



Wellbeing for Life Exploring End of Life Care



Learning Outcomes

- To understand your role and responsibilities to support a person at the end of their life.
- Understand how role blurring will affect your practice.
- How to look after yourself whilst giving end of life care.
- Working as a team to provide the best support.
- Being aware of everyone's emotions.
- Understanding the “Six Steps to End of Life Care” programme and its practical application.



Your Roles and Responsibilities Caring for a Person at their End of Life

Compassionate care has to be at the forefront of all care that is given. It is important to think about the person, as well as the people that are close to the dying person as they go through a whole range of emotions.

You may have many responsibilities in end of life care. These could include having a sensitive conversation with a person about their care and preferences, recognising any changes in their condition and offering compassion and support to the person and their loved ones; this includes other staff, peers and friends.

You have a key role to support the person who is reaching or receiving end of life care to have as much control as possible over treatment choices, the care they receive and life style choices. Supporting a person with final choices such as funeral plans and where a person chooses to die is a conversation you will need to have to ensure their end of life wishes are known and respected.

Having these conversations may include the person's family and other staff members. Always remember to document anything that is discussed.



Your Roles and Responsibilities Caring for a Person at their End of Life

Helping a person to plan and see their loved ones (if this is something they want to do) is something that you might find yourself organising. Remember the person may become weak, and in some cases forgetful, so if it was in their Advance Care Plan to see family and loved ones towards their end of life, make sure this happens.

The list of things that you may find yourself doing when giving end of life care will vary day to day but here are some things that it might include:

- Listening to the person
- Giving the family updates (if the person wanted this to happen)
- Supporting peers and friends
- Looking after your own and colleagues' wellbeing
- Caring for the person



Your Roles and Responsibilities Caring for a Person at their End of Life

- Giving the best support and being able to identify the changing needs of the person
- Creating an environment that meets the needs of the person and/or is supportive for the person (see our Dementia Friendly Environment, Theme 5, The Dementia Pathway for more information)
- Reporting bad practice
- Sharing information and recording the care provided
- Liaising with healthcare/palliative care professionals
- Giving the person a well-balanced day based on their preferences, needs and wants
- Acknowledging pain and distress, and taking action to minimise (For more information, please see our Module on 'Pain and Distress in Theme 3 Health and Wellbeing')

Your Roles and Responsibilities Caring for a Person at their End of Life



- Advocating for the person... being their voice
- Communicating clearly to everyone and being mindful that the person does understand
- Respecting the person's wishes



Looking After Yourself

It comes naturally to us as care staff to put the person first and to provide great care and support. We also need to be mindful of our own wellbeing, and that of our team and colleagues. Some days may feel easier than others but some days may be hard and may have an impact on you and your emotions.

Remember to take time out to reflect on your day and don't overload yourself as this is going to be a very sensitive, emotional time for everyone involved.

Your role will vary from day to day as you will start to include a number of different tasks and you will find yourself with different responsibilities that may be new learning experiences for you.

If you get to a point when you are worrying or need further advice then speak to your Line Manager.



Looking After Yourself

You might be going through similar experiences in home life, or recently have gone through a death of a loved one yourself. Always speak to your line manager so that they can provide you with additional support if you need it.

You might feel that it is not always possible to make time for yourself, but it is important for you, and the person that you are caring for as you need to stay well.

Your needs can be put to one side as you have a lot to do at this time but try not to let this happen as you need to stay healthy and your own wellbeing is so very important.

Keeping yourself healthy in all ways - physically, mentally and emotionally - can help you function better and provide the best care and support possible.



What Can We do as a Staff Team?

End of life care will challenge you and it is important that you look after yourself and be aware of the emotions that you are feeling and experiencing. Resilience is a person's capacity to respond to pressures and demands of everyday life. People manage this in different ways.

Building resilience helps you to cope with everyday pressures and strains and not allow them to adversely impact your health.

Here are some things that may help:

- Work as a team to make this process more manageable
- Share job responsibilities and use each other's strengths
- Be supportive of each other



What Can We do as a Staff Team?

- Have regular meetings to talk about what you are going through
- Debrief at the end of your shift
- Buddy up with a team member so you always have the opportunity to talk about what you are experiencing
- Take up offers of a counselling service (MacIntyre use MediGold, a free counselling service for staff that provide over the phone 24 hour support – ask your Line Manager for more information)
- Keep track of your responsibilities and remember to be realistic about what is achievable in a day
- Be aware of your stress levels; if things get too much speak up and tell someone - you are the only person who will know how you are feeling
- Ask questions - there will be new challenges and you don't want to feel out of your depth



Role Blurring

Role blurring can happen where you are caring for a person but still have others to care for and support. This could entail having more than one job, children and other responsibilities. This can make you feel torn in what to do first. This could cause feelings of guilt, among many other feelings.

This can place added pressures on you, as you can feel that you are juggling lots of things at once and need to be in many different places. It can make you feel overwhelmed. You may often be faced with many different things that you need to do at the same time. This can be difficult to manage and can leave you feeling exhausted – both physically and mentally.

As much as you may want to be able to manage everything, it is not always possible.

It is important to remember that you are only one person and you cannot do everything. Try to focus on what is most important and don't be too hard on yourself about the things you can't manage.

Role Blurring

Sharing responsibilities with your staff team will make things feel more manageable and will give you a chance to balance your time more efficiently. For more information, please see our module on 'Loss, Change and Grief' in Theme 6 End of Life Care.



Remember: Always talk to your Line Manager if you are ever unsure, this will be seen as a sign of strength and not weakness.



Case Study - Katy

Katy has worked with Fred since he was diagnosed with cancer. They have both been involved in all the planning that Fred needs to support him at his end of life journey.

Katy works with Fred 5 days a week for allocated hours each day and provides day to day support. When Katy is not with Fred she will be supporting the rest of Fred's house mates or spending time in the office liaising with families and health professionals.

Katy has lots of different responsibilities in her life – both at work and at home.

One day, Katy is working with Fred and she is asked to stay on to support Fred as there is no other person available who feels confident with providing the end of life care he needs. Katy says yes but will now be unable to collect her daughter from school. She starts to panic and felt that she should have thought her decision through but didn't want to let Fred down. Katy takes a moment to consider her options, then calls her Mother to pick up her child so Katy can continue her time supporting Fred at work not feeling to guilty.

There will be times when you can be more flexible with your day, but when you have other commitments in your life be honest and not afraid to say no. It's important to get the right balance.

For more information, please see our Module on 'Providing the Best Support' in Theme 6 End of Life Care



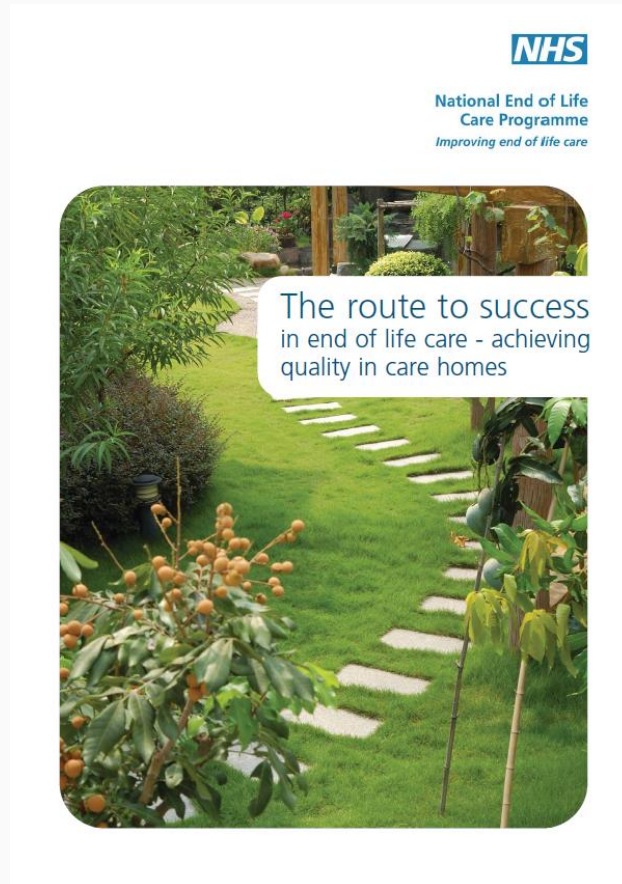
The Six Steps to Success Programme

The Six Steps to Success Programme has been developed to support and develop staff around their roles with end of life care. The aim is to ensure all people that we support receive a high quality of care.





The Six Steps to Success Programme



Can be found on the MacIntyre Health Noticeboard.

This End of Life Care eLearning is based on the Six Steps to Success. St Luke's Hospice in Plymouth adapted the original six step programme and it is now a recognised end of life quality mark for practice. The language has changed to reflect MacIntyre's ethos and values for person centred practice. The Six Steps booklet can be found in the Resource tab. Also look at www.Sixsteps.net which provides some good practice examples and further support.



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