



Children's Hospices Across Scotland



NHS Education for Scotland
Palliative and End of Life Framework
Informed Level

The Framework



ICE BREAKER

Pick A Sweet



ICE BREAKER Questions

Pink - Cremation or Burial

Purple - What one thing would you like to do before you die?

Red - Where would you like to be when you die?

Green - What song would you like played at your funeral?



DOMAIN 1

FUNDAMENTALS OF PALLIATIVE CARE

Fundamentals of Palliative Care

What is Palliative Care?

What is End of Life Care?

Is there a difference?

Discuss in groups



WHO (2017) Palliative Care Definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. **World Health Organisation (2017)**

Children's Palliative Care Definition

An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Together for Short Lives (2017)

End of Life Care

End of Life Care is a term that is being used more and more across the UK for care in the last few days or weeks. Just like palliative care it includes physical, emotional, social and spiritual care but it is used to describe the last year of life.

Scottish Government (2015)

What Matters To You Exercise?

What would matter to you if you knew you had weeks or days to live?

Discuss with a partner?



WHAT MATTERS TO YOU

- Retaining control
- Dignity and privacy
- Pain & Symptoms managed
- Choice of place of death
- Access to spiritual & emotional support
- Access to hospice care
- Who is present at the end
- ACP
- Time to say goodbye

(Age Concern 2010)

Person-Centred Care

What does this mean to the child?

What does it mean to the family?

The ChiSP Study 2015

- 15,400 babies, children, young adults
- 4,800 of these under 5yrs
- 2,200 are unstable or deteriorating
- 195 deaths each year
- 26% live in the most deprived areas

CHILDRENS CONDITIONS

- Different from adults
- Congenital
- Unpredictable
- Neurodegenerative
- Some cancer
- More babies and young children
- More complex healthcare needs
- More technologically dependent

Diversity, Culture and Beliefs

Scotland is described as a diverse and multi-cultural society.

The people we provide palliative and end of life care and support to will come from all walks of life, faiths, nationalities and cultures.



A person's culture or beliefs may influence how they would wish to be cared for or the support they would wish to receive.

Your Role



Key Learning Points

- Palliative and end of life care takes a whole person approach
- Many people, services and agencies can be involved in the care and support of someone with palliative and end of life care needs
- Everyone in health and social care has a duty to protect and promote people's rights and safety
- Treating everyone with dignity and respect, including our co-workers is essential in health and social care
- Attitudes to death, dying and bereavement have an impact on how we provide care and support



DOMAIN 2
COMMUNICATION AND
CONVERSATIONS

COMMUNICATION SHOULD BE

- Open and Honest
- Sensitive
- Compassionate
- Polite
- Respectful
- Confidential
- Private



NON VERBAL COMMUNICATION

- Tone
- Touch
- Silence
- Facial expressions
- Eye contact/expression
- Sounds
- Gestures
- Body language



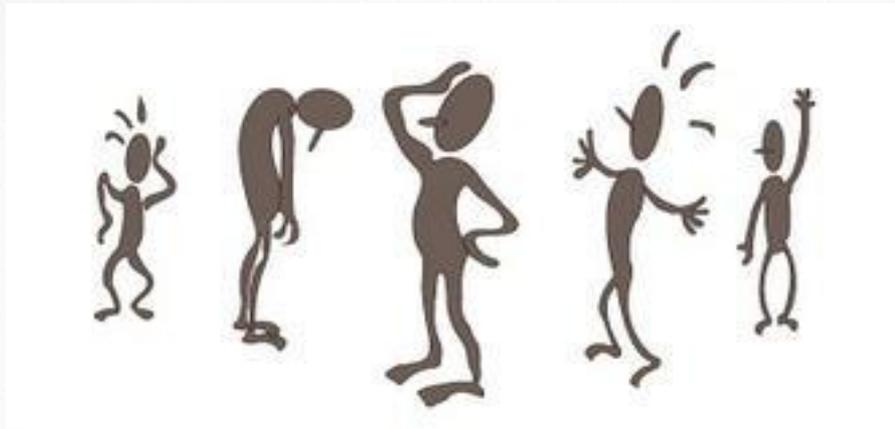
Effective Person Centred Communication Skills

- Non-verbal actions
- Sitting down beside the person
- Creating a sense of privacy
- Active listening
- Use facial expressions
- Silence
- Reflection
- Empathy
- Connecting



COMMUNICATION CHALLENGES

- Difficult questions
- Anger
- Knowledge
- Time
- Uncertainty



Boundaries

A boundary is crossed when a relationship becomes a blurred line between professional/personal relationship.

Chas Boundaries Policy

Boundaries Exercise

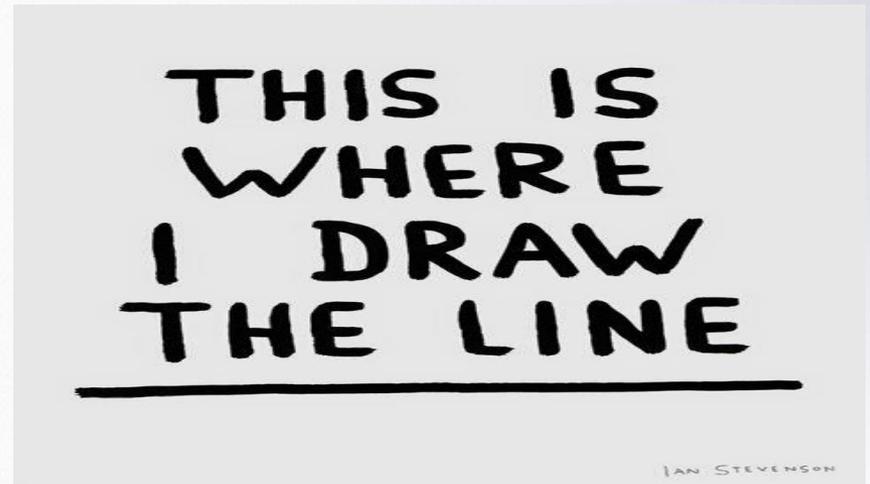
Scenarios to discuss in groups.



Boundaries

Boundaries are in place to protect families who are vulnerable and staff and volunteers from risk of false allegations?

- Child protection
- Confidentiality
- Personal safety



Key Learning Points

- In palliative and end of life care people can experience a range of feelings and emotions and providing support is not easy
- Sometimes we worry that we will say the wrong thing, cause people to become upset, not know what to say, or not know how to finish the conversation
- Good conversations are helpful for everyone involved in palliative and end of life care and this includes the people giving care and support.
- Hopefully this helps you to identify what helps and what to avoid during your conversations with people who are receiving palliative



DOMAIN 3

LOSS, GRIEF AND BEREAVEMENT

Understanding the terms Loss, Grief, Bereavement

- Loss: is being deprived of someone or something of value
- Grief: is the emotional response to loss and death
- Bereavement: is when you have lost someone through death and the time when grief is experienced and mourning happens

(Wilson 2014)

LOSS

Loss and change are part of life and everyone will experience these in their life time

In palliative and end of life care people can experience many forms of loss and it is not always about death and dying



How someone feels about and copes with the loss will vary and this may influence the support they require

TYPES OF LOSS

- Loss of a relationship you have had with someone through death, divorce, friendships, moving away
- Loss of self-image caused by hair loss, a limb or body part being removed, losing or gaining lots of weight
- Loss of not being able to do things that give you pleasure and enjoyment
- Losing your security, your job, your home
- Loss of how you see your role in life such as being a parent, a partner, a valued member of your workplace

EXERCISE

Lost House Keys



RESPONSES TO LOSS

- Feelings – anger, guilt, regret, anxiety, helpless, lonely, relief, numb
- Physical sensations – hollow stomach, lump in throat, tightness in chest, sore head, nausea
- Thoughts – disbelief, confusion, repeatedly go over events, responsible, seeing person
- Behaviors – sleeping too much/little, forgetful, poor concentration, lose interest, cherish/remove items
- Social difficulties – changes in relationships, difficulty with everyday tasks
- Spirituality – questioning beliefs or holding onto them, wonder what's important

LOSS

There is no right or wrong way to express or cope with grief.

Some people may want to talk to others and express their feelings or they might find support groups help them.

Sometimes people may wish to be alone.

They may use social media as a way of seeking support or expressing their grief.

Some may talk to family or want to talk to someone who isn't part of their family and that might be you.

RESPONDING TO LOSS

- People don't always remember what you say but they will remember how you made them feel. Be kind, compassionate
- People will remember if the experience could have been better. Do your very best



CARE OF SELF

- Looking after your own physical, emotional, social and spiritual health
- Recognising when you might be getting stressed at work and taking steps to get support
- Having a good balance between your personal life and your working life



SELF CARE EXERCISE



KEY LEARNING POINTS

- Loss, grief and bereavement affects us all at some point in our life
- Grief is a normal response to loss, however everyone will have a different experience and reaction to it
- Dealing with loss, grief and bereavement is challenging and can be stressful
- Personal experiences and circumstances can have an impact on how we cope with loss, grief and bereavement in our workplace
- Taking time to reflect on our experiences can support our learning and well-being



DOMAIN 4
CARE PLANNING AND
DELIVERY

PLANNING CARE AND SUPPORT

- People should be at the heart of the assessment and planning of their care, as they are the experts in their own lives
- Having choice and control about decisions, care and support is central to maintaining a person's dignity at a time in their life when they may be facing uncertainty and feeling vulnerable
- As well as physical symptoms it is important also to consider their emotional, psychological, spiritual and social wellbeing

WHAT MATTERS

- Being listened to, treated with respect and being included in decision-making
- Good communication and conversations are the key to care and support planning
- Sometimes people need support and encouragement to take part in discussions and to make decisions about their health and social care.
- You may not be directly involved in assessment or planning care but you can listen, and encourage them participate in decision making to help ensure that care and support is right for them

ANTICIPATORY CARE PLANS

- General information
- Plans for when child becomes unwell
- Wishes around end of life
- Wishes during life
- List of professionals involved in care

REVIEW OF CARE AND FORWARD PLANNING

- A need to recognise that things can change. Some happen slowly over time while others happen more quickly or unexpectedly.
- Sometimes there are changes in family or social circumstances
- A plan of care and support will need regular review.
- When things change the plan should be reviewed and a response coordinated
- It is helpful to think ahead about future changes in health and wellbeing.
- Thinking ahead is not just about the end of life but can be helpful when someone's needs are changing and becoming more complex

- Palliative and end of life care and support planning takes a whole person approach
- What matters to the person and their family should be central to the plan of care and support
- Having choice and control supports dignity and quality of life
- Anticipatory care planning is a ‘thinking ahead’ approach that can help people receive the right care and support at the right time in the right place.

KEY LEARNING POINTS

- Palliative and end of life care and support planning takes a whole person approach
- What matters to the person and their personal outcomes should be central to the plan of care and support
- Having choice and control supports dignity and quality of life
- Families are equal partners in care and have a right to their own care and support plan
- Anticipatory care planning is a ‘thinking ahead’ approach that can help people receive the right care and support at the right time in the right place.



DOMAIN 5

CARE IN THE LAST DAYS OF LIFE

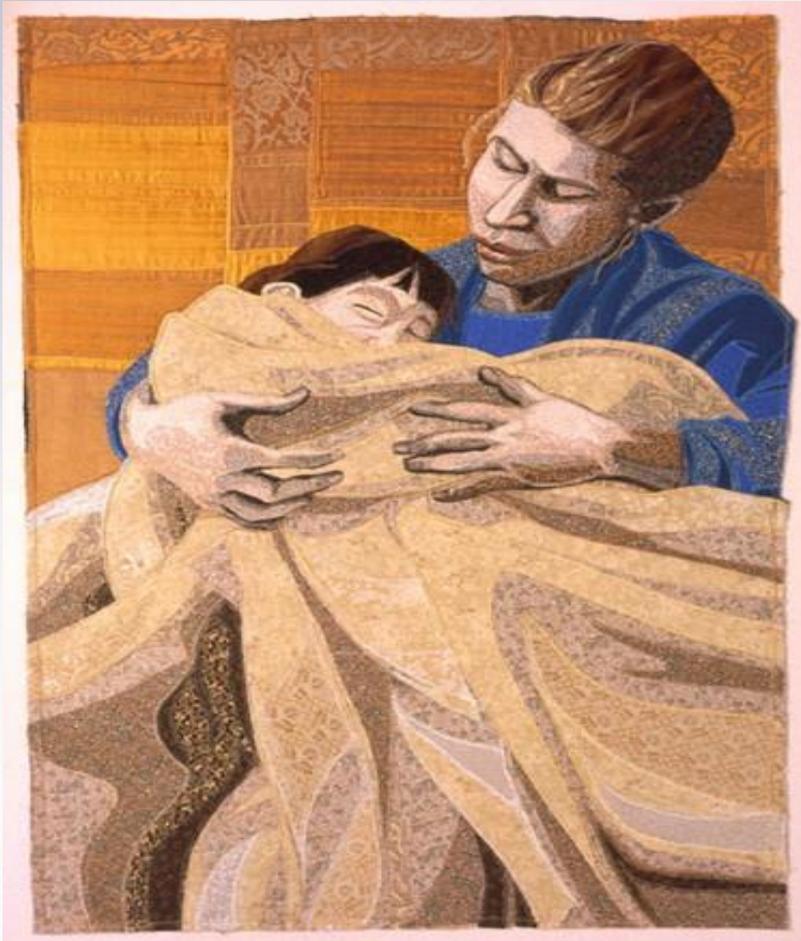
Wake UP!

THE MOVIE



Keep the joy alive

Heading



Cure sometimes,
Relieve often
Comfort always
(Dr Edward
Livingston Trudeau
1848-1915)

GOALS OF SYMPTOM MANAGEMENT

- Relieve Suffering
- Provide Comfort
- Enhance Quality of Life

RECOGNISING END OF LIFE

- There can be uncertainty involved in identifying when someone is dying, even when death is expected.
- Each person is individual and their experience of dying is unique to them
- Illness or someone's condition can be unpredictable and change can occur suddenly and unexpectedly.
- Some people may have a sudden change in their illness/condition or equally could have a longer period in the dying phase.
- Knowing when someone is in the last days of life is not always easy. It is important to get the views of all those involved so that everyone is in agreement that the person is in the last days of life and a death is expected

COMMON SYMPTOMS AT END OF LIFE

- Pain
- Nausea & Vomiting
- Breathing Difficulties
- Seizures
- Constipation
- Distress, Anxiety & Depression
- Anorexia
- Fatigue

PRIORITIES

- Communication - the correct information to inform care and choices at the time, be sensitive to what is happening to the child and family
- Team approach to decisions and care for the child.
- The child's care needs should be assessed, planned and managed with respect and dignity. Their physical, psychological, social and spiritual needs require to be reviewed daily.
- Identify what matters to the person and family and try to achieve this, as far as is possible

Scottish Government 2014



LEGLISTATION AND PROCEDURES AFTER DEATH

- The child's death should be verified as soon as possible
- The death needs to be certified by doctor before a body can be removed from the place of death or a funeral can take place
- Family members should be offered the opportunity to participate in personal care of child afterwards
- Child is moved to Rainbow Room
- Funeral Director is contacted

KEY LEARNING POINTS

- Dying is part of life and is surrounded with uncertainty as to how and when someone will die. This can cause distress to the child and family as well as those providing care and support.
- It is important to check the choices and preferences of the child, family in the last days of life. This allows some control over the last days of their child's life
- Legislation, policy and guidance directs the actions that need to be taken when a person is approaching death and when a death occurs

DEBRIEF





Keep the joy alive

www.chas.org.uk     SupportCHAS

Children's Hospices Across Scotland is a trading name of Children's Hospice Association Scotland. Scottish charity number SC 019724.