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DAISY VOLUNTEER

Training Programme 2021



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Care and support
through terminal illness



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Funded by Marie Curie

INTRODUCTIONS

- ❖ Emotional Support
 - ❖ The role and its boundaries
 - ❖ Processes
 - ❖ Personal safety
 - ❖ Support / bereavement
 - ❖ Online training
 - ❖ Human rights
 - ❖ Endings
- Why are you interested in supporting people at the end of life?



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THE BIGGER PICTURE

Death and dying have always been a part of life and healthcare provision. It is only in the last 10 years that the case of the dying began to receive the attention that it has long deserved.

It has been suggested that how we care for the dying is an indicator of how we care for all the sick and vulnerable people.

EOLC is care that helps all those with advance, incurable conditions to live as well as possible in the last year of their lives. This enables for supportive and palliative care needs, for both patient and family to be identified and met throughout the last phase of their lives and into bereavement.

This care includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Six Ambitions were identified:

- Each person is seen as an individual
- Each person gets fair access to care
- All staff including volunteers are prepared to care
- Maximising comfort and wellbeing
- Care is coordinated



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Aims and objectives of training

Aim of the service

- For no one to die alone
- To improve the experience for people who die in hospital
- To emotionally support patients and their families



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DAISY VOLUNTEER TRAINING

Mandatory Training – Week One

This will be done on-line

- ❖ MS Teams Training
- ❖ Dementia Level 1
- ❖ Autism Awareness
- ❖ End of Life Care Level 1
- ❖ Equality, Diversity & Human Rights
- ❖ Fire Safety
- ❖ Health Safety & Welfare
- ❖ Infection Prevention & Control Level 1
- ❖ Sustainability and Waste Management
- ❖ Pride-way Introduction
- ❖ Workshop to Raise Awareness of Prevent
- ❖ Information Governance
- ❖ Moving & Handling Level 1
- ❖ Resuscitation Level 1
- ❖ Adult Safeguarding Level 1&2
- ❖ Child Safe guarding Level 1&2

Week Two - Training Programme

Topics to be covered

- ❖ End of life signs and symptoms
- ❖ Dying / Key worries at the end of life
- ❖ Grief and Bereavement
- ❖ Communication Skills
- ❖ Ward etiquette (Chaplaincy)
- ❖ Spirituality
- ❖ Diversity
- ❖ Looking after yourself
- ❖ Confidentiality and Safeguarding



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With this training we aim to provide you with:

- Clear understanding of the Daisy role
- An opportunity to enhance your own communication skills
- An understanding of how to work in end of life care
- Increased confidence in your own abilities
- An opportunity to raise awareness and management of your own responses



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IMPORTANT INFORMATION

Do

- Be passionate,
- Be supportive,
- Be caring,
- Be a great listener and
- Be a companion.

Don't

- Read patients' medical files or share this information,
- Assist with cleaning duties of any kind or repair any item of equipment.
- Volunteers will not assist with anything of a medical nursing nature,
- As you are in a position of trust you should never abuse that trust or use it to









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Opt-in symbols

Ward Etiquette

These symbols will be found across the two hospitals. They tell us a bit of information about our patients to help us provide the right support.

					
Learning Disabilities	Hearing difficulties	Sight difficulties	Dementia patient	Memory loss	Dignity in Death
<p>Please ask patients before using this symbol—it is an opt-in sign</p> <p>Please consider the following reasonable adjustments:</p> <ul style="list-style-type: none"> -Read the patients hospital passport -Find the best way to communicate -Do not use jargon; use simple language -Provide easy read information -Use more visual information -Give more time to process information -See the person not the disability -Be aware of missing serious illness -Consider mental capacity 	<p>Please ask patients before using this symbol—it is an opt-in sign</p> <p>If the patient is severely deaf, offer the use of a translator</p> <ul style="list-style-type: none"> - Always talk directly to the deaf/hard of hearing patient - Do not shout - Talk at a normal speed - Don't gesture or use your arms when talking - Offer to write things down - Repetition may be Necessary - If you're in a group, talk one at a time 	<p>Please ask patients before using this symbol—it is an opt-in sign</p> <ul style="list-style-type: none"> - Identify yourself - don't assume the person will recognise you by your voice. - Don't shout - Avoid situations where there is competing noise - Offer assistance, wait until the offer is accepted - Don't touch or grab a blind person - Use your body language - If you're in a group, introduce the other people present -When leaving the patient, let them know 	<p>The Butterfly scheme is an opt-in scheme. Only use the butterfly if family/carer agrees</p> <p>Use REACH Remind - patients what you are doing & why</p> <p>Explain - what is happening next & why</p> <p>Arrange - make sure patient has bell, drink, items from home</p> <p>Check - do they need help to get to the toilet or need encouragement to drink</p> <p>History - check patient's answers with records or carers</p>	<p>Patients with temporary or partial cognitive Impairment</p> <p>Please use the REACH technique as described under Dementia patient</p>	<p>Please ask patients/ carers/family before using this symbol - it is an opt-in symbol</p> <p>For those patients who will be cared for within the hospital as they enter the dying phase of their life</p>

Food and mealtime, patient safety symbols

Ward etiquette

More symbols found around the hospital

Nil by mouth	Assistance with eating	Fluid intake monitored	Diabetes Mellitus	Falls risk	Risk of pressure Ulcer 2 hour turn	Risk of pressure Ulcer 4 hour turn
<p>ONLY to be used when a patient is NIL by mouth.</p> <p>Must be removed once no longer required</p> <p>If a patient is likely to remain nil by mouth for more than two days, please contact the Nutrition Team for advice on alternative feeding methods</p>	<p>Patients who may need:</p> <ul style="list-style-type: none"> -Encouragement with eating and drinking -Assistance due to swallowing problems -Their food intake recording 	<p>Patients who may need:</p> <ul style="list-style-type: none"> -Special fluids (e.g. thickened) -Their fluids Restricted -Their fluid intake recording 	<p>Signifies the patient has diabetes mellitus</p> <p>Ensure Blood glucose monitored appropriately</p> <p>Ensure mealtime insulin given with food</p> <p>Use Hypobox for the treatment of Hypoglycaemia</p>	<ul style="list-style-type: none"> - For patients identified as having a risk of falls or have fallen while in hospital - Remember to report falls in hospital via an Incident Report form (IR1) - If the patient has hurt themselves this needs escalating to your manager and matron who will escalate this further 	<ul style="list-style-type: none"> - All patients with any grade of pressure damage, regardless of the braden score, should be checked and encouraged/ helped to reposition at least 2 hourly - This is the same for patients with a braden score of 12 and below 	<ul style="list-style-type: none"> - All patients with a braden score of 13-18 with no pressure damage should be encouraged/ helped to reposition at least 4 hourly -This can also be used for any patient who does not fit the above criteria but in the nurses clinical judgement may be at risk
<p>-On admission, a patient's MUST score has to be recorded</p> <p>-If MUST score is 3 or above, or if you are concerned about a patient's nutritional intake, please commence food chart and refer to a Dietician</p>					<p>Check skin with each change of position to identify early any changes in the condition of the skin</p> <p>Follow the skin pathway protocol</p> <p>Remember to report patients with pressure ulcers via the Trusts reporting system, using IR1 forms</p> <p>Refer to the tissue viability service for advice if required</p>	



Daisy volunteer project

Write up on what the Daisy project is all about , i.e , the hope that no one should die alone

DAISY PROGRAMME

This project has been funded by Marie Curie and in partnership with BHRUT

- **Marie Curie**

Support people with a terminal illness. They offer specialist care and support for patients family and loved ones be it in-patients or out-patients.

- **End of Life Care Team**

This team aims to promote the highest quality of end of life for the patients through the provision education, support and advice.

- **Palliate Team**

Are a specialist care team who care for those who have a life limiting disease through Symptom Control and discharge planning.

- **Chaplaincy**

Spiritual care involves exploring what matters most. It can include reflecting on our relationships, activities and beliefs that matter to us. By understanding how those things give us our sense of value and purpose in our lives. Illness or a hospital stay can affect all of these areas of of our lives.



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The Daisy Project



Our End of Life team, Palliative Team and Chaplaincy team were identified as providing 'An outstanding service' by the CQC in 2019 Inspection for End of Life Care.



By

- Providing individual and tailored support for patients and those that are important to them
- The provision of companionship during the dying phase
- Practical information
- Practical tasks such as requesting a review by the clinical team
- Facilitating and supporting conversations lead by health professionals



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How does it work?

- Part of individual end of life care planning
- Patients and their families are identified by healthcare professionals
- Conversations about what might be helpful with the volunteer coordinator or a volunteer
- Referral made and responded to



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Dying in Hospital

- Can be a lonely and isolating experience for the patient and for those that are important to them
- Can be the only choice of the patient or those that are caring for them.
- There may be nowhere else for them to go.



Feedback

From the families

“...thank you for all your help,... it has helped us during this worrying time”

“...it was extra special knowing someone is by her side”

From the volunteers



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Feedback from healthcare professionals

- To hear from anyone of these
- **Clinical Nurse Specialists**
- Heather Wright (Lead for Specialist Palliative Care and End of Life Care Team)
- Bid Newport
- Evelyn Asiam
- Bridget Sallis
- Tracy Wells
- Sara Newson
- Asha Bhullia
- Sharon Roberts
- **Specialist Social Worker**
- Michelle Sheldrick
- **Occupational Therapist**
- Ursula Abbott
- **Discharge Coordinator**



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Feedback from healthcare professionals

Feedback from anyone of these professionals

Doctors

- Dr Claire Bates (Clinical Lead)
- Dr Andrew Gage
- Dr Lucy Pain
- Dr Lucy Bemand-Qureshi
- Dr Robert Chew



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Tea and Coffee Break



Skills Training



Listening & communication

What is communication?

How do we communicate ?



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Listening & Communication

- ❖ How do we listen to others in our everyday lives?
- ❖ How does it feel when you have been listened to?
- ❖ How do we show we are listening?
- ❖ Focus
- ❖ Open Questions
- ❖ Summarising
- ❖ Reflecting
- ❖ Clarifying
- ❖ Silences
- ❖ Hearing/Listening
- ❖ Responses
- ❖ Our body language



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Communication

Blocking

- ❖ Making judgements
- ❖ Our stuff in the way
- ❖ Preoccupation
- ❖ Emotional blocks
- ❖ Hostility
- ❖ Past experiences
- ❖ Ambiguity
- ❖ Hidden agendas
- ❖ Stereotypes
- ❖ Defensiveness



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Different perspectives on life and death

- The factors that can affect an individual's views on death and dying
- Our own views on death and dying



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Factors that affect how people view death and dying

- Age
- Gender
- Social attitudes
- Cultural factors
- Relationships
- Spirituality
- Psychological and emotional factors
- Religious factors
- Sexual orientation



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Minority group

Many older LGBT people have significant fears about palliative and end of life care services. They are concerned that service providers and health and social care professionals will be indifferent to their sexuality and gender identity, or, at worst, actively hostile. They worry that palliative and end of life care services are simply 'not for them', or that they will receive worse treatment than their straight peers.

(Marie Curie, 2016)



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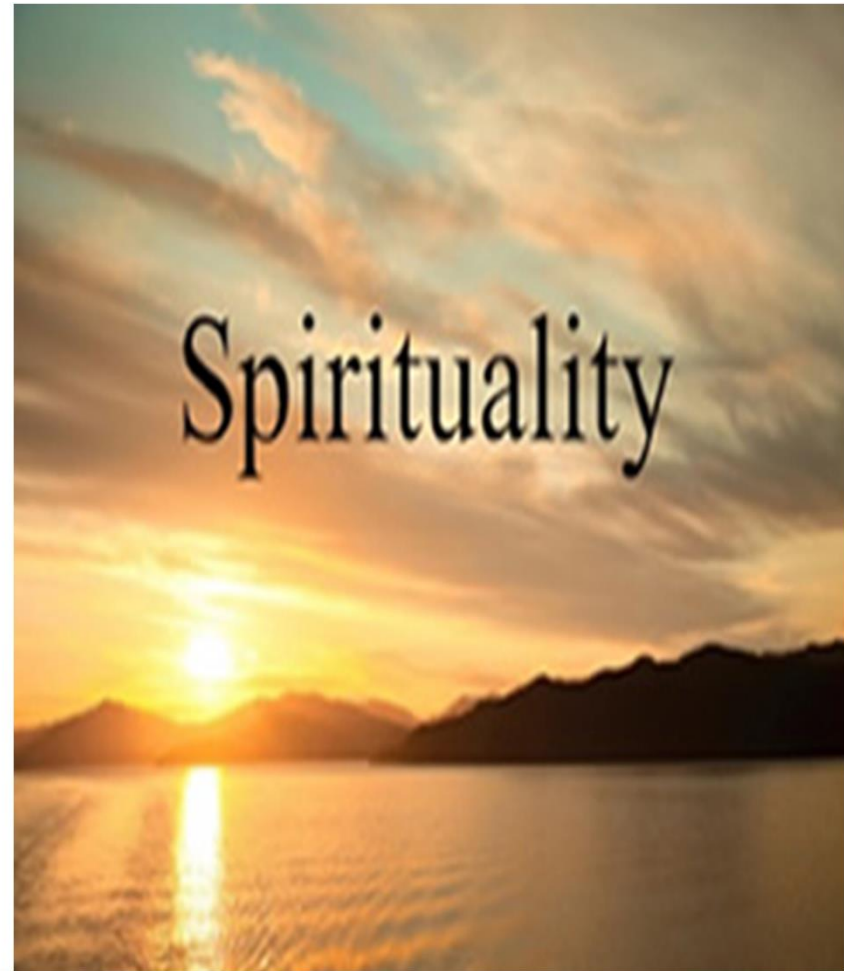
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Spirituality

Spirituality

Think about what spirituality means to you.



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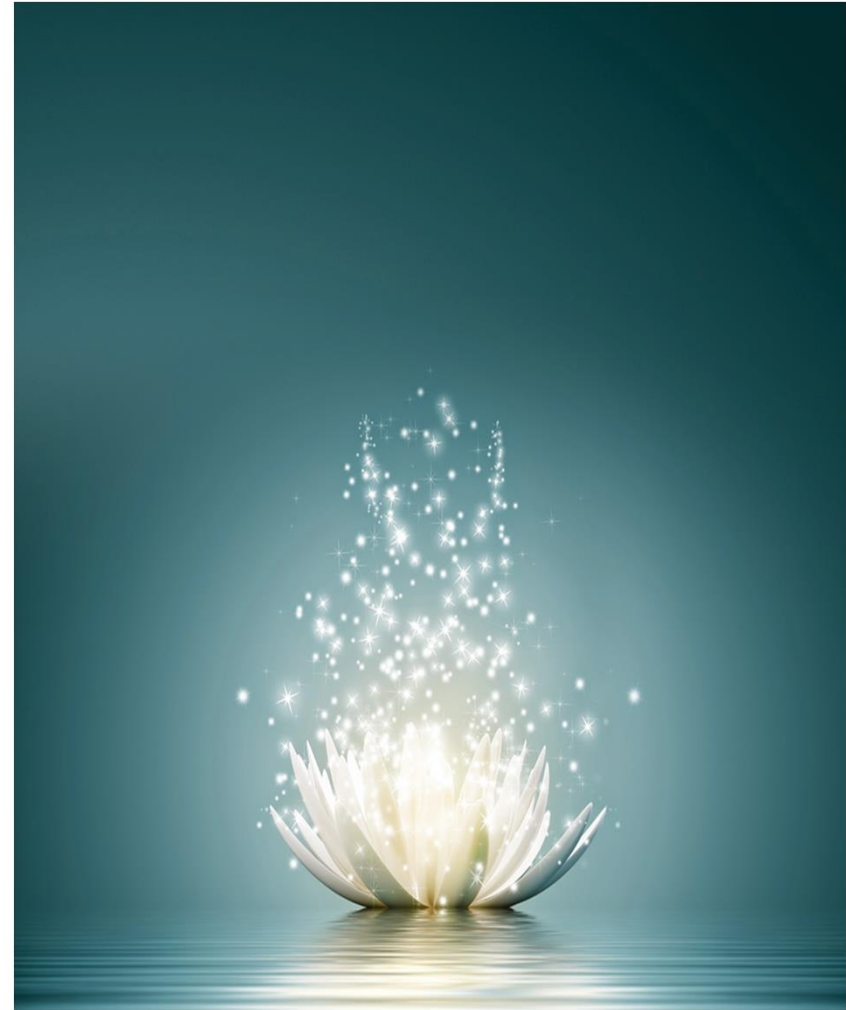
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Spirituality

What makes me, me

How do I express my
humanity?

What does it mean to be
human?



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What are human rights?
Human rights are the basic rights and freedoms that belong to every person in the world, from birth until death. They apply regardless of where you are from, what you believe or how you choose to live your life.

They can never be taken away, although they can sometimes be restricted – for example if a person breaks the law, or in the interests of national security.

Human Rights

A white banner at the bottom of the slide. On the left is the Marie Curie logo, featuring a yellow flower and the text 'Marie Curie' and 'Care and support through terminal illness'. In the center is a large, vibrant orange flower. On the right is a circular logo of a tree with colorful leaves, with social media handles listed below it: 'Twitter @AntWeb7', 'YouTube BHRUT Patient Experience', and 'Instagram BHRUTPatExp'.

“Home now, but will never forget the kindness and dedication of all the staff.”

“...thank you for all the hard work you are doing,...appreciated your visits very much as did my daughter and son”

Terminally ill recovered patient



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Emotional Support



Key worries at end of life



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Common symptoms at the end of life

- Pain
 - Weakness
 - Anorexia
 - Constipation
 - Laboured breathing
 - Insomnia
 - Sweating
 - Diarrhoea
 - Drowsiness
 - Depression
- Swelling
 - Dry/Sore mouth
 - Nausea / Vomiting
 - Anxiety
 - Accumulation of fluid in the abdomen
 - Cough
 - Confusion
 - Bleeding
 - Itch



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Emotional Support

EMPATHY

EMPATHY



SYMPATHY

SYMPATHY



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To Touch or Not To Touch?

- Touch is a powerful emotion
- Some cultures deem touch unacceptable/offensive
- Expressive touch is a spontaneous expression to support and show concern
- Evidence suggests that touch can be related to lower levels of anxiety

How do you know if the patient wants or likes to be touched?



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A question for you

What do you think makes good End of Life care?



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Good End of Life Care

- Pain free / symptom free
- Dignity
- Respect
- Compassion
- Empathy



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Challenging questions

Aims

- Explore reasons why we may find it hard to handle challenging questions
- Identify principles for responding to and handling challenging questions
- Identify causes of anger and how to use de-escalation techniques to manage situations



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Challenging Questions

- What makes a challenging question?
- Can you think of challenging questions you have been asked?
- Why was it a challenge?
- Why is it challenging for the person?



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Why are they a challenge?

- There isn't an answer
- The question is unexpected
- Unsure about answering truthfully/ removing hope
- Not knowing the answer
- Worried about the emotions behind the question



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Responding to challenging questions

- Find out why the person has asked the question
- Confirm the person's thoughts if correct and offer support
- Answer realistically
- Invite further questions if appropriate
- Offer information only on what the person has asked about
- Give assurance of support and continuity of care
- If you don't know the answer ... say so



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Unpeel the layers

- What has the person been told?
- What do they understand?
- What do they think is happening?
- What are their greatest concerns?
- How do they feel about that?
- How can we help with that?

Our role is to affirm and support them



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Tricky Questions

Group activity



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Manging anger

Managing Anger

Group Work... Discuss

- Why may a patient or relative express anger?
- Is anger justified?
- How difficult do you find it to deal with someone who is angry?



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Causes of Anger

- Delayed diagnosis/treatment
- Poor communication
- Loss of future/other losses
- Feelings of hopelessness
- Guilt
- Worry/Fear
- Loss of control



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Signs of Anger... Discuss

May be openly expressed...

❖ *What signs can you think of?*

May present as a withdrawal

❖ *What signs can you think of?*



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Principles for Defusing Anger

- Acknowledge the anger/problem
- Use active listening skills
- Show genuine concern and empathy
- Encourage expression of their feeling
- Consider the environment
- Be non-judgemental
- Remain calm and assertive
- Don't use phrases such as 'Don't be silly'
- Apologise if appropriate
- Use open body language
- Tone of voice

References

Maguire P. Improving communication with cancer patients. European Journal of Cancer 1999.Dec. 35(14) 2058-65



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Lunch



Grief and bereavement.



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Think of a time when you have lost something, not a person or a pet.

Try and remember the feelings around that?



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Grief

What helped you ?



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Normal Grief

- Grieving is described as the transition between the original situation and the new. The transition is not smooth or linear but there is oscillation between the past and the future.
- Grief can be described as the intense emotional and physical reaction that someone experiences following loss



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Bereavement

- Our contact with bereaved people can be at the beginning of what maybe a lifetime's work, or at any point along that journey.
- The experience of family and friends around the time of death is very important. It is likely to be remembered for a long time and can effect their grieving.



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Factors which can effect the outcome of bereavement

- The nature of the death
- Characteristics of relationships before the death
- Characteristics of the survivor
- Family and social circumstances
- Opposition to let go – refusal to accept death
- How the bereaved are supported.



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It is normal for people to be dysfunctional in the immediacy of their loss and in their intense grief.



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In the immediacy of significant loss we need to provide watchful waiting, low intensity support aimed at normalising the emotions and experiences.



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The importance of uncertainty



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Principles of good practice

This involves

1. Listening and responding to each person as an individual
2. Taking account of each person's circumstances, experiences, feelings and beliefs.
3. Asking about needs and preferences and offering choices
4. Avoiding assumptions
5. Being non – judgemental



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Ensuring quality practice

Perceptions....

- Individually Imagine you are the person or family member waiting for the Daisy volunteer to arrive. It's your first experience of the service
- What are your expectations?
- Jot your thoughts down and then share with the group



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Perceptions and Awareness

Patient expectations

- Positive image
- Polite
- Professional
- Respectful
- Caring
- Trained
- Calm
- Good communicator
- Confident

Self aware

- Act as an ambassador
- Remember you are a guest
- Self awareness....
- Acknowledge your abilities and limitations
- Think about your own attitudes, beliefs and perceptions
- Be non-judgemental
- Remember- how you are feeling can and will come across



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Daisy Volunteer Role



The boundaries of the Daisy volunteer role

What do you think they are?



Personal Boundaries

- I can work most effectively with people if I have the same experience
- When the person asks for your opinion on their situation, should you give it?
- It should always be the same Daisy volunteer who sees the same person



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Personal safety and lone working

What are the issues you would normally consider when travelling alone or visiting someone you have not met before?



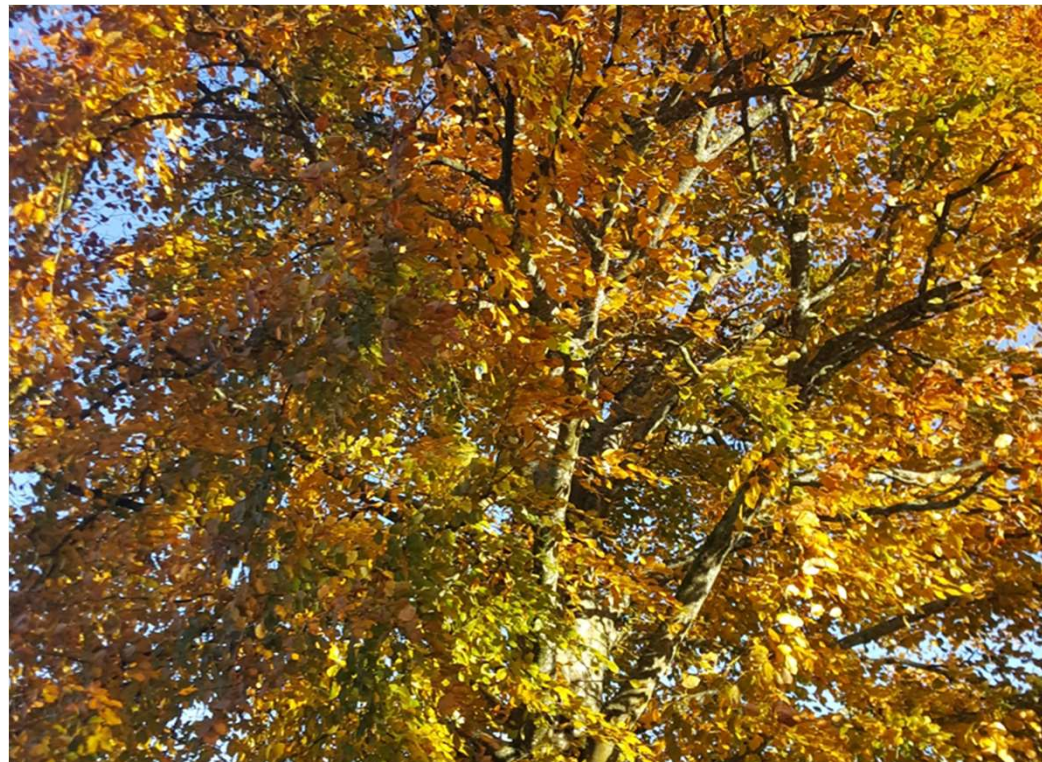
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Looking after yourself

How do you reward yourself?

How do you relax?

How do you wind down?



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NEXT STEPS

- Receive an email
- On-line mandatory training
- On-site shadowing



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Any questions



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**Thank
You**