



Making the Final Decisions (Easy Read Version):

A report about advance care planning

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What is Advance Care Planning?

Advance Care Planning means planning for the end of your life. Anyone can do an Advance Care Plan.



It helps you make choices. It helps other people know what you want if you get sick, or if you are dying. For example,

- Things you want to do before you die
- How you want to be cared for – any treatments you do or don't want
- Where you want to die – for example, at home, hospital, hospice
- Legal and financial decisions – such as making a Will, and deciding who will make decisions for you if you can't do it yourself
- What you want after you die – caring for your body, celebrating your life, funeral plans

Our Research Project



Not many people with intellectual disabilities have done an Advance Care Plan.

There isn't much information about doing Advance Care Plans with people who have intellectual disabilities.

We wanted to find out what makes advance care planning successful.



We did a project about it. It was funded by the Frozen Funds Charitable Trust. IDEA Services looked after it. The Donald Beasley Institute helped with research advice.

We talked to four people who were sick and dying. We talked to their families/whanau. We talked to their support teams.

They all told us what they thought.



Things that made Advance Care Planning good

Everyone said that these things helped make their plan a success:



- Having goals for things they still wanted to do. They didn't want to focus on dying.



- Support to make their own choices.
- Going at their own pace. Some people needed to take their time.
- Having support people who were open and honest. They wanted to know the truth about their health and their choices



- Having information they could understand. Sometimes they needed information with pictures. Sometimes they needed a more simple explanation.

Support People

Support people helped the planning to go well. Some of the good things they did were:



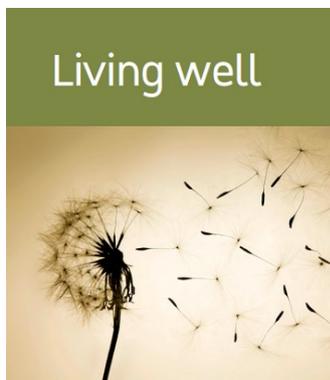
- Being comfortable talking about dying.

- Planning how to support the person if they got upset.

- Helping people to start planning as soon as possible.



- Working as a team with the person, family, staff, and doctors.



Thinking and planning for the end of your life

- Using the Living Well booklet to help them. It is a form to use for advance care planning.



Things people didn't like

The main thing that people didn't like was being left out of discussions.

Sometimes people weren't included in all the discussions.

This was usually if:

- Staff/family were worried about upsetting the person.
- It was something that staff/family didn't know a lot about.

This included things like:

- Choosing if they do/don't want CPR in an emergency.
- Special medical choices.
- Writing a will.





Rights

There were 11 other people who could not be part of the research.

They were all sick and dying.
They did not know they were dying.

All people have the right to know if they are dying.

This was a big worry for the researchers. We hope it will change in the future.



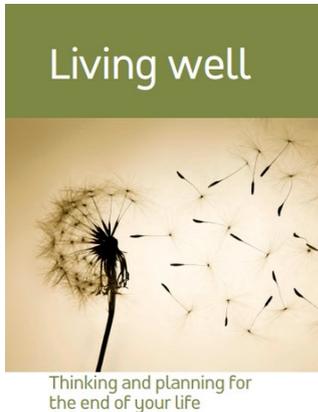
Recommendations

We think some things could make advance care planning even better. This includes:

- Disability and health services working together more. This would help all of the tough topics to be talked about. For example, medical choices and CPR.
- Doing advance care planning when people are well, not just if they are dying. It is easier to do an advance care plan when your health is good.
- Telling people if they are dying.
- Having policies and systems that encourage ALL people to be included in advance care planning.

If you want to make an Advance Care Plan

If you want to make your own Advance Care Plan you can:



- Get a copy of Living Well
<http://www.helensandersonassociates.co.uk/papers/living-well-planning-end-life/>

OR



- My Advance Care Plan
<http://www.advancecareplanning.org.nz/resources/>
- Talk to someone who knows about advance care planning. It could be a Health Advisor, your doctor, or family or friend.

You can get a full version of this report from
www.donaldbeasley.org.nz It will be in the Publications Section. Look under “Frozen Funds.”