

# MAKING THE FINAL DECISIONS (FULL REPORT):

Factors contributing to a positive experience of  
advance care planning for people with intellectual  
disabilities and life limiting conditions

Nic McKenzie, Sharon Brandford, Jenny Conder, Brigit Mirfin-Veitch  
February 2016

## **Acknowledgements**

A very heart-felt thanks is given to the research participants, your support teams and families and whanau, for taking part in this research and sharing the intimate details of your lives and your end of life planning with us. You have been confident, brave, articulate, well-humoured, and clear about what is important to you. What we have learnt from your experience will help others in the future. Your generosity of spirit will not be forgotten.

Sincere thanks are extended to the Frozen Funds Charitable Trust for funding this research, and IDEA Services for sponsoring and overseeing the project. Without such a timely and generous grant, and openness to the challenges and changing parameters of the project, it would not have been possible for this research to take place.

Likewise, the project's Advisory Group members have contributed an enormous amount – skill, knowledge, critique, guidance, and encouragement. Many thanks to Dianne Pelvin, Nathan Solomon, Dr Jenny Conder, Dr Kate Grundy, Trisha Ventom, and Jane Goodwin for this very valued contribution.

*"Not everything that is faced can be changed, but nothing can be changed until it is faced."*

**- James Baldwin**

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# **Making the Final Decisions: A report on the factors contributing to a positive experience of advance care planning for people with intellectual disabilities and life limiting conditions**

## **1.0 Background**

This report shares the outcomes of a formal research project aimed at identifying what contributes to a positive experience of advance care planning from the perspectives of people who have intellectual disabilities and life limiting conditions.

The research was funded by the Frozen Funds Charitable Trust, and overseen by IDEA Services.

### **1.1 Advance care planning: What is it?**

There are various definitions of, and approaches to, advance care planning. Essentially it is understood that advance care planning is a process of planning for the end of a person's life, which captures and records what is important to them. Advance care planning usually includes, but is not limited to, the following discussions and decisions (Dying Matters, 2015, <http://dyingmatters.org/page/planning-dying-well>):

- **Where I want to die** – for example, at home, in a hospice, in a hospital, in a care home, or somewhere else
- **Things I want to do** – for example, “bucket list” activities and ideas
- **How I want to be cared for** - for example, medical and treatment preferences, advance directives (such as Do Not Resuscitate orders), preferred carers, spiritual support
- **Legal and financial matters** - for example, wills, costs, funeral plans, care of dependents, power of attorney
- **What I want to happen after I die** – for example, organ donation, cultural preferences about how my body is looked after, the detail of my funeral

Primarily, advance care planning helps people understand what the future might hold and say what treatment they would and would not want. It helps people, their families and their healthcare teams plan for the future and for their end of life care. Secondly, it is intended to make it easier for families and healthcare providers to know what the person would want if they become unable to speak for themselves (NZ Advance Care Planning Co-operative, 2015)

### **1.2 Rationale for the Project**

The recent global focus on supporting the rapidly growing ageing population of people with intellectual disability has led to the need to consider how and where end of life care is provided. Quality end of life care includes advance care planning as a key component.

It is well understood that advance care planning within the general population leads to improved end of life care and patient and family satisfaction, as well as reducing stress, anxiety, and depression in surviving relatives. In a study carried out by Detering, Hancock

and Reade (2010), end of life wishes were likely to be known and followed for 86% of those who had developed an Advance Care Plan, compared with only 30% of those who had not.

*“Talking about death doesn't bring death closer. It's about planning for life. Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family.”*

- Dying Matters, <http://dyingmatters.org/overview/why-talk-about-it>

There is plethora of research regarding how to carry out successful advance care planning within the general population (Bernacki and Block, 2015). However, there is very little evidence as to best practice in the support of people with intellectual disability, a population for whom end of life care has added complexities. Disadvantage and circumstance (such as having co-morbid conditions, communication or comprehension difficulties,) contribute to this (Tuffrey-Wijne et al, 2015) and mean that people with intellectual disability are particularly vulnerable to having their wishes and needs de-valued, misunderstood, or dismissed at the ends of their lives (Bigby, 2004).

Some movement has been made toward exploring and supporting advance care planning for people with intellectual disability, including:

- Research in two community residences, which provided useful insights into the perspective and needs of staff and families (Bellamy, Gott, Prebble, Boyd, Neill, 2012) but did not include the perspectives of people with intellectual disability
- Some advance care planning resources have become available, such as “Living Well” (Helen Sanderson Associates, 2010) and “Our Voice” (NZ Advance care planning Co-operative, 2012), but these are yet to be tested either a) in the NZ context or b) outside of the non-disabled population.

In addition, there is a strong philosophical argument for involving people with intellectual disability in planning their advance care (Bigby, 2004). Article 12 of the United Nations Convention on the Rights of Disabled People, to which New Zealand is a signatory, outlines the rights of people with disability to be involved in all aspects of the decision-making that affects their lives. Advance care planning is essentially a decision-making process, and when seen within this context, the need to improve and offer advance care planning more broadly is strengthened further.

Despite the will to make headway in this area of support, there has been little in the way of concrete detail or tested approaches to how to do this. The need for evidence-based research in this area has never been greater.

It is for this reason that the research described in this report began, with the intention of being to identify which ancillary tools, resources, processes and practices would best support people to be actively engaged in decision-making about this most critical part of their lives.

### **1.3 Project Aims**

The study aimed to explore the experience of people with intellectual disability who also have life limiting conditions (described through this report as “primary participants”). It intended to identify, from the primary participants’ perspective, the factors that strengthen or inhibit advance care planning. In doing so, it was hoped that the sector would become better prepared to support people with intellectual disability, to ensure that they are informed, less afraid and uncertain, and are in greater control of how they are supported toward the end of their lives.

## **2.0 Research Method**

This research was an in-depth qualitative study, exploring the experience of people with intellectual disability and life limiting conditions who were also involved in advance care planning.

Ethics approval was granted for the research via Northern B Health and Disability Ethics Committee, on 3/5/13 (reference 13/NTB/13).

### **2.1 Recruitment Processes**

Initial plans were to recruit up to ten people with intellectual disability to take part in the project. All were to be clients of IDEA Services, and based in Auckland, Christchurch and Dunedin, where utilisation of advance care planning was predicted to be highest.

To be eligible to take part in the research, primary participants needed to meet set criteria. This criteria was a requirement of the project's ethical approval, and though stringent, was necessary to ensure that a) primary participants were not placed in un-safe situations (for example, where their prognosis could be disclosed to them unwittingly during the research process), and b) that their contributions would be seen having validity from a formal research perspective.

Eligibility criteria for primary participants included:

- Having a formally diagnosed life limiting condition
- Being aware of their condition and the fact that it was life limiting
- Are participating in/have completed a process of Advance care planning because of their life limiting condition
- Able to communicate sufficiently well to contribute in an interview situation

Potential primary participants were initially identified by their managers or in-service health professionals. The managers/health professionals checked that the primary participants met specific eligibility criteria, outlined below, and then initiated a process of sharing information about the project with the person and having them complete an "expression of interest" form.

Expression of Interest forms were sent to the researcher, who then instigated a formal consent process with potential participants. Family/whanau members and disability service provider staff (described as "support team members" throughout this report) were then invited to take part in the research when consent to do so was given by the primary participants.

Recruitment difficulties meant that the invitation to enlist primary participants was extended to include all branches of IDEA Services, and then later to a range of other large disability service provider organisations within New Zealand.

## **2.2 Data Collection**

Data was collected through:

- Audio recording of an initial structured interview with each individual, their families/caregivers, and staff
- Audio recording of a follow-up interview with each individual, their families/caregivers and staff. Follow up interviews took place between 4-6 months following the initial interviews. This enabled the researcher to identify how the advance care planning process progressed over time. Review of case notes and associated documents (with permission from participants), to provide additional information on the implementation, sharing, and documentation of the advance care plan.

A topic guide was used to structure the interviews. Interviews ranged in length from 20 minutes to 90 minutes.

Audio data files were transferred to a password protected computer and were transcribed verbatim, and saved to the same computer. For the purpose of publication, data (names, dates) were anonymised but care was taken to ensure that alteration of this data did not distort meaning.

## **2.3 Analysis**

An inductive approach (Braun and Clarke, 2006) was taken to the analysis of the transcribed interviews and file information. Codes were developed (see Table 1 below) in response to the data gathered, for ideas/concepts that either occurred more than once, had an intensity of strong emphasis, had ready agreement or disagreement between individuals, or where mistakes were indicated, and these codes were applied to all data fragments.

All data was analysed with the intention of identifying:

- Factors that contributed to a positive lived experience of advance care planning – such as practices, tools, resources
- Factors that inhibited or were detrimental to a positive experience of advance care planning



**Table 1** Codes used in Analysis of the Research Data

Theme	Code	Sub Codes
<b>Deciding when to start</b>	Starting as soon as possible	
	Starting when I am ready	- Participant - Family - Staff
<b>Support Team Member Facilitation Skills</b>	Comfort talking about death and dying	
	Being open and honest	
	Introducing ACP gently	
	Supporting Emotional Wellbeing	
	Ongoing conversations	
	Working as a team (collaborating)	
	Sharing the plan	
<b>Supporting Participant's Decision Making</b>	Having clear information	- Treatment options - Legal and Financial matters - Support/service information
	Adapting the process to suit me	- Going at my pace - Drawing on my past experiences - Making sure I understand
	Making my own choices	
<b>Content</b>	Planning my life (not only my death)	
	Covering typical content areas	- Where I want to die - Treatment options - After I have died (my body) - My funeral - Advance directives - Legal and financial matters
	Having a resource to guide us	

## 2.4 Research Participants

Details related to the participants are outlined in Table 2 below. The project's ethical approval requires that participants are not identified, and that their privacy is protected. Additionally, all of the participants have generously contributed and shared intimate detail of their lives and/or their work practice. In honouring both this contribution, and the ethical requirements of the project, pseudonyms have been used throughout the reporting of results. To further protect the confidentiality of all participants some identifiable details have also been altered.

Throughout the rest of the report the following terminology will be used to refer to the various groups of participants:

- Participants with intellectual disabilities are referred to as “primary participants”
- Family and whanau members of the primary participants are referred to as “family/whanau”
- Staff (such as Managers, Health Advisors and Support Workers) employed by disability service providers are referred to as “support team members”

**Table 2** Participant Overview

Primary Participants	Living situation	Family/Whanau Participants	Disability Service Support Team Participants
Frankie	Residential service	0	7 - Residential Manager, Support Workers
Tony	Supported Independent Living	2 – Sibling and Other	3 – residential manager, residential support worker, health advisor
Lee	Semi-independent flat attached to a residential service	1 – Parent	3 – Manager/Health Advisor, Residential and Vocational Team Leaders
Alex	Residential service	1 - Parent	2 – Health Advisor, Residential Team Leader, Residential Support Worker

A total of four primary participants were recruited to take part in the research – Frankie, Tony, Lee and Alex:

- Age range: 28-68 years old
- Ethnicity: 1 was Maori, and 3 were European
- Living situation: 2 lived in residential services, 1 in a semi-independent situation attached to a residential service, and 1 in a supported independent living situation
- Diagnosis: 3 of the primary participants had chronic life-limiting conditions (and had experienced significant declines in their health), and 1 had an incurable cancer
- 2 primary participants died during the course of the study. One passed away following the first interview. This person's support team took part in a second interview, following their death. All other primary participants and their families and support teams were interviewed twice.

In addition to the four primary participants, the researcher was notified by service providers of another fourteen potential participants. These individuals were people who, after further discussion, were deemed not to meet the full criteria for the study and were therefore ineligible to take part.

Of these fourteen:

- One met all criteria but declined to take part. It was reported that he was not interested in taking part
- Two others met all criteria but died unexpectedly quickly, with the consent process underway but not completed
- Eleven met all but one criteria – crucially, none of the eleven were aware that they were dying.

Reasons given for the lack of disclosure of prognosis to this group fell into two main areas – 1) concern that the person may not understand what was happening to them, or 2) concern that the person may not cope with knowing that they were dying. For some it was the wishes of their family that influenced this, and for others it was a disability service decision.

## 3.0 Results

Analysis of the data set resulted in the emergence of clear themes becoming apparent. These themes indicate that some specific factors contributed to a positive (and sometimes a negative) experience of advance care planning for the primary participants. Each of these themes is discussed in detail below:

- Deciding When to Start
- Facilitation Skills
- Decision Making
- Content

### 3.1 Deciding When to Start

Deciding when to start the advance care planning process was a key theme for support team members and family/whanau, but there were divergent views related to this. Some support team members saw that it was very important to start the advance care planning process quickly following a diagnosis, while others felt that all involved needed to be “ready” to start.

For one of the primary participants, it took almost three years of gentle encouragement from the support team before the family were ready to start. At that point the family engaged in the planning and were very pleased to be involved. They later questioned their decision to “wait”, and felt that starting earlier could have been possible. Their advice to others would be to start as soon as possible.

*“Yes, as hard as it might be, get the discussion going, get something simple put in place.”* [Family/whanau member]

The support teams of the two participants who started advance care planning soon after diagnosis expressed confidence in their decision to start discussions early.

Prognostic, treatment, and medical information was provided by the primary participants’ health specialists, but in all four cases it was the disability service who led and carried out the key activities of advance care planning. This included translating/sharing of information, discussion of options, supporting the person’s decision making, recording choices, seeking additional information where required. For the two primary participants who had chronic conditions, the advance care planning process was also initiated by the disability service, and otherwise would not have started. This differs from the general population, where it is usually doctors or palliative care staff who encourage/initiate/lead the advance care planning process for people with life limiting conditions.

*“Then all of a sudden, after all that time, they were ready”* [Support team member]

*“We had a big rush at the beginning, it was about gathering information, what are we going to do, how will we cope, getting family on board.....and now we have time it’s that halting stuff now, like um, to start asking those hard questions.”* [Support team member]

*“For me, as a manager, of the home where [primary participant] lives, it’s part of our policies around having that whole advanced care plan. I mean, for me, it starts giving us some direction about where we go and how we gather some of that information. And again like [support team member] says, when somebody is given the, the you*

*know, the, information about having a life-limiting disease or terminal illness, we do need to stop and take note of where we are, where we're going to go, and include people, and this plan sort of, it's sort of just started like that."* [Support team member]

## 3.2 Facilitation Skills

There was a high degree of agreement across support team members, and families/whanau, about what was required of them to ensure that primary participants had a positive experience of advance care planning, including:

- Comfort in talking about death and dying
- Being open and honest
- Introducing advance care planning gently
- Supporting emotional wellbeing
- Ongoing conversations
- Working as a team (collaborating)
- Sharing the plan

### 3.2.1 Comfort talking about death and dying

Of the support team members who led/facilitated the advance care planning process, three were registered nurses who work in a Health Advisor role for their organisation, and one was a residential service manager who was closely supported by the organisation's Health Advisor. Each of these support team members had previous experience in supporting people who had died, and one had a specific palliative care background. All agreed that their past experiences and knowledge gave them a level of confidence in talking about death and dying that many of their colleagues possibly did not have. All felt that they wouldn't have been able to take on the planning role without their training and/or experience.

### 3.2.2 Being Open and Honest

All participants stated that openness and honesty were very important. Being open and honest was helpful in allaying fears, and meant that primary participants could come to terms with changes in their health, or situation, and make decisions based on what was right for them.

*"Just be honest, ask questions and don't worry. Don't try to dodge things."* [Primary participant]

*"She wants them to be straight with her, because otherwise she keeps thinking about things all the time."* [Family/whanau member]

*"I didn't know that she had thoughts like that, had even gone there [speaking about cremation vs burial], so, you don't know until you go and ask."* [Support team member]

*"And although it's hard knowing that a person might be at the stage it's also good not to put your head in the sand."* [Support team member]

There was a correlation between support teams/ family/whanau comfort in discussing end of life issues, and the primary participants' level of participation in their advance care plans.

For example, Frankie was involved mainly in hypothetical, rather than specific, discussions about advance care planning – this meant that Frankie was given opportunities to share his opinion on a range of topics related to his Advance Care Plan (such as funeral preferences), but without knowing that the information would be used to plan his own advance care. It is unknown whether having the full information would have altered his decisions. In Lee’s case, a lack of clarity about who could make advance directives, and in what situations, lead to discussions about advance directives being had in her absence.

*“We were all around the table so we just... I actually did not tell him that you know Frankie, you’re dying, but I just casually, generally asked like you know, everybody’s going to you know...[to die]... We have no other choice but everybody will go there so just in case this will happen to you, what do you want to do? Where do you want to keep all your stuff, and you know? So we discussed with him and he actually articulated...”* [Support team member]

Support teams and families/whanau reported it was easier to be open and honest on topics they were familiar with, more certain of, or had prior experience of. A lack of knowledge, or experience reduced their comfort level and made it harder to be open and honest. This appears to have been a significant factor in situations where participants did not receive open or honest information. This is discussed further in section 3.3.

*“If we found a way of doing that and making it informed consent, then that would be her choice.”* [Support team member]

### 3.2.3 Introducing advance care planning gently

Alongside openness and honesty, support teams were in agreement that their approach needed to be sensitive, and start gently – this was a really important factor in ensuring that the primary participants were comfortable with the advance care planning process, and could engage in it in a meaningful way. They found it useful to start by talking about the immediate situation, exploring what a good day and bad day looked like, and planning schedules and routines to fit with each of the primary participant’s health needs.

There were strong links between this and other themes identified by primary participants, which are inter-twined, such as:

- Going at my pace
- Supporting emotional wellbeing
- Having ongoing conversations

### 3.2.4 Supporting my emotional wellbeing

Each of the primary participants reacted differently to knowing that they were dying. Variation came as a result of personality, level of understanding, and access to people to debrief with following discussions about their advance care.

*“I certainly didn’t figure on the impact it would have on people once we started discussing this.”* [Support team member]

In two instances, support team members planned in advance how the primary participant would be supported emotionally if they needed it. This appeared to allay the primary participant’s concerns, and minimised difficulties. For example, Tony was provided with a telephone next to the bed, with pre-programmed numbers for key people, so that they could be called any time that they were needed. Tony was also supported with extra visits from staff and friends, who would drop by to “chat”.

Some support teams learnt over time that they needed to prepare not only for the advance care discussions but also for follow up. They found ways to make sure that the primary participant was well supported, and they also identified that the passage of time helped the primary participants to come to terms with the conversations and find peace with their decisions.

*“He doesn’t seem to get distressed about it now. I think he’s getting used to the idea.”*  
[Support team member]

*“But read your people, because um while Lee looks ok on the outside, once it sinks in, it can fall apart and you’ve got to be prepared for that. I wasn’t. I wasn’t. Because Lee is so vibrant so out there, , I came away thinking it was so good, yes, we’ll come back to it in a couple of weeks....but a few days later, bingo, ouch....that was a learning curve....”* [Support team member]

It is also important to note that the advance care discussions, though valued, also took an emotional toll on families/whanau, and on the staff involved, particularly those who were responsible for leading/facilitating the process. The support needs of this group of staff appears to be under-estimated, and under-planned too. They are often vulnerable, and may feel isolated, being the only person in their local organisation base with experience in advance care planning.

*“It has been difficult. It’s a very emotional thing to do. It’s horrendously emotional. You have to make sure that you’re in the right frame too. I know, leading up, that I’ve got that to do, and so I always try and get ready at home and prepare myself for that hard part of the day.”* [Support team member]

### 3.2.5 Ongoing Conversations

Analysis showed that the support team members who led/facilitated the advance care planning process approached it as an ongoing process; a conversation to be had over a period of time, with time to ponder and consider options, and to be revisited as required.

### 3.2.6 Working as a Team (Collaborating)

For the individuals who participated in this research, their advance care planning process was led and/or facilitated by a support team member from their disability service; either a health advisor or manager with experience in supporting people with life limiting conditions. Collaborating with others helped to guide the disability service staff in terms of the plan’s content, to fill in knowledge gaps, to suggest resources, and to help with planning what was predicted to be needed in the future.

Collaboration usually occurred with:

- Other disability service team members
- Medical specialists
- The person’s GP
- Family and whanau
- Palliative care service staff (for those who had involvement from the palliative care service).

One particular support team discussed the range of people and services that they collaborated with:

*“I think we just need to realise because we’re not the health professionals, so we really [need to] get some knowledge and ideas from health advice, or the doctor and the people involved, like the hospice and the [specialist] clinic.”*

*“And um, I think it’s quite good sometimes having different ideas, and I think that when it gets to that real time of different drugs and treatments and things like that then I would expect them to take the lead, and I can do the bit of giving information ...connecting the dots for him.”*

*“For me, the one thing that’s been really good for him, is to have lots of lots of avenues to go and have those conversations with.”*

*“He’s Maori, so again we really wanting to support the whole whanau system.”*

*“We’re hoping that there’s enough grey matter between us that we can cope.”*

### 3.2.7 Sharing the Plan

In addition to having the actual planning document, in all instances details from it either had been, or were planned to be, transferred and written into the main support documentation relevant to the primary participant (i.e. their personal file or health documentation). This was intended as an additional way to ensure that the information was accessible, easy to find, and able to be acted on as required.

Sharing the plan was reported as an important action to ensure that it would be acted upon. In all instances the plan was shared (or about to be shared) across the support team, and with family/whanau. Only in some instances was the plan also shared with the person’s medical specialists and GP. Given that some of the advance care plans did not contain information on treatment preferences or advance directives, it is possible that this influenced the limited sharing with medical teams. It is also possible that, having the disability service lead/facilitate the development of the plan influenced this as well - the outcome may have differed if the plan was led/facilitated by a medical or palliative care professional.

## **3.3 Supporting the Primary Participants’ Decision Making**

Analysis identified some key strategies that positively influenced decision making practices within the advance care planning process. These included:

- Having clear information
- Adapting the process to suit me
- Making my own choices

### 3.3.1 Having Clear Information to Make Decisions

The primary participants and their support teams and families/whanau commented on the importance of having good clear information to help them make the many complex decisions that were required throughout the advance care planning process.

Support team members and families/whanau agreed that they needed clear information from others so that they could then translate and share it with the primary participants.

The primary participants all said that they wanted their support team and family/whanau to “talk straight” with them. Support teams indicated that being able to do this was reliant on them first being well informed and un-biased.

Overall, analysis showed that clear information was required from:

- Medical professionals, particularly regarding prognosis, progression of the condition, and treatment options
- The disability service provider and funder re possible future living options, and at what point the person may not have been able to stay living at home
- Legal information regarding the rules and application of welfare guardianship, power of attorney, and advance directives.

The clarity and depth, as well as accuracy, of this information impacted significantly on the planning process. When good information was available those leading/facilitating the process felt able to discuss complex topics and pass on information to the primary participants.

*“The priorities are around making sure the person is comfortable, that they’ve got as much information as they need, and we’re asking the dumb questions for them from the medial professionals, that they can make some choices about their treatment.”*  
[Support team member]

At times support team members and families/whanau described receiving conflicting information. For example, one support team received conflicting information from the medical specialist and their service’s advisors regarding who is allowed to make advance directive decisions. They found the conflicting information hugely frustrating, as well as creating undue stress, and making it difficult to then share information with the primary participant.

*“Mmm, and again with the doctor, they were saying “well, you’ve got power of attorney or welfare guardianship, so you can do this [prepare an advance directive to not resuscitate]. So, are they putting us wrong?”* [Support team member]

### 3.3.2 Adapting the Process to Suit Me

Those leading/facilitating the advance care planning process described the ways that they adapted the process, as they would normally do for other forms of person-centred planning. This occurred for each of the primary participants and was a key factor in them being able to make sense of the information they were presented with, and assisted them in making their own choices. The main areas where adaptations were made are outlined below:

- Going at my pace
  - Drawing on my past experiences
  - Making sure I understand
- a) Going at my Pace: progressing with advance care planning at a pace that suited the participant was important in ensuring a positive experience. For some the planning was able to progress relatively quickly, with most of the content discussed and agreed on over a couple of sessions (with breaks in between). For others, it progressed much more slowly, with long breaks between topics of discussion, while the primary participants digested information and considered their options.



Those leading/facilitating the process followed the primary participants' lead regarding how quickly they progressed – they checked in with them, and made sure they were ok about continuing. They looked for signs (such as being unsettled, acting out with behaviour, or asking to stop) that the person had had enough or might need to have a break for a number of days or weeks. They respected this, but made sure to encourage and resume when the person appeared ready. At one stage one of the primary participants contacted and asked her disability service health advisor to carry on after she had had a break from her ACP for several weeks.

*“We did it in a few sessions, not all at once.” [Support team member]*

*“I don’t want to do it [Advance care planning] anymore until I get retired.” [Alex]*

*“We have to do it in little bits and pieces. Tony understands but we can’t have a whole conversation about it [in one go]. You can only go at the person’s pace and with what they want to talk about. It’s about giving the information but not needing them to bring it up.” [Support team member]*

*“And I think that moving forward it will be little tiny steps, smaller steps, time to process, revisit that, move to the next thing. [That’s] how I would go forward with it.” [Support team member]*

- b) Drawing on my past experiences: this encompassed using the primary participant’s experiences of other people’s deaths to frame and start conversations. Each of the primary participants had experienced the death of someone close to them, and could relate to their experiences to help them think about funeral options, the support they might want, and how they would want their body to be treated following their death. Gentle handling of the topic meant that primary participants were reported to find this discussion less difficult than was anticipated by their support teams and/or family/whanau.
- c) Making sure I understand: three of the primary participants spoke of how important it was to them for their support teams and/or family/whanau to make sure that they understood what was happening to them, and what their options were. They felt that this greatly assisted with their decision making.

*“They have to explain it to me properly so then I can understand” [Lee]*

Those leading/facilitating the planning process were particularly aware of the need to explain information carefully to the primary participants, and to make sure that they provided all of the detail required in a way that could be easily understood by the primary participant. They felt that this was something that they could do well, given that it’s a skill that they use every day in their work with people with intellectual disability. For example:

- Disability Service Health Advisors all sought easy-read versions of information about health conditions, hospital visits, and treatments to share with the primary participant as needed
- One person had most of their information shared with them pictorially as well as verbally
- Another person had their planning document completed largely in pictorial format, which she had created herself. It included some large easy-read text that she could read independently.

*“And explain it to her so she can understand. You can’t sugar coat it.” [Support team member]*

*“He can’t read or write, so we had to do visuals and we had to be **really really straight up** and not muck around, but be careful not to put words into his mouth.” [Support team member]*

*“We had a chat a while back about if he would like to stay at home, and he said no [abbreviated]. So, it’s about making sure that the information is the right information, eh. Cause sometimes he thinks that something is going to happen, but when it does it’s a little different.” [Support team member]*

Again, the confidence, and ease with which these adaptations can be made by disability service support team members points to the benefit of having them heavily involved in the planning process.

### 3.3.3 Making my own choices

A key concern for primary participants was that they were able to make their own choices and be in control of the decisions being made. All had strong opinions that were sought and understood by those around them, and subsequently recorded in their plan.

*“I want to stay home. Stay home. [Support person] can look after me – ‘cause she’s my maid!” [Lee]*

*“”I make the final decision, ‘cause I’m an adult, and I’m responsible” [Lee]*

*“I want to be cremated like my Mum and I want the staff to come to my funeral, and Dad to come up here.” [Alex]*

In the three situations where primary participants were actively involved in their own planning, it was significant that their support teams and family/whanau had a clear sense of the importance of the primary participant making their own choices.

*“I absolutely love the fact that Lee is so involved in it when it’s so important – it’s all her wishes, her thoughts” [Support team member]*

*“He’ll go back to the marae, yeah, we’ll do that. That’s no special thing, eh. It’s just protocol in our life. I don’t know if he wants to be buried or cremated. It’s really up to him, ain’t it?” [Family/whanau member]*

The primary participants were reported to need support to make decisions for themselves, and sometimes to be informed that there was a decision to be made. This support usually came in the form of easily understood information on the options available, a summary of benefits and disadvantages of the options, and honest and open answers to questions that arose. It often required a topic to be discussed repeatedly, for answers to be reviewed and checked again to make sure that the person was certain and comfortable with their choice. During advance care planning this process needed to be undertaken again and again, on a range of diverse topics. Those leading/facilitating the process had skill and experience in facilitation, and a high degree of comfort in discussing the sensitive topics that arose.

The primary participants took part in their planning to varying degrees. Some were very actively involved, and some more indirectly, either by choice or by the way that it was initiated and led.

The differing levels of involvement, and reasons for this, are interesting. All support teams reported that advance care planning was started because they believed it was important for people's needs and wishes to be met at the end of their lives. There was a clear philosophical basis for this. However, there were times when some family/whanau and/or support team members felt the need to take a more substitute decision-making approach, which they perceived to be in the primary participant's best interests. There was a sense of not wanting to cause harm, discomfort, or distress to the person. This typically took place around the "big" issues of treatment decisions, and advance directives.

### 3.4 Content

#### 3.4.1 Covering Typical Content Areas

Typically advance care planning would cover the five areas outlined in section 1.1, and often with a particular focus on legal/financial matters and care/treatment preferences. For the primary participants all of their advance care plans covered the following three areas:

- Where I want to die
- Things I want to do (bucket list type ideas)
- What I want to happen after I die (largely focused on funeral plans).

Less attention was paid to legal and financial matters, and/or care/treatment preferences. For example, none of the primary participants had a formal will in place. All of those leading/facilitating the advance care planning process indicated that these were likely to be addressed closer to the person's death. However, of the two primary participants who died during the course of the research, these topics were only addressed for one person.

It is again possible that the perceived lack of clear information, guidance, and experience around legal and financial matters and care/treatment preferences (particularly as relates to advance directives), created a level of uncertainty and discomfort, which reduced the likelihood of these topics being discussed.

#### 3.4.2 Planning my life (not only my death)

The strongest theme through all of the interviews was that primary participants wanted there to be a significant focus on the life they were still living.

The primary participants did not want the focus to always be on dying and end of life issues. This was re-iterated by support team members and family/whanau, who recognised this important need.

*"I tell people, I'm still here aren't I? I'm sick of talking about f\*\*\*ing dying!" [Tony]*

*"It's about making sure that the important things on his bucket list are done before he gets too sick" [Support team member]*

*"They could get more things for us to do here" [Frankie, speaking about what is important]*

*"[Primary participant] wants to live and have fun and join in things too"* [Support team member]

*"I'd say 'keep on going, have a good life'"* [Lee]

*"So, now he's trying things and starting to enjoy things that he's never done, and that's about living well – still discovering what you are capable of and developing into. It doesn't all have to shut down because he was a runner. Now he's a walker! To him living well is about having 6 beers and some cigarettes! So, [the "Living Well" guide] it's more a guide for the people that are supporting him than to him."* [Support team member]

### 3.4.3 Having a Resource to Guide us

Two different resources/approaches were used to develop the primary participants' advance care plans:

- One person's support team developed their own template for the plan, and used this alongside their organisation's Funeral Plan form. This person was less directly involved in the decision making related to their plan than the other three primary participants.
- The three other support teams used the "Living Well" document (Helen Sanderson, 2010) as their guide.

Living Well (Helen Sanderson, 2010) has two distinct sections. The first section is focused on goals un-related to end of life. It encourages focus on identifying what makes the person happy, what is important to them in their life, and what they want for the future in general terms. The second section is more focused on what would be seen as more traditional topics for an advance care plan – where I want to live, treatment preferences, what I do and don't want, funeral planning, advance directives, and the like.

Those who led/facilitated the use of "Living Well" felt that it was a key factor in being able to directly involve the primary participant in their own planning. They commented that it aided conversation, and made it easier to find out what the primary participant thought and felt, without being led, or having "words put in their mouth". They described using the guidance material within "Living Well" to help them know what topics to speak about and how to go about it.

*"It helped me from putting words in her mouth."* [Support team member]

*"To be honest I don't think I would have thought about asking a person to decide about different aspects around death. It was fabulous."* [Support team member]

*"I tried really hard not to say anything other than what's in there, just to get an honest....so, most of it came straight from her. It was really really interesting for me."* [Support team member]

*"It brought up things that weren't even in the book. Just talking about it [Primary participant] was like 'oh actually I don't want this at my funeral, and I do want this', and things that the book didn't specifically ask as well. It's just because we were having the conversation already."* [Support team member]

*"Know your document, and just let it unfold as it goes. So have your base questions, and then just let it flow from there."* [Support team member]

All those who used “Living Well” completed this first section, reflecting perhaps their greater familiarity with these topics. The second section was less fully complete in all instances, and in two of the three instances avoided any mention of treatment preferences or advance directives. It’s possible that the booklet/guide makes it feel like a lot has been done, when in fact there is still more to do. Despite this, all facilitators felt that the person’s ACP was finished, but they did concede that some decisions may need to be made closer to the time of death, when it was more real for the person. The risk of this is that time may run out and the conversations may not be possible.

*“That has taken a lot of time because what we thought was straight forward actually is not, and every time we sort of thought we had it right we didn’t.”* [Support team member]

## **4.0 Discussion**

This study was prompted by the dearth of information to guide the implementation of advance care planning with people who have intellectual disabilities and life limiting conditions. It has been recognised within the sector that there is a need to better support people toward the end of their lives. Doing so requires us not just to look at processes and systems, but to consider what is important to people with intellectual disability, and what makes the most difference for them. This study offered the opportunity to do this.

### **4.1 Factors of Importance to the Primary Participants**

In analysing the findings above it became clear that there was a small set of factors that were of key importance to the primary participants:

- Planning my life (not only my death)
- Making my own decisions
- Going at my pace
- Being open and honest
- Making sure I understand

The primary participants all strongly agreed that they wanted their ACP to plan for living, not just dying. Interestingly, research around the content of ACPs in the general population indicates that most people want a much greater focus on “life” and personal goals than is usually included (Bernacki and Block, 2014). The use of the “Living Well” guide seemed to address this need, meaning that the primary participants’ achieved what they wanted to from the advance care planning process. There is perhaps learning that the medical and palliative care sectors could take from this and apply to their work with the general population.

Also important to each of the primary participants was the need to make their own decisions. There were times when upholding the participant’s right to make their own decision (as per the United Nations Convention on the Rights of Disabled Persons) was a challenge. At times those leading the advance care planning process either did not address a topic that should have been addressed (typically treatment preferences and advance directives) or reverted to substitute decision-making. It is possible that the perceived lack of clear information, lack of guidance, and limited experience around legal matters created a level of unfamiliarity and discomfort, which reduced the likelihood of these topics being adequately addressed. Decision-making is a topic of research in the current literature around intellectual disability (Kohn and Blumenthal, 2014; Douglas et al, 2015), and it is therefore unsurprising to see it raised within the context of advance care planning. Although great strides have been made there is still room to improve the way that people with intellectual are supported to make the “tough” or “big” decisions in their lives, including those that are part of advance care planning. Until people with intellectual disability are seen as competent decision-makers, and appropriate support strategies are embedded in practice in all areas of support, people with intellectual disability will struggle to have complete control over the outcomes of their advance care plans.

### **4.2 Facilitation and Collaboration**

Most of what the primary participants reported as being important was relatively easily achieved by the person who led/facilitated the advance care planning process. The approach taken by these individuals aligned with what they would normally do when facilitating any other person-centred planning process.

The additional end-of-life support and planning needs of people with intellectual disabilities are in many ways no different than for the general population (Tuffrey-Weijne et al, 2015), but require adaptation of processes, systems, tools, and approach to ensure equal access to advance care planning. In the absence of specific evidence-based guidance for people with intellectual disability, the support teams involved in this research have followed and adapted the guidance for the general population, with good results.

For example, Bernacki and Block (2014) list a set of basic principles for end of life communication, suggesting that there are some key truths that advance care planning facilitators should be aware of and/or follow in order to achieve a positive outcome for their patients:

- Patients want the truth about prognosis
- You will not harm your patient by talking about end-of-life issues
- Anxiety is normal for both patient and clinician during these discussions
- Patients have goals and priorities besides living longer
- Learning about patient goals and priorities empowers you to provide better care

This is further reinforced by the findings of Bekkema et al (2014) who suggest that the key requirements for advance care planning are to respect each person's autonomy by:

- Connecting with the person
- Helping the person understand new information
- Familiarising the person with transitions and changing needs
- Seeking to understand their wishes and important decisions.

There does appear to be an additional requirement though - a high degree of comfort and skill in the content areas related to advance care planning. In this study the plans were strong in their coverage of the content related to "where I want to die", "things I want to do", and "what I want to happen after I die". They only covered "how I want to be cared for" and "legal and financial matters" (regarding treatment preferences and advance directives) in a fairly superficial way, even when facilitated by skilled Health Advisors. These weak areas are typically seen as the focus points of advance care plans, which are usually led/facilitated by medical/palliative care professionals. Other research demonstrates that medical professionals are often less skilled in addressing non-medical goals, or providing enough information to allow the general population to make informed choices (Bernacki and Block, 2014). It is likely that these factors are exacerbated for people with intellectual disability, who require a higher level of support to complete an advance care plan.

This study therefore highlights the value of having an experienced disability service health advisor or senior staff person involved. It does, however, raise questions about why this role was largely taken on by the disability service team when, for the general population, it would usually be carried out by health professionals. Increased collaboration between disability service staff and medical and palliative care professionals, could address some of the content issues raised above, and would allow each service to make the most of the other's complimentary skill set. Further exploration is required to identify how best to do this.

### **4.3 Starting Early**

This study suggests that it is preferable to start the advance care planning as early as possible following diagnosis of a life limiting condition, mirroring the findings in the research in the general population (Bernacki and Block, 2014). Earlier discussions lead to benefits to quality of life, reduced use of non-beneficial medical care near death, care that matches goals, positive family outcomes, and reduced medical costs. Disability services need to find ways to

ensure that this occurs, and include advance care planning requirements and guidance within policy, and have these policies backed up by systems that flag the need for the process to be initiated.

#### **4.4 Addressing Distress**

Some degree of distress is to be expected when confronting end of life issues, no matter how sensitively the subject is approached and discussed (Bernacki and Block, 2014). This was the case during the study, but hadn't been anticipated by some of the support teams. There may be a need for pro-active planning of emotional support to be included in guidance materials for disability service support teams, so that they are better equipped for when a person's emotional needs require support. This may include having an identified counsellor available if required, ensuring that a familiar and preferred person is available for follow up, or allowing for down-time from usual activities.

The support team members also found that the end of life discussions took an emotional toll on themselves, and that they, and their managers, hadn't planned for how they would receive support. They often kept this distress to themselves, when it may have helped if they had had someone to talk to, or debrief with. Again, this support should be pro-actively planned for, and needs to be considered by organisations who are planning on supporting advance care planning.

#### **4.5 Inequitable Access to Advance Care Planning**

An unintended outcome of the study was it was possible to analyse data regarding the eleven individuals who were referred to the study but unable to take part. Prognostic information had not been shared with these individuals, making them ineligible. It was indicated by support team members of each of these people, that prognosis wasn't shared because of concerns that the person would not cope with knowing, or would not understand. This fits with what existing research tells us that a) that this is also common in the general population, where there is variability in the way that clinicians view and approach end of life discussions with their patients (Dunlay et al, 2015) - varying clinician perception and confidence contributes to this, and b) that there is less openness to discussing death and dying with people who have intellectual disability than there is with the general population (Todd 2005; Tuffrey-Wijne et al. 2006), and c) that end of life tends to be a topic not openly discussed, even when death approaches (Weise et al 2013).

However, there is strong evidence to suggest that this hesitation is often un-founded and that disclosure of prognosis is desirable to the vast majority of individuals. Research tells us that speaking about end-of-life issues does not cause distress. (Bernacki and Block, 2014). In actual fact, discussion about end of life care, and engagement in advance care planning, is associated with better quality of life, reduced use of non-beneficial medical care near death, enhanced goal-consistent care, positive family outcomes, and reduced costs.

There is conversely some harm in failing to address goals of care and end of life issues for individuals (Bernacki and Block, 2014). These include:

- Receiving treatment and care not consistent with personal goals
- Worse quality of life
- Prolonged death with increased suffering
- Worse bereavement outcomes for family members
- Increased costs without benefit to patients.



It is important to consider this in the context of the current study, given its finding that, when given the opportunity, people with intellectual disability handled the news of their diagnosis and prognosis, and were able to engage in a successful advance care planning process.

The current approach of continuing to withhold prognostic information denies people with intellectual disability the opportunity to take part in any meaningful planning for the end of their lives, and contravenes the rights afforded to people via the United Nations Convention for the Rights of Persons with Disabilities. Attention needs to be given to how to address this inequity, and to ensure that advance care planning is more accessible and available to people with intellectual disability.

## 5.0 Recommendations

Advance care planning is still in its infancy within the intellectual disability sector, and it is hoped that the way that it is approached and implemented will continue to evolve, grow and strengthen.

The recommendations below are intended to be considered at an organisation-level (to guide policy and practice) as well as a sector-level, where collaboration could lead to a marked change in equity of access to advance care planning, as well as opportunities to link with advance care planning bodies within New Zealand.

Recommendations	Commentary
<p>Health/palliative/ACP professionals should be encouraged to initiate and lead the advance care planning process for people with intellectual disabilities, with ongoing collaborative support from disability service providers.</p>	<p>In the general population health/palliative/ACP professionals are the usual initiators and leaders of advance care planning, and would be the rightful holders of this role for people with intellectual disabilities as well. However, there is, immense benefit in having disability sector staff directly involved in the ongoing facilitation of discussions and supported decision-making processes for people with intellectual disability – these functions are likely to be outside of the capability and capacity of the medical/palliative/ACP professionals.</p> <p>It is hoped that increased collaboration between medical and disability staff would result in people with intellectual disability being made aware of their prognosis, starting a planning process early, and addressing content related to treatment preferences and advance directives more regularly.</p>
<p>Increase the uptake of advance care planning for people with intellectual disabilities (both those with life limiting conditions, and those who are well).</p>	<p>Doing this will require:</p> <ul style="list-style-type: none"> <li>• Increasing the awareness of advance care planning amongst people who have intellectual disabilities, their families/whanau and support networks</li> <li>• Increasing awareness within the health/palliative/ACP sectors regarding tools/resources/processes that strengthen advance care planning for people with intellectual disabilities</li> <li>• Sharing tools and resources, such as “Living Well”, with palliative care/health organisations, people with intellectual disability and their families/whanau</li> <li>• Continued efforts to increase knowledge/skill and/or comfort in lead staff within the disability sector. Several options are available: <ul style="list-style-type: none"> <li>– The free on-line courses offered by the NZ ACP Co-operative are a good starting point, and would be recommended for all Health Advisors/Managers/Champions who support people with life limiting conditions. Without skilled staff there is significant risk of advance care planning not being utilised.</li> <li>– Conversations that Count is another excellent programme which focuses on increasing comfort around end of life discussions, and promotes advance care planning.</li> <li>– Hospice NZ and local hospice training programmes for managers and support workers have great value in a wide range of topics related to death and dying.</li> </ul> </li> <li>• Development of systems that trigger early discussions about advance care planning</li> </ul>

<p>Disability service provider organisations to link with organisations in the health and palliative care sectors (such as the NZ ACP Cooperative, and Hospice NZ) to ensure that people with intellectual disability are represented and considered in policy, research, and processes related to advance care planning</p>	<p>There is risk of people with intellectual disability being unrepresented in the development of policy, processes and research within the advance care planning sphere. People with intellectual disability are largely invisible at present.</p> <p>This may require a sector-wide response.</p>
<p>Continue process improvements to ensure that people with intellectual disability have positive experiences and successful outcomes as a result of advance care planning.</p>	<p>Particular areas where improvements could be made include:</p> <ul style="list-style-type: none"> <li>• Developing or increasing access to clear guidance materials re legal matters, and advance directives</li> <li>• Encouraging and monitoring the uptake of advance care planning for people who have intellectual disabilities and life limiting conditions</li> <li>• Utilising decision-making frameworks that support the rights of people with disability to be involved in ALL decisions about their life (including advance directives and treatment preferences)</li> <li>• Implementing checks and balances to ensure that the “hard” topics (treatment preferences, legal issues, advance directives) have been discussed</li> <li>• Ensuring that strategies to meet people’s emotional support needs are put in place prior to starting the advance care planning process</li> </ul>

## **6.0 Strengths and Limitations of the Research**

The way this research elicited information about people's experiences during the advance care planning process had both strengths and limitations. These are outlined below.

### **5.1 Strengths**

There were several strengths to the study's method:

- Interviewing participants on two occasions over time was a useful method. It allowed the researcher to view the progression of the advance care planning process over time, providing deeper insight into how and when different aspects of the plan were developed
- The method enabled primary participants to share their thoughts about what helped and hindered the planning toward the end of their life. This first-person information is valuable, as it hadn't previously been collected. Rich information was able to be gathered and will inform the way that advance care planning is approached in the future
- The inclusion of the primary participants' families/whanau and support team members also allowed the researcher to capture a range of opinions and thoughts – generally there was agreement across all participants. This strengthened the limited information provided directly by primary participants, and gave the research increased depth.

### **5.2 Limitations**

The most significant limitation of the study is the small number of primary participants (four) and the limited data set resulting from this. The research team was advised that extending the study's time frame (to achieve the desired number of recruits) could lead to early data becoming obsolete. It was also felt that there was no guarantee that additional time would result in additional recruits. This advice was accepted and acted upon. In addition, there was no attempt to be representative of the intellectual disability population during the study. The combination of these factors mean that it is difficult to draw strong conclusions from this small sample, although the outcomes do provide an emerging picture of what still remains a relatively new type of planning for people with intellectual disability.

The research focused only on those with life limiting conditions, where in reality advance care planning is increasingly being encouraged for all people at any stage in life, with or without health concerns. It is possible that what contributes to a positive experience of advance care planning for people who are well, and carrying out pro-active (rather than reactive) planning, may be slightly different. Although it is surmised that many of the same factors apply in achieving successful outcomes, this cannot be concluded from this research.

## 7.0 Future Research

Research in advance care planning and utilisation with people with intellectual disability is in its infancy. There is plenty of scope for future research in this area, particularly to explore and identify:

- The factors that contribute to people with intellectual disability being fully involved in making decisions about treatment preferences and advance directives
- The benefits, or otherwise, and process differences involved when advance care planning takes place pro-actively (when people are well)
- Approaches to advance care planning that lead to increased collaboration between medical/palliative care professionals and disability service providers

## 8.0 Conclusions

People with life limiting conditions who were supported to undergo advance care planning gave strong feedback about how it was helpful to them, and how much they were aware of being involved in critical decisions in their lives. They provided rich information on ways to continue this support. They also challenged support teams and their families/whanau to keep a balanced perspective so that they are still supported to live, rather than just being supported while they die.

The support teams and families/whanau involved in this study have demonstrated how to facilitate a positive experience of advance care planning for the people they support. They have shared their challenges in negotiating complex situations for which they were often unprepared. They deserve whole hearted congratulations. The need for greater leadership and guidance from health/palliative care professionals was also highlighted.

The purpose of this research was to hear from people with intellectual disability about their experiences of advance care planning. The hesitancy and concerns expressed by some support team members and families/whanau provides possible insights into why so many potential research participants were excluded. They were not part of an advance care planning process because they were not aware they were dying. This raises important challenges for health professionals, families, disability staff and agencies, in making real the rights of people to be involved in decision-making about their lives.

## 9.0 Correspondence

Any correspondence should be directed to Nic McKenzie, Disability Sector Consultant, email [nicmckenzie5@gmail.com](mailto:nicmckenzie5@gmail.com), phone (021) 745 774.

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