hospice UK

Royal College of Nursing

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THE BOUNCE BACK BOY FACILITATOR HANDBOOK

ACKNOWLEDGEMENTS

Our special thanks to:

- Lynn Cawley for sharing her and Josh's story
- Brian Daniels, playwright
- Partners: Skills for Care, The Royal College of Nursing, and Keele University
- Claire Henry MBE, Director of Improvement and Transformation, Hospice UK
- Anita Hayes, Associate, Hospice UK
- Sally Gretton Head of Area (Yorkshire and Humber/North East) lead on Integration, Skills for Care
- Victoria Collier, Project Manager SLQA, Skills for Care
- Amanda Cheesley, Professional Lead for Long Term Conditions and End of Life Care, RCN
- Dr Kate Lillie, Lecturer in Adult Nursing School of Nursing and Midwifery, Keele University

Funding generously supported by Skills for Care.

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Published by Hospice UK in November 2018.

MESSAGE FROM LYNN CAWLEY

“Joshua’s life was full of adventure and love.

“Our daily experience with Josh was always one of discrimination and fighting for his rights but we never imagined that his death would be so very unfair.

“We hope that Joshua’s life and ultimately his death will inspire people to see the whole person and not just a ‘medical case’.

“Josh lived his life to the max, he deserved a death that was befitting such a warrior with the same access to care and dignity afforded to others.

“Josh was often described as someone with ‘complex needs’ and because of that label he was discriminated against even at the end of his life.

“Josh always made his voice heard, he was stubborn, independent and a huge flirt.

“We pledge to continue his legacy with the hope that other young people like Josh might have the same rights to a good death as their peers.

“Thank you for allowing Josh to be part of the change for better, no life is ever insignificant.”

Lynn

#BemoreJosh

CONTENTS

INTRODUCTION

> **"You matter because you are you, and you matter to the end of your life."**
>
> **Dame Cicely Saunders, founder of the modern hospice movement**

This facilitator handbook is based on a play called 'Bounce Back Boy' written by playwright Brian Daniels to share the lived experiences of Josh Cawley and his family. Josh had complex needs caused by catastrophic injuries his birth parents inflicted on him when he was a baby. He was adopted by Lynn Cawley who cared for him until his death aged just 22 years old. The play explores how Josh's family had to accept that Josh's needs were too 'complex' for the hospice as well as support Josh's transition from boy, to teenager to adult; and all the time being his advocates, carers, interpreters and so much more. In May 2018 the play was made into a film by the Royal College of Nursing working in partnership with Skills for Care and Hospice UK.

PURPOSE

The primary purpose of the film and this resource is to share this true story as a catalyst for learning. We invite facilitators and learners to work through Josh and his family's journey from their own perspective: to consider it in the light of their own roles and responsibilities and think about how they might make improvements to end of life care in practice.

The key objectives of the film are to provoke discussion and:

- raise awareness of the multiple challenges that can arise when a young person with complex needs is dying
- promote understanding of the human impact of inadequate support for individuals and those that love them at the end of life
- highlight the importance of tailoring care to individual and family needs at the end of life
- improve the quality and experience of palliative and end of life care for young adults and people with learning disabilities.

The core educational content aligns to national guidance, good practice and existing end of life care publications that facilitators and learners may already be familiar with. It has been developed to provide a unique opportunity to bring together lived experience and personal narrative with reflective practice, to support and enable ongoing learning in practice.

These resources are not intended to replace existing end of life care training and education programmes already underway. Rather, they will complement them, providing a specific vignette enabling an in depth exploration of the specific topics raised by the film 'The Bounce Back Boy'.

WHO IS THIS RESOURCE FOR?

The film and facilitator handbook are for a variety of people involved in end of life care; whether that's in providing care and support, managing services, or designing services.

You can use these resources to support the delivery of end of life care training, particularly in relation to tackling inequalities, improving access to personalised care for people with complex needs, and to support the provision of quality care.

The resources are for:

- those providing end of life care, such as care workers, senior care workers and healthcare assistants
- those managing and leading end of life care services, such as registered managers, team leaders and service managers
- those designing and taking a strategic lead in end of life care services, such as organisation directors, CEOs and commissioners.

HOW TO USE THE HANDBOOK

The handbook can be used in a variety of ways to promote discussion, reflection, learning and action.

Whilst the activities could be completed individually, learners will benefit from the inclusion of discussion and debate. Therefore, we encourage activities to be either:

1. led by facilitators in group learning environments, e.g. as part of a learning module on end of life care or as a short study session in a team meeting
2. used during supervision sessions, e.g. as reflective practice or as an assessment of understanding (supervisees may benefit from watching the films prior to supervision and having some time to prepare their thoughts and make notes).
3. The films can be used to support co-designed commissioning activities to ensure that the user voice is central to future service design.

THE FACILITATOR ROLE

The suggested activities take a step-by-step approach and do not assume you are experienced in delivering training. However, knowledge of good practice in end of life care is important to enable educated discussions. Throughout the handbook you will find prompts to consider and directions about how to talk through each activity. There are a series of templates, which can be downloaded, to support learner activities and retained as part of ongoing personal development portfolios.

The handbook has been designed for you to work through chronologically. However, you will find that discussions naturally move between themes and activities. You could choose to select different activities to use at different times and shouldn't feel like you have to work through all of the activities in one session.

The activities are timed, colour coded and designed to support you with easy navigation from the contents page throughout the handbook.

Two of the activities, Activity 3 and Activity 4, are split into four sub-sections. These sub-sections are based on the roles described in the Leadership Qualities Framework and reflect different leadership behaviours expected in different roles:

a. care assistants, care workers, volunteers, students, graduates
b. supervisors, team leaders, shift leaders
c. registered managers, service managers
d. senior leaders, directors, managers responsible for directing and leading organisations (we have also included commissioners in this group as they have an important role in shaping service development).

WHY IS END OF LIFE CARE IMPORTANT?

In 2014 'One Chance to Get it Right'[1] was published, which acknowledged the importance of staff being equipped and supported to care for someone who is dying. The report highlighted five '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'[2] (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.

INTRODUCTION

> *“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)[3] 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’[4] in response to the Choice Review (2015) articulating a six-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.

Also, in May 2016 the Care Quality Commission (CQC) published a thematic review into inequalities in end of life care.[5] The review identified that “people from certain groups in society sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs”.

The report identified people who have a learning disability as one such group. The Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD) found that for many people with a learning disability who were dying, end of life care was not coordinated and the support for the person and their families could have been improved. It also identified that people with a learning disability were less likely to have access to specialist palliative care services and opioid analgesia than a comparison group of people without a learning disability.

Other work has suggested that hospice, palliative and end of life care professionals report limited contact with people with learning disabilities and therefore have a lack of confidence in working with this group and understanding their needs.

Bounce Back Boy provides an opportunity to consider how to improve the quality of end of life care across the whole system, keeping the person/family at the centre, understanding the human impact of poor care and supporting the development of knowledge, skills and confidence to provide high quality end of life care for all.

THE FILMS

There are two films. The first is a recording of the play, and the second is an interview with Lynn Cawley, Josh's mum, where she talks about what would have made a difference to their experience.

The two films last 26 minutes in total. Allow 15-20 minutes to discuss and debrief afterwards.

Access the two films at: www.hospiceuk.org/bounce-back-boy

If you would like to read the script please go to:
www.hospiceuk.org/bounce-back-boy

Facilitator notes

When facilitating a session and introducing the film, we suggest that you highlight the sensitive nature of the film and respect individuals' choice to view the film as it is a very emotive subject and may be upsetting.

Before beginning the learning activities, we would advise that you create an opportunity for open discussion so that the participants are able to comment, ask general questions and spend a little time debriefing.

SECTION 1

QUALITY OF LIFE AND QUALITY OF DYING

“We work for my goals and the quality of my life and death.“

INTRODUCTION

Every person accessing care and support should be seen and respected as a whole person – not as an illness. Their care and support should enable them to achieve their personal goals and improve their quality of life. They should be asked ‘What matters most to me?’ and are enabled to remain as in control of their care and support as possible, for as long as possible.

ACTIVITY 1

ACTIVITY 1 is an ‘opener’ to encourage learners to start the discussion about what ‘good’ looks like in care and support, and end of life care. It is expected to take approximately 20-25 minutes. Allow 15-20 minutes to ***Discuss*** and 5-10 minutes to ***Learn***.

25:00

Learning outcome:

To understand that care and support include all elements of an individual’s life that are important to them, not just their symptoms or illness.

FACILITATOR TO ASK PARTICIPANTS:

How was Josh supported to live well, make choices and achieve a good quality of life?

Facilitator prompts

The quotes from the film can support discussions and set the scene to initiate conversations in the group...

Lynn and Josh’s relationship:

“She didn’t see a twisted, crippled body – she saw a child who needed a mum.”
“He was a whole person, emotionally, physically and spiritually.”

How Josh communicated, and how Lynn supported this:

“When the professionals wanted to talk to us they would talk to Lynn – never to me. She wouldn’t answer. She would just look at me. They got the message. They started to talk to me directly.”
“I would communicate back through Lynn because she always knew what I wanted to say. Or thought she did!”

Lynn and Paula’s ‘battles’ on Josh’s behalf:

“To give Lynn and Paula their due they also fought loads of battles on my behalf – to have a customised wheelchair, to get me into a school, to get the best treatments for me, to organise the care rotas, the adaptation of the house and to deal with a very sick little person.”
“Eventually Lynn got a letter from the hospital, to say I was on a palliative care programme and there would be no point taking me to hospital.”

Josh’s personality, his likes and how he spent his time:

“One of the few pleasures in my short life was food.”
“So while other families would spend two hours getting ready to go on holiday for a week, we would spend two hours getting ready to go to Starbucks.”
“Going abseiling and going on holidays.”

ACTIVITY 1

FACILITATOR TO ASK PARTICIPANTS:

- **What, if anything, have you learned from this discussion?**
- **What, if anything, will you do differently?**
- **Write down your learning points and actions.**

Facilitator notes and ideas

- Learners could discuss this with a partner or contemplate silently.
- Encourage learners to write down key points to reinforce their learning and commit to take action.

Additional related resources

Person centred care and support framework
http://www.skillsforhealth.org.uk/services/item/575-person-centred-approaches-cstf-download

Dignity toolkit
https://www.skillsforcare.org.uk/Topics/Dignity/Dignity.aspx

Delivering high quality end of life care for people with a learning disability
https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

Download 'learning reflection' template

ACTIVITY 2

45:00

ACTIVITY 2 is expected to take approximately 30-45 minutes. Allow approximately five to eight minutes for each question. Some questions, such as ***Describe***, may be quicker, and others, such as ***Evaluate***, take more time.

Activity 2 aims to encourage learners to consider Josh's end of life care and his death, what went wrong, and to discuss how end of life care is currently provided in their place of work.

Learning outcome:

To explore the potential barriers and challenges that individuals face in accessing individualised end of life care that respects their choices and how you might find ways to overcome any challenges where you work.

The activity is based on a reflective cycle. Ask learners each question, giving them time to consider and discuss before moving to the next question.

FACILITATOR DIRECTION:

***Facilitator to read out:* Josh didn't die in his preferred place of death "where [his] needs would have been dealt with by professionals and [his] mums could have visited, held [his] hand and brought [him] DVDs and other little treats." Instead he died at home "with blood and vomit on the walls and carpet, without [his] sister beside [him] and with [his] mum still fighting for better."**

Facilitator notes and ideas

- Encourage learners to write down key points to reinforce their learning and commit to taking action.
- Some people may feel Josh's experience could not be repeated in their organisation. If this is the case, explore why they think that and what they have in place. Others could learn from them and it allows an opportunity to reflect on, as well as challenge, good practice.

ACTIVITY 2

FACILITATOR TO INVITE PARTICIPANTS TO DESCRIBE:

- **How do you identify a person's preferred place of care and death in your place of work?**

Facilitator prompts

- Where was Josh's preferred place of care and death, and why?
- How can you identify a person's preferred place of care, and support them to achieve their choice in your place of work?

FACILITATOR TO INVITE PARTICIPANTS TO DISCUSS:

- **How did you feel hearing about Josh's death?**
- **How do you think Josh and his family felt?**

Facilitator prompts

- What care and support did Josh's mums and sister receive? What should they have received?

FACILITATOR TO INVITE PARTICIPANTS TO EVALUATE:

- **Think about your own area of practice and a time when you cared for someone who was dying.**

Facilitator prompts

- Were you able to support their needs for their end of life care?
- How were you able to support them and their family?
- How were you able to support the carer/family in bereavement?

ACTIVITY 2

FACILITATOR TO INVITE PARTICIPANTS TO ANALYSE:

- **What helped or hindered you in providing care and support?**

Facilitator prompts

- Who else in your team can support you in providing care for someone who is dying?
- What are the challenges of providing care and support?

FACILITATOR TO INVITE PARTICIPANTS TO CONCLUDE:

- **What could have been done differently to make care and support even better in your place of work?**

Facilitator prompts

- How can the experience dying and death have been improved?
- How can a family's experience of dying, death and bereavement have been improved in your experience?

FACILITATOR TO INVITE PARTICIPANTS TO ACT:

- **What could you, your team or organisation do differently to improve end of life care?**

Facilitator prompts

- Is it possible that someone accessing your service could have a similar experience to Josh?
- Could you have supported Josh and his family? If not, why not?
- What could you improve?
- Who can you talk to if you are not able to provide care and support in line with good practice?
- How would you raise a concern?

Additional related resources

Palliative Care Knowledge Zone
https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone

A different ending: end of life care review
https://www.cqc.org.uk/news/stories/different-ending-our-review-looking-end-life-care-published

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)
http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/finalreportexecsum.pdf

Download 'learning reflection' template

SECTION 2

EXPLORING THEMES

2A: COMMUNICATION

Facilitator prompts to lead discussion

Being able to communicate effectively is the **key** skill that many want or need to improve. It's quite natural to feel nervous about, or lack confidence in, talking to individuals and their families facing end of life issues especially if this is new to you. You may also have personal experiences, which may cause you some concerns or affect your confidence. Communication in end of life care also, importantly, includes care after death and bereavement support or information.

FACILITATOR TO ASK:

- **How confident do you feel talking to people accessing services and families about end of life care issues?**
- **Do you know what training is available to you?**
- **Have you completed any training in communication skills?**
- **What aspects of communicating with people accessing end of life, or their families, might you benefit from improving?**
- **How could you improve these skills?**

Additional learning resources for social care professionals working in end of life care

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

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

Royal College of Nursing – End of life care
https://www.rcn.org.uk/clinical-topics/end-of-life-care

Below are a few examples of freely accessible learning modules that are available from e-End of Life Care for All:

- 0301 – The importance of good communication
- 0302 – Principles of communication
- 0306 – Communication skills for administrative staff, volunteers and other non-clinical workers
- 0308 – Understanding and using empathy
- 0314 – Information giving
- 0318 – Communicating with children and young people
- 0322 – “Am I dying?” “How long have I got?” – handling challenging questions
- 0335 – Challenging communication with colleagues

Access them at: https://www.e-lfh.org.uk/programmes/end-of-life-care

2B: SUPPORTING CARERS AND FAMILIES

Facilitator prompts to lead discussion

"A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."

Carers Trust

Carers play an essential role in the journey of the person approaching the end of life, and they should be supported throughout.

Sadly, as in Lynn and Josh's experience, the reality is often different, with many carers feeling unsupported and not included in decisions about the person's care.

FACILITATOR TO ASK:

- **How confident do you feel involving carers/families about end of life care issues?**
- **Do you know what support is available for carers in your area?**
- **What information resources are available for carers?**
- **How can you prepare carers/families for a death?**

Additional learning resources

What to expect when someone close to you is dying – A guide for carers, families and friends of dying people
https://hospice-uk.myshopify.com/collections/dying-matters-publications-resources/products/what-to-expect-guide

Support for young people when a close family member is diagnosed with a life-threatening illness
http://www.hopesupport.org.uk

Further resources for social care professionals working in end of life care:

Carers assessments – Workforce development opportunities based on carers' experiences
https://www.skillsforcare.org.uk/Documents/Topics/Supporting-carers/Carersassessments.pdf

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

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

Royal College of Nursing – End of life care
https://www.rcn.org.uk/clinical-topics/end-of-life-care

Below are a few examples of freely accessible learning modules that are available from e-End of Life Care for All:

- 0314 – Information giving
- 0702 – Assessment of carers

Access them at: https://www.e-lfh.org.uk/programmes/end-of-life-care

2C: SUPPORTING TRANSITION

Facilitator prompts to lead discussion

A growing number of children and young adults with life-limiting and life-threatening conditions are now living into adulthood and evidence shows moving from children's to adults' services can be a particularly stressful time for them and their families. Lynn and Josh experienced good support from the children's hospice but then found that the adult services were not able to cope with Josh's complex needs and they felt abandoned without support. Consider your remit and role in caring for and supporting a child in transition into adulthood to deliver the best possible care.

FACILITATOR TO ASK:

- **How would a young person with disabilities be supported when transitioning from children's to adults' services in your area?**
- **What information is available to support families?**
- **How do children's and adults' services teams work together in your area?**
- **What model of care can best support children and their families as they grow up into adulthood?**

Additional learning resources

Transition from children's to adults' services for young people using health or social care service
https://pathways.nice.org.uk/pathways/transition-from-childrens-to-adults-services

Together for Short Lives – Moving to adult services what to expect
https://www.togetherforshortlives.org.uk/changing-lives/developing-services/transition-adult-services

Stepping up – Transition care pathway
https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/02/ProRes-Stepping-Up-Transition-Care-Pathway.pdf

NICE – Moving between hospital and home, including care homes
https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/moving-between-hospital-and-home-including-care-homes

Principles of Good Transitions
https://scottishtransitions.org.uk/summary-download/

2D: CARE AFTER DEATH

Facilitator prompts to lead discussion

Good support for bereaved families is vital to help them deal with grief and loss. There is only one opportunity to get things right for individuals and their loved ones after death and it is very important that siblings are supported when there is loss of a child in the family.

FACILITATOR TO ASK:

- **What information resources are available in your area to support bereaved families and siblings?**
- **What services are available in your area to support bereaved children and families?**
- **What model of care would best support families after the death of a child?**

Additional learning resources

Hospice UK – Guidance for professionals who provide care after death
https://www.hospiceuk.org/what-we-offer/publications?cat=72e54312-4ccd-608d-ad24-ff0000fd3330

What to do after someone dies
https://www.gov.uk/after-a-death

How to plan a funeral service
https://www.funeralzone.co.uk/help-resources/arranging-a-funeral/planning-the-service/how-to-plan-a-funeral-service

Cruse Bereavement Care
https://www.cruse.org.uk

Winston’s Wish
https://www.winstonswish.org

Together for Short Lives – Bereavement support
https://www.togetherforshortlives.org.uk/get-support/your-childs-care/bereavement-support/

SECTION 3

WORKING TOGETHER

“I have responsive, timely support day and night.“

INTRODUCTION

Coordinated care means that the right people, at the right time, are able to provide the right care and support for both the person approaching the end of life and those important to them. Everyone involved in providing care and support works together, regardless of the service or sector they work in, to solve problems quickly. Specialists are available, as is support and advice from those experiencing similar circumstances. Organisations are able to appropriately support those approaching the end of life, and the people important to them.

Facilitator prompts

Within the story of Bounce Back Boy we hear about the lack of care coordination that was available to support Josh and his family. Lynn was very much the care coordinator communicating with all of the many people involved in supporting Josh’s ongoing care. She was his carer, advocate, nurse, coordinator all at a time when time is very precious and she just wanted to be “mum”, to sit beside Josh and spend time with him before he died not on the telephone ensuring that important conversations were relayed to others in the care team.

ACTIVITY 3

30:00

ACTIVITY 3 gives learners the opportunity to consider how the people and services they work with, work together effectively, as well as asking learners to assess their own practice. The behaviours are taken from the 'Working with others' dimension of the Leadership Qualities Framework.

The activity is split into four sub-sections, 3a to 3d. Each sub-section is relevant to a different audience as leadership behaviours may look different, depending on an individual's role.

Behaviours have been selected based on their relevance to the information shared in the films. You may wish to refer to the Leadership Qualities Framework for more detail and for additional behaviours. You can choose a focus for this activity based on your role and area that you work in.

You may wish to talk through each behaviour as a group, asking participants to share their personal reflections, or you may wish to suggest participants make notes and feed back.

In multi-disciplinary sessions, ensure participants have the appropriate templates. You may wish to group people in similar roles together to have table discussions.

Download 'learning reflection' templates

ACTIVITY 3A

Audience

Care assistants, care workers, volunteers, students, graduates

Learning outcome

Understand how to work in partnership with others involved in an individual's end of life care in a coordinated way organised around the individual's needs.

Good leaders…	**Do you…? Give examples thinking about your own experience of working with others**
Invest time in and actively build and maintain effective and respectful relationships, adapting their approach according to the individual, situation and context.	
Confidently communicate in an open, accurate and straightforward way using appropriate language, both verbal and non-verbal.	
Demonstrate effective communication skills (listening, feedback, recording, sharing) to promote the needs of people who use services and to ensure they, and their family/carers, understand what is happening.	
Ensure that care and support takes into account a person's whole life, including physical, mental, cultural, emotional and spiritual needs.	

FACILITATOR TO ASK PARTICIPANTS:

- **What, if anything, have you learned from this exercise?**
- **What, if anything, will you do differently?**
- **Write down your learning points and actions.**

ACTIVITY 3B

Audience

Supervisors, team leaders, shift leaders

Learning outcome

Understand how to work in partnership with others involved in an individual's end of life care in a coordinated way organised around the individual's needs.

Good leaders…	**Do you…?** **Give examples thinking about your own experience of working with others**
Identify and engage with other organisations and networks.	
Model and promote effective and respectful relationships within the team.	
Show an understanding of people's motivations and actively engages with them. Confidently communicate in an open, accurate and straightforward way, using appropriate language, both verbal and non-verbal, suitable for internal and external audiences.	
Demonstrate effective communication skills (listening, feedback, recording, sharing) to enable the team to promote the needs of people who use services, ensuring they and their family/ carers understand what is happening.	

ACTIVITY 3B

Good leaders…	Do you…? Give examples thinking about your own experience of working with others
Encourage and support people who use services and staff to express their views, enabling them to participate in joint decision-making.	
Create a team ethos which takes into account a person's whole life, including physical, mental, cultural, emotional and spiritual needs.	

FACILITATOR TO ASK PARTICIPANTS:

- **What, if anything, have you learned from this exercise?**
- **What, if anything, will you do differently?**
- **Write down your learning points and actions.**

ACTIVITY 3C

Audience

Registered managers, service managers

Learning outcome

Understand how to work in partnership with others involved in an individual's end of life care in a coordinated way organised around the individual's needs.
Understand the importance of being able to engage in challenging conversations with other professionals, demonstrating a commitment to partnership working to facilitate care.

Good leaders…	**Do you…?** **Give examples thinking about your own experience of working with others**
Identify and engage with other organisations and networks to share views and approaches.	
Appropriately challenge, share expertise and have an ongoing dialogue with community groups to ensure that they meet the requirements of people who use services.	
Create a service that values and promotes effective and respectful relationships between people.	
Intervene personally to establish good relationships to support people to live the life they want.	
Retain a connection to, and understanding of, what happens at the front line of services.	

ACTIVITY 3C

Good leaders…	**Do you…?** **Give examples thinking about your own experience of working with others**
Demonstrate effective communication skills (listening, feedback, recording, sharing) to promote the needs of others within the service.	
Translate policy and guidance into understandable information according to users’, families’, carers’ and audiences’ needs.	
Create a service ethos which takes into account a person’s whole life, including physical, mental, cultural, emotional and spiritual needs.	
Builds a service based on the combined contributions of different people.	

FACILITATOR TO ASK PARTICIPANTS:

- **What, if anything, have you learned from this exercise?**
- **What, if anything, will you do differently?**
- **Write down your learning points and actions.**

ACTIVITY 3D

Audience

Senior leaders, directors, managers responsible for directing and leading organisations (including commissioners)

Learning outcome

Understand how to work in partnership with others involved in an individual's end of life care in a coordinated way organised around the individual's needs.
Understand the importance of being able to engage in challenging conversations with other professionals, demonstrating a commitment to partnership working to facilitate care.

Good leaders…	**Do you…?** **Give examples thinking about your own experience of working with others**
Promote relationships at the highest level with other organisations and networks within and beyond the sector.	
Establish and promote an effective and respectful relationship-based culture.	
Intervene personally to ensure that practice, culture and performance are based on quality relationships to enable people to live the life they want.	
Demonstrate the highest level of communication skills to lead and promote the needs of others beyond the immediate organisation.	

ACTIVITY 3D

Good leaders…	Do you…? Give examples thinking about your own experience of working with others
Demonstrate how to relay complex and technical information simply and appropriately to a range of audiences.	
Actively create a culture of co-production, joint responsibility, joint decision-making, support and community participation.	
Model behaviour that identifies strengths, challenges and issues for other people and engages positively with them.	
Champion and model rights and entitlements within the organisation and beyond, creating a culture which takes into account a person's whole life including physical, mental, cultural, emotional and spiritual needs.	

FACILITATOR TO ASK PARTICIPANTS:

- **What, if anything, have you learned from this exercise?**
- **What, if anything, will you do differently?**
- **Write down your learning points and actions.**

Additional related resources

Working together to improve end of life care
https://www.skillsforcare.org.uk/Topics/End-of-Life-Care/Working-together-to-improve-end-of-life-care.aspx

SECTION 4

MAKING IMPROVEMENTS

INTRODUCTION

As a child Josh was supported and cared for by a children's hospice, but as he got older, this became less appropriate as Josh 'didn't fit into their mould'. However, Josh was refused access to a hospice for adults because his care needs were assessed to be too complex.

Lynn and Ruth cared for Josh at home, but they had a young daughter too who suffered post-traumatic stress disorder as a result of Josh's death. Whilst carers, nurses, doctors, and therapists visited regularly, they were under time-pressure and were not always familiar faces.

The family had limited access to specialist support and advice when they needed it the most and no one prepared them for the traumatic way in which Josh died.

After Josh's death, no one offered them support.

Clearly, this is not acceptable care.

This section provides an opportunity to explore some of the themes within the film, and of the interview, in more depth. Questions are split into four sections, depending on your role and responsibilities. They encourage you to think about how Josh and Lynn's experience might have been improved, and what you might learn from their story so that no other family have to suffer in the same way.

Activity 4 focuses learners' attention on their own practice and the practice of their team and organisation. It is split into 4a – d, providing different questions and prompts depending on the audience's roles and responsibilities, moving from how individuals could improve their own practice, to how organisations can work better together, to how strategic improvements can be made across organisations and services. The questions and prompts are designed around 'what leadership looks like' in the 'Improving services' dimension of the Leadership Qualities Framework.

ACTIVITY 4

45:00

Download 'learning reflection' templates

ACTIVITY 4A

Audience

Care assistants, care workers, volunteers, students, graduates

Learning outcome

Understand the importance of reflecting on practice, identifying learning needs and accessing further support for such needs.

FACILITATOR TO ASK:

Ask participants the following questions and allow time for discussion, reflection and debate. Questions are clustered based on themes.

- **Were Josh and Lynn's rights upheld?**
- **How do you uphold the rights of people accessing services?**
- **Was Josh's end of life care designed around his needs and aspirations?**
- **How do you know that the care and support you are providing is continuously improving and is designed around people's whole lives?**
- **Think of a time when you have needed to improve your own knowledge and skills to improve the lives of people accessing care and support:**
    - ***Describe*: What happened?**
    - ***Feel*: How did you feel? How did others feel?**
    - ***Evaluate*: What went wrong? What went well?**
    - ***Analyse*: What sense can you make of this?**
    - ***Conclude*: What else could have been done?**
    - ***Act*: What could you have done differently?**
- **What have you learnt about your own thoughts, behaviours and skills during these discussions and reflections?**
- **What have you learnt about your team or organisation?**
- **What action will you take as a result of this learning?**
- **What support is available to you to achieve this?**
- **How will you know if your action has been successful?**

ACTIVITY 4B

Audience

Supervisors, team leaders, shift leaders

Learning outcome

Understand the importance of working in partnership with others, and implementing strategies to empower and support staff involved in the delivery of end of life care to ensure positive outcomes for individuals and others.

FACILITATOR TO ASK:

Ask participants the following questions and allow time for discussion, reflection and debate. Questions are clustered based on themes.

Discuss:

- **Were Josh and Lynn's rights upheld?**
- **How do you influence others to uphold the rights of people accessing services?**
- **What do you think of the quality of care provided for Josh and his family – before, during and after Josh's death – and why?**
- **How could the quality of care have been improved?**
- **Describe a time when you have raised concerns about quality. What happened?**
- **What improvements could have been made to better support Josh and Lynn?**
- **How do you seek and act on feedback to make improvements?**
- **How do you work with others to promote and adopt good practice?**
- **What innovative ideas or new ways of thinking might have improved Josh and Lynn's experiences?**
- **How do you, or could you, create an atmosphere where staff are empowered to seek change and innovation, and strive for continuous improvement?**

Learn:

- **What have you learnt about your own thoughts, behaviours and skills during these discussions and reflections?**
- **What have you learnt about your team or organisation during these discussions and reflections?**

Act:

- **What action will you take as a result of this learning?**
- **How will you know if your action has been successful?**

ACTIVITY 4C

Audience

Registered managers, service managers

Learning outcome

To understand the importance of promoting effective relationships between organisations to facilitate wellbeing for people approaching the end of life and those important to them.

FACILITATOR TO ASK:

Ask participants the following questions and allow time for discussion, reflection and debate. Questions are clustered based on themes.

Discuss:

- **What do you think of the quality of care provided for Josh and his family – before, during and after Josh's death – and why?**
- **How could the quality of care have been improved?**
- **How do you create a culture of improvement, were workers feel able to challenge?**
- **What difference/s would access to the hospice have made?**
- **How can you ensure that appropriate services are available and/or that services adapt and are responsive to individuals' wishes and needs?**
- **How can you ensure that services are coordinated?**
- **In many ways Josh, Lynn and Ruth were very much on their own:**
    - » **How could support and services have been designed better around Josh and his family's abilities and contribution, as well as their needs?**
    - » **How do you work within your organisation, and with other organisations, to drive improvements?**
- **What improvements do you suggest the operational leaders related to Josh and Lynn's experience should have made?**
- **What improvements might you want to consider making, to ensure Josh and Lynn's experience is not repeated?**
- **Who will you involve in these improvements?**
- **What have you learnt about your own thoughts, behaviours and skills during these discussions and reflections?**

Learn:

- **What have you learnt about your team or organisation?**
- **What have you learnt about your relationship with other services?**

Act:

- **What action will you take as a result of this learning?**
- **How will you know if your action has been successful?**

ACTIVITY 4D

Audience

Senior leaders, directors, managers responsible for directing and controlling organisations (including commissioners)

Learning outcome

To understand the importance of integrating services and ensuring care is coordinated, and how this can achieve better outcomes for individuals approaching the end of their life and those important to them.

FACILITATOR TO ASK:

Ask participants the following questions and allow time for discussion, reflection and debate. Questions are clustered based on themes.

Discuss:

- **Were Josh and his family at the centre of their support?**
- **Are people accessing care and support at the centre of your strategic planning?**
- **How could this have been improved?**
- **Were Josh and Lynn empowered as Josh approached the end of life?**
- **How do you value and empower individuals?**
- **How could you improve on this?**
- **What improvements do you suggest the strategic leaders related to Josh and Lynn's experience should have made?**
- **What improvements might you want to consider making, to ensure Josh and Lynn's experience is not repeated?**
- **What innovative ideas or new ways of thinking/working might have improved Josh and Lynn's experiences?**
- **How do you, or could you, encourage innovation and new ideas?**
- **How can you demonstrate that your organisation leads as an example of excellent practice?**

Learn:

- **What have you learnt about your own thoughts, behaviours and skills during these discussions and reflections?**
- **What have you learnt about your team or organisation?**

Act:

- **What action will you take as a result of this learning?**
- **How will you know if your action has been successful?**

Additional related resources

Quality improvement made simple
https://www.health.org.uk/publication/quality-improvement-made-simple

End of life care and human rights: a practitioner's guide
https://www.sueryder.org/for-healthcare-professionals/education-and-training/human-rights-end-of-life-care/download

ADDITIONAL LEARNING RESOURCES

Additional learning resources for social care professionals working in end of life care

Hospice UK
https://www.hospiceuk.org

Royal College of Nursing – End of life care
https://www.rcn.org.uk/clinical-topics/end-of-life-care

Skills for Care
https://www.skillsforcare.org.uk/Home.aspx

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

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

Quality improvement in health and social care
A new online learning resource has been added to the Social Care Institute for Excellence's website (June 2018). This resource is designed to support managers and staff working in health and social care to be more knowledgeable about – and understand – the process of using and implementing quality improvement methodology.
https://www.scie.org.uk/e-learning/quality-improvement

Below are a few examples of freely accessible learning modules that are available from e-End of Life Care for All:

- 0201 – Introduction to principles of assessment in end of life care Part 1
- 0202 – Introduction to principles of assessment in end of life care Part 2
- 0402 – Agreeing a plan of management and care
- 0107 – Mental Capacity Act: aims and principles
- 0108 – Mental Capacity Act in practice
- 0601 – Supporting people to live and die well
- 0521 – A unified DNACPR

Access them at: https://www.e-lfh.org.uk/programmes/end-of-life-care

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5. Care Quality Commission (2016). A different ending: addressing inequalities in end of life care. Newcastle upon Tyne: Care Quality Commission.
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