



# Wellbeing for Life

## Providing the Best Support



## Learning Outcomes

- Respecting a person's dignity and privacy.
- Advocating for equal access to health and social care for the person that you support.
- How and why to maintain independence of choice and control.
- How to live well with a life limiting condition.
- Being able to read the road ahead to adapt the environment and type of support a person may require.



## The Importance of Dignity and Privacy

Dignity and privacy are two vital, intertwined themes that run throughout end of life care. We all have a right to dignity and privacy in our lives, and that doesn't change at the end of a person's life; indeed it may become an even more enhanced priority.

The definitions of both words (as defined by the Oxford English Dictionary), offer an important insight into the practicalities that are involved in affording a person their dignity and privacy:

- **Dignity:** “The state or quality of being worthy of **honour** or **respect**”
- **Privacy:** “A state in which one is **not observed or disturbed** by other people”

Both definitions also provide an indication of the sensitivities that exist as you support a person by ensuring their dignity and privacy is respected.



## Why might Dignity and Privacy be Compromised?

Most people naturally recognise the need for dignity and privacy in end of life care but, despite our best intentions, sometimes we don't always achieve dignity and privacy for a person who is receiving care at the end of their life.

There can be a variety of reasons why dignity and privacy might be compromised, including:

- The person being seen as a set of 'tasks' rather than as a person in their own right.
- The person being 'talked over', ignored or not included.
- The person being disturbed by visits (from people they know personally or health or social care professionals) that they may not want at the time, or at all.
- Staff or visitors feeling the need to be with the person for their own reasons (e.g. peace of mind, or wanting to engage the person in conversation or activity) rather than understanding the person's need not to be observed – the person is not an exhibit in a museum to be stared at.



## How can you respect a Person's Dignity and Privacy

Respecting someone's dignity and privacy includes:

- Ensuring every aspect of a person's wishes are adhered to, even if this is to the exclusion of people who feel they should be involved in the person's end of life care.
- Ensuring every interaction you have with the person uses respectful language, and honours their status and qualities as a person in their own right.
- Ensuring the person has the time and space they need to conduct their day as they wish, and in a way that makes sense to them.
- Ensuring the person has absolute privacy when they need support with personal care, or when medical interventions are needed.
- Ensuring that you have the knowledge, understanding and confidence to advocate for the person in situations where their voice needs your support.
- Ensuring all of the above at all times, including when the person may be unresponsive and close to death.

## When the Person's Voice Needs your Support



There are likely to be many occasions during the end of a person's life when their voice will need your support in both everyday situations and one-off events. This is an informal, but vital, advocacy role.

One of the most common examples of the need for the person's voice to be augmented is often when the person experiences barriers in accessing services because of their learning disability (and dementia).

In end of life care this can have serious implications for the aspiration that the person will have a 'good' death.



## Equal Access to Health and Social Care – A Right, Not a Luxury

A person with a learning disability (and dementia) is likely to have been subjected to unequal access to health and social care services in comparison to other people in society even before they need end of life care.

During end of life care, this may be more acute due to stigmatising practices, misconceptions about the person's value to society, and a lack of understanding about the person's needs and wishes (and their ability to make those choices).

Advocating for the person in circumstances like this is about using your knowledge of the person and your empathy with their position to articulate what the person's needs and wishes are.



## Your Role as an Advocate for the Person you Support

Successful advocacy for a person with a learning disability (and dementia) at the end of their life is:

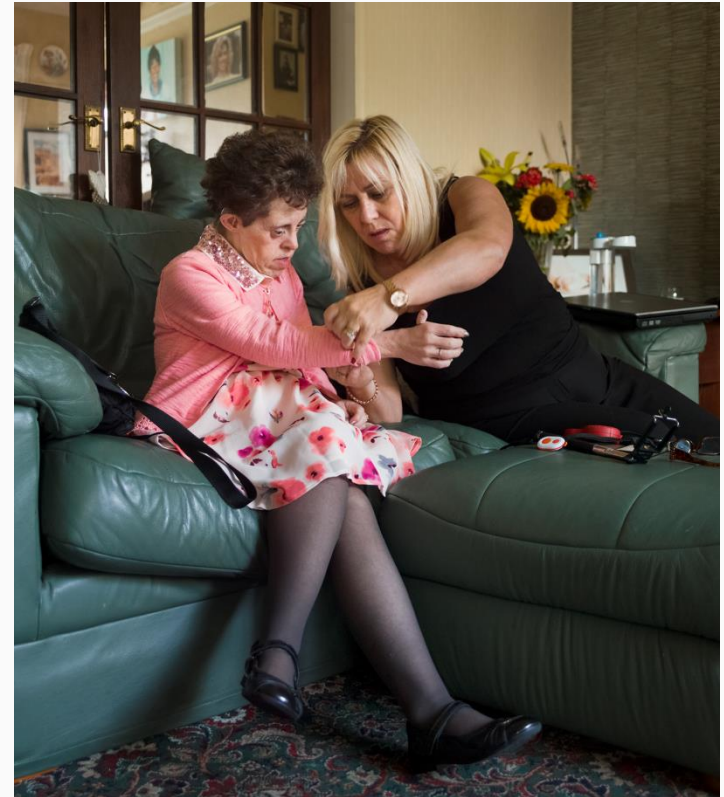
- Being confident, tenacious and persistent in speaking up and challenging decisions that you feel are not in the person's best interests.
- Working with colleagues to develop a clear and consistent message about the person's needs and wishes, and articulating that message 'as one' even when different people are communicating.
- Through your person-centred approaches, enabling external professionals who may be 'strangers' to the person you support to understand as much as possible about the person to positively inform the decisions they are making, or are likely to make in the future.
- Seeking a second opinion, or an alternative source of care and support for the person (if necessary) to preserve their right to independence of choice and control about their care and support.



## Independence of Choice and Control in End of Life Care

At the end of a person's life, perhaps more than at any other time, the person may feel as though choice and control has been taken away from them. This may be due to:

- The attitudes of the people around the person and the assumptions those people are making.
- Medical interventions the person is receiving that they have never previously experienced.
- The way the person is feeling physically and mentally due to the end of life process. This may be confusing and frightening for the person if they don't understand what is happening.





## Why Maintaining Independence of Choice and Control is Important

At the end of a person's life, their ability to communicate may be even more severely limited than it has been in their earlier life.

This inability to communicate will severely detriment how the person participates in making choices and how much control they have over what happens to them. This can lead to feelings of helplessness and isolation, which could make the person feel like 'giving up'.

In extreme circumstances the person may end up feeling like a body in a bed who is having things 'done to them', regardless of whether they want those interventions or not and what they might prefer if they had the choice. This does not represent good end of life care.



## How to Maintain Independence of Choice and Control

Ways you can support the person include:

- Spend additional time with the person. This is often the best way to gauge what the person wants and to tailor your response effectively.
- Enable the person to communicate in whatever way they can. This may be a very different method of communication to the communication method(s) that the person has used in the past, and may be difficult for you to understand. You will need to persevere, and seek the advice and input of colleagues if you feel you are struggling to reciprocate the person's communication and respond appropriately.



## How to Maintain Independence of Choice and Control

- Be creative in how you offer the person choices. Again, this may be a departure from the previously considered 'norm' for the person, but creativity in how you think and what you do is vital in opening up the world of choice and control to the person when more traditional methods of doing this aren't working.
- Believe in the person, and advocate for their right to independence of choice and control. Your positivity can be a hugely influencing factor in how the person perceives the world around them and their part in it. Be enabling and undefeated in your support for the person to live well throughout the end of their life.



## How to Live Well with a Life Limiting Condition

Living well with a life limiting condition may well be something you associate with stories you've read about ambitious 'bucket lists' and pioneering campaigners championing the condition they are living with.

Whilst it's easy to associate ambitions, dreams and 'making a difference' to how other people live well with a life limiting condition, these qualities are just as relevant for the person you support.

What often prevents people with a learning disability from living well with a life limiting condition are the negative attitudes they encounter, or restrictions others place around them.

By offering support that is inspiring for the person you can help to counterbalance this and ensure that the person can live as well as possible.

## Living Well in Practice



First and foremost, you need to understand what is important to the person and what they might want to achieve.

Often the person's needs and wishes will be less about eye-catching endeavours and will instead focus on simple pleasures – perhaps a peaceful nap or a luxurious bath.

Never underestimate the importance of what you might perceive as 'basic' achievements – for the person they are incredibly important and must be both facilitated and respected.

Time, space, peace, sensory pleasures, immersion in favourite interests and sometimes just knowing you are needed, wanted and loved may feature highly on the 'bucket list' of the person you support.



## Risks Versus Living Well

If the person expresses more ambitious desires, don't dismiss them out of hand.

Regardless of whether the person has always wanted to experience what you feel is a 'risky' activity, or whether the desire is a more recent one borne out of knowing that they are approaching the end of their life (if the person has this knowledge), it is still important that the risks versus the benefits are assessed in the present context.

You must consider the principles of the Mental Capacity Act – “A person is not to be treated as unable to make a decision merely because he makes an unwise decision” – and Best Interests Decisions.

If, after a risk assessment, you conclude that fulfilling more ambitious desires isn't possible, try to think creatively about how something that appears unattainable might be facilitated using a different approach.

It is important to balance your desire to avoid any risks with the person's need to feel alive and to live well.



## What the Future may Hold...

Trying to future-proof a person's end of life care is one way in which you may feel you are making an active contribution to the person's future, and preparing for a difficult time in the most practical and useful way possible.

Whilst it is almost impossible to accurately predict every element of what a person needing end of life care might require in the future, if you maintain a flexible and adaptable approach this should ensure that what you do now will have real benefits in the future.

Remember: the most important element to future-proofing a person's care lies in continuously evaluating the person's needs; by doing this you will gain valuable clues as to what you might need to be thinking about in the future.





## **Adapting the Person's Environment**

(for more information, see our Dementia Friendly Environment Module or ebook in Theme 5)

One practical way of future-proofing a person's end of life care is by adapting their environment. Think about the following questions in relation to the person's environment:

- Does it offer the person privacy and dignity?
- Is it personalised and reflective of the person's life story and everything they enjoy and love most?
- Does it provide high levels of cleanliness, comfort and relaxation?
- Will the person's environment support any reduced mobility that they experience?
- Is it soothing for the person's senses? Think particularly about smell, touch, sight and hearing.



## Adapting your Support

Being able to adapt your approach is important to ensure you can respond to the person in the most appropriate, kind, compassionate and gentle way possible.

Don't be afraid of supporting the person, but do so in a way that takes account of how they might be feeling both physically and mentally.

Draw strength and positivity from your relationship with the person and use this to provide comfort and familiarity for them.





## Maintaining Familiarity

When so much is changing for the person at the end of their life, maintaining that which is familiar to them will provide a constancy and reassurance that can help the person to relax and embrace what lies ahead in a peaceful way

You can maintain familiarity through:

Your conversation (tailoring this to the person's needs – they may need a day of less words and more quietness today than they did yesterday)

**A comforting touch – this sometimes says more than words can...**

Offering the person their favourite clothes to wear, favourite foods/drinks (if the person is able to consume these), or by ensuring that they have contact with peers or friends who they actively want to spend time with (and who want to see the person), even if it is only for a very short amount of time.



**Produced by the MacIntyre Dementia Project with the support of an Innovation, Excellence and Strategic Development Fund Award from the Department of Health**

**A special thank you to Beth Britton, and for all her hard work on the MacIntyre Dementia Project.**

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