

Glancing Back Planning Forward

Facilitating End of Life Conversations
with Persons with an Intellectual
Disability: A Guide for Carers



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Facilitating End of Life Conversations with Persons with an Intellectual Disability: A Guide for Carers

This guide provides a tool for families and carers of people with intellectual disabilities to use as they pause to think about the future. This guide will help carers to reflect on their own thoughts and knowledge about end of life and on what to say when they begin this conversation with the person with an intellectual disability.

Supporting End of Life Care Planning

The focus of end of life care is to promote life, ensure comfort and support the person to have a good death. End of life care planning and openness around death is an essential element ensuring people have a sense of control and autonomy in their final days. Although there has been increased openness to these topics in the general population, engaging people with intellectual disabilities in end of life planning is not common practice. The aim of this document is to support carers to facilitate end of life conversations with people with intellectual disabilities. This will enable the person to feel an element of autonomy and control regarding their own death and will increase the likelihood that the person's wishes are respected as they approach the end of their life.

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Why is this important?

- There will be less confusion and fear when end of life comes after having engaged in the care conversation about death and dying.
- People with intellectual disability have the right to know about death and have opportunities to make informed decisions about their care.
- People with intellectual disability have expressed a desire for concrete, unambiguous information around death and dying.
- Discussions about end of life help the person understand and cope with their illness.
- Involvement in end of life planning allow the person to exercise control and autonomy about how they spend their last days.

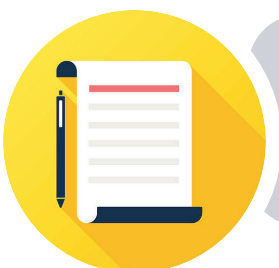


Reflect

Ask yourself the following questions
What are my values about death and dying?
If I was sick would I want to know?

Identifying Opportunities to Start the Conversation

Discussing death and planning for end of life is a sensitive topic and it can be difficult to find the right time to broach this subject. However, it is important to remember that talking to someone with intellectual disability about different aspects of dying and end of life should happen at different points in the person's lifetime, not just in old age. It is important to carefully document each of these conversations and any issues and decisions that may arise. Being able to identify and maximise opportunities to engage in these conversations is key to having effective end of life care conversations.



Take a moment to consider how and when to
have these conversations?
Write and Record

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Engaging in the conversation

- **When family members or friends die:** Openly discussing death of family members, friends and fellow residents may help the person understand that death is a natural part of the life cycle. Introducing end of life issues at this time provides the person with a frame of reference from which to understand the concept of dying.
- **Incidental opportunities:** Incidental opportunities such as when death is brought up on TV shows, or in day to day conversation can be used to introduce and familiarise the person with intellectual disability with the concept of death. An existing understanding of death and dying will make a discussion of the person's own end of life more possible.
- **When the person is dying:** It is never too late to engage in a conversation about death and this is an obvious time and may also be a time when the person will indicate a wish to talk. If conversations have not already occurred, a diagnosis of a terminal or life limiting condition should encourage a conversation as soon as possible. The person then has more time to process the information and make end of life plans before they may lose the capacity to do so.
- **Language:** Use concrete plain language and short simple sentences, not euphemisms such as Jane has passed away (died) or metaphors such as Jane has gone to sleep (dead). People with intellectual disability are more likely to understand what is being said if the language used is simple, concrete and succinct.

Reflect

Ask yourself the following questions:

Am I prepared?

What would I say?

How would I describe this illness to someone with an intellectual disability?

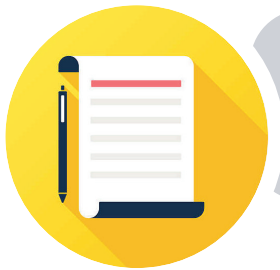


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How do I facilitate and engage persons with ID in end of life care conversations?

In the general population, disclosure about life limiting conditions often involves a one-off consultation with a medical professional. For people with intellectual disability end of life conversations may be an ongoing process which involves a range of different people such as family, friends, health and social care staff from their intellectual disability service, and medical professionals. People with intellectual disability should be given time to process information in small bite sizes, that is one piece at a time, with support from those with whom they are familiar family members and/or support staff or medical practitioners.



Take a moment to consider what you know?
Write and Record

The Four Elements of Care Conversations

1. Build Knowledge

- Break complex information down into smaller pieces of information. Small bite size pieces make it easier for the person to process their situation gradually so they do not become overwhelmed, confused or distressed.
- Give the person the pieces information one by one. This allows time for processing, and gradual building of knowledge.
- Base the information given on person's existing background knowledge of the subject, using examples from their lives, or the lives of their friends and family.
- For some people their understanding of the future may be limited, therefore only provide information about what is happening right now or in the very immediate future. There will be more opportunities to engage in conversations as the person's situation changes.

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2. Understanding

- Assumption of capacity: everyone is assumed to have capacity to understand unless otherwise shown not to have capacity
- Capacity is a flexible concept, the easier and simpler you make a topic, using as much accessible material such as drawings, pictures or photos, the greater the capacity the person will have to understand.
- Where someone is shown not to have capacity, there should be one of the following three representatives appointed as outlined in the Decision Making (Capacity) Act (2015)
 - (1) Co-Decision Maker
 - (2) Decision-Making Representative
 - (3) Enduring Power of Attorney

More information on the Decision Making (Capacity) Act (2015) can be found at

http://www.citizensinformationboard.ie/downloads/relate/relate_2016_04.pdf

or

<http://www.hse.ie/eng/about/Who/qualityandpatientsafety/nau/AssistedDecisionMaking/national-conference-assisted-decision-making.html>

- Remember to use plain language supported with accessible material

3. People

- Collaboration is key, an interdisciplinary team approach to meet the complex needs of the person who is dying is important for everyone involved to know what is happening, why and with whom.
- No one party holds all of the information, therefore, family members staff carers and medical professionals should guide and support each other in this process
- The team ought to adapt to the needs of the person and deliver care wherever the person calls home
- To the extent possible and assuming this is the desire of the person who is dying, significant others should be present and/or be informed of end of life conversations, changes in condition and other important information.

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4. Support

- The person with intellectual disability should be psychologically and emotionally supported particularly by members of the interdisciplinary/ multidisciplinary team.
- Prior adapted material ought to be prepared, available and utilised to support explanations and future plans, keeping in mind the 'small bite size' rule.
- Carers may be affected by the individual's illness. Carers may require supports themselves before they discuss end of life with the person with intellectual disability.
- The interdisciplinary team must help all stakeholders understand and come to terms with the complexity of the forces that influence a good death.

Reflect

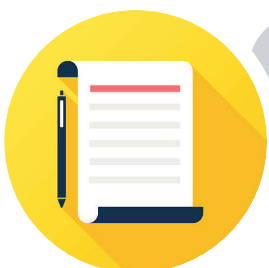
Ask yourself the following questions:

What is known about the prognosis?
How am I framing the care plan or pathway?
Are all the multi-disciplinary team involved?
Have all family or significant others been included?



To tell or not to tell?

In the case of non-disclosure, the person should be supported to understand any immediate changes in their situation.



Take a moment to consider what you know?
Write and Record

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- **Personal preferences:** If the person expresses a wish not to be informed or involved in end of life discussions this should be respected. The right not to know is just as important as the right to know. However, do not assume; confirm and document that the person does not want to know.
- **Inability to balance information:** The person not having a perspective on time may make the conversation distressing. Again in such a situation the knowledge of the carer who knows the person well is paramount. Time sequencing is a difficult concept for people with intellectual disability however with appropriate support and explanation understanding can be reached.
- **Inability to understand:** Not understanding some of the information increases misunderstanding and upset. Problems may be reduced by tailoring the information to the person's ability and using accessible materials.
- **Inability to retain information:** this might be harmful if it leads to repeated re-disclosure of upsetting news, news that is new to them every time. Repeated disclosure will be of upsetting information and will require ongoing support for the person.

Things to keep in mind when considering non-disclosure

- Protecting the person from potentially upsetting news is not a reason to choose non-disclosure.
- Carefully consider if information is being withheld for reasons that are person-centred and based on a strong expectation that the person will not be able to cope/ become unduly distressed at the information.
- Ensure to audit and review all end of life decisions and engagement of people with intellectual disability at regular intervals to ensure continual organizational learning.
- When developing policies ensure people with intellectual disability and their families are involved.
- Ensure training for staff to support these decisions and actions.
- It is always important to help people understand changes to their situation even if end of life care is not going to be discussed.

Reflect

Ask yourself the following questions

What is my attitude toward - to know or not?

Am I aware of the thoughts and wishes of the person I'm supporting?

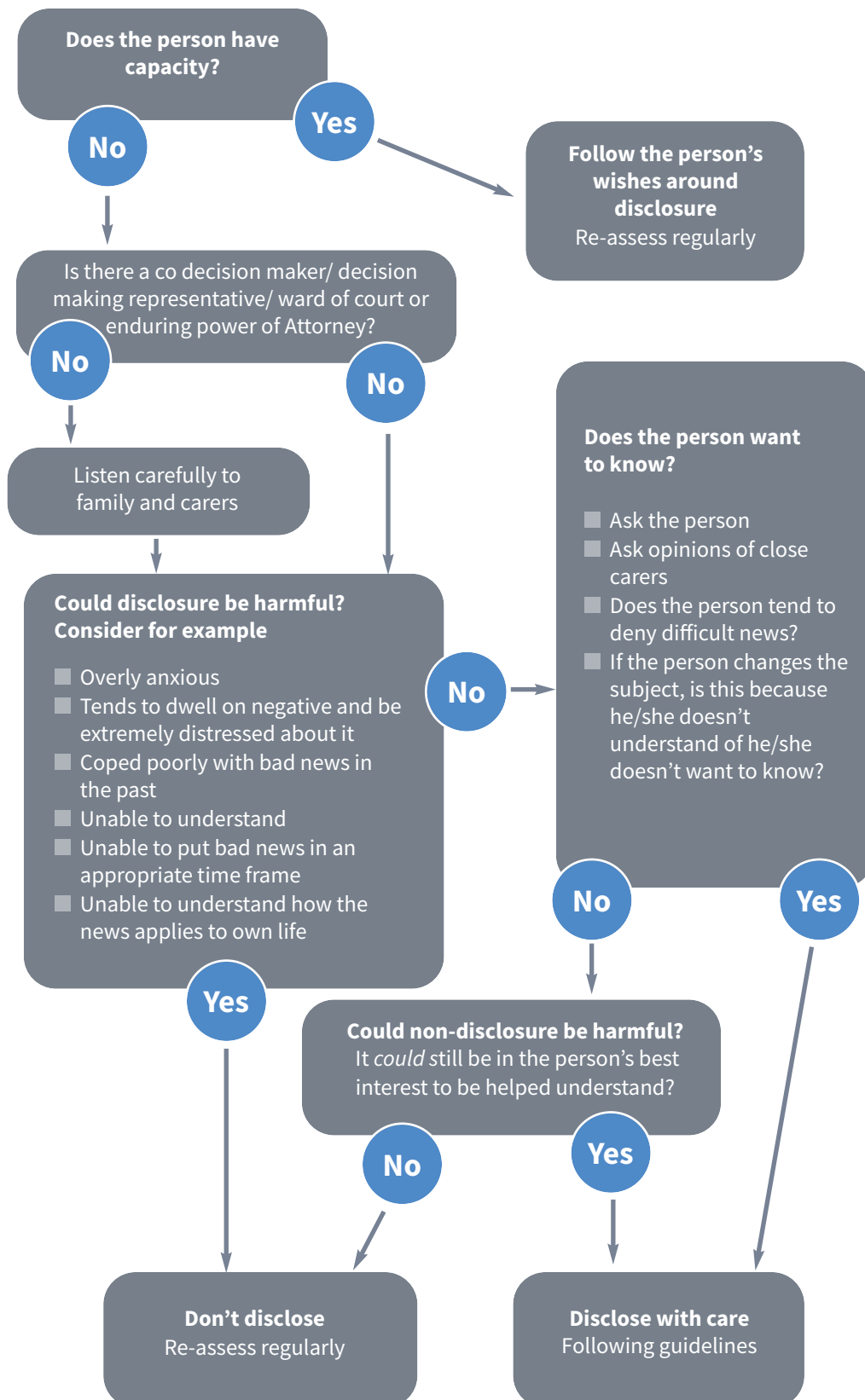
Do I know his/her dislikes?

Do I understand how to build capacity?



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Barriers to engaging in care-conversations

Broaching the topic of end of life is never easy, especially when carers may also be upset by the idea of a loved one approaching their end of life.



Take a moment to consider what you know?
Write and Record

Some commonly identified barriers to involving people with intellectual disability in care conversations include:

- Misguided desire to 'over-protect'
- Preventing distress
- Too difficult for bearer of bad news
- Bearer of bad news lacks knowledge of illness
- Lack of sense of time
- Conflicting views of stakeholders

Overcoming these barriers

- **Misguided desire to 'over-protect':** Frequently adults with intellectual disability are thought unable to comprehend or to lack the ability to engage in such conversations on death and dying. Be aware of how you speak to the person, how you engage and how you want to make them feel. Establish what they know and use every opportunity to investigate and discover their knowledge. Don't assume or underestimate the person with intellectual disability. Provide opportunities and support them to gain knowledge and understanding.
- **"Preventing distress":** remember that the person has the right to know and be involved in the dying process. Withholding information often does not protect against distress. In fact the opposite may occur where the person with intellectual disability is isolated and fearful and is unable to share their concerns and stress. Sensitive disclosure may in fact reduce distress as it helps the person understand the changes in his/her situation and gives them the opportunity to be involved in end of life decisions.

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- **“Too difficult for the bearer of bad news”:** Understandably, carers may be personally affected by the news of the illness of a loved one and so may find it difficult to discuss it with the person with intellectual disability. In this case, they may need support from other professionals or family members.
- **“Bearer of bad news lacks knowledge of illness”:** Unlike the general population, end of life discussions and news about serious illness is often imparted by family or staff carers rather than by a medical professional. Carers may be unfamiliar with the characteristics of the person’s condition. They should ensure that with the support of the medical professional that they are familiar with the symptoms and progression of the specific medical condition so they can support the person with intellectual disability to understand.
- **“Conflicting views of stakeholders”:** Family/medical professionals/staff may have different views around disclosure. It is important that these are openly discussed and that the decision made is in the person’s best interest. These guidelines should be helpful to all stakeholders when making this decision.
- **“Lack of sense of time”:** If person cannot put the information into a time perspective, then it may be too upsetting or confusing for the person to be involved in future end of life plans. Non-disclosure may be an option in this case. However, carers should continually support the person to come to terms with the changes to his/her current situation.

Reflect

Ask yourself the following questions:

- What is my general approach to [name] and how do I talk to [him/her]?
- What are my thoughts on being the bearer of bad news?
- Do I know the views of all stakeholders?
- Do I understand the abilities of the person with ID to understand?
- Who can help me if I find myself unable to understand the abilities of the person or engage in the conversation?



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Remember

Engaging in care conversations is all about supporting the person toward a comfortable and good death, keeping their interests at heart and engaging them as much as you feel they want to, they will decide when they are ready to engage.

Evaluate and Review

Having had the conversation it is always good to review and consider that depending on the situation this may be only the beginning, it does not stop; you must continue to review and revise sensitively and appropriately.



Review

Ask yourself the following questions:

How do you think this conversation is going?

What was easy or difficult about the conversation?

Did anything unusual occur (record and document) for example organ donation?

Do you think the preferences of the person differs from your assumptions?

Get the thoughts and opinions of other people at the meeting, include the person with intellectual disability.

Consider having a colleague sitting in on occasional meetings as a mentor that can provide you with feedback.



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