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Supporting people with an intellectual disability at end of life: Making the care conversation meaningful

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Welcome

Very great change starts from very small conversations, held among people who care

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Life expectancy



JARID

Journal of Applied Research in Intellectual Disabilities

Journal of Applied Research in Intellectual Disabilities 2015, 28, 406–413

bild

Published for the British Institute of Learning Disabilities

Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012

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Palliative care and people with intellectual disability



Who wouldn't want to die a death that is free of pain and other symptoms, or spend time with their family or friends, or be listened to and involved when choices and decisions are made about their care and treatment?

(Irene Tuffrey- Wijne)

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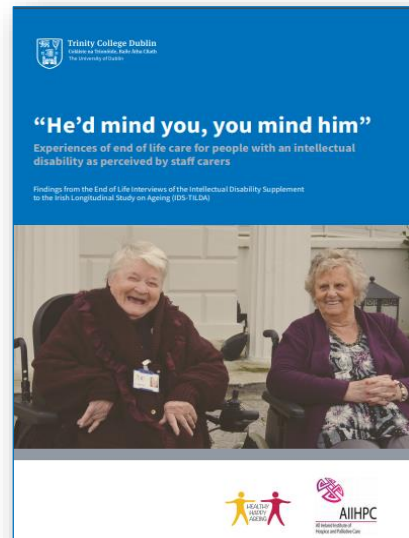
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Background to the toolkit development



- Not Joining the dots
- Living the life desired in one's last days
- Dealing with death and beyond

(McCarron et al 2017)



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Why it is important



- Avoid confusion and fear at end of life
- Uphold people's rights
- Provide information to people with intellectual disability in an unambiguous manner
- Support people with intellectual disability to understand and be involved in their care

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Glancing back planning forward: the toolkit



Glancing Back Planning Forward

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



Glancing Back Planning Forward

How to Use the
Accessible Planning Tool



Accessible Planning Tool

Glancing Back
Planning Forward



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Carer's guide

Glancing Back Planning Forward

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



- Foundation to preparing yourself as the carer
- Supports identifying opportunities to start the conversation
- Provides you with hints and tips on opportunities, facilitating and engaging in the care conversation
- Prompts you to reflect on your experience and take a moment to assimilate your own learning
- Four elements of the care conversation – boost your understanding
- Addresses the 'to tell or not' dilemmas

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Boost your own knowledge



Reflect

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



Take a moment to consider what you know?

Write and Record

The four elements of a care conversation

Build Knowledge

Establish the individuals
 understanding & capacity

Team approach, no one persons
 responsibility

Establish Support – for the person,
 carer and remember small bite size
 pieces of information

A GUIDE FOR CARERS

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    graph TD
      Q1{Does the person have capacity?} -- No --> B1["Best interest" decision  
Listen carefully to family and carers]
      Q1 -- Yes --> B2[Follow the person's wishes around disclosure  
Re-assess regularly]
      B1 --> Q2{Could disclosure be harmful?  
Consider, for example*:  
• Overly anxious  
• Tends to dwell on the negative and be extremely distressed by it  
• Copied poorly with bad news in the past  
• Unable to understand  
• Unable to put bad news in an appropriate time frame  
• Unable to understand how the news applies to own life}
      Q2 -- No --> Q3{Does the person want to know?  
• Ask the person  
• Ask opinions of close carers  
• Does the person tend to deny difficult news?  
• If the person changes the subject, is this because s/he doesn't understand, or because s/he doesn't want to know?}
      Q2 -- Yes --> B3[Don't disclose  
Re-assess regularly]
      Q3 -- No --> Q4{Could non-disclosure be harmful?  
It could still be in the person's best interest to be helped to understand}
      Q3 -- Yes --> B4[Disclose with care  
Following guidelines**]
      Q4 -- No --> B3
      Q4 -- Yes --> B4
  
```

*NB These do not necessarily mean that disclosure is harmful, but careful consideration is needed
**Tuffrey-Wijne 2012, 2013

Tuffrey-Wijne et al 2013,2016

A GUIDE FOR CARERS

Capacity – adhere to their wishes

Best interest – consider their advanced care plan who do they want to speak/decision make on their behalf.

Consider what you have to say to the person so could disclosure be harmful – careful consideration needed

If not ask does the person want to know

If not could non-disclosure be harmful?

If so don't disclose at the moment re-assess regularly.

When do you have the conversation?

Transition points

- Time of Diagnosis
- The surprise question – the person starts
- Change in setting or frequent hospitalisations
- Care plan review

Healthcare events

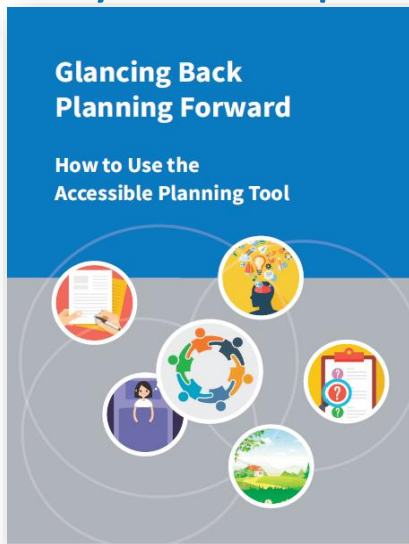
- Deterioration or decline
- need for further treatments
- new complex health conditions for example epilepsy
- Discussion about CPR
- Decreasing response to antibiotics
- Difficulty with nutrition and hydration



“Discussions about end of life issues should be conceptualised as a process of ongoing conversation over time, rather than a single event or discussion”

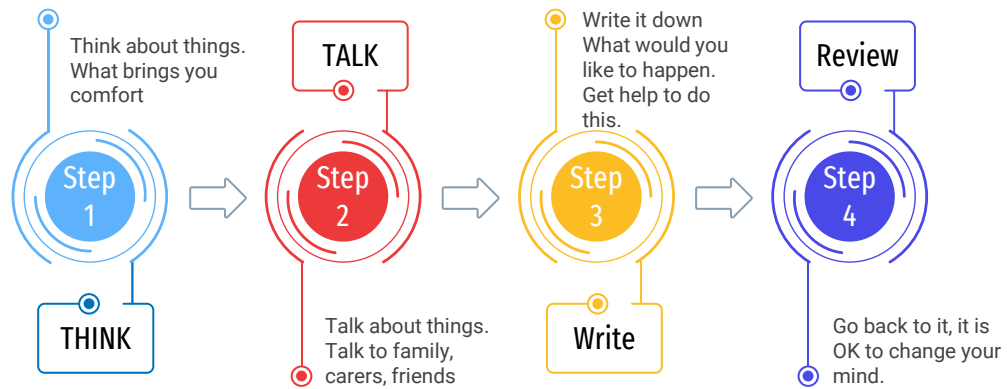
(Clayton et al 2007)

Easy read explanatory



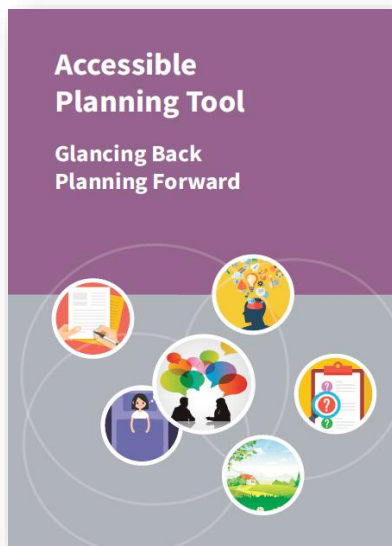
- Support the conversation
- Support understanding
- Provides a process on how to complete the end of life planning tool

Four steps for a living document



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The tool



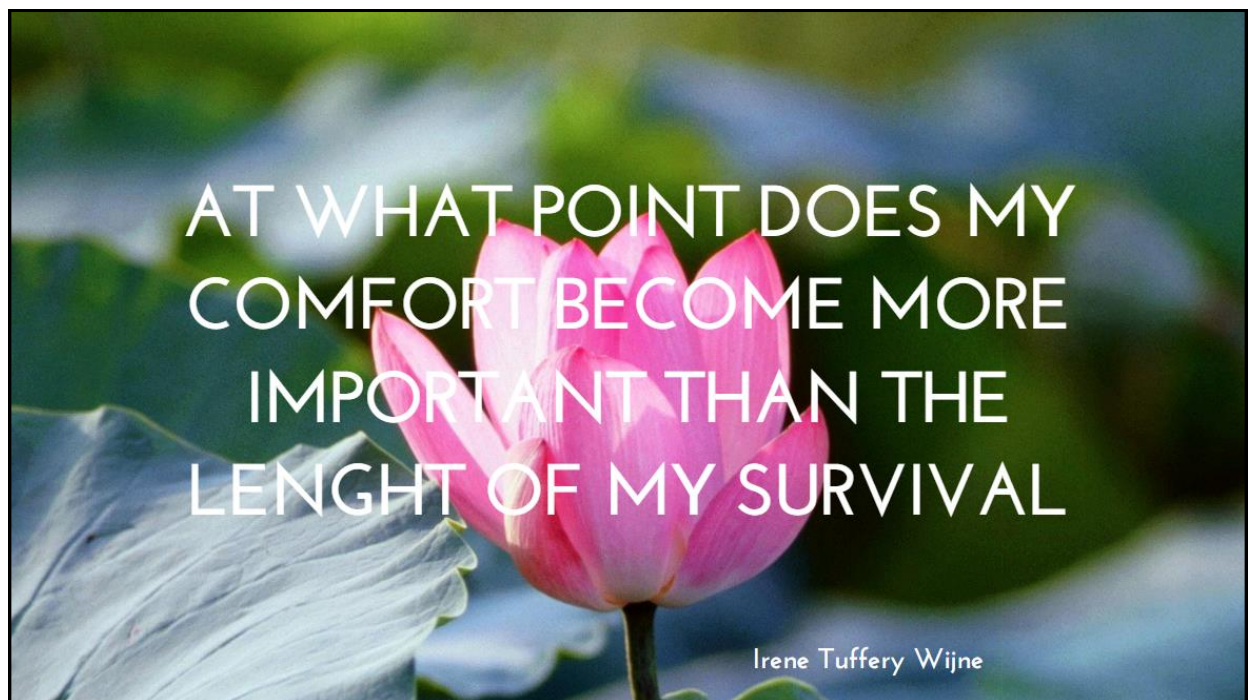
- Document personal details
- Identify what you want
- Identify what you want to do
- And what you would NOT want to do
- Identify your comforts
- Plan to live
- Plan to die

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Engage in Informal conversations

Use **AFRIM** to guide conversations

- **A**cknowledge the persons concerns or questions?
- **F**ind out what the person knows about the condition
- **I**mmEDIATE concern addressed by providing adequate information within the scope of your work
- **R**espond to subsequent questions by providing accurate information within the scope of your work
- **M**eeting suggested to discuss their concerns with a senior clinician



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Resources

- Prof Irene Tuffrey-Wijne - https://youtu.be/2Ge2_Jbvm48
- Prof. Sheila Hollins - <http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>



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Thank you

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