POSTGRADUATE

My Plan for a Good Life, Right to the End

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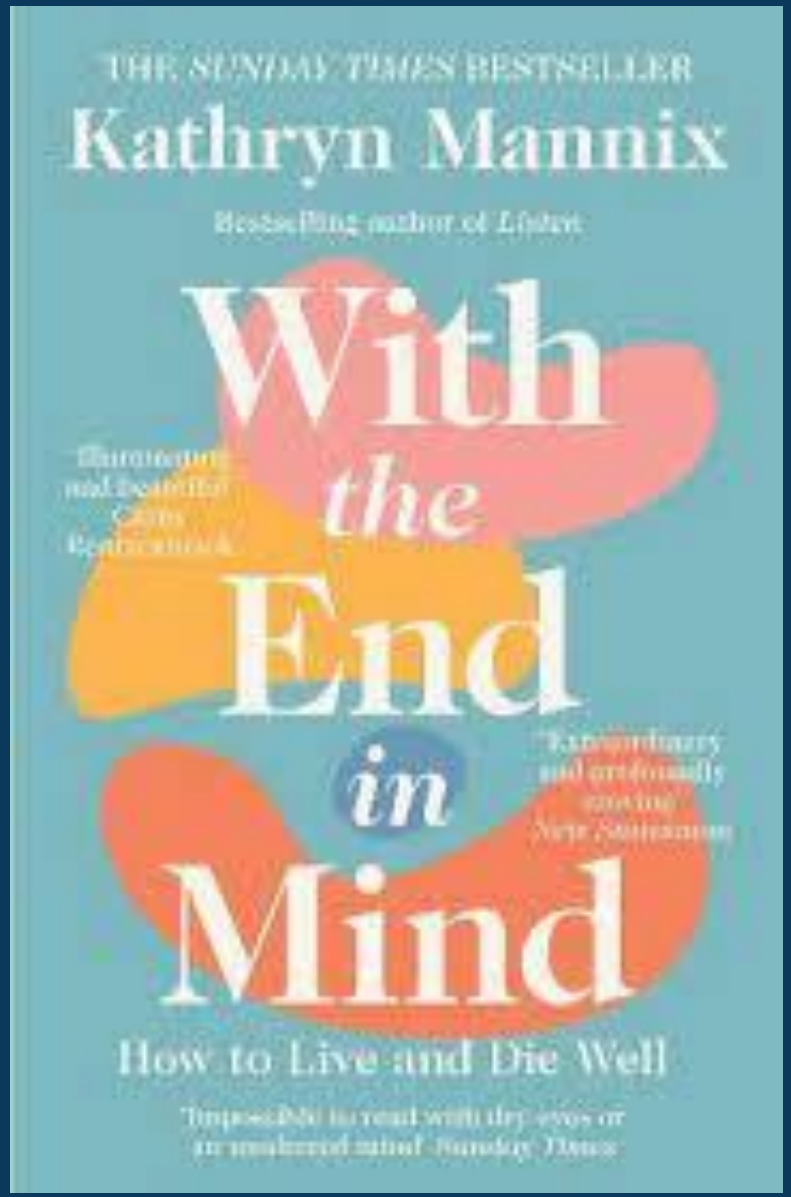
iatemyglutenfreeplate

ADVANCE CARE PLANNING

- What's important to me
- The life I want while seriously unwell/dying
- Treatments I do/don't want
- Legal and financial matters
- What I want after I die


THE SUNDAY TIMES BESTSELLER
Kathryn Mannix
With the End in Mind
How to Live and Die Well

My Advance Care Plan & Guide

Plan the healthcare you want in the future and for the end of your life

Name:

Date:

our voice | Advance Care Planning
tō tātou reo

4 How I make decisions

Think about the decisions you might need to make about your health.

Think about how you like to make decisions.

Do you need time? Do you like lots of information and options or do you prefer to let others decide?

Sometimes you might be faced with having to make a healthcare decision in a crisis (such as an accident or when you are really sick). This can be made easier for you if you have already thought about how you like to make decisions and who you want involved.

Who can make decisions on your behalf when you are unable to?

If you are too unwell to speak for yourself others will need to help make the decisions for you. Talk to them about what matters to you and what you want *or* don't want to happen while you still can.

If you want a person to have the power to make decisions for you, consider appointing them as your enduring power of attorney for personal care and welfare (EPOA). This means they can be involved in most decisions about your care. This person will not make decisions for you unless you can no longer decide for yourself.

For more information, contact the Citizens Advice Bureau, a solicitor or the Public Trust.

These scales might help you think about how you like to make decisions and how you prefer your medical information is shared. *Mark along the scale what you would want:*

I like to know...

only the basics ○ ○ ○ ○ ○ all the details about my condition and my treatment

As doctors treat me, I would like...

my doctors to do what they think best ○ ○ ○ ○ ○ to have a say in every decision

If I had an illness that was going to shorten my life, I prefer to...

know my doctor's best estimate for how long I have to live ○ ○ ○ ○ ○ not know how quickly it is likely to progress

How involved do you want your loved ones to be?

I want them to do exactly as I have said, even if it makes them uncomfortable ○ ○ ○ ○ ○ I want them to do what brings them peace, even if it goes against what I have said

When it comes to sharing information...

I don't want my loved ones to know anything about my health ○ ○ ○ ○ ○ I am comfortable with my loved ones knowing everything about my health

ADVANCE CARE PLANNING RESEARCH

- Aimed to find a better way to initiate and develop Advance Care plans
- A Participatory Action Research study
- In partnership with co-researchers: with learning disabilities, and managers from disability services

THE USUAL APPROACH

Starting is the hardest part

We need a plan template that suits us

Give me a chance

The right support from the right people

Guide the guides

Karesanui

Or

Stuart?

Karesansui

Dry
Rocks
Rakes

Stuart

Italianate
French
Formal

- Policy

Trained guides

- Get started, with:
  - A Guide
  - Learning resources
  - Easy-read plan
  - Input where needed

Health professional approves the plan and keeps an electronic record

My Plan for a Good Life, Right to the End

Easy Read Advance Care Plan

People to make choices if I can't

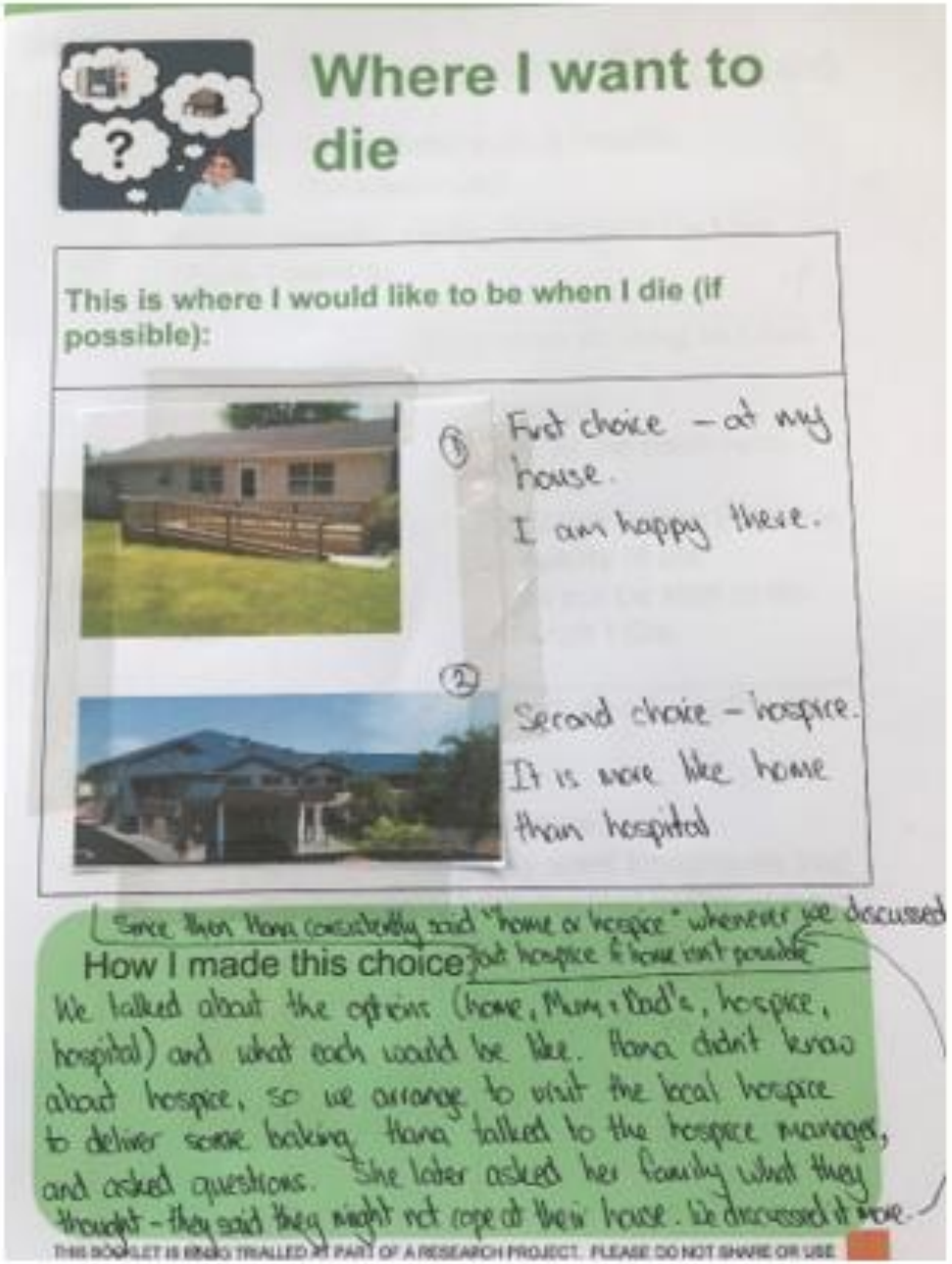
☐ Enduring Power of Attorney OR ☐ Welfare Guardian [Only fill this in if you have an EPA or Welfare Guardian]		
Insert photo	**Name**	
	Phone	
	How I know them	

Person 2		
Insert photo	**Name**	
	Phone	
	How I know them	

Donating my body

✔	Choose one	
☐		I want to be an organ donor when I die. Body parts I do not want to give away (if any):
☐		I do not want to be an organ donor when I die.
☐		I want to give my body to medical science.

The process followed to make this choice:



Where I want to die

This is where I would like to be when I die (if possible):

① First choice – at my house.
I am happy there.

② Second choice – hospice.
It is more like home than hospital

Since then Hana consistently said "home or hospice" whenever we discussed

How I made this choice

We talked about the options (home, Mum + Dad's, hospice, hospital) and what each would be like. Hana didn't know about hospice, so we arranged to visit the local hospice to deliver some baking. Hana talked to the hospice manager, and asked questions. She later asked her family what they thought – they said they might not cope at their house. We discussed it more.

just hospice & home isn't possible

THIS BOOKLET IS BEING TRIALLED AS PART OF A RESEARCH PROJECT. PLEASE DO NOT SHARE OR USE

In this example, Hana has used photos to illustrate her choices. Her support person has written short sentences in Hana's words, to explain her choice.

In the "How I Made This Choice" section Hana's support person has recorded the process of how the decision was made.

OUTCOMES

Positive experience

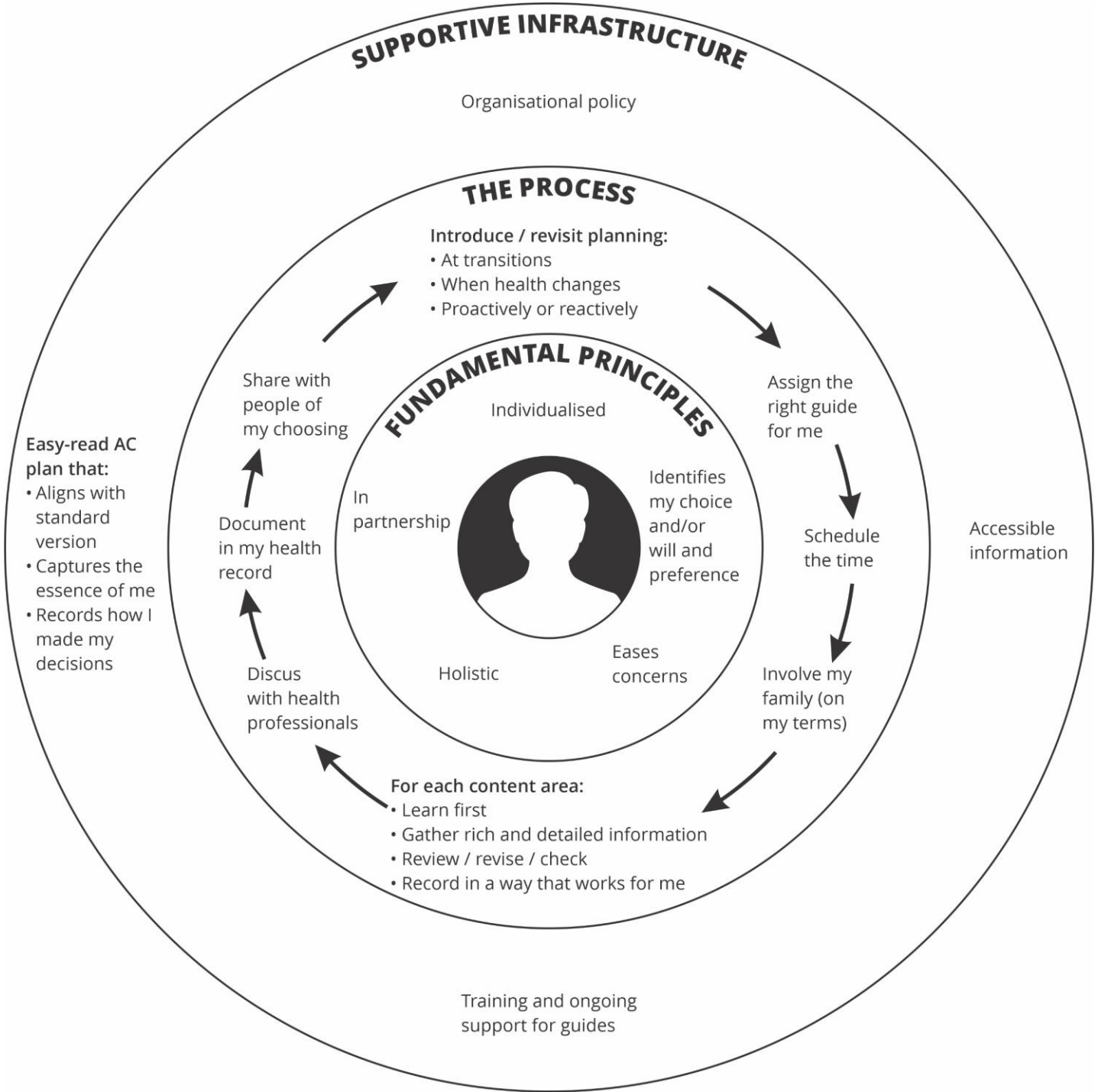
Straight forward AND challenging

Useful, trusted, accepted

Captures the essence of me

Increased confidence and growth

Planning creates comfort



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SUPPORTIVE INFRASTRUCTURE

- Policy
- Accessible information
- An accessible plan template (aligned to standard version, captures the essence of me, space to record how decisions were made)
- Training and support for Guides / organisations

FUNDAMENTAL PRINCIPLES

- In partnership
- Holistic
- Individualised
- Ease my concerns
- Identify my choices and/or will and preference

PROCESS

1. Introduce planning
2. Assign the right Guide
3. Schedule the time
4. Involve my family (on the person's terms)
5. For each content area: learn first, gather rich and detailed information, revisit/review/clarify, and record
6. Discuss with health professionals, and have the plan documented in the person's health record (AC Plan or AC file note)
7. Share with people of my choosing

Moving forward: Where are the gaps?

Supportive infrastructure

- Organisational policy
- Access to training and support for guides and health professionals
- Access to appropriate easy-read plan templates
- Resource constraints and unclear costs with pro-active planning

Research gaps:

- Limited knowledge of use with more diverse groups
- How to best engage with families and whānau and health professionals
- The impact at end-of-life
- Factors that influence operationalisation of plans
- Best ways to initiate planning

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Future research

Explore how to promote ACP for people with learning disabilities

Identify the factors that influence implementation

Use and test the emergent framework with more people

Measure the impact

Thank you

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