



My Future and End of Life Care Plan

Guidance for Support Staff

Why support individuals to make a future and End of Life Care Plan?

- **Helps people talk about their wishes and what's important to them**
- **Prepares for their Future**
- **Enables person centered decision making if an individual is unable to communicate their views at the time.**

Supporting an individual to think and talk about how and where they would like to be cared for in the future helps to inform future decision making if they are not able to either make and/or communicate their health or social care choices at that time.

This is known as Advance Care Planning (ACP), and it is appropriate to talk about these choices and wishes at all times of life. If individuals are only given the opportunity to discuss their choices when they are in ill-health they may not feel physically or emotionally strong enough to do so or they may not be given the time they need to communicate, consider or understand what choices are available to them. Therefore talking about care choices in advance helps to reduce stress and anxiety for individuals, their families and carers as it enables decisions to be carefully considered and based on the individuals wishes and beliefs which is key to person centred care.

Why is advance care planning often avoided?

Taboo and Sensitive Subject, Incorrect Assumptions and Time commitment

“As a society we do not talk openly about death and dying. Even professionals find it difficult to raise the topic. This can mean that people do not have an opportunity to express their choices and caring teams do not learn about individual's preferences. This can be even worse if we make incorrect assumptions about an individual's ability to explore the topic.

**Good communication is the cornerstone
of a joined up service to care for all people at the end of life**

NHS Nottinghamshire (2011) - Improving End of Life Care for People with Learning Disabilities

“Whilst learning disability services advocate personal autonomy for service users, many people with learning disabilities will not have extensive experience of making choices or controlling their own lives. This will need to be borne in mind in any end of life care planning and will inevitably slow the process.

Supporters will need to be committed to ‘taking as long as it takes’ to ensure individuals understand the implications of any information and the consequent decisions that need to be made”.

NHS Improving Quality (2015) - The route to success in end of life care:
Achieving quality for people with learning disabilities

What is my role as a Support Worker?

Start the conversation

- Provide the opportunity for an individual to talk, think, consider and understand the care choices that they have available to them. You may need to use the communication aides and resources. Please approach your Self Advocacy Teams.
- Broach the subject informally to get a sense of how the individual may respond to the conversation. Conversations may be triggered after watching a TV programme, reading the paper or listening to the news. Start the conversation with less sensitive topics like ‘Who is important to them?’ ‘What sorts of things make them happy or make them sad’. ‘How they would like to be remembered to their friends’. They may have a pet so perhaps find out if they have thought about who could look after their pet if they were feeling unwell. As the individual feels more comfortable these topics can lead to more specific topics about funeral planning or if they have any worries if they were to become ill. Please see the dying matters leaflets www.dyingmatters.org.uk which give some handy tips on talking about these topics.
- If an individual raises the subject than that’s a good time to talk about it. Listen out for cues that they want to talk about these topics but don’t really want to say. If you dismiss them by trying to avoid the subject they may not bring it up again and they may never get the opportunity to say what they would really like or not like.
- Be prepared that the conversation may become emotional for some people especially if they think back to how others have been cared for or what has prevented them from making these decisions in the past. But remember this topic can be an emotive subject for everyone just because it may upset them does not mean they should not be given the opportunity to think or talk about these things. Active listening, empathy and time are key skills to help an individual talk about these subjects. Seek support for yourself if you want help to develop these skills.
- Always remember that making an Advance Care Plan is always voluntary and no-one should be coerced into the conversation. However, do not let this be an excuse for avoiding the conversation.

Help an individual understand

- Help the person to understand some of the language and terms. There is a glossary on page 27 of the plan to explain some of the key or more complex words. There is also a key resource list at the end of the guide if you need to read more about some of the aspects of the plan. **But**
- Don't worry if you don't know all the answers to their questions – your role is to guide them to access the resources or additional services if they need further information to help them make their choices. See page 24 – 26 of the plan.
- If a person has an illness it is important that they talk with a Doctor or a Health Care Professional to talk about some of the treatments that they may or may not want. Also, some treatment or medical decisions need to be formally documented, signed and witnessed. It may be your role to arrange or go with the individual to support them to have these conversations.
- **It is important** that you help an individual understand why some choices may not be possible or why they need to change. For example:
 - A person may not realise that some choices may cost money and they may not be able to afford what they want.
 - Or they may prefer to be cared for at home when they are very ill or dying but due to the amount or type of care they require this may not be practical.
 - Or they may wish to die in a hospice or care home but sometimes there may not be any beds available at the time they are ill.
- Take all the time it needs - give the person time to complete this plan in a time frame which is comfortable for them. – it may be a very long process and not all aspects of the plan need to be considered or talked about all at once. Pace and plan the discussion to suit the person you are supporting.
- Help an individual record this and tell the appropriate people that it has been written and where it is kept. Advise the individual they may wish to record that they have a care plan in their 'emergency message in a bottle' if they have one. **Also advise not to store the plan in the same place as they would valuables / money etc.**
- Ensure the person knows that feelings and priorities can change over time so they can change their mind at any time. Every now and then encourage the person to look at and think about if anything has changed.
- Help the person understand that this plan will only be used when they are unable to express what they want for themselves at that particular time. When they are ill, they should always be asked and just because it says something on their plan does not mean they cannot ask for something else if they have changed their mind at the time.

Useful resources to help you to support others to make an Advance Care Plan

Communication

- CHANGE books - 5 copies of each available free from [Macmillan Cancer support](#).
- [We are Living Well but Dying Matters](#)
- [Dying matters – Let's talk about it](#).
- Let's talk about death and coping with loss leaflets / mini poster. Available from [Down's Syndrome, Scotland](#).
- [Why talking about death and dying matters](#).
- [Conversation Cards](#)
- [Easy read booklets - Marie Curie](#)

Best Practice Guidance

- Mencap (2008) - [Living and dying with dignity - the best practice guide to end of life care for people with a learning disability](#)
- NHS Improving Quality (2015) - [The route to success in end of life care: Achieving quality for people with learning disabilities](#)
- PCPLD, NHS England (2018) - [Delivering high quality end of life care for people who have a learning disability](#)
- PCPLD Network – [Palliative Care of People with Learning Disabilities FREE membership!](#)
- Help the Hospices (2015) - [Towards Excellence in Hospice Care](#)