

HOMEWARD BOUND EDUCATIONAL RESOURCES AND LEARNING UNITS



*"You matter because you are you,
and you matter to the end of your life."
Dame Cicely Saunders*

Homeward Bound Educational Resources and Learning Units

"We share stories because we know how powerful they can be. Through stories we can connect, and change the way we think, and understand better how someone's experience is different to our own. Homeward Bound is a powerful story, and an even more powerful catalyst for change. We all have a responsibility to treat each other with respect and dignity as death approaches: every word and every action can make a difference to a person who is dying and their family."

Claire Henry MBE, Chief Executive, The National Council for Palliative Care.

NCPC has worked in partnership with NHS England, Pancreatic Cancer UK, Leeds NHS Teaching Trust Palliative Care Team and St Giles Hospice to share Lesley and Seth's story and develop a suite of educational resources and learning units.

We invite you to read the script or view the film, explore these educational and learning resources and commit to take action by becoming an advocate for person centred compassionate end of life care for all.

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A. Relational Mapping PDF

B. Ambitions for Palliative and End of Life Care : A national framework for local action 2015-2020

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INTRODUCTION

This work book is based on a play Homeward Bound written by playwright Brian Daniels to share the personal experiences of Lesley and Seth Goodburn. Seth was 49 years old when he died soon after a diagnosis of Stage IV pancreatic cancer and this play recounts his life and his care and treatment towards the end of his life. It shares the experiences of his wife Lesley and their relationship throughout his illness, their contact with the care team and the services where Seth received his care. Lesley talks about the preciousness' of time when it is known to be limited, and the significance of every day, every hour, every minute and every second.

In 2014 'One Chance to Get it Right' was published which acknowledged the importance of time and the importance of staff being equipped and supported to care for someone who is dying. The report highlighted 5 Priorities for Care at the end of life, such as recognition of dying, clear and sensitive communication, patient led decision making and individualised care planning.

In 2015 "Every Moment Counts" the National Voices Narrative talked about what's important to individuals including a series of 'I' statements highlighting the significance of listening to the person within.

"Everyone's experience is unique: one size cannot fit all. This narrative reminds professionals and volunteers to stop, think and respond in a way that is, and feels, honest and personal to that person in front of them. It helps service providers and commissioners to look at the service they are entrusted to deliver through the eyes of the person who needs that care." Professor Bee Wee, National Clinical Director for Palliative and End of Life Care, Every Moment Counts National Voices (2015).

In 2015 "What's important to me – a review of choices in end of life care" (Choice Review) focused on the person as the centre of their care and identified key statements for professionals to listen to and to hear.

In July 2016 the government published a new National Commitment – 'Our commitment to you for end of life care' in response to the Choice Review (2015) articulating a 6 point pledge to the person at the centre of care. Within this there was strong endorsement for the Ambitions for Palliative and End of Life Care, as a national framework for local action. The Ambitions framework set out 6 ambitions that represent what good looks like (the full framework can be viewed in the further resources accessible online at: www.ncpc.org.uk/homewardboundresource).

The primary objectives shared in the play Homeward Bound, and the accompanying four learning units in this workbook are:

- To raise awareness about the signs and symptoms of pancreatic cancer.
- To understand the human impact of receiving a late diagnosis of disease on an individual and those important to them.
- To improve communication between professionals and individuals with life-limiting illness and their families and ensuring involvement and shared decision making.

- To improve the quality and experience of palliative and end of life care for people affected by pancreatic cancer.

The play Homeward Bound takes place primarily in two locations; home and hospital, and portrays the challenges that care and treatment can bring towards the end of someone’s life. Importantly the play focusses attention on the need for compassion, empathy, care and choice to be present throughout. As such, this educational resource provides an opportunity for both providers and educational organisations e.g. Universities to highlight the need for understanding of each unique individuals needs towards the end of life and to support the delivery of education and training competencies.



The Choice in End of Life Care Programme Board (TCEoLCP) (2015)
What's important to me. A Review of Choice in End of Life Care.

HOW TO GUIDE: ABOUT USING THESE RESOURCES

This workbook is based on a play Homeward Bound written by playwright Brian Daniels to share the story of Lesley and Seth Goodburn. The play has been written to give people especially health and social care professionals, the opportunity to reflect on the importance of compassionate person and family centred care at the end of life and to help individuals to understand how little things mean a lot to the person who is dying and to their family.

The workbook includes four learning units that have been designed to be used as standalone units or together they make up a comprehensive educational learning package.

These resources can therefore provide a catalyst for learning in a variety of different ways including individuals self-learning, or as a flexible educational package for lecture practitioners, educators, and trainers.

These resources could be used for example in the context of:

- Group learning via a study day.
- Work based learning.
- Taught sessions.
- Part of a learning module on End of Life Care (EoLC).
- Short ward based teaching session.
- Short burst sessions within induction training - delivering compassionate care.
- Clinical Supervision.
- Leadership programmes - focused training sessions on End of Life Care.
- Professional and multidisciplinary groups.

Who can benefit from these learning resources?

The professional groups outlined in the table overleaf have been divided into three tiers within the End of Life Care Core Skills Education and Training Framework (2017). Each tier outlines the knowledge and skills that a professional group or an individual practitioner will have or aim to obtain as part of their personal and professional development.

Tier 1 - Those that require general end of life care awareness, focusing on a community development, asset based approach to care.

The tier will be relevant to you if:

- You are a member of the public.
- You have been diagnosed with a life limiting condition.
- You support someone with a life limiting condition.
- You work in the adult health and social care sector but have limited contact with anyone approaching the end of life. For instance, you might deliver care and support in ophthalmology or physiotherapy, or may be in a role that doesn't deliver care and support such as administration or maintenance.

Tier 2 - Health and social care professionals who require some knowledge of how to provide person centred high quality end of life care as they often encounter individuals who need such support within their working environment. However, they do not work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

The tier will be relevant to you if:

- You work in adult health and social care. Most of the individuals you support are not approaching the end of life, but some are. For instance, you might work on an acute ward, in a GP's surgery or in a residential care home.
- You work in adult health and social care and provide supervision and professional support to other professionals. Most of the people they provide care and support for are not approaching the end of life, but some are.
- You do not work in adult health and social care but your professional role means you often provide support for individuals approaching the end of life. You might be a religious leader, work for a community development project or offer art or activity therapy to individuals approaching the end of life.

Tier 3 - Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

The tier will be relevant to you if:

- You work in adult health and social care. Most of the individuals you support are approaching the end of life. For instance, you may work in a hospice or in a palliative care service.
- You work in adult health and social care and provide supervision and professional support to other professionals. Most of the people they provide care and support for are approaching the end of life.
- You work in adult health and social care. Most of the individuals you support are not approaching the end of life, but some are. Your role is to lead the end of life care offer within your team or organisation.

Although the content of this play is based on the experience of someone with pancreatic cancer, the learning objectives and outcomes can relate to the care of any individual diagnosed with a life limiting condition and applies within any care setting. A number of nationally recognised resources are used throughout the learning units and will guide the educator/ learner throughout by aligning to and highlighting good practice. The [Pancreatic Cancer UK Patient Charter](#) (2016) sets out the standard of care for all pancreatic cancer patients and is intended to empower patients and their carers to enable high quality end of life care. It is used throughout to focus attention on the primary importance of person centred care and what's important to each individual.

The [Ambitions for Palliative and End of Life Care](#) (2015) is a national framework for local action and sets out the 6 ambitions that represent what good looks like. Ambition 1 "Each person is seen as an individual" highlights the need for honest conversations, clear expectations and helping people take control. Supported by Ambition 3 "maximising comfort" and Ambition 5 "all staff are prepared to care" all provide the foundations for the delivery of high quality care for all individuals at the end of life (the full framework can be viewed in the Appendices). The

opportunity of this resource is that it can be used as a reflective case study and create discussion about what good care should look like.

Each of the four Units in this workbook has been designed to represent a particular phase of Seth's and Lesley's journey and to highlight where the delivery of care may potentially have been different, if there was a greater understanding from staff of their needs and choices at the time.

At the end of each Unit there is a "key learning objectives and outcomes table" which outlines the essential components of high quality care as defined by the [NICE Quality Standards](#) (2011) within End of Life Care. Included within each table are the End of Life Care [Core Skills Education and Training Framework](#) (2017) and the Health Education Yorkshire and the Humber "End of Life Care Learning Outcomes for: Unregistered Support Workers Pre-qualifying Students Registered Professionals in Health and Social Care" (2015). These resources are set out to support the learner with an opportunity to obtain further competencies in EoLC.

In addition for further learning, each Unit identifies a range of e-learning for end of life care ([e-ELCA](#)) modules that may support further training needs. e-ELCA

is an e-learning resource developed by Health Education England e-Learning for Healthcare (e-LfH) designed to enhance the training and education of all those involved in delivering end of life care (EoLC) to those individuals who have been diagnosed with life limiting illnesses and are usually within the last 12 months of their life. In addition there are identified EoLC learning Resources for General Practitioners and Social Care professionals.

Each component within this table provides an opportunity for the [Pancreatic Cancer UK Patient Charter](#) (2016), educational frameworks and e learning modules to be taken into consideration within a discussion and / or reflection about the scenes of the play and to work towards achieving the learning outcomes within a training session.

This resource highlights that person-centred and individualised care is everyone's responsibility and this includes dignity, compassion and empathy at the end of life for an individual and those who are important to them. Maximising comfort and wellbeing, good communication skills, managing clinical uncertainty and the recognition of dying are all essential to ensuring the provision of compassionate individualised care both before and after

death are met for all patients and family/ carers.

What to consider when using these resources

End of life care is a very sensitive subject and affects everyone at a personal level and it is important to acknowledge that both the educator and the learner will have their own personal experiences and beliefs about dying, death, bereavement, and loss. The [Ambitions for Palliative and End of Life Care](#) (2015) states that "All staff are prepared to care" so that "Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care" Staff are prepared to care includes supporting staff and understanding their support needs when caring for people towards the end of life.



The cycle of care and support: assessing needs and providing care and support

Skills for Care and for Health (2014) *Common Core Competences and Principles for Health and Social Care Workers Working with Adults at the End of Life.*

UNIT 1: THE FIRST CONTACT - DID IT MATTER?



THE PLAY OPENS WITH RUSSELL WATSON SINGING NELLA FANTASIA.
THE FIRST VERSE FADES AND SETH SPEAKS

SETH: In my imagination, I see a fair world
Everyone lives in peace and honesty there
I dream of souls that are always free
Like the clouds that fly
Full of humanity in the depths of the soul

SETH AND LESLEY STAND IN SEPARATE SPOTLIGHTS. THEY FACE THE AUDIENCE.
THEY ARE IN THEIR LATE 40s.

LESLEY: I caught this cold. I can't shake it off. It's gone to my chest.

SETH: She told me not to give her a kiss because she didn't
want me to catch it. Difficult to resist though!

LESLEY: I don't want you taking time off work.

SETH: She's a stickler.

LESLEY: He's being made redundant on his 50th birthday. Overseas
outsourcing. How kind. I didn't want them to think he
was shirking. That's one thing he's never done. He's a proud man.

SETH: I came down with a bad chest all the same.

LESLEY: Mine cleared up but....

SETH: Now I can't shake it off. And I've got an awful backache.

LESLEY: I'm calling the GP. You're not yourself.

SETH: Don't make a fuss. It'll clear up. Don't bother the doctor. She's got
more important people than me to see.

LESLEY: There's nobody more important than you. I'm calling the surgery now.

SHE CALLS THE NUMBER ON HER MOBILE

It's engaged.

SETH: I'll be alright.

LESLEY: Still engaged.

SETH: There's a lot of these chest infections about. I think it's the change in the temperature.

LESLEY: It's ringing.

SETH: I'll make myself a lemsip .

HE GETS UP AND GOES TO THE KITCHEN

LESLEY: Hello. Good morning. Can I make an appointment for my husband please? Yes, Dr Higgins.

Seth Goodburn. 6.10.64. When? No I'm sorry we can't wait 2 weeks. I'd like an earlier appointment please. No, as I said I want him to see Dr Higgins. Alright then - the Prescribing Nurse it will have to be. No, he's not poorly enough for A & E. Fine - tomorrow between 8 and 12 - how long might we have to wait? Right. Well I hope nobody else in the waiting room catches it. No, I know it's not you who makes the rules. He's seldom ill. I think he's only been twice in the last 10 years.

SETH RETURNS

LESLEY: You can't even get to see the Doctor - it's the Prescribing Nurse.

LESLEY: Right, we'll have to be up early tomorrow to get there for 8 to the walk in surgery.

SETH: I'm not up to walking anywhere!

LESLEY: I said 'walk in' not 'walking'. Stop teasing me Seth. Do you want a go at the crossword? I'm stuck on 4 down.

SETH: How many letters?

LESLEY: Eight. Ends in an S.

SETH: A plural then.

LESLEY: Not sure. The clue is 'Care Plans for a glandular organ'. It might be an anagram.

SETH: Care plans. Glandular organ. Heart? Lungs? Liver? Have you got the first letter?

LESLEY: P. (SHOOTS HIM A LOOK) No it's definitely not that!

SETH: Did I say anything?

LESLEY: You didn't have to. I've got it.

SETH: What?

LESLEY: Care plans - Plan Scare. No, that can't be right...I've got it. Pancreas. There's no 'L' but its near enough.

SETH: Pancreas. You are brilliant. What is the pancreas exactly?

LESLEY: I'll google it. Hang on. Er it's a (READ) 'glandular organ in the digestive system located in the abdominal cavity' blah blah blah-producing important hormones. Oh we don't need to know all that.....

LIGHTS FADE.



KEY LEARNING OBJECTIVES AND OUTCOMES

This Unit explores the first contact made with the G.P Practice by Lesley and relays the experience with the receptionist and Seth's initial assessment and his diagnosis of pancreatic cancer.

Each Unit in this workbook has been designed to represent a particular phase of Seth's and Lesley's journey to highlight where the delivery of care may have been different, if there was a greater understanding of their needs and choices at the time. Each component within the table overleaf provides an opportunity for these to be taken into consideration within either a facilitated discussion and / or personal reflection and to achieve the learning outcomes associated within a training session.

The [NICE Quality Standard for End of Life Care \(EoLC\)](#) for Adults defines clinical best practice. It provides specific, concise quality statements and measures to provide the public, health and social care professionals, with definitions of high-quality care (NICE 2011). The table overleaf outlines these key components and standards of high quality care and the Core Skills Education and Training Framework (2017) with optional learning outcomes and identified e learning modules that may support further training needs. The [Pancreatic Cancer UK Patient Charter](#) (2016) sets out the standard of care for all pancreatic cancer patients and is intended to empower patients and their carers to enable high quality end of life care.

Communication Skills in Identification and Assessment

<u>Pancreatic Cancer UK Patient Charter (2016)</u>	<u>End of Life Care Core Skills Education and Training Framework (2017)</u>	Health Education Yorkshire and Humber EoLC Learning Outcomes (2015)
<p>2. Your diagnosis and treatment options should be clearly explained to you. Your family should be offered information and support (but patient confidentiality must be respected).</p>	<p>1. Person-centred end of life care. 2. Communication in end of life care. 3. Equality, diversity and inclusion in end of life care. 6. Assessment and care planning for individuals at the end of life. 9. Support for carers. 14. Improving quality in end of life care through policy, evidence and reflective practice.</p>	<p>1.1a. Communicate with a variety of people and ways. 1.1b. Communicate with people about difficult and complex matters or situations. 1.1c. Present information in a range of formats. 1.1d. Listen to individuals, and their families / friends about their concerns. 1.1e. Operate in a sensitive and flexible manner. 1.1g. Ensure that information is clear, and non-jargonistic. 1.2a. Work in a person centred way.</p>

Further learning opportunities for all professionals working in EoLC

Below are a few of examples of freely accessible learning modules that are available from e-learning for end of life care (**e-ELCA**) online and are referenced as per module number and topic as below:

03_01 The importance of good communication

03_06 Communication skills for administrative staff, volunteers and other non-clinical workers

A table of all cross-referenced modules per Unit of learning can be found in the appendices (accessible online at: www.e-lfh.org.uk/programmes/end-of-life-care)

Access to the Royal College of General Practitioners (RCGP) EoLC learning Resources

RCGP Palliative and End of Life Toolkit or

URL Address www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

A range of suggested learning materials has been recommended by the GMC such as the e-ELCA session: 05_18 Treatment and care towards the end of life: good practice in decision making.

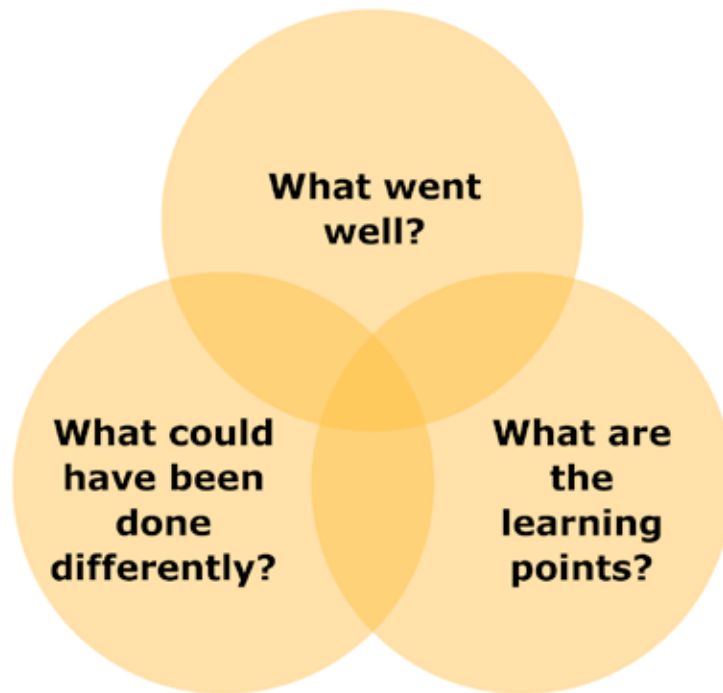
Other available learning resources

Social Care Institute for Excellence - Get connected to e-learning - for social care providers or URL Address www.scie.org.uk/publications/getconnectedtoelearning/freeelearning.asp

Ambitions Knowledge Hub for Palliative and End of Life Care Resources or URL Address www.endoflifecareambitions.org.uk/resources/



REFLECTIVE LEARNING EXERCISE



Prompt questions to enable further discussion and /or reflection:

- How could the receptionist have showed more compassion, empathy and recognition of how Lesley was feeling?
- Think about your current area of practice and how you might respond in this situation?

The questions below may generate additional points for discussion:

WHAT ELSE MIGHT BE IMPORTANT TO CONSIDER:

- FOR SETH?
- FOR LESLEY AS A CARER?
- FOR THE GP PRACTICE?

UNIT 2: WHAT HAPPENS NEXT - ARE YOU GOING TO INVOLVE ME?

LIGHTS FADE. THEN LIGHTS UP ON LESLEY AND SETH BACK AT HOME AFTER THE DOCTOR'S APPOINTMENT. LESLEY IS HOLDING A PAPER PHARMACY BAG AND SHE REMOVES DIFFERENT ITEMS FROM IT.

LESLEY: Right, well this is an antibiotic. That's good. And this one looks like a steroid. I'm surprised you didn't have to have a Doctor prescribe that one. That'll help with your breathing. The nurse was very nice but even she said you should definitely have seen the doctor.

SETH: I just want to go to bed. I'm so tired. All that hanging around for a ten-minute appointment. It's taken the wind out of my sails.

LESLEY: Seth – it's not like you to be so lethargic. I'm worried. You're not yourself. Go and get yourself into bed love.

SETH: Are you not going into work this afternoon?

LESLEY: I booked the day off. It's OK I've still got 23 days owing.

SETH: Oh, I'm glad you'll be here. I do feel poorly.

LESLEY SPEAKS DIRECTLY TO THE AUDIENCE.

LESLEY: That was on the 21 April 2014. He started on the medication and he started to feel a little better - then he started to feel poorly again. I tried to get another appointment with the GP. Nothing doing. In desperation took him to a different walk-in centre where he was diagnosed with breathing problems - they gave a prescription for a different antibiotic and more steroids. It went from bad to worse. Seth said he felt that there was fluid in his abdomen. I managed to get an emergency appointment with the GP on Monday 12 May when she looked concerned and apologised that we had had to wait so long for an appointment. She referred Seth to A & E for blood tests and X-Rays. We went straight there.

LESLEY LEAVES THE STAGE. SETH APPEARS IN A WHEELCHAIR WITH A BLANKET. HE WHEELS HIMSELF IN. HE ADDRESSES THE AUDIENCE.

SETH: When I woke up this morning I thought - now what's the date - oh my heart sank. May 13th. Not a lucky number for me. Never mind - they can work wonders these days - whatever I've got they'll get to the bottom of it. I mean, I'm not 50 until October. We're going to the Great Wall of China. I can't wait. I want to see the giant pandas - there's so much I want to see and do.

HE TAKES OUT HIS MOBILE AND DIALS A NUMBER

Hello love. Did you collect the car? A ticket. Oh great. You'd think that if it's left there overnight there must be a good reason for it. Never mind, we'll just have to pay it. Are you at work? Oh, OK my love. Yes, see you at 4. How do I feel? - I feel sticky and a bit weak - and I feel so stupid This has really knocked me for a 6. Alright darling. See you soon. I love you. Bye.

LESLEY ADDRESSES THE AUDIENCE DIRECTLY

LESLEY: When I got there just after 4, he was in a single room, he'd been for his scan and was waiting the results. He was anxious and tired. I helped him have a shower and got him dressed in his own clothes, washed and brushed his lovely hair and I fell in love with him all over again. I left about five but promised I would be back at 6.30 and stay until the end of visiting time. I had to do a bit of shopping, go to the bank and pay that wretched parking fine. I didn't want that hanging over me on top of everything else.

LIGHTS DOWN ON LESLEY AND UP AGAIN ON SETH SITTING IN THE WHEELCHAIR.
LESLEY APPEARS WITH SOME ICE LOLLIES

LESLEY: I've brought you some ice lollies. They should be cool on your tummy. They don't let you bring flowers now - something about the water and contamination. It's a pity because they would have brightened the room up a bit. Seth? Seth, what is it love?

SETH: The Consultant's been round.

LESLEY: Go on.....

SETH: Les - whatever happens - you must promise me that if the day arrives and I'm not here anymore, that you will make the most of your life without me.

LESLEY: What are you saying Seth? What is it? What did he say?

**SETH AS
THE**

DOCTOR: Good afternoon Mr Goodburn, my name is James, I'm a Senior Oncologist here.

SETH: I said pleased to meet you James.

**SETH AS
THE**

DOCTOR: And how are you feeling today? Oh dear, oh dear. Now we've had the results of the scan. We can't be absolutely certain until the biopsy results come back but to all intents and purposes it looks as though it might be a carcinoma of the tail of the pancreas. I said, 'Cancer?': He said, I'm afraid so. I said, what can you do for me? He said, We'll try an intensive course of chemotherapy.

LESLEY: Chemotherapy? (SHE GETS A PAPER TISSUE TO STEM HER TEARS) It doesn't make sense. You've only been poorly for a couple of weeks. You were responding to the antibiotics and the steroids. It can't be right. I want another opinion.

SETH: There was no doubt. He showed me the scan. He said I had all the classic symptoms - backache, indigestion and lethargy. It's terminal. We have to talk; we have to plan. Hold me Les - just hold me. Together we can fight this.

THEY HOLD ONE ANOTHER TIGHTLY.

LESLEY ADDRESSES THE AUDIENCE

LESLEY: How do you describe the day that your world falls apart? It's the day we never want to come. You feel physically sick and you don't want to believe what is true, is true. You see the one you love and who loves you unconditionally asking you to promise to make the most of your life without him. You mourn the future stretching ahead without him. I sit in the car. I scream, I howl, I sob, I grieve, I am angry and I am terrified. I need to be strong and I will be strong for him.

LIGHTS DOWN

LIGHTS UP ON SETH SITTING IN A CHAIR WITH HIS BLANKET. HE IS IN A 6-BEDDED WARD SEATED NEXT TO HIS BED. HE LOOKS AT HIS WATCH. HE'S DEPRESSED BUT TRIES TO PUT ON A CHEERFUL FRONT WHEN LESLEY APPEARS.

LESLEY: You should have texted me to say they'd moved you. I was just about to barge into that side room and that nurse, Greg I think he's called, blocked me. He said your husband's been moved to a ward. He didn't know which one. It's taken me ages to find you. How are you feeling?

SETH: I should've texted you. I'm sorry my love.

LESLEY: Oh Seth, no I'm sorry. I shouldn't have snapped at you.

SETH: I hate it in here.

LESLEY: (LOOKS ROUND) I see what you mean.

SETH: No, I mean they're a lovely bunch of blokes. I just don't, oh I don't know what I want and what I don't want any more. I just need time and privacy to think. Look, if this is the end then I don't want to stop here. Take me home with you Les. Let me die in my own bed with you next to me. That's all I want now, just to be with you.

LESLEY: That's what we both want. I've been on the website. We do have options.

SETH HOLDS HIS TUMMY AND WINCES WITH PAIN

What's wrong? I'll call the nurse.

SETH: It's OK – It's that fluid in my stomach again. It makes it difficult to breath properly.

LESLEY ADDRESSES THE AUDIENCE

LESLEY: The next day he had a drain inserted. He was more comfortable and his breathing improved. The drain was removed three days later. In those three days there were 10 litres of fluid drained from his abdomen. The Consultant came to see us. He was so kind, so understanding. It's just a pity we had to see him on the ward with five other patients and their families listening in. When he confirmed the worst he stooped to our level and touched Seth's arm and held my hand as he delivered the blow. The ward went silent.

SETH: When you're in the business of prolonging and saving lives then breaking bad news must be one of the most difficult of jobs. You need a quiet and private place to have those personal and intimate discussions. The second Consultant's empathy and innate human compassion was clear and heartfelt – it's just the environment that was wrong.

LIGHTS DOWN



KEY LEARNING OBJECTIVES AND OUTCOMES

This Unit recounts how Seth received his diagnosis of pancreatic cancer and the communication with him by members of the multi-disciplinary team. It explores how these experiences compared throughout and what might have been done differently.

Each Unit in this workbook has been designed to represent a particular phase of Seth's and Lesley's journey to highlight where the delivery of care may have potentially been different, if there was a greater understanding of their needs and choices at the time. Each component within the table overleaf provides an opportunity for these factors to be taken into consideration within a facilitated discussion and /or personal reflection and to achieve the learning outcomes within a training session.

The NICE Quality Standard for End of Life Care (EoLC) for Adults defines clinical best practice. It provides specific, concise quality statements and measures to provide the public, health and social care professionals, with definitions of high-quality care (NICE 2011). The table overleaf outlines these key components and standards of high quality care and the Core Skills Education and Training Framework (2017) with optional learning outcomes and identified e learning modules that may support further training needs. The Pancreatic Cancer UK Patient Charter (2016) sets out the standard of care for all pancreatic cancer patients and is intended to empower patients and their carers to enable high quality end of life care.

Communication Skills, Assessment & Care Planning - Breaking significant news

<u>Pancreatic Cancer UK Patient Charter (2016)</u>	<u>End of Life Care Core Skills Education and Training Framework (2017)</u>	Health Education Yorkshire and Humber EoLC Learning Outcomes (2015)
<p>2. Your diagnosis and treatment options should be clearly explained to you.</p> <p>Underpinning values</p> <p>4. You should be treated with compassion, dignity and respect and given practical and emotional support.</p> <p>5. Your family should be offered information and support (but patient confidentiality must be respected).</p>	<p>1. Person-centred end of life care.</p> <p>2. Communication in end of life care.</p> <p>3. Equality, diversity and inclusion in end of life care.</p> <p>5. Practical and emotional support for the individual approaching the end of life.</p> <p>6. Assessment and care planning for individuals at the end of life care.</p> <p>7. Symptom Management in end of life.</p> <p>8. Working in partnership with health and social care professionals and others.</p> <p>9. Support for carers.</p> <p>10. Maintain own health and wellbeing when caring for someone at the end of life.</p> <p>14. Improving quality in end of life care through policy, evidence and reflective practice.</p>	<p>1.1a. Communicate with a variety of people and ways.</p> <p>1.1b. Communicate with people about difficult and complex matters or situations.</p> <p>1.1c. Present information in a range of formats.</p> <p>1.1d. Listen to individuals, and their families friends about their concerns.</p> <p>1.1e. Operate in a sensitive and flexible manner.</p> <p>1.1g. Ensure that information is clear, and non-jargonistic.</p> <p>1.2a. Work in a person-centred way.</p> <p>Underpinning Values</p> <p>1.5a. Person-centred practice.</p>

Additional note: It is a patient's choice if they wish to have significant news about their diagnosis and prognosis communicated alone or with someone to support them. This should form part of the discussion and professionals choosing the opportune appropriate time and place.

Further learning opportunities for all professionals working in EoLC

Below are a few of examples of freely accessible learning modules that are available from e-learning for end of life care (e-ELCA) and are referenced as per module number and topic:

- 01_12 How to get started and get the timing right.
- 01_13 How to handle patients' questions and concerns.
- 03_15 Breaking bad news.
- 04_03 Communicating the plan of management and care.

A table of all cross-referenced modules per unit of learning can be found in the appendices.

Access to the Royal College of General Practitioners (RCGP) EoLC Learning Resources

RCGP Palliative and End of Life Toolkit or

URL Address www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

A range of suggested learning materials has been recommended by the GMC such as the e-ELCA session: 05_18 Treatment and care towards the end of life: good practice in decision making.

Other available learning resources

Social Care Institute for Excellence - Get connected to e-learning - for social care providers or

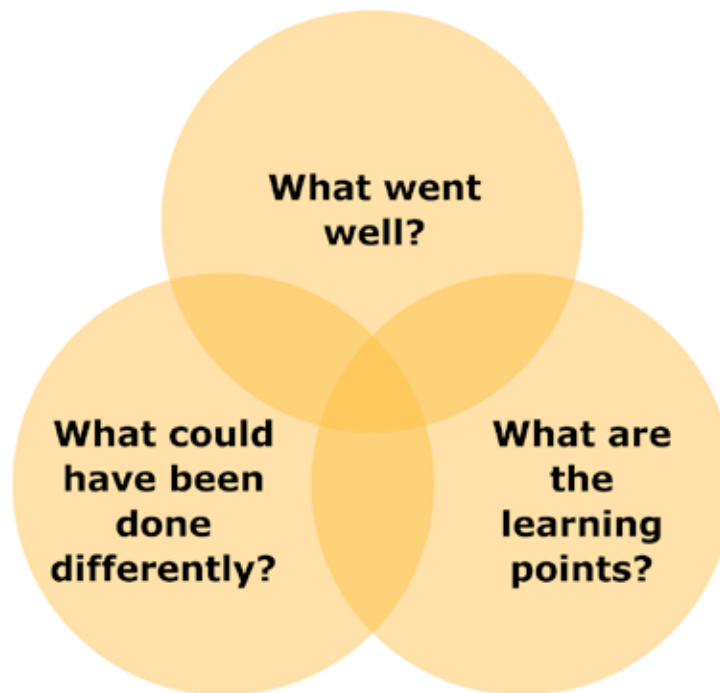
URL Address www.scie.org.uk/publications/getconnectedtoelearning/freelearning.asp

Ambitions Knowledge Hub for Palliative and End of Life Care Resources or

URL Address www.endoflifecareambitions.org.uk/resources/



REFLECTIVE LEARNING EXERCISE



Prompt questions to enable further discussion and /or reflection:

- Think about both of the conversations and how the significant news was explained to Seth and how might this have been communicated differently?
- What support could have been given to Seth and Lesley at this stage?
- What do you think is Seth's understanding of the information he has been given?

The questions below may generate additional points for discussion:

WHAT ELSE MIGHT BE IMPORTANT TO CONSIDER AT THIS STAGE:

- FOR SETH AND LESLEY'S CHOICE AND CONTROL OF THE CARE OPTIONS?
- FOR THE SENIOR ONCOLOGIST?

UNIT 3: IT'S THE SMALL THINGS THAT MAKE A BIG DIFFERENCE



LIGHTS DOWN AND UP AGAIN. SETH AND LESLEY ARE AT HOME

SETH: I love this house. I know it like the back of my hand. It's so warm, it feels safe and ordered. It will be just the same when I'm gone. It seems unreal – everything will go on just the same without me.

LESLEY: Without you it's a house, not a home – it's our home created by us together. I don't want it to be just my home. The thought of it makes me shudder.

SETH: I'll be here in spirit though.

LESLEY'S PHONE RINGS

LESLEY: Hello. Lesley Goodburn speaking. Yes, oh thank you for ringing. Yes, the 28th is fine. 11am, so that's a week today. Lovely, thank you so much.

SETH: Who was that?

LESLEY: That was the Palliative Care Nurse. They're coming on the 28th to go through options.

SETH: Sounds ominous.

LESLEY: No. They offer a 'hospice at home' support and that's what we want. She sounded lovely.

SETH: I'm not ready to go. I've been robbed and you've been robbed of our future.

LESLEY: There's nothing to say.

SETH: Nothing at all. Nothing.

IT'S A WEEK LATER. SETH AND LESLEY ARE AT HOME. THEY ARE WAITING FOR THE VISIT FROM THE PALLIATIVE CARE TEAM. SETH IS WRAPPED IN HIS BLANKET SEATED IN HIS ARMCHAIR. HE IS REFUSING TO TALK TO LESLEY AND COMMUNICATES ONLY IN SIGN LANGUAGE.

LESLEY: It's turned 11 o'clock now and they said they'd be here at 11. Oh hang on, there's a car pulling up now. That's not them – oh its Dr Higgins. She did say she might pop in after morning surgery to review the medication. There's another car pulling up behind her. This looks like the Hospice people. I'll go and let them all in.

SHE EXITS

SETH: That GP – Dr Higgins – Angela by name and Angelic by nature. Nothing is too much for her – that's when you can get to see her, She actually phoned Mr Khan the pharmacist one Sunday. He was closed but she sweet talked him into getting the prescriptions made up. When she brought them I asked if I could have a little word – Les was making her a coffee. She held my hand. I said it's about Les. She said – go on – I said who will take care of her when I'm gone? She comes across as strong and capable but nobody knows her like I do. She'll most likely go to pieces. I feel so guilty. She squeezed my hand and assured me that Lesley was her patient too and she would make certain that Lesley had all the support she needed – when the time came. A weight lifted.

LESLEY ENTERS

LESLEY: I'm so sorry Seth – we need to go back to the hospital in the morning for a chemotherapy assessment. You need to have that drain re-inserted too for the excess fluid. It should only be for 24 hours then you'll be back home.

SETH: I certainly hope so. (To AUDIENCE) The nurse was a treasure. She looked me straight in the eye and asked me what I knew about my illness. I told her that I knew it couldn't be cured. PAUSE. She said so tell me Seth how we can make your life more comfortable. I said it's the pain. If you can get rid of the pain it would be bearable. She said she was sure they could do something for the pain when I was in the hospice – or at home. She thought though that it might be easier in the hospice. I said I didn't want to be apart from Les. She said that Les could be there day and night. There was another bed in the room she had in mind for me. I can't face that hospital again. They're so clinical about everything.

LESLEY: I know it's the way it seems but some of the staff are lovely.

SETH: And some not so lovely!

LESLEY: It should only be for 24 hours. I'll go and pack a few things for you. I've told work that I'm not coming in this week so you won't be on your own with this.

SETH: I am on my own with this though.

LESLEY: That's enough. Whatever we've got to go through, we go through it together, for better for worse, for richer for poorer.....

TOGETHER In sickness and in humour! (THEY MANAGE A SMILE.)

IT'S THE EMERGENCY ASSESSMENT UNIT THE FOLLOWING DAY

SETH: We've been here hours.

LESLEY: So much for an emergency assessment.

SETH: Is she the only nurse on duty then?

LESLEY: Seems to be. I don't like to bother her. One thing for sure though. You are not spending the night in that chair. I'm staying until they've sorted out a bed for you.

SETH: (TO AUDIENCE) It was 12 hours before they found me a bed. They moved me to Room 24. The windows were filthy. It's funny the things that bother you when the chips are down. I was in agony all night. Early in the morning a gentle knock at the door and a cleaner asks very kindly if it's OK to clean the room. She asks if I need anything. I said I'm sweating and she gets a cool flannel and mops my brow. I fight back the tears. I'm so vulnerable and I hate it. It was the following afternoon before they got round to fitting the drain. The Consultant was very nice but a bit brisk. She explained the reason for the long wait was that they could only fit the drain

in the radiology department. They used to fit them in the ward. The world's gone mad!

LESLEY: When I got to the hospital they'd started him on oxygen therapy. He was constantly vomiting. He couldn't hold down food or liquid. I asked the doctor about the possibility of a catheter to drain the ascities at home. Sorry Mrs Goodburn, this is not a routine option. I'd researched it. I knew that Seth met the NICE guidelines. Oh and that's not nice as in nice but nice as in National Institute for Health and Clinical Excellence. I guess he was just sticking to the rules.

LIGHTS DOWN AND UP AGAIN.



KEY LEARNING OBJECTIVES AND OUTCOMES

This Unit highlights how the contrast of responses to Seth's individualised care and his future concerns by individual professionals made a notable difference to him towards the end of his life. It clearly demonstrates that person-centred care is everyone's role and responsibility.

Each Unit in this workbook has been designed to represent a particular phase of Seth's and Lesley's journey to highlight where the delivery of care may have been different, if there was a greater understanding of their needs and choices at the time. Each component within the table overleaf provides an opportunity for these to be taken into consideration within a facilitated discussion and / or personal reflection and to achieve the learning outcomes within a training session.

The [NICE Quality Standard for End of Life Care \(EoLC\)](#) for Adults defines clinical best practice. It provides specific, concise quality statements and measures to provide the public, health and social care professionals, with definitions of high-quality care (NICE 2011). The table overleaf outlines these key components and standards of high quality care and the Core Skills Education and Training Framework (2017) with optional learning outcomes and identified e learning modules that may support further training needs. The [Pancreatic Cancer UK Patient Charter](#) (2016) sets out the standard of care for all pancreatic cancer patients and is intended to empower patients and their carers to enable high quality end of life care.

Communication Skills, Assessment & Care Planning

<u>Pancreatic Cancer UK Patient Charter (2016)</u>	<u>End of Life Care Core Skills Education and Training Framework (2017)</u>	<u>Health Education Yorkshire and Humber EoLC Learning Outcomes (2015)</u>
<ol style="list-style-type: none"> 1. Your case should be assessed by the relevant health professionals and you should be treated by a specialist team of health professionals. 2. Your diagnosis and treatment options should be clearly explained to you. 3. Your treatment should be tailored to your own situation and any symptoms and side effects should be properly managed. 4. You should be treated with compassion, dignity and respect and given practical and emotional support. 5. Your family should be offered information and support (but patient confidentiality must be respected). 	<ol style="list-style-type: none"> 1. Person-centred end of life care. 2. Communication in end of life care. 3. Equality, diversity and inclusion in end of life care. 5. Practical and emotional support for the individual approaching the end of life. 6. Assessment and care planning in end of life care. 7. Symptom Management in end of life. 8. Working in partnership with health and social care professionals and others. 9. Support for carers. 10. Maintain own health and wellbeing when caring for someone at the end of life. 14. Improving quality in end of life care through policy, evidence and reflective practice. 	<ol style="list-style-type: none"> 1.1d. Listen to individuals, and their families friends about their concerns. 1.1e. Operate in a sensitive and flexible manner. 1.2a. Work in a person-centred way. 1.2g. Review assessments and communicate these changes with others. <p>Underpinning Values</p> <ol style="list-style-type: none"> 1.5a. Person-centred practice. 1.5b. Practice that keeps the person at the centre of multi-agency integrated care and support. 1.5c. Practice that is sensitive to the support needs of family/friends.

Further learning opportunities for all professionals working in EoLC

Below are a few of examples of freely accessible learning modules that are available from e-learning for end of life care (e-ELCA) and are referenced as per module number and topic:

- 01_03 Benefits and risks of ACP to patients, families and staff.
03_22 "Am I dying?" "How long have I got?" - handling challenging questions.
03_26 ADV "What will it be like?" - talking about the dying process.
04_05 Influence of transition points and crises on decision-making in symptom management.

A table of all cross-referenced modules per unit of learning can be found in the appendices.

Access to the Royal College of General Practitioners (RCGP) EoLC Learning Resources

[RCGP Palliative and End of Life Toolkit](#) or

URL Address www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

A range of suggested learning materials has been recommended by the GMC such as the e-ELCA session: [05_18 Treatment and care towards the end of life: good practice in decision making](#).

Other available learning resources

[Social Care Institute for Excellence - Get connected to e-learning - for social care providers](#) or

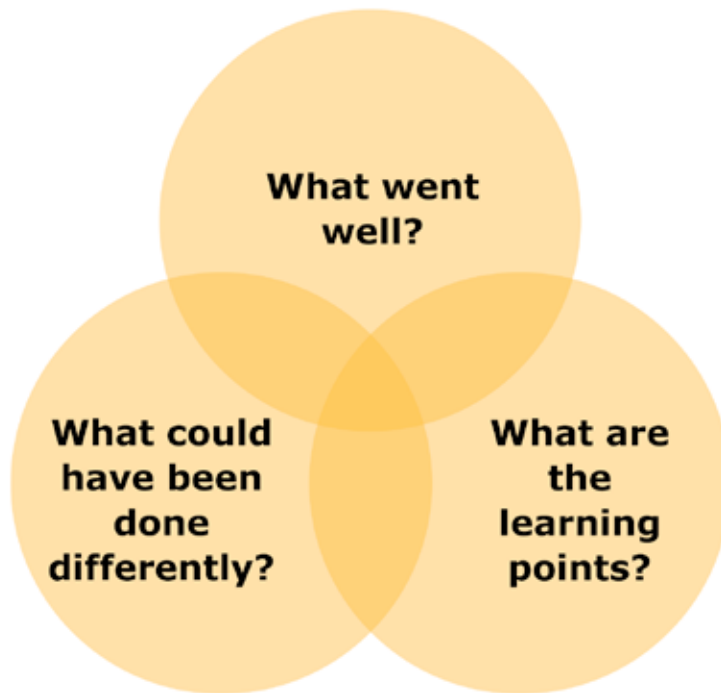
URL Address www.scie.org.uk/publications/getconnectedtolearning/freelearning.asp

[Ambitions Knowledge Hub for Palliative and End of Life Care Resources](#) or

URL Address www.endoflifecareambitions.org.uk/resources/



REFLECTIVE LEARNING EXERCISE



Prompt questions to enable further discussion and /or reflection:

- How did individuals within the Multi-Disciplinary Care team demonstrate compassion, empathy and respect for Seth and Lesley?
- How did the member of the care team demonstrate an individualised approach to care?

The questions below may generate additional points for discussion:

OTHER FACTORS THAT MIGHT BE IMPORTANT TO CONSIDER:

- HOW DO YOU RESPOND TO PATIENTS AND FAMILIES PRESENTING YOU WITH INFORMATION FROM THE INTERNET?
- CARERS BEING INVOLVED IN THE CARE IN A HOSPITAL ENVIRONMENT?
- HOW TO MEET INDIVIDUAL NEEDS WITHIN THE CONSTRAINTS OF OPERATIONAL POLICIES?



UNIT 4: CARING TILL THE END...

LIGHTS DOWN AND UP AGAIN. IT'S THE FOLLOWING DAY. LESLEY IS ASLEEP IN HER CHAIR. SETH STIRS. LESLEY OPENS HER EYES.

LESLEY: I must have dropped off.

SETH: What day is it?

LESLEY: Tuesday, no Wednesday now.

SETH: I feel terrible putting you through all this. Worthless.

LESLEY: You're not worthless. You are precious – my golden man. I love you. Seth.

SETH: I love you too. Now please go home, get some proper rest. I'll be OK. Go and feed the cat.

LESLEY: You are daft. Alright. I'll nip home and pop back at lunchtime. (THEY KISS)

LESLEY LEAVES

SETH: So in comes another doctor. Good morning Mr Goodburn, my name is Adrian. I'm a senior registrar. Good morning Adrian. No Mrs Goodburn here at the moment. Oh well if she'll be in later I can pop back. Oh alright then. Now then Seth you know that we have been trying really hard to make you better and to treat your cancer. Unfortunately, we have reached a stage where the side effects of the treatment are impacting on your quality of life. I need to discuss some really difficult decisions with you now about your wishes in the event of you having a cardiac arrest when your heart stops beating and you are unable to breathe anymore. From a medical perspective we feel that any attempts to resuscitate you in this event would be futile due to your disease progression. I am really sorry to have to discuss such a sensitive issue with you when you are not very well. Discuss it with your wife and family by all means. No need to make a decision now. Well I'll pop by later.

LESLEY APPEARS

LESLEY: (ADDRESSES THE AUDIENCE) When I arrived he was distressed, frightened and anxious. He said he had been having vivid dreams and described a conversation with a doctor who told him if his heart stopped they would let him die. I didn't know whether he had imagined this – so I just spent the afternoon comforting him. I looked at the Trust's website on the policy which said that the patient must be treated with respect and dignity. So why was he left feeling frightened and upset?

SETH: Five weeks ago I had everything to live for. Three weeks ago I was diagnosed with Stage 4 Pancreatic Cancer that had spread to other organs. The Consultant told me that if I had a stent fitted it would buy me a bit more time. I signed it for Les's sake. I waited three hours only to be told the stent could not be fitted and I was returned to my room. For the staff it was another day, another dollar, another procedure – for me it was entering the final stage of life. I was right. The Oncologist told me that they had exhausted all possibilities and I should think about my options for my final days and hours. It was like being on death row. I was on a feeding tube at this point. I wanted the tube out – the nurse told me that it was not in my notes to have it removed. I was dumbfounded.

LESLEY: Carol – the staff nurse overheard. She said that the patient's feeling of wellbeing came first I told Carol that Greg had denied Seth a fan. Hygiene risk. Not if the fan itself is concealed she said. I'll get one for you.

SETH: I was sweating, it's so hot in those places. Oh and they do have lollies and ice cream – they just didn't think to offer them until Les asked them. I don't know how a less assertive person would manage! You get yourself home Les. Take that bag of stuff. I won't be needing it again.

THEY LOOK AT ONE ANOTHER IN SILENCE. SETH WHEELS HIMSELF FROM THE STAGE. LESLEY SETTLES HERSELF IN A CHAIR FOR SLEEP. HOURS PASS. LESLEY IS AWAKENED FROM HER SLEEP BY THE SOUND OF HER TELEPHONE. SHE LOOKS AT THE SCREEN. SHE REALISES IT'S THE HOSPITAL.

LESLEY: I've never driven so fast. I knew that this was the end. I arrived at the Ward at 4.45 am. The door was locked. I banged on the door, tried to phone them, shouted. I was desperate to see my husband one last time. I only managed to get in when someone else came out. Seth was sitting on the edge of his bed being comforted by a healthcare assistant. I took over. I talked to him, told him that whatever it was we were facing we were facing it together. Everything would be OK. He became restless and fearful he was at the end. Nobody told me he was at the end, nobody had a conversation with me about what I might need to do, what might help. Nothing. Just nothing. He died at 9.45 am. We were together.

SETH: I died just before 10.00 am on 14 June 2014. 'after a short illness borne with fortitude and dignity'. I could write a book about that stay in Hospital. Like the time the lovely dinner lady popped in – I had the feeding tube but she was happy to announce that it's Friday so fish, chips and mushy peas for you Seth? Then there was the well-meaning physiotherapist who wanted to assess me. I could barely get out of bed and he wanted me to stand and raise first one leg and then the other. Honestly, you couldn't make it up. Oh and that toilet!

LESLEY: Oh I thought you'd want to mention the toilet. The shredding toilet. It took two and a half minutes to flush. I timed it. It was noisier than a jumbo jet. And do you remember that girl whose job it was to re-fill the plastic glove dispenser. She just barged in, clattered about with the dispenser for all of 10 minutes – it's not that she didn't care, she just didn't think. Seth had made it very clear that he wanted nobody to see his body after he had died – apart from me and the close family.

SETH: I just had this thing about the indignity of it all. I didn't even like people seeing me ill so I definitely didn't want them gawping at my body. What did they do Les?

LESLEY: They didn't close the door properly and left the curtains to your room partly open so everyone passing could see you laid out. It was so undignified.

It was as undignified as me sitting on a hard chair in the corridor crying my eyes out – nobody offered to console me, to find a quiet space for me or to tell me about the procedure. They didn't say anything but I could tell they were itching to reclaim the bed.

SETH: I was homeward bound – but didn't make it. I just wish that some people in the hospital would have been more sensitive to our needs. I wanted to feel supported and safe – I felt neither. And the last word goes to my dear wife – the love of my curtailed life.

LESLEY: I so needed someone who could help and support me. I wanted a quiet place to sit and be comforted. Hospitals are busy, busy places. Space must be at a premium but I too needed dignity and respect. I know It's a big ask but maybe our story can inspire more thought and consideration. Seth's courage and compassion sustains me and gives me the strength to share our story in the hope that hospital care may be a little more person centred, a little more bearable and much more supported.

Love is a freely given gift of the heart – care comes at a price.



KEY LEARNING OBJECTIVES AND OUTCOMES

This Unit demonstrates the importance of compassion, communication, dignity, empathy and care at the end of Seth's life and how this impacted on Lesley's grief and loss.

Each Unit in this workbook has been designed to represent a particular phase of Seth's and Lesley's journey to highlight where the delivery of care may have potentially been different, if there was a greater understanding of their needs and choices at the time. Each component within the table overleaf provides an opportunity for these factors to be taken into consideration within a facilitated discussion and /or personal reflection and to achieve the learning outcomes within a training session.

The NICE Quality Standard for End of Life Care (EoLC) for Adults defines clinical best practice. It provides specific, concise quality statements and measures to provide the public, health and social care professionals, with definitions of high-quality care (NICE 2011). The table overleaf outlines these key components and standards of high quality care and the Core Skills Education and Training Framework (2017) with optional learning outcomes and identified e learning modules that may support further training needs. The Pancreatic Cancer UK Patient Charter (2016) sets out the standard of care for all pancreatic cancer patients and is intended to empower patients and their carers to enable high quality end of life care.

**Communication Skills (Do Not Attempt Cardio-Pulmonary Resuscitation Discussion)
& Assessment and Care Planning, Care After Death and of The Bereaved**

<u>Pancreatic Cancer UK Patient Charter (2016)</u>	<u>End of Life Care Core Skills Education and Training Framework (2017)</u>	<u>Health Education Yorkshire and Humber EoLC Learning Outcomes (2015)</u>
<ol style="list-style-type: none"> 1. Your case should be assessed by the relevant health professionals and you should be treated by a specialist team of health professionals. 2. Your diagnosis and treatment options should be clearly explained to you. 3. Your treatment should be tailored to your own situation and any symptoms and side effects should be properly managed. 4. You should be treated with compassion, dignity and respect and given practical and emotional support. 	<ol style="list-style-type: none"> 1. Person-centred end of life care. 2. Communication in end of life care. 3. Equality, diversity and inclusion in end of life care. 5. Practical and emotional support for the individual approaching the end of life. 6. Assessment and care planning in end of life care. 7. Symptom Management in end of life. 8. Working in partnership with health and social care professionals and others. 9. Support for carers. 10. Maintain own health and wellbeing when caring for someone at the end of life. 11. Care after death. 12. Law, ethics and safeguarding. 14. Improving quality in end of life care through policy, evidence and reflective practice. 	<ol style="list-style-type: none"> 1.1a. Communicate with a variety of people and ways. 1.1b. Communicate with people about difficult and complex matters or situations. 1.1d. Listen to individuals, and their families friends about their concerns. 1.1e. Operate in a sensitive and flexible manner. 1.1g. Ensure that information is clear, and non-jargonistic. 1.2a. Work in a person-centred way. 1.2f. Meeting the needs of carers, children and young people. 1.2g. Review assessments and communicate these changes with others. 1.3e. Developing an EoLC Plan. 1.3f. Review the EoLC plan.

<p>5. Your family should be offered information and support (but patient confidentiality must be respected).</p> <p>Carers needs: Refers to 3 - 5 of the above standards.</p>		<p>Underpinning Values</p> <p>1.5a. Person-centred practice.</p> <p>1.5b. Practice that keeps the person at the centre of multi-agency integrated care and support.</p> <p>1.5c. Practice that is sensitive to the support needs of family/friends.</p>
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Further learning opportunities for all professionals working in EoLC

Below are a few of examples of freely accessible learning modules that are available from e-learning for end of life care (e-ELCA) and are referenced as per module number and topic:

- 03_30 ADV Discussing 'do not attempt CPR' decisions.
- 04_23a Recognising the dying phase, last days of life and verifying death.
- 07_02 Assessment of carers' needs.
- 07_03 Practical support after a bereavement.

A table of all cross-referenced modules per unit of learning can be found in the appendices.

Access to the Royal College of General Practitioners (RCGP) EoLC Learning Resources

RCGP Palliative and End of Life Toolkit or

URL Address www.rcgp.org.uk/clinical-and-research/toolkits/palliative-and-end-of-life-care-toolkit.aspx

A range of suggested learning materials has been recommended by the GMC such as the e-ELCA session: 05_18 Treatment and care towards the end of life: good practice in decision making.

Other available learning resources

Social Care Institute for Excellence - Get connected to e-learning - for social care providers or

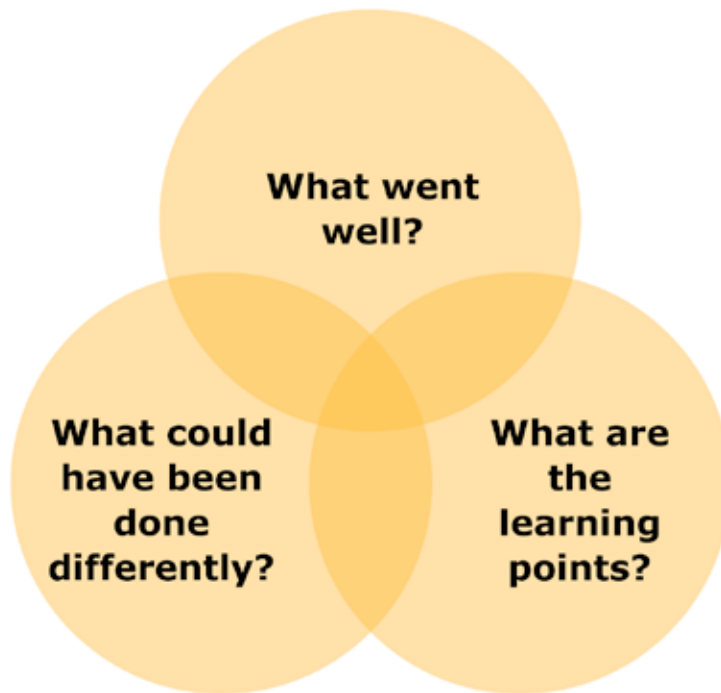
URL Address www.scie.org.uk/publications/getconnectedtoelearning/freelearning.asp

Ambitions Knowledge Hub for Palliative and End of Life Care Resources or

URL Address www.endoflifecareambitions.org.uk/resources/



REFLECTIVE LEARNING EXERCISE



Prompt questions to enable further discussion and / or reflection:

- How do you think Lesley's arrival on the ward could be handled differently?
- Think about how information that was given and received and how this may have impacted on what was being understood?
- Discuss the importance of dignity and respect for care after death?

The questions below may generate additional points for discussion:

OTHER FACTORS THAT MIGHT BE IMPORTANT TO CONSIDER:

- THE WARD STAFF'S UNDERSTANDING OF THE 6 C'S (CARE, COMPASSION, COMPETENCE, COMMUNICATION, COURAGE AND COMMITMENT)?
- "HOW PEOPLE DIE REMAINS IN THE MEMORY OF THOSE WHO LIVE ON"

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FURTHER RESOURCES

Ambitions Knowledge Hub for Palliative and End of Life Care Resources. URL Address: <http://endoflifecareambitions.org.uk/resources/>

Nurse led verification of death guidance. URL Address: <https://www.hospiceuk.org/what-we-offer/publications>

What to expect when someone important to you is dying. URL Address: http://www.ncpc.org.uk/sites/default/files/What_to_Expect_FINAL_WEB.pdf

Supporting self-management: A guide to enabling behaviour change for health and wellbeing using person- and community-centred approaches. URL Address: <http://www.health.org.uk/sites/health/files/RtVSupportingSelfManagement.pdf>

NHS Choices – End of Life Care Information Page. URL Address: <http://www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx>

Your guide to decisions about cardiopulmonary resuscitation (CPR). URL Address: http://www.dyingmatters.org/sites/default/files/DNACPR%20Patient%20leaflet_A4.pdf

Royal College of Nursing: Fundamentals of nursing care at the end of life. URL Address: <http://rcnendoflife.org.uk/>

We are Macmillan Support: Learning Zone. URL Address: <http://learnzone.org.uk/professionals/>

Marie Curie Knowledge Zone for Professionals. URL Address: <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone>

Hospice UK: learning events. URL Address: <https://www.hospiceuk.org/what-we-offer/courses-conferences-and-learning-events>

Training and Education in End of Life Care: Recommendations for Health Education England. URL Address: https://hee.nhs.uk/sites/default/files/documents/091015-HEE-End-of-life-Care-Report_0.pdf

Purple Rainbow website in support of Pancreatic Cancer UK. URL Address: <https://purplerrainbow.co.uk/about-us/homeward-bound/>

APPENDICES

All of the resources below are available online at: www.ncpc.org.uk/homewardboundresource

A. [RELATIONAL MAPPING PDF:](#) The relational mapping resource has been designed to support additional learning and understanding of the key components of person centred care. The Common Core Principles and Competencies is the benchmark on which the other three resources have been derived from and how “best practice” can be delivered.

B. [AMBITIONS FOR PALLIATIVE AND END OF LIFE CARE : A NATIONAL FRAMEWORK FOR LOCAL ACTION 2015-2020](#)

C. [HEALTH EDUCATION YORKSHIRE AND THE HUMBER “END OF LIFE CARE LEARNING OUTCOMES FOR: UNREGISTERED SUPPORT WORKERS PRE-QUALIFYING STUDENTS REGISTERED PROFESSIONALS IN HEALTH AND SOCIAL CARE” \(2016\)](#)

D. [FURTHER LEARNING OPPORTUNITIES VIA E-LEARNING FOR END OF LIFE CARE E-ELCA MODULES - CONTENTS TABLE](#)

E. [HOMEWARD BOUND COMMITMENT TO ACTION POSTCARD \(OVERLEAF\)](#)

F. [GLOSSARY](#)

Available online at: www.endoflifecareambitions.org.uk/glossary/

E. HOMEWARD BOUND COMMITMENT TO ACTION POSTCARD

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

HOMEWARD BOUND - A PLAY ABOUT RELATIONSHIPS, LOVE, EMPATHY AND COMPASSION


HOMEWARD BOUND

A play about relationships, love, empathy and compassion

Name _____ Tel. _____

Email _____

Job Role _____

 HOMEWARD BOUND

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

HOMEWARD BOUND - A PLAY ABOUT RELATIONSHIPS, LOVE, EMPATHY AND COMPASSION

Three things I plan to do are:

1. _____
2. _____
3. _____

 HOMEWARD BOUND

Follow us on Twitter: @hwb999 or #HWBPlay 

Our special thanks to

Lesley Goodburn for sharing her and Seth's story.

Brian Daniels, playwright.

Partners NHS England, Pancreatic Cancer UK,
Leeds NHS Teaching Trust Palliative Care Team
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