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An Introduction to End of Life Care

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Learning Outcomes

- To understand the differences between end of life and palliative care.
- To understand why it is important to talk about end of life, death and dying.
- To be aware of the Human Rights of a person with a learning disability to know about their death and the death of others.
- An overview of how to support a person with a learning disability to know about their final stages of life.
- To have the knowledge to know how to keep a person you support at the centre of their end of life journey.

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The Importance of Good Quality End of Life Care

End of life care should help you to live as well as you can and to die with dignity.
NHS Choices 2016.

What if I was told I had a week to live?
Would people around me know how best to support me, what I like and who I love?
Would they know what my wishes where? Would they know if I had a will?
Would my family know if I had anything planned for after my death?
Just taking a moment to think how this would make you feel and the potential stress and upset it would cause.

Yes it is a difficult topic, but now imagine if those things weren't spoken about.
If people around me didn't feel confident in supporting me in my last few hours.
If people around me didn't know MY wishes for what I wanted after I died.
If people around me didn't prompt me to create a will and didn't know what I wanted regarding my belongings and personal items.
If family and staff had not planned anything for after my death.

Yes, you can speak to my family and ask them, but their wishes may not be the same as mine.
Their views, religion and opinions may be different to what I want. *Me.*

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The Importance of Good Quality End of Life Care

It is SO important to be able to talk about end of life with the people we support. It is not a topic that should remain taboo. We must break through barriers, and remove any stigma associated with talking about end of life care. The people we support are entitled to a ‘good’ death, everyone is. We MUST as a team respect their end of life wishes, and have those ‘difficult’ conversations so that we know what these wishes are.

We must do this regularly. As we get older, our needs and wishes may change, and if we are not asked if there are any changes, we might not think to mention it. The person we support should be able to speak openly to a person of their choice. This might not be a manager, this could be anyone in a service, so we must prepare all staff for End of Life care discussions. We already know that a person with a Learning Disability and Dementia progresses more rapidly than the rest of the population. As the conditions could change rapidly, we might have no control over what may happen and when. So we must be prepared. These conversations need to happen prior to suspicions, whilst the person has capacity so that they are at the centre of their care and they are heard and respected.

What is the Difference between End of Life Care and Palliative Care?

It is important to understand the difference between end of life care and palliative care.

End of Life Care

End of life care is a plan of care and support for a dying person who is in their last months or year of their life; a person has an advanced, progressive, incurable illness.
People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this isn't always possible to predict. For most people it may come much later than this. End of life care should help a person live as well as they can to retain their dignity throughout.

Palliative Care

Palliative care is an holistic approach given to a person with a serious illness where the person is unlikely to recover. It is given to manage pain and make a person feel as comfortable as possible. This means that a person is seen as a "whole person". So focusing on all aspects of the person, not just their illness but also looking at their social, emotional and spiritual needs and wishes. The treatment will not prevent or cure the illness but will aim to relieve pain and discomfort. Palliative care is also there to provide support to family and carers as providing palliative care can have an impact on everyone.

Useful Words that Can Help you Understand End of Life Care

Advance Care Plans:

It is best practice to make a plan for care that will be provided in the future. Planning ahead in this way will give you confidence knowing that the person you are supporting has all of their wishes and needs recorded and important things recorded, so that we respect and can follow either their end of life wishes. Also be mindful that this a document that will change depending on the person's needs and progression of their health needs. A person can change it at any time. For more information, please see our module on 'Person Centred Care and Support' in Theme 2 Person Centred Approaches and 'Advance Care Planning' module for more information on this specific topic.

Useful Words that Can Help you Understand End of Life Care

Advance Decision Making:

An advance decision allows a person to decide what care and treatments they would **not** wish to receive in the future. Making an Advance Decision to Refuse Treatment when the person still has the capacity to do so enables control on how their future could be and be content knowing that the treatment and care they receive in the future will be to their wishes. Guidance for making an Advance Decisions to Refuse Treatment is in the Mental Capacity Act (2005)

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Useful Words that Can Help you Understand End of Life Care

Capacity:

Capacity is the ability to use and understand information to make a decision, and communicate any decision made. When a person becomes unwell and no longer able to make a decision themselves they may depend on someone they can trust to start to decision make on their behalf in their Best Interests if Advance Care Planning has not taken place

DNACPR:

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION. This is a form that a person will have if this decision has been made and it must be shown to everyone who is providing care for the person. You will also be asked by a paramedic or health professional if the person has DNACPR.

Useful Words that Can Help you Understand End of Life Care

Second Opinion:

Getting another person's view on the situation in hand (usually from a GP, Doctor or health professional). You may need this if you need further explanation or just need that the reassurance of a professional to ensure the best health care is being offered. Always feel you can ask for this.

Holistic Care:

Looking at the whole person, physically, psychologically, socially and spiritually while you are caring for a person at the end of life.

Progressive:

When something happens gradually over a period of time

Talking about Death and Dying

Death and dying can often be difficult to talk about, and it is something that can be easy to avoid as it is such a sensitive and upsetting topic to discuss with people. We may try and avoid as it can generate a number of negative feelings that can make a person sad, scared, confused and angry. However, it is important to talk about death and dying.

- The importance of sharing thoughts and feelings and wishes about this subject and how it can make people feel is vital.

- The more you talk about death and dying will build your confidence and may not be as negative as you first expected. Once you do start these conversations, you may feel a sense of relief as the person you are supporting probably wants you to talk about what is happening. A person at the end of life needs the best support and care that you can give them.

- You need to be able to respond to a person’s emotional and physical needs and keep the person at the centre of their care at all times. Providing open and honest care to a person that you support can make the person feel included and valued. This will help with their understanding about what is happening.

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Talking about Death and Dying

A person who is at their end of life should:

- Have the maximum level of independence
- Have choice and control about their care
- Feel listened to about their preferences and wishes
- Have their spiritual needs and wishes about faith supported
- Have their wishes and plans for funerals recorded

Remember to share the right amount of information in the right way with the right people. This means everyone understands in a way that makes sense to them.

Talking about Death to the Dying Person

Being honest about dying and having open discussions with a person can be hard. You don’t want to upset, create negative emotions or leave a person feeling sad or confused. Understanding their worries and fears about dying may help make the process feel more bearable and less frightening.

Everybody has the right to acknowledge they are at the end of their life – if they want to. Some people do not want to and this is their way of coping and also needs to be respected.

It is important for a person to know so they get a chance to say goodbye and have that much needed time to spend together.

Everyone has the right to express their wishes about where they would like to receive care and where to die.

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12 Tips for talking about Death and Dying

1. You cannot always plan where and when to have the conversation. The person may bring it up in conversations at unexpected times.
2. Always listen to the person, allow them to communicate their thoughts and feelings to you.
3. Allow enough time; never rush the person.
4. There is no ‘right’ setting; it can be wherever the person feels most comfortable.
5. Think about non-verbal communication such as body language, gestures and your facial expressions.
6. If you show fear or unwillingness to talk, they might not continue sharing their thoughts and feelings.

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12 Tips for talking about Death and Dying

7. Ask open, focused questions
8. Use active listening
9. Maintain eye contact (if appropriate)
10. Show empathy
11. Avoid jargon
12. Give people time to absorb what is being said, leave the person resources to look at in their own time.

Remember: Family members may also want to be part of the conversation, or further conversations, but it is the person’s choice. If they choose not to include family (and have capacity to make this choice, we must respect it).

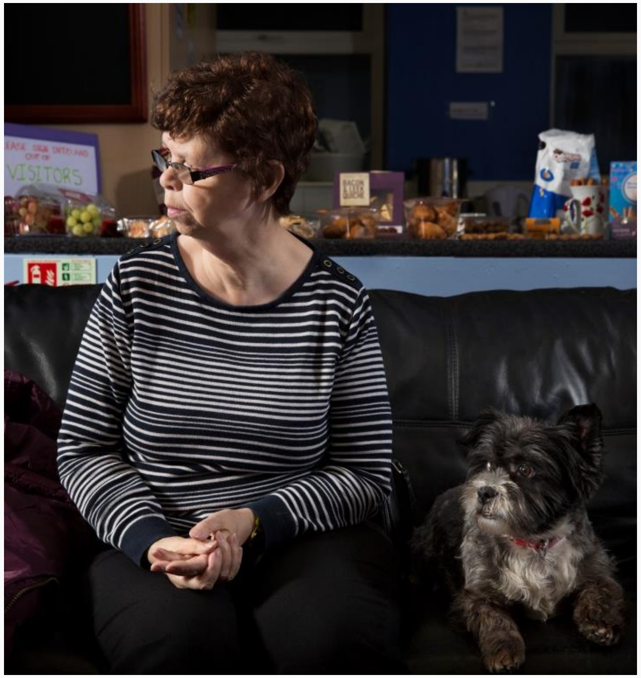
Respecting Human Rights and a Right to Know

It is a basic Human Right for people with a learning disability to know about their death and the death of others.

A person with a learning disability has just the same rights as the rest of the population and should be treated with equity, this includes human rights.(Human Rights Act ,1998) Human rights are in place to support a person with their rights and choices, and they apply to everyone including a person at their end of life. At times this doesn't happen and a person with a learning disability can be excluded from news and decision making.

Health professionals, families and carers at times may think that it is better for the person not to know about what is happening as it may cause distress or the person won't understand. An assumption should never be made based on the fact the person has a learning disability.
A person with a learning disability may not understand ALL of the information that is given to them in the way it is first presented but it is our job to spend time finding a way that the person will understand, in a way that makes sense to them and this may take time.

Respecting Human Rights and a Right to Know



By not being told or involved can stop the person having those very important last times and shared memories with their loved ones.
If people are hidden and protected from death, they will struggle to cope as they are unfamiliar with this and have not built up any coping skills.

People's health can deteriorate slowly, over periods of weeks and months, but also it is important to consider the risk of sudden death occurring. A person that has a learning disability may be more exposed to sudden deaths due to people being reluctant to tell the person in a timely way. This could be due to a lack of confidence from the carer who does not know how to approach the conversation, or about protecting the person's feelings.

Human Rights and End of Life Care

The Human Rights that distinctly apply to End of Life care are:

- Right to life
- Right not to be tortured or treated in an inhuman or degrading way
- Right to liberty
- Right to respect for private and family life, home and correspondence
- Right to freedom of thought, conscience and religion
- Right not to be discriminated against in relation to any of the Human Rights Acts
- Right to be free from slavery or forced labour
- Right to a fair trial
- Right not to be punished for something which was not law when you did it
- Right to freedom of expression
- Right to freedom of association and assembly
- Right to marry and found a family
- Right to peaceful enjoyment of possessions
- Right to education
- Right to free elections
- Abolition of the death penalty

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Supporting People at the End of their Life

"When death is not openly acknowledged with the dying person, and where the dying person is socially excluded from the process of dying and deliberately excluded from the decision making process surrounding the terminal illness, it is described as disenfranchised death" (Read, 2006)

How would you do this? Think about:

- Communication should be at the forefront of supporting a person at their end of life.
- A full and active life can be led by a person with a terminal illness, it's about being creative in how you approach and plan the conversation.
- Adapting a person's current hobbies and interests and making them accessible for the person to still take part.
- Holding on to a person's abilities and strengths and using these as much as you can to keep the person involved and feel a sense of worth.
- Continually asking what the person wants and needs

"Delivering bad news is a process rather than an event. To communicate successfully it is important to break up information and provide it in small pieces"

*(*Tuffrey- Wijne, 2012)

Supporting People at the End of their Life

Make sure the person you support is at the centre of their care at all times.
Think about these statements, do you agree with them?
I would like the care I receive to be specific to me and include everything that. I need and be aware of changes that are happening to my health, and be told in a way that makes sense to me.
I need people to understand my needs and wishes and to be listened to.

Look at me when you talk to me and don’t stand over me, make sure I can see you.
Give me control in making my own decisions.
Don’t keep secrets from me; I want to know what is happening and what is planned for my future.
I would like everyone in my life to come together and communicate what's important for me as this will help give me the best care that I could receive.

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