, due to the sensitivity of the subject.

Outline the contents of session:

- Exploration of grief, both personal and professional.
- Discussion of how grief can affect our experience of working with people in end of life situations.
- Strategies to protect wellbeing.

Outcomes of part 4b
Trainees have been introduced to the session and its contents.

Part 4c: Grief: Assumptions and understandings

Activity: quiz and discussion

Time: 10 minutes

Materials: Power point slides nos. 16 and 17 (16 shows the questions, 17 reveals the answers one by one). Workbook page 21.

Facilitator actions:

- Ask the trainees to work individually, answering questions in the quiz which is in their workbooks on page 21.
- Allow 3 or 4 minutes for this.
- Follow this with a facilitator led discussion of the answers.

Suggested answers as follows:

- We only grieve deaths: **False** – we may grieve all losses.
- Only family members grieve: **False**, all who are attached grieve.
- Grief is only an emotional reaction: **False**, grief is manifested in many ways
- Individuals should leave grieving at home: **False**, we cannot control where we grieve.
- We slowly and unpredictably recover from grief: **True**, grief is an uneven process, a roller coaster with no timeline.
- Grieving means letting go of the person who has died: **False**, we never completely let go.
- Grief will not last for ever: **True**, over time most people learn to live with loss.
- Grievers are best left alone: **False**, grievers need opportunities to share their memories and their grief.

Outcomes of part 4c

Trainees have thought about grief and the assumptions that we often make about it.

Part 4c: Additional facilitator information

Much has been written about grief and those who grieve, and ideas about what constitutes healthy grieving have changed over time. Within the context of this training programme it is important to remember that individuals grieve differently, and there is no one right way in which people should grieve. Until recently, for example, it was believed that all those who had been bereaved needed to go through certain stages of grieving and that at the end of this process they would move on and leave behind the person who had died. Today it is acknowledged that some who are bereaved will maintain continuing bonds with those who have died, and that this may be the right way of dealing with grief for them. While grief is natural when one has suffered a loss, there are occasions when an individual may need assistance in dealing with their grief.

There are many resources available if you would like to read more on grief before running the programme. Cruse Bereavement Care has a website which offers insight into grief and grieving, and this can be found here:

<http://www.cruse.org.uk/about-grief>

The NHS also has information about dealing with loss and grief on its website:

<http://www.nhs.uk/Livewell/emotionalhealth/Pages/Dealingwithloss.aspx>

Part 4c: extra activity suggestion

This is a more advanced exercise that you may want to use with a group who have previous experience of dealing with grief, or who have done some prior learning about grief.

Make copies of the extract on page 10 and ask the group to read the extract, which is from the book 'Before I Say Goodbye'. Explain to the group that the book documents the experience of Ruth Picardie, a journalist who worked for the Observer, as well as being a wife and mother to two young children. Ruth was diagnosed with breast cancer, and wrote a series of columns in the Observer newspaper about her experiences. These are reproduced in the book, along with a collection of e-mails and personal letters that chart her developing illness and her approaching death.

The book was published after her death, and Ruth's words are accompanied by a foreword and 'afterword' written by her husband, Matt Seaton.

This extract is taken from the 'afterword' in which Matt reflects on his observations of dying and death and the frustrations of being a carer and husband for someone living with terminal illness.

Once the trainees have read the extract facilitate a group discussion about it. Use the following questions as prompts:

- How does Matt Seaton describe the dying and death of his wife?
- How does Matt feel about his wife as she approached the end of her life?
- What challenges does he describe in the extract?
- Could these challenges be solved?
- As a supporter, what might you have done if Matt was your client?
- How does reading this extract make you feel?

You always imagine death as a sudden event, a clean break between being and non-being, possession and loss – and for some, facing perhaps the dreadful trauma of losing a loved one killed suddenly in an accident, that is how it must be. But with a progressive disease like cancer, dying is a relentlessly attritional process of estrangement. You want so much to do and say the right thing, but you are doomed to frustration, failure and regret. The only really ‘right thing’ would be to make that person you love well again, and that is the one great godlike task you cannot perform.

I know I was wrong in many important ways: our relationship is an irreducible historical fact – for eleven years, before the cancer, it was what it was, and nothing can alter that. And it lives on, too, in the most real possible way in our children; there is no greater saving grace.

I know also that regret and guilt are the classic symptoms of bereavement. In a sense, I’m aware that what I feel is almost a cliché. None of that, though, alters the angrily chafing, subjective truth of the feeling. I just wish – how I wish – I could have somehow got round it: loved Ruth, or made her feel loved, in the old way, to the very end.

But the truth is that it was no longer possible. The cancer had interpolated itself, sending out its rogue cells to multiply madly and lay waste like an army of termites. Cancer changed everything: it put us on different tracks, stretching our grasp of one another to the limit and eventually forcing us apart. In the end, I could not reach her, and it felt like a failure in me. And then she was gone.

Before I Say Goodbye. Picardie et al, 1998, pp. 103-104.

Extract taken from Picardie, R (1998) Before I Say Goodbye. Penguin Books: London. pp. 103-104. Reproduced with the kind permission of Matt Seaton.

Part 4d: Grief, personal biography and wellbeing

Activity: group discussion

Time: 20 minutes

Materials: power point slides nos. 18 and 19, flipchart and pens

Facilitator actions:

- Introduce by suggesting that our life experiences can impact on how we feel and behave when we are supporting carers.
- Remind trainees that we all grieve for professional as well as personal losses; give trainees time to read the content of slide 18.
- It is important to acknowledge professional as well as personal grief, and to consider how to manage it.
- Use slide 19 to suggest the 'rucksack' metaphor. This is one way of managing work related anxieties, concerns and grief. The rucksack, or bag, is an item into which all the worries and concerns that are loaded on you are placed at the end of the working day and the bag closed. This is the bag you leave at your front door when you return from work.
- Ask trainees for their tips on managing wellbeing and write their responses on the flipchart. If trainees are slow to respond the following may be used as prompts:
 - Talking with colleagues
 - Healthy lifestyle (food, rest, exercise etc.)
 - Managing stress
 - Taking breaks
 - Family time
 - Feeling supported
 - Supervision in the workplace
 - Support from boss/organisation
 - Enjoying work

Outcomes of part 4d

Trainees understand how personal biography can impact upon their work/volunteering.

Trainees have begun to think about strategies for looking after their own wellbeing.

Trainees have been introduced to some strategies to help promote their wellbeing.

Part 4d: Additional facilitator information

It is easy for those who work in the caring professions to think that they should maintain an emotional distance from the people with whom they work, and that this means they should be unaffected when someone with whom they have a professional relationship dies. While it is important that supporters establish and maintain a professional relationship with the people they are supporting (this forms the content of session six), it is also important that they are able to acknowledge that they may be affected by grief in relation to the people whom they support.

This does not mean that they are bad at the supporting role, but it does mean that they are human! Professional grief can occur in a number of situations, including when the supporter is reminded of a personal situation in the course of their work, and when someone they are supporting becomes bereaved. Supporters need to allow themselves this grief, to find ways of recognising it and to develop coping strategies that help them deal with it.

Part 4d: Extra activity suggestions

Activity one:

Ask trainees to make a list of the various emotions that people might feel when someone dies. Allow about 5 minutes for this, and then ask trainees to share their thoughts. Answers may include:

- Shock
- Distress
- Anger
- Disbelief
- Depression
- Tiredness
- Loss of interest
- Acceptance

Activity two:

This is a group activity which is intended to explore how patients, families and supporters may react to loss.

Read out the following scenario to the whole group:

Rita is a 30 year old woman who has two children aged five and eight. She is a single mother and has a younger sister who lives with her. A few weeks ago Rita was discovered to have a brain tumour. Rita has been discharged from hospital to die at home, as there is nothing further that the doctors can do.

Divide the trainees into three groups. Each group should think about one character from the scenario, imagining and discussing how they might feel. Allow about 10 minutes for this.

Group 1 is Rita

Group 2 is her sister

Group 3 is her sister's supporter

Each group has a piece of flip chart paper and writes down all their thoughts and feelings.

FEEDBACK (allow about 10 minutes)

Put the papers alongside each other and see the similarities and differences between them. There will probably be similarities between the responses of the 3 groups.

Highlight to trainees that they go through many of the same emotions as those they are supporting when they are faced with bereavement and loss.

Part 4e: Putting it into practice

Activity: group discussion

Time: 10 minutes

Materials: power point slide number 20, workbook pages 22 and 23.

Facilitator actions:

Suggest that trainees should read or listen to the case study, and read the associated questions in their workbooks.

Lead a full group discussion of answers to the questions:

1. Why might Sarah have become upset after leaving Joyce's house?

- Reminded Sarah of her dad and family circumstances when he was dying.
- Natural reaction to be upset and cry.

2. Should Sarah continue to work with Joyce?

- Trainees might disagree on this.
- If she wants to continue working with Joyce, Sarah will need to take steps to manage her emotions.
- Sarah also needs to take steps to look after her own emotional wellbeing.
- Good idea to talk through the issues with her manager/supervisor.

3. What could Sarah do to promote her own wellbeing?

- Make use of some of the strategies discussed earlier, e.g. support from colleagues; someone to talk to; ensure she has supervision at work; take a break; make time to do something she enjoys etc.

Outcomes of part 4e

Trainees have applied the learning from this session to a real world scenario.

Part 4f: Identifying support for trainees

Activity: paired discussion

Time: (10 minutes)

Materials: workbook page 24.

Facilitator actions:

- Ask the group to break into pairs to discuss the support that is available to them in their organisations.
- You might like to suggest that trainees work with someone from a different organisation (if this is possible).
- Point trainees to the workbook page (number 24) on organisational support and the questions there that can guide their responses.
- Allow about 5 minutes for these discussions.

Lead group discussion of what to do if there is no organisational support available:

- Make approach to organisation/line manager.
- Arrange own support.
- Ask colleagues how they access support.
- Identify mentor.
- Think about other organisations that may be able to help.

Outcomes of part 4f

Trainees have identified sources of support that are available to them.
If support is not readily available trainees have begun to develop ideas of where they can access some support.

Session 5: The principles of supporting in end of life care

Objectives

At the end of this session, trainees will have learned that:

- There are a number of principles which underpin the supporting role.
- The supporting role needs to be adapted to trainees' own specific role and working environment.

Suggested timetable: 30 minutes

Part	Time needed	Content	Activity	Resources required	Outcomes
5a Introduction to principles	5 minutes	Introduction to principles Introduction to activity	Facilitator presentation	Power point slide 21 Workbook page 26. Power point slide number 22 with principles listed	Trainees have been introduced to the principles
5b Putting principles into practice	20 minutes	Discussion of how the principles may be put into practice	Trainees will write examples of how their work fits the principles on post-it notes and stick on flip chart sheets. As they move around the room they can talk to each other about the principles and which aspects of their work fit with the different principles.	Each principle written at the top of a separate sheet of flip chart paper Post-it notes Lots of pens Power point slide 23 Workbook pages 27 and 28	Trainees have had the opportunity to talk and think about the principles. Trainees also have the chance to consider how they put them into practice in their work
5c Summing up	5 minutes	Summary of responses	Facilitator presentation	Filled in flipchart sheets Facilitator's note of responses	Trainees have the opportunity to hear how others have applied the principles

Part 5a: Introduction to the principles

Activity: Facilitator presentation

Time: 5 minutes

Materials: workbook page 26 power point slides nos. 21 to 23

Facilitator actions:

- Guide trainees towards the principles as listed in their workbooks (page 26) and on power point slide 22.
- Remind trainees how important it is when working directly with individuals who may be vulnerable – such as carers in an end of life situation – that professionals work in a manner that is consistent with the principles of good practice.
- The principles are designed to offer a framework for good practice which those who support carers in end of life contexts can follow.
- The principles listed here are suggested as broad principles that underpin the work of supporting carers at end of life.
- Trainees are likely to put the principles into practice when they are supporting carers, but do not necessarily realise this.

Outcomes of part 5a

Trainees have been introduced to the principles that underpin their work with carers.

Part 5a: Additional facilitator information

The principles are a set of statements intended to reflect the scope of the supporting role, the principles of the palliative approach and the domains of the Carers Support Needs Assessment Tool ©(CSNAT, see Session 2 page 37). They were initially developed by researchers, and then mapped against the National Institute for Health and Care Excellence (NICE) 'Quality standard for end of life care for adults' published in 2011 and the Department of Health's 'Common core competences and principles for health and social care workers working with adults at the end of life' published in 2009. The principles were reviewed and refined in collaboration with stakeholders.

The principles are designed to offer a framework for good practice which those who support carers in end of life contexts can follow.

The principles

- a) The supporter is someone who will listen.
- b) The supporter will have an awareness of the palliative approach to care.
- c) The supporter appreciates the wider context of 'caring' and recognises that carers may have a variety of responsibilities.
- d) The supporter understands that they are part of a larger team of people involved in supporting the carer and the person being cared for.
- e) The supporter will be aware of his or her own knowledge and skills.
- f) The supporter and carers are clear about the supporter's role and that the relationship is constrained by professional boundaries and contractual obligations.
- g) The supporter will work within the scope of their own organisation's policies and procedures.

Part 5b: Putting principles into practice

Activity: post it note exercise.

Time: 20 minutes

Materials: seven sheets of flip chart paper, each with one principle written on it; power point slide no. 23; post-it notes; pens; workbook page 28.

Facilitator actions:

Introduce the activity:

- Think about how, as a supporter, you put these principles into practice, either through work you already do with carers at the end of life or as part of your supporting role more generally.
- There are some possible ideas on the power point slide to get you going.
- As facilitator, you may like to read out the examples from the slide or to give some examples of your own.
- Around the room are sheets of flipchart paper, each with one of the principles written on it.
- You also have some post-it notes.
- For the next 15 minutes write on separate post-it notes things you do in your work that illustrates the different principles.
- Move around the room and talk to colleagues about how you apply the principles.
- Try to talk to someone you haven't already worked with today.

While trainees are doing this one of the facilitators could make a note of one or two responses for each principle (for use during summing up).

Outcomes of part 5b

Trainees have had the opportunity to talk and think about the principles with colleagues.

Trainees have had the chance to consider how they put them into practice in their work.

Part 5c: Feedback on putting the principles into practice

Activity: Facilitator led summary of work

Time: 5 minutes

Materials: filled in flip chart sheets, facilitator's note of responses

Facilitator actions:

- Summarise for the group some of the ways in which trainees put each principle into practice.
- Read out one or two from each principle.
- Reiterate the importance of working in a principled way.
- Highlight the fact that the principles are intended to promote discussion and thought about ways of working.

Outcomes of part 5c

Trainees have the opportunity to hear how others have applied the principles.

Parts 5b and 5c: Additional facilitator information

Both the activity and the feedback lend themselves well to adaptation. For example, the activity can be run in a more structured way so that if the group lacks experience of support work they could work in pairs. The feedback can be handled as a discussion, if you feel that it would be helpful to trainees to take extra time to think and talk about the principles. Equally, if the space in which the training session takes place is too small to allow trainees to move about freely the activity can be carried out in small seated groups with the flip chart papers being passed on to the next group after an allocated period of time.

Session 6: Boundaries and exit strategies

Objectives

At the end of this session, trainees will have learned that:

- Boundaries are an essential element of an effective relationship between carer and supporter.
- It is important to have an exit strategy when a supporting relationship comes to an end.

Suggested timetable: 30 minutes

Part	Time needed	Content	Activity	Resources required	Outcomes
6a Introduction	5 minutes	Introduction to topic	Presentation by facilitator	Workbook page 30 with key learning points Power point slide 24	Trainees understand topic
6b Considering boundaries	10 minutes	Scenario and questions	In groups or pairs read allocated scenario and answer questions	Workbook pages 31 and 32	Trainees have together worked through an example on either boundaries or exit strategies
6c Feeding back responses	12 minutes	Groups report back on their answers	Facilitator led discussion of feedback from activity	Power point slides 25 and 26. Flipchart and pens	Trainees have the opportunity to hear others' ideas Trainees understand some of the issues around boundaries and exit strategies and their importance
6d Summary	3 minutes	Session summary	Facilitator presentation	Power point slide 27.	Trainees take away key importance of boundaries and exit strategies

Part 6a: Introduction

Activity: Facilitator led presentation

Time: 5 minutes

Materials: workbook page 30 and power point slide no. 24

Facilitator action:

- Highlight key learning points of this session: importance of boundaries and exit strategies in working with carers in end of life context.
- If relevant remind trainees they have transferable skills from carrying out a supporting role in other contexts.
- Refer back to relevant principles, particularly:
 - d) Supporter works as part of larger team
 - f) Importance of role clarity
 - g) Importance of working within organisational policies.

Outcome of part 6a

Trainees understand the topic

Part 6a: Additional facilitator information

The relationship which supporters enter into with carers whom they support is not a personal one, rather it is a professional relationship. The supporter has a defined role, with a number of activities which make up that role and which collectively provide support to the carer. In order to offer the most effective support the supporter needs to remember that they are not friends, but that the relationship is a professional one. This in turn means that boundaries need to be set around the relationship and that the supporter should take care not to cross those boundaries. For example, the supporter should not borrow money from a carer (as they might from a friend), as this would change the nature of their relationship and make it impossible for the supporter to continue offering effective support. They would also be taking advantage of the carer who is in a vulnerable position.

The majority of supporting relationships will come to an end at some point. When this happens it is important for the supporter to plan their exit strategy, so that the carer knows what is happening and is not left feeling abandoned.

Many of the individual trainees who take this course will be familiar with the concepts of boundaries and exit strategies, although some may be less familiar with them. Boundaries and exit strategies are very important when working with carers in end of life contexts. Carers can be particularly vulnerable at this time and once the person they were caring for has died they are already feeling grief, without their supporter adding to their difficulties by disappearing and apparently abandoning them.

Part 6b: Considering boundaries and exit strategies

Activity: Small group activity

Time: 10 minutes

Materials: exercise 1, workbook pages 31 and 32. Power point slides nos. 25 and 26.

Facilitator action:

Introduce activity:

- Trainees will work in small groups of 2, 3 or 4.
- Allocate groups either scenario 1 (boundaries, slide 25) or scenario 2 (exit strategies, slide 26).
- Scenarios and questions that guide the trainees' discussions are in the workbook on pages 31 and 32.
- Allow 10 minutes for activity.
- Each group or pair will need to report back on their answers.

Outcomes of part 6b

Trainees have worked collaboratively through an example on either boundaries or exit strategies.

Part 6c: Feeding back responses

Activity: group feedback

Time: 12 minutes

Materials: workbook pages 31 and 32, flipchart and pens, power point slides nos. 25 and 26.

Facilitator actions:

Facilitator invites each group or pair to feedback their responses. These responses can be recorded by the facilitators (or their assistant – either a co-facilitator or a volunteer from the group) on flipchart paper. The trainees will raise varied issues, the following lists highlight some of these, but trainees may also come up with their own.

Scenario 1(boundaries):

- Context is key, client may want reassurance that it is okay to worry.
- Possibility that carer has become dependent upon supporter.
- May be appropriate to suggest contacting other agency, e.g. GP.
- Important to recognise limits to supporter's own expertise and skills.
- Overstepping the limits may have detrimental effects on carer and supporter.
- It is a professional relationship, not a friendship.
- Carers in an end of life context may be vulnerable.
- Carers need to know what to expect from supporters.
- A worker has a duty of care towards clients.
- Boundaries help to establish a safe working environment.
- Keep a clear separation between working life and personal life.
- A professional relationship.
- Not sharing personal details or problems with clients.
- Not seeking personal information from clients that is not needed.
- Leave clients' issues at work.
- The supporter is there to support the carer, not take on all their problems

Scenario 2 (exit strategies):

- Discuss your role with carer at the start of the relationship.
- Always be clear about what your role is.
- Your organisation may use written contracts/support plans.
- Be careful about self-disclosure and providing too much personal information.
- Be mindful of your role, as laid out in any job description/support plans.
- Take care not to overstep the boundaries yourself.
- Discuss with carer how the relationship is going.
- Does your organisation have client reviews?
- Discuss concerns with your line manager/mentor.
- Ensure that you have support in your role.
- Ensure that you are clear about your role and what is expected of you by your employing organisation.
- Be aware of when it is appropriate to refer, or signpost, a carer to another agency.
- Be clear from the start of the relationship that it is time limited.
- Make it clear that if the carer needs ongoing support of a particular kind, such as bereavement support, you will help them access it before leaving.
- Be clear that you will not simply vanish.

Outcomes of part 6c

Trainees have the opportunity to hear others' ideas.

Trainees understand some of the difficulties that may arise with regard to boundaries and exit strategies.

Trainees understand the importance of boundaries and exit strategies.

Part 6c: Extra activity suggestion

- This activity can be carried out so that each group or pair first work on scenario 1 (boundaries) and then feedback on it.
- Groups or pairs then work on scenario 2 (exit strategies) and feedback on that.
- The activity and feedback are otherwise as described above.
- More time can be allowed for discussion of the issues that arise if the facilitators feel that this is appropriate.
-

Part 6d: Summary

Activity facilitator led presentation

Time: 3 minutes

Materials: power point slide no. 27.

Facilitator actions:

Give a brief summary of the session.

You may like to cover some of the following points:

- Remind trainees of the importance of boundaries and exit strategies for the wellbeing and safety of both carers and themselves.
- Remind trainees that they are not alone in supporting carers, they are part of a larger team and there are resources available to support their work.
- Suggest that there may be areas of knowledge or skills that they have identified during the day that they would like to work on.
- The final session will offer the opportunity to think about this further.

Outcome of part 6d

Trainees take away the importance of boundaries and exit strategies.

Session 7: Ongoing learning and personal development

Objectives

At the end of this session, trainees will have learned that:

- There are a range of resources available that are suitable for use with carers and which can aid the supporter in carrying out their role.
- Supporters have the responsibility to consider and address their own ongoing learning needs.
- Supporters need to develop their own knowledge about local services available for carers and be ready to signpost carers on when necessary.

Suggested timetable: 50 minutes

Part	Time needed	Content	Activity	Resources required	Outcomes
7a Introduction	2 minutes	Introduction to session	Facilitator presentation	Power point slide 28 Workbook page 34	Trainees know what the session is about
7b The resource pack	15 minutes	Introduction to the resource pack for carers	Facilitator led: Demonstrate use of 'find me help' resource Full group discussion of how resources might be used	Power point slide 29 with resource list Power point slide 30 with link to 'find me help' website	Trainees are aware of the resource pack for carers and its contents
7c Planning to support carers in an end of life context	15 minutes	Discussion of what trainees have learned from the day and how they will use this	Discussion in pairs	Workbook page 35-37 Power point slide 31 and 32	Trainees have the chance to talk about their learning and what learning they might need in the future

Part	Time needed	Content	Activity	Resources required	Outcomes
7d Individual planning	10 minutes	Trainees think individually about how they will use what they have learned	Individual planning	Workbook page 37 Power point slide 33	Trainees have begun to think about their personal ongoing learning in relation to supporting carers in an end of life context
7e	5 minutes	'Top tips for supporters' film	Watching film	Power point slide 34	Key aspects of the training are highlighted to trainees.
7f Summing up	3 minutes	Summing up session Highlight key learning points	Facilitator presentation		Trainees have an awareness of the range of resources available to support them in their work They have begun to think about their own ongoing learning and personal development
Evaluation		Thank trainees for attending Ask them to complete an evaluation form	Filling in evaluation form	Evaluation forms – facilitator handbook page 100 Power point slide 35	You gain information about trainees views of the course, its content and its delivery

Part 7a: Introduction

Activity: Facilitator led presentation

Time: 2 minutes

Materials: Power point slide no. 28, workbook page 34

Facilitator action:

The Facilitator outlines the content of the session:

- The session will introduce the resource pack for carers.
- There will be an opportunity for trainees to reflect on their learning during the course.
- There will be an opportunity for trainees to begin making decisions about future learning needs and plans to implement learning.

Outcomes of part 7a

Trainees know what the session is about.

Part 7b: The resource pack

Activity: familiarisation with the resource pack

Time: 15 minutes

Materials: workbook pages 40-43, power point slides nos. 29 and 30, resource list

Facilitator actions:

- Guide trainees to look at resources on slide 29. If you have acquired a copy of one of these resources for each trainee guide their attention to this.
- If you have identified some local resources beforehand, you might like to introduce them at this point.
- Using the power point slide (30), open up the 'find me help' website <http://help.dyingmatters.org/>
- Demonstrate how it works, perhaps by putting in a local postcode (*if there is no internet connection suggest trainees look at this resource later*). Highlight to trainees that this will continue to be populated with new local services.
- Ask trainees how the resources could be helpful to them in their work supporting carers in an end of life context.

Responses might include:

- To increase personal knowledge.
- To answer specific queries which have come up.
- Resource to give to carers.
- Suggest carers read particular sections covering issues they have talked about.
- Resources to offer colleagues who wish to know more.

Outcomes of part 7b:

Trainees are aware of the resource pack for carers and its contents.

Part 7c: Planning to support carers in an end of life context

Activity: paired discussion

Time: 15 minutes

Materials: workbook pages 35-37, power point slides nos. 31 and 32

Facilitator actions:

Introduce the activity - trainees will work in pairs: you may like to suggest that if there is anyone they have not yet worked with, they could do so now.

Pairs will discuss 4 things:

- Something that they have learned from the day.
- How they will use that learning in their work or volunteering.
- One further skill or piece of knowledge that they could gain which would benefit their work.
- How they might go about acquiring the necessary training.

You may like to offer some possible responses to get trainees started:

- Thinking about how you establish boundaries in your working relationships.
- Visiting the Marie Curie website to see what it has to offer for carers.
- Talking to your line manager about how you can access training to help you gain knowledge and confidence in talking to carers about issues around dying.

Point out to trainees that there are examples in their workbooks and on the power point slide.

Outcomes of part 7c:

Trainees have the chance to talk about what they have learned and how they might further develop their knowledge

Part 7d: Individual planning

Activity: personal reflection and planning

Time: 10 minutes

Materials: workbook page 37, power point slide no. 33

Facilitator actions:

- Suggest trainees spend a few minutes thinking quietly about their personal responses to the questions from the last activity.
- Point out to trainees that they will find some information about sources of further training on page 39 in their workbooks.
- Suggest they make a note in their workbooks of any ideas they have about this.
- They can then return to their notes at a later date.
- These notes may be useful in talking to their line managers about training needs.

Outcomes of part 7d:

Trainees have begun to think about their personal ongoing learning in relation to supporting carers in an end of life context.

Part 7e: 'top tips for supporters' film

Activity: watch film

Time: 5 minutes

Materials: Power point slide no. 34

Facilitator actions:

We asked our research partners (who are all bereaved carers) to think of their 'top tips' for people who were supporting carers in home based end of life care. This film has been made from their suggestions. Explain to trainees how the film was made, and ask them to watch this and think about how the carers 'tips' relate to the information they have learned during the day.

Outcomes of part 7e:

Trainees have chance to reflect on some of their learning from the day, and the information in the film will reinforce their learning from the course.

Part 7f: Summing up

Activity: Facilitator summary of session

Time: 3 minutes

Resources: none required

Facilitator actions:

You may like to:

- Remind trainees of the range of resources available.
- Reiterate that it is useful to explore what resources are available locally for carers.
- Remind trainees that they have had time to begin thinking about what they have learned during the day.
- They have also had time to start thinking about how they will use what they have learned, and their future learning needs.
- Thank trainees for attending.

Evaluation of day

There is an evaluation form on the next two pages which you can ask trainees to fill in, to give you some feedback on the day. You can either use it as it stands, or add to it/change its content, depending upon what suits your local needs.

Introduction to supporting carers in end of life contexts

Course evaluation: trainees

We would really appreciate it if you would take a few minutes to complete this evaluation form. Please circle the number which reflects your view.

	Poor			Excellent/ Useful
Overall Verdict	1	2	3	4
Training Structure	1	2	3	4
Training Content	1	2	3	4
Session Length	1	2	3	4
Trainer(s)	1	2	3	4
Venue	1	2	3	4
Pace of Training	1	2	3	4
Activities	1	2	3	4
I learnt something useful	1	2	3	4
I'm glad I came	1	2	3	4

What did you like about the course?

What do you think could be improved?

Outline 3 things that you will take with you/have learnt today

If you don't mind, please could you give us a little more information about yourself?

Gender: Male/Female/Prefer not to specify

Age: 16-21 22-30 31-40 41-50 51-60 61-65
65+

Work/volunteer role: