Holding Hope
WORKBOOK

For People With a Longstanding Eating Disorder

Shannon Calvert
NATIONAL EATING DISORDERS
COLLABORATION | 2025

National
Eating Disorders
Collaboration

Evidence Experience Expertise

NEDC acknowledges the traditional custodians of lands throughout Australia. We pay our respects to Aboriginal and Torres Strait Islander Elders, past and present, and recognise the important role of Aboriginal and Torres Strait Islander peoples, as well as their cultures and customs across Australia.

Recommended Citation

Calvert, S. (2025). *The Holding Hope Guide: A collaborative, ethical guide for supporting dignity, choice, and person-centred care in longstanding eating disorders.* National Eating Disorders Collaboration (NEDC).

Acknowledgement of Origin

The Holding Hope Guide builds upon the foundational work of the Holding Hope Discussion Paper, which was funded by the Commonwealth Department of Health and Aged Care and released to the public in June 2024 via the NEDC website (nedc.com.au). The Discussion Paper initiated a national conversation about the complex intersection of longstanding eating disorders with palliative, person-led, and quality-of-life-oriented care. This Guide extends that work by offering practical tools, frameworks, and ethical prompts to support individuals, families, and professionals in navigating care with dignity, compassion, and clarity.

The Holding Hope Guide Project Team

Shannon Calvert

Lived Experience Advisor & Educator - Author

Dr Sarah Trobe

NEDC National Director

Amy Woods

NEDC Workforce Development and PHN Coordinator – Holding Hope Project Lead

Dr Sarah Giles

NEDC Research and Evaluation Lead

If you require this document in a different format for accessibility, please email info@nedc.com.au

We'd love to hear from you

Please take a few minutes to complete our short survey and help us improve this resource to better support your needs. You can learn more and access the 5-minute survey via the link below:

https://su.vc/wzjrfwco

Support Services

If the content of this document brings up concerns for you, or you are concerned about someone else, please contact:

Butterfly Foundation National Helpline	1800 ED HOPE (1800 33 4673) support@butterfly.org.au Webchat
Eating Disorders Victoria Helpline	1300 550 236 hub@eatingdisorders.org.au Webform
Eating Disorders Families Australia Support for families and carers	1300 195 626 admin@edfa.org.au https://edfa.org.au/
Beyond Blue Mental health support	1300 22 4636 Webchat
Lifeline 24/7 Crisis Support	13 11 14 Webchat
Kids Helpline 24/7 Helpline and Webchat	1800 55 1800 counsellor@kidshelpline.com.au Webchat
Suicide Call Back Service 24/7 phone and online counselling for people affected by suicide	1300 659 467
MensLine Australia 24/7 phone counselling support for mental health, relationships, and family violence	1300 78 99 78 Webchat
13 YARN To talk with an Aboriginal or Torres Strait Islander Crisis Supporter	13 92 76
Qlife LGBTIQ+ peer support	1800 184 527 Webchat

If you or someone you are with is in immediate danger, please call triple zero (000).

Table of Contents

Before you Begin

This workbook was created for individuals with lived or living experience of an eating disorder, especially when that experience has been long, complex, or shaped by many chapters.

It doesn't ask you to explain where you are in your journey, or to frame your hopes in a particular way. Instead, it offers space to reflect, to clarify what matters to you, and to support conversations that feel more aligned with your values and needs.

We know that some tools and conversations can feel heavy, especially when trust has been stretched or when care has been difficult to access, sustain, or feel at home in. This workbook won't pretend to have easy answers. But it does aim to offer language, structure, and a sense of steadiness, especially in moments that feel uncertain.

You might choose to use this workbook on your own, with someone you trust, or as a way to prepare for discussions with services, loved ones, or care teams. Some people find it helpful to work through it alongside a support person, whether that's a family member, a clinician, a peer worker, or someone else who understands and respects their journey.

There's no expectation to complete everything, and no one path you need to follow. It can be picked up and put down at your pace, and used in the ways that feel most useful to you.

Each tool has been included because it may support one of the following:

- making sense of your priorities and values
- preparing for conversations or decisions
- planning ahead or naming boundaries
- navigating care that may not fully reflect who you are

Wherever you are right now, this resource was designed with care, to help hold space for what's important to you, and to make it a little easier to feel seen, understood, and supported as the person you are.

You don't have to be sure, ready, or defined by any one story.
You just need to know that it's okay to begin here, gently, and in your own way.

With appreciation,

Shannon Calvert and the NEDC Project Team

National
Eating Disorders
Collaboration

Evidence Experience Expertise

How Can This Workbook Help?

I feel overwhelmed and want help sorting through my thoughts or figuring out what I need.

- **Individual Values and Goals Worksheet**
- **What Matters to Me?**

I want to express my preferences or concerns about my care.

- **Advance Care Planning Workbook**
- **Advance Care Snapshot Summary Sheet**
- **Comfort-Focused Care Planning Tool**

I'm trying to work out what's okay for me right now - especially around risks, goals, or expectations.

- **Weighing Risk vs Value Worksheet**
- **Harm Reduction Planning Template**

I want to create a snapshot of my experiences and my needs for those involved in my care and support.

- **Crisis and Transition Planning Template**
- **Care History and Service Access Audit Tool**
- **Care Collaboration Summary Sheet**

Introduction

This workbook is a companion to The Holding Hope Guide: A collaborative, ethical guide for supporting dignity, choice, and person-centred care in longstanding eating disorders. It is part of the Holding Hope series, which offers practical, trauma-informed tools to support meaningful dialogue, values-led planning, and collaborative care.

This workbook focuses on people who have a longstanding eating disorder.

It offers thoughtfully developed tools - templates, prompts, and reflections that can help build insight, guide planning, and strengthen your voice in your care journey, regardless of the direction that it takes.

The tools are not formal assessments or rigid checklists. Instead, they are flexible resources that can be revisited and adapted over time, based on your unique experiences, values, and goals. They're here to honour the complexity and individuality of your path.

You are welcome to:

- Use this as a purely personal reflection or journalling prompt
- Use these questions as discussion prompts in clinical sessions, family conversations, or team meetings
- Create your own care plan workbook using these templates or adapt the questions into your own documents
- Photocopy or print individual tools from the workbook

Whenever possible, we encourage using this resource in partnership, whether with a trusted health professional, peer worker, family member, or care coordinator. These tools work best when grounded in respectful, ongoing collaboration that centres your experience.

Access the Holding Hope Guide here

Individual Values & Goals Worksheet

Purpose

This worksheet is designed to help you reflect on what matters most to you in your life and care journey. You can use it independently, with a support person, or during care planning conversations with your team.

There are no right or wrong answers - complete the parts that feel helpful and return to it as your needs or goals evolve.

Reminder:

- You don't have to be 'ready' or 'recovered' to deserve care.
- Your experiences, hopes, and boundaries are important and they are enough.

This worksheet can be used alongside:

- Advance Care Planning Workbook (Page 25)
- Harm Reduction Planning Template (Page 31)

1. What Matters Most to Me?

What gives your life meaning, connection, or purpose right now - even small things?

What helps you feel like yourself, outside of your eating disorder?

Who or what helps you feel safe, seen, or supported?

2. What I Want to Avoid

What types of care or experiences have felt unsafe, or unhelpful in the past?

Are there any personal boundaries you would like others to know and respect?

What makes you want to withdraw or stop engaging with care?

3. What I've Already Tried

Reflecting on the treatments and supports you've had, what helped? What didn't?

Were there services or clinicians you found challenging to connect with? Why?

Were there services or clinicians you found it easy to connect with? Why?

Are there approaches you might be open to trying again - perhaps differently? (e.g. with a different service/clinician, with different goals to work towards etc.)

4. How do I Define Support Right Now?

Tick any that feel true for you:

- ☐ **I want to stay connected to certain people in my treating or support team, even if I don't want treatment right now (e.g. a peer worker, support person, or clinician)**
- ☐ **I need care that focuses on my comfort, function, and wellbeing**
- ☐ **I don't want to be monitored (e.g. weight, blood pressure, food intake) or assessed without my consent**
- ☐ **I'd like someone to help me explore my options without pressure**
- ☐ **I want a plan that doesn't change without involving me**
- ☐ **I want care that respects my identity and lived experience**
- ☐ **Other:**

5. My Current Priorities

What are you hoping to maintain, improve, or protect - even a little?

Examples:

"I want to feel less tired."
"I want to keep my connection with my sister."
"I want to walk outside a few times a week."
"I want to still get support with my dietitian/psychologist/peer support worker."

6. Talking With My Care Team

What would you like your care team to know about your current preferences or needs?

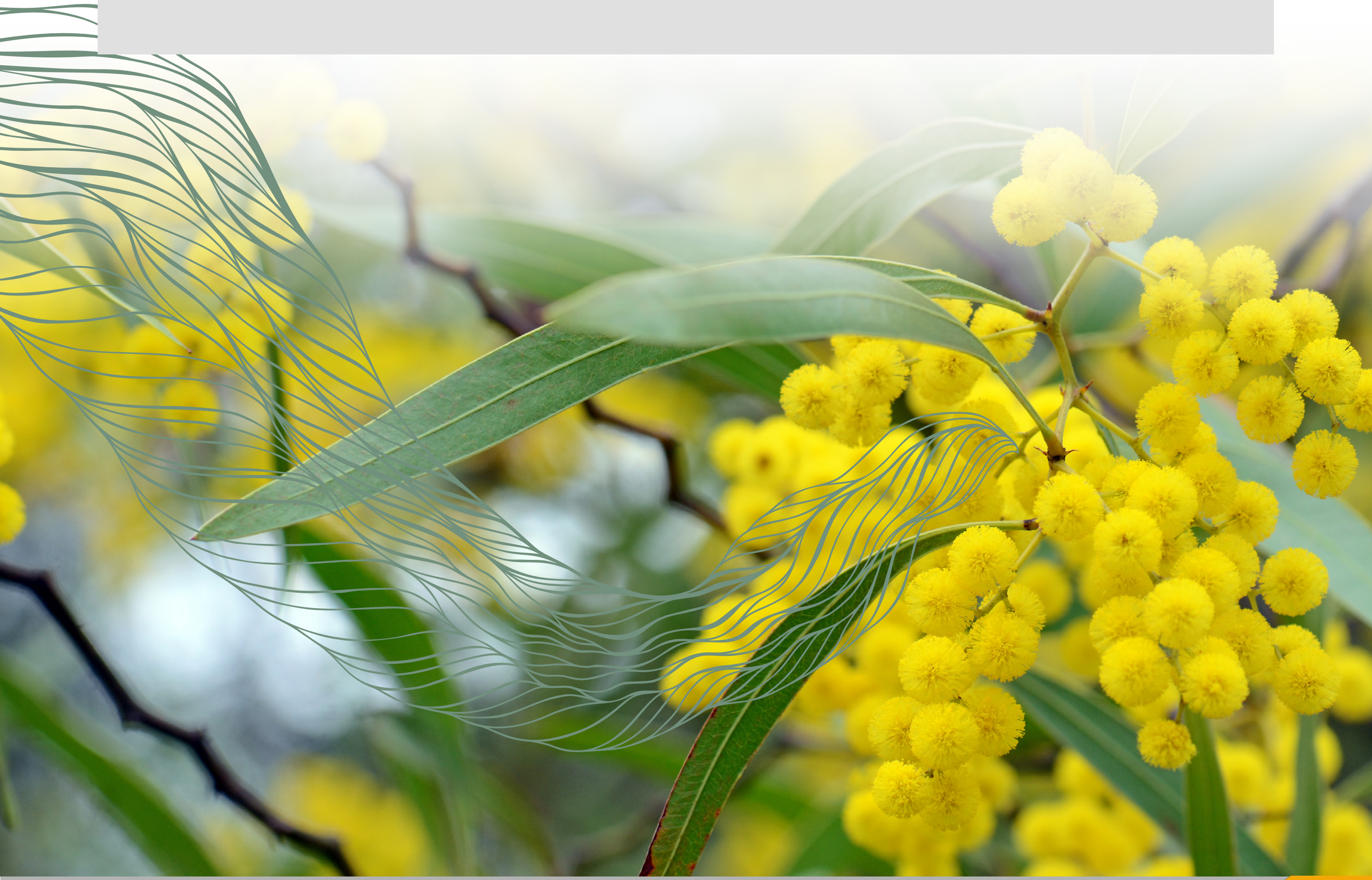
Is there anything you find difficult to talk about right now?

What does a respectful conversation look like to you?

My Personal Message or Statement of Needs

This is a space for you to write a message about your care preferences - particularly if there is ever a time when it's difficult for you to speak for yourself.

Prompt: *"If I become unwell or disconnected, I want people to remember that..."*



What Matters to Me?

Purpose

A gentle reflection tool to explore meaning, connection, and what gives you strength.

This page is for you - not to be "filled in the right way," but to help you reflect on what matters most, especially during times of uncertainty, change, or planning for future care.

You can use it on your own, with someone you trust, or in care planning conversations.

There are no right or wrong answers. Use only what feels helpful.

1. Who am I, beyond my illness or treatment?

(e.g. what do I love? what makes me laugh? what is most special to me?)

2. What helps me feel grounded or safe?

3. What gives me comfort - even if just a little?

(e.g. music, ritual, nature, story, silence, faith, humour, people, place)

4. What helps me feel connected?

(Think about people, values, community, or anything that gives you a sense of belonging or meaning)

5. If there was one thing I want to be remembered for, it would be...

You may also wish to explore:

What brings me peace, or could bring me peace?

Is there anything unresolved that I'd like to talk about?

What kind of support feels respectful and right for me currently?

What do I need others to know if I become too unwell to speak for myself?

Crisis & Transition Planning Template

Purpose

This planning template offers a way to name and prepare for moments that may feel uncertain, distressing, or overwhelming. It helps you and your team understand what care and support look like for you - in ways that are grounded in dignity, compassion, and collaboration.

It's not about predicting every possibility. Instead, it invites a shared understanding of how to respond in ways that feel safer, more respectful, and more aligned with your values.

This is a living document. It can be changed, paused, revisited, or redefined as your needs, relationships, or preferences shift.

Let the guiding question be:

"What response will best support my dignity and safety - especially when things feel hard?"

1. Early Warning Signs

Physical indicators (e.g., fainting, fatigue):

Emotional or behavioural signs (e.g., withdrawal, agitation):

Specific patterns others might notice:

Known triggers that increase risk or distress:

2. What I Need and What Doesn't Help

Things that help when I'm struggling:

Things that make it worse:

How to respond if I become non-verbal, withdrawn, or overwhelmed:

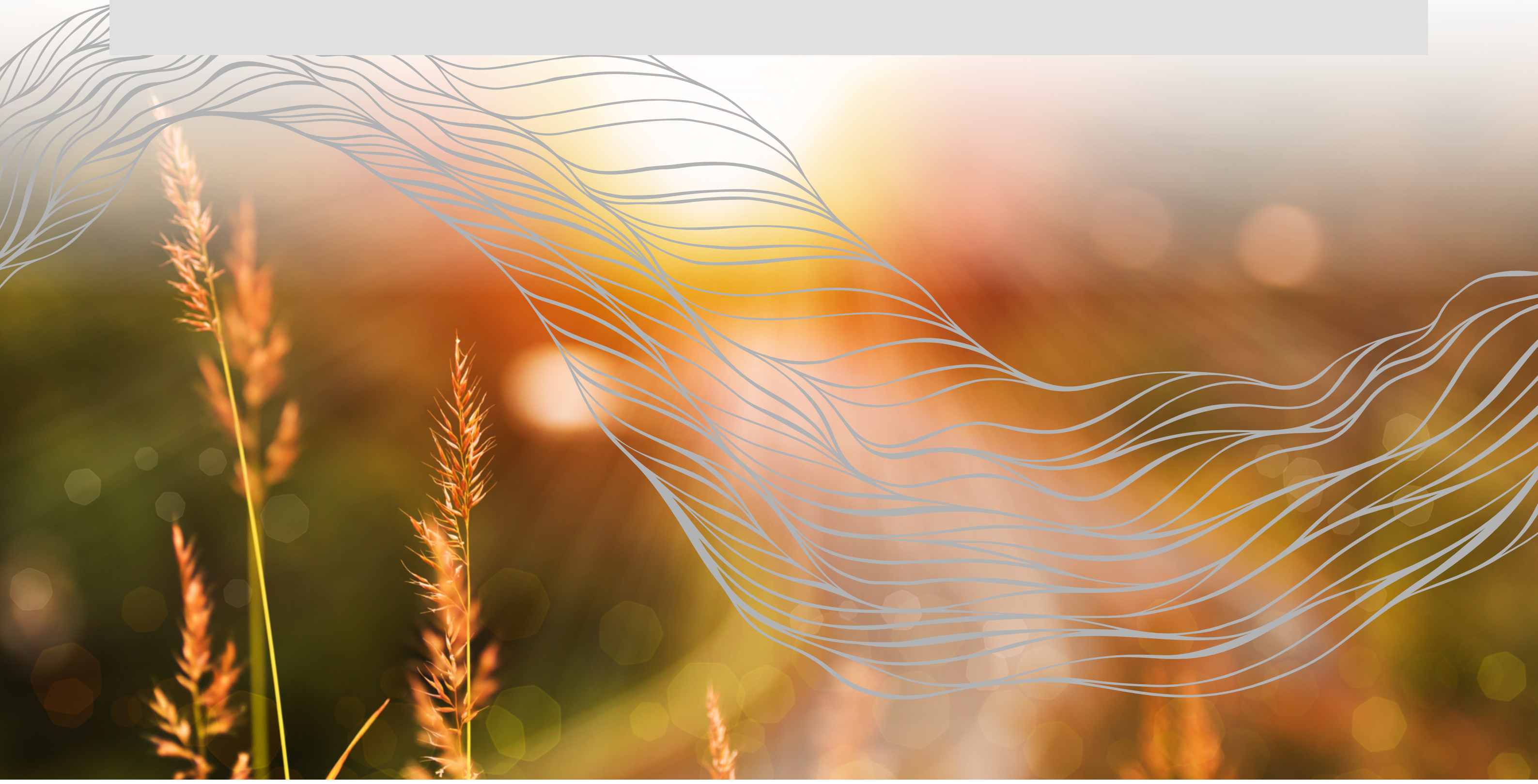
3. Communication Preferences

These preferences help others support me without making things worse. They're here to guide respectful, calm, and clear communication - especially during distress or crisis.

How I want to be supported or spoken to during a crisis:

- ☐ Calm tone
- ☐ Clear explanations
- ☐ Inclusion in decisions wherever possible
- ☐ Avoid clinical/judgmental language
- ☐ Other:

If I cannot speak for myself, please remember:



4. Trusted Contacts and People to Avoid

Primary Contact Name:

Role/relationship:

Contact:

Other Trusted People:

People I prefer not to be involved (unless absolutely necessary):

5. Emergency Response Preferences

First action if urgent medical support is needed:
(e.g., access usual GP, preferred hospital, attend urgent care rather than emergency department etc...)

Second option if first is unavailable:

Other preferences:

- ☐ **Bypass ED and admit to ward directly if possible**
- ☐ **No enteral feeding unless imminent risk**
- ☐ **No consultation with mental health team once in hospital**
- ☐ **Dietary preferences**
- ☐ **Sensory preferences**
- ☐ **Other:**

Location of Advance Care Plan or Advance Health Directive:

Preferences regarding hospitalisation:

- ☐ **Avoid if possible**
- ☐ **Cultural/spiritual needs respected**
- ☐ **Use of restraint is avoided unless risk to self and others cannot be supported through a less restrictive intervention and used for the shortest possible duration.**
- ☐ **Other:**

6. Transitions in Care

If exiting or changing care (e.g., leaving a program, goal shift):
What I want to maintain:

What I want to avoid:

People I want involved in planning:

If I disengage or pause care you can respectfully check in by:

7. Pathways for Reconnection

Signs I may be open to reconnecting to recovery oriented treatment or other forms of care:

How to support me in returning to recovery oriented treatment:

What makes it safer for me to ask for help?

8. Review and Update Plan

This crisis and transition plan will be reviewed:

- ☐ **Monthly**
- ☐ **Every 3 months**
- ☐ **After a crisis**
- ☐ **As needed**

Next review date (if known):

Who will check in with me about this plan?

Name:

Role:

Contact:

Where this plan is stored:

- ☐ **With me**
- ☐ **GP or clinician - Name:**
- ☐ **Support team file - Service:**
- ☐ **My Health Record**
- ☐ **Other:**

Final Reflection

This plan is here to support me with care, clarity, and respect - even when things get hard.

I have the right to change, pause, or revisit this plan whenever I choose.

I deserve to be supported in ways that honour my humanity, not just my risk.

Care History & Service Access Audit Tool

Purpose

This tool supports ethical, transparent care planning by offering a structured way to map an individual's treatment history, experiences of disengagement, and system-related barriers. It is particularly useful when considering a shift in care goals (such as harm reduction, respite, or palliative care) or when advocating for alternatives to standard treatment pathways.

It honours the weight of your care journey - moving beyond assumptions toward informed, values-led decision-making.

This tool may be particularly useful when planning case reviews, shifting care goals, or preparing for multidisciplinary meetings where service decisions are being made.

1. Overview of Eating Disorder History

Approximate duration of ED:

Diagnosis/es (if known):

Age of onset:

Has the diagnosis changed over time?

☐ **Yes** ☐ **No**

2. Medical, Psychiatric, and Allied Health Care Received

Include traditional, non-traditional, online, or overseas care if relevant

Type of Care	Accessed?	Approx. Years	Helpful?	Notes
GP/ Primary Care	**Yes** **No**		**Yes** **No** **Mixed**	
Dietitian	**Yes** **No**		**Yes** **No** **Mixed**	

Type of Care	Accessed?	Approx. Years	Helpful?	Notes
Psychologist/ Therapist	Yes No		Yes No Mixed	
Psychiatrist	Yes No		Yes No Mixed	
Peer Worker / Lived Experience Support	Yes No		Yes No Mixed	
Social Worker /Case Manager	Yes No		Yes No Mixed	
Culturally-Specific Services	Yes No		Yes No Mixed	
Gender-affirming or LGBTIQ+ service	Yes No		Yes No Mixed	
Other (please specify):	Yes No		Yes No Mixed	

3. Intensive or Inpatient Treatments

Service Type	Accessed?	Number of Admissions	Approx. Dates	Notes
Inpatient ED Program	Yes No			
Day Program	Yes No			
Medical Hospital Admission	Yes No			
Mental Health Inpatient (general)	Yes No			
Community or Outreach Team	Yes No			
Other	Yes No			

4: Engagement and Disengagement

Have I ever chosen to disengage from services?

☐ **Yes** ☐ **No**

If yes, what were the reasons?

Have services withdrawn care or refused engagement or re-engagement?

☐ **Yes** ☐ **No**

If yes, under what circumstances?

Have I ever experienced coercive treatment or medical trauma?

☐ **Yes** ☐ **No**

If yes, has this been explored and acknowledged in future care planning?

5: Barriers to Accessing Care

Tick all that apply

- ☐ Financial cost
- ☐ Wait times
- ☐ Geographic or rural isolation
- ☐ Co-occurring disability or neurodivergence
- ☐ Past trauma or mistrust of services
- ☐ Experiences of racism, ableism, transphobia, weight stigma, etc.
- ☐ Care options did not feel culturally safe or inclusive
- ☐ Services focused only on weight/BMI
- ☐ Services required weight restoration before offering support
- ☐ No peer-informed or trauma-informed options available
- ☐ Other:

6. Opportunities for Reconnection or Re-engagement

Are there approaches or supports I might be open to, if adapted or offered differently?

What would increase the likelihood of engagement at this stage (e.g., peer support, harm reduction, online options)?

7. Summary for Ethical Care Planning

Has my team clearly documented the care options that have been explored and whether they were accessible, inclusive, or appropriate for me?

☐ **Yes** ☐ **No** ☐ **In Progress**

If significant gaps exist, how will they be addressed or acknowledged?

If moving toward an alternative care approach (e.g., harm reduction, ACP), is there a transparent and respectful shared understanding of why?

Final Reflection

This audit is not a scorecard.

It is a way to honour my history - ensuring that decisions moving forward are grounded in my lived reality, not assumptions.

Advance Care Planning Workbook

Purpose

This workbook is to help individuals with longstanding eating disorders reflect on and communicate their care preferences in a way that protects their voice, dignity, and values, even during times when they may be unable to advocate for themselves.

Advance Care Planning is not about giving up.

It's about ensuring the care you receive is aligned with what matters most to you.

This resource can be used alone, with a trusted peer worker, family member, or clinician.

Your preferences may evolve over time - this workbook is a living document that can be revisited, updated, or adapted whenever you wish.

1. What matters most to me

What gives my life meaning, purpose, or joy - right now, even in small ways?

When I'm unwell, what helps me feel safe or supported?

Are there things I want to keep doing or being part of no matter what?

2. My Preferences for Care

Are there treatments or settings I want to avoid? Why?

Are there supports I would like, even if I don't want to pursue active recovery-oriented treatment?

- ☐ **Pain relief**
- ☐ **Hydration**
- ☐ **Enteral Feeding (i.e. tube feeding)**
- ☐ **Peer support**
- ☐ **Creative therapies**
- ☐ **Other:**

If I become more unwell or unable to speak for myself, what kind of care would feel respectful and manageable?

3. My Hopes, Fears, and Protective Boundaries

What fears or past experiences do I want my care team to understand?

Are there situations or treatments I never want to go through again?

How can people support me if I'm scared, overwhelmed or unable to express myself?

4. My Trusted Decision-Maker

If I cannot speak for myself, I trust the following person to help make decisions:

Name:

Relationship:

Phone:

Have I spoken with them about my wishes?

☐ **Yes** ☐ **No**

Do they feel ready to support me in this way?

☐ **Yes** ☐ **No**

Would I like to legally appoint them as my decision-maker (Enduring Guardian)?

☐ **Yes** ☐ **No**

NB: It's okay to change your decision or revisit this if your preferences shift over time.

5. Sharing My Plan

Who needs to know about my preferences?

- ☐ **GP**
- ☐ **Psychiatrist**
- ☐ **Psychologist**
- ☐ **Carer or family**
- ☐ **Other:**

Where is this plan stored?

- ☐ **My Health Record**
- ☐ **GP's file**
- ☐ **With a trusted support person**
- ☐ **Carer or family**
- ☐ **Other:**

When should this plan be reviewed or updated?

6. Final Reflections

If I could say one thing to my care team, it would be:

If I could say one thing to my future self, it would be:

Important Notes:

This workbook complements, but does not replace formal legal documents like Advance Health Directives (AHDs) or Enduring Powers of Guardianship (EPGs).

It helps ensure your values and preferences are documented even if legal instruments are not completed or available.

You can update or change this plan at any time.

This plan is about ensuring my care reflects who I am.

I deserve to be seen, heard, and supported, always.

Advance Care Planning Snapshot Summary Sheet

Purpose

This one-page summary is designed to highlight the key values, care preferences, and priorities you've identified in your Advance Care Plan.

It offers a quick reference to help loved ones, clinicians, or other support people understand what matters most to you, especially in times of uncertainty, crisis, or care transitions.

You can update or change this at any time.

Important Note: This Snapshot is not a legal document. It complements your Advance Care Planning Workbook and formal legal documents (such as an Advance Health Directive or Enduring Power of Guardianship) where available.

This document is intended to quickly communicate your values and priorities to those supporting you, especially during transitions, emergencies, or times when you cannot speak for yourself.

My Name:

Date Completed:

Next Review Date (if known):

1. Top 3 Things That Matter Most to Me, In Life or Care

What are the personal values, relationships, goals, or needs that feel most important to protect, honour, or prioritise - in your life, in care, or both?

2. Key Care Preferences and Any Boundaries I Want Respected

3. Trusted Person/Substitute Decision-Maker

- **This person is someone I trust to help make decisions if I am unable to speak for myself.**
- **They may or may not be my legally appointed Enduring Guardian**

Name:

Relationship: **Phone:**

4. Storage and Access

Where this plan is stored?
(e.g., GP file, My Health Record, with a peer worker, with a family member)

5. Other Important Notes or Instructions

Harm Reduction Planning Template

Purpose

This tool is for anyone who wants to create a flexible, values-aligned support plan when traditional recovery-focused care is not the right fit - right now. It helps individuals and care teams work together to reduce harm, build safety, and support dignity, even when change feels uncertain or recovery isn't the goal.

Harm reduction is not about doing less, it's about doing what matters most, in a way that feels possible, respectful, and grounded in trust. This plan can be completed individually or collaboratively with peer workers, carers, clinicians, or supporters.

1. Getting Started

Name:

Date Created:

Care Team Representative(s):

Others Involved:

Have I had access to evidence-informed care options?
(completing the Care History & Service Access Audit Tool may help answer this)

☐ **Yes** ☐ **No** ☐ **Not Sure/Partially**

If no, briefly explain (e.g. past trauma, service inaccessibility, personal values, neurodivergence):

2. What Matters Most

What's most important to me right now is...

Things that make life feel worth living are...

What I want to avoid is...

Risks or concerns noticed by the team (to be discussed together)

This section can be used to share any health, safety, or wellbeing concerns others have raised. Use it for collaborative discussion, not assumptions.

How do I define safety or stability?
What does feeling safe or stable mean to you - physically, emotionally, or in relationships?

Emotional safety
What helps you feel emotionally safe in care or in relationships?
(e.g. being listened to, not feeling judged, being able to say no, clear boundaries, calm tone)

Minimising physical distress

Are there specific physical symptoms or situations you want to reduce or avoid?
(e.g. fatigue, pain, intrusive procedures, sensory overload)

Predictability in relationships

What kinds of consistency or reliability in people or services help you feel more secure?
(e.g. knowing what to expect, clear roles, not being surprised by changes)

Not feeling pressured to change

What helps you feel supported rather than pushed?
(e.g. space to talk about change without pressure, having your pace respected)

Other

Are there any other factors or definitions of safety/stability that are important to you?

3. Concerns and Priorities

My view of my risks or priorities:

What worries me most right now is...

If things got worse, I'd want you to...

Team-identified safety or health risks (to be discussed together)

This is not a checklist for judgment, but a space for shared understanding and planning)

Medical instability *(e.g. physical health concerns, changes in weight, blood pressure, or vital signs)*

Self-harm or suicidality *(e.g. thoughts or behaviours that may place you at risk)*

Housing or financial stress **(***e.g. insecure housing, difficulty meeting basic needs, financial overwhelm)*

Isolation *(e.g. feeling disconnected from others, avoiding contact, limited support)*

Burnout or overwhelm *(e.g. emotional exhaustion, care fatigue, feeling unable to cope)*

Substance use *(e.g. using substances to cope, concerns around dependency or safety)*

Other

4. Harm Reduction Goals

These goals don't need to be perfect or permanent. They can reflect small actions, hopes, or strategies that help you stay connected to what matters.

Area of Focus	My Goal (in my words)	What I need	Who Will Help
Eating or nutrition			
Movement or rest			
Emotional regulation			
Medical monitoring			
Social connection			
Other			

5. Boundaries and Non-Negotiables

I do not consent to…

If these boundaries are not respected, I may respond in ways such as…
(e.g. withdrawing, feeling unsafe, avoiding appointments, becoming overwhelmed)

I feel most safe or supported talking about my eating disorder when…

NB: You have the right to name what you do and don't consent to. These boundaries help others understand how to support you in ways that feel respectful and safe.

6: Reconnection and Flexibility

If I become ready for more support, I'd like…

You'll know I'm open to change if I…

Please don't assume I'm in crisis just because…

Signs I might be struggling or need a different kind of support include:

- ☐ **Missed appointments**
- ☐ **Avoiding contact**
- ☐ **Engaging less than usual (e.g. only with some people or for certain topics)**
- ☐ **Noticeable changes in mood, energy, or communication**
- ☐ **Other:**

7. Plan Review and Follow-Up

This plan will be reviewed:

☐ **Monthly** ☐ **Every 3 months** ☐ **As needed**

Who is responsible to check in about this plan?

Name:

Contact:

Where is this plan stored?

☐ **With the person responsible for reviewing this plan**
☐ **Care team file**
☐ **My Health Record**
☐ **Other:**

Final Reflection

Harm reduction is not about giving up on people.

It's about showing up for them - with humility, with respect, and with care. Every person deserves to feel safe enough to stay connected, even when change is slow or uncertain.

Comfort-Focused Care Planning Tool

Purpose

This comfort-focused care plan builds on earlier values and planning conversations but is intended for times when treatment is no longer the focus - or when you are seeking comfort, dignity, and peace as your priority.

You can use this tool instead of, or alongside, other planning tools in the workbook. It's okay to skip sections you've already explored elsewhere or just use the prompts that feel most helpful right now. Some of the questions may feel familiar, but each tool offers a unique focus to support different stages, needs, and conversations in your care journey.

This plan is designed to reflect what comfort, dignity, and meaningful support look like for you - across physical, emotional, relational, and spiritual domains. It can guide care even if circumstances change, ensuring that your humanity remains central to all decisions.

Comfort-focused care is a valid and compassionate form of care. It honours your needs, values, and definition of wellbeing - even when those differ from traditional treatment goals.

1. My Physical Comfort

What helps me feel physically at ease is...

Things that cause me distress or discomfort are...

I would like support with... (e.g. pain relief, sleep, hydration, temperature regulation)

2. My Emotional and Spiritual Wellbeing

When I'm struggling emotionally, what helps is...

Things that give me a sense of calm or meaning include...

I find spiritual or existential support in... (e.g. nature, rituals, prayer, music, connection)

Would I like to explore support from a spiritual or cultural care provider?

☐ **Yes** ☐ **No** ☐ **Unsure / maybe later**

3. My Environment and Daily Life

Where I feel most at ease or safe is...

If I could choose, I would want to be cared for... (e.g. at home, in a familiar setting, near loved ones)

Small comforts that make a difference include... (e.g. pets, scent, lighting, music)

4. Connection, Legacy, and Meaning

People I want to stay connected to are…

Things I want to create, share, or leave behind include…

“Values or lessons I want to pass on include…

Ways I want to be remembered or honoured are…

I would like support to create something meaningful (e.g. letters, photos, recordings, rituals)?

☐ **Yes** ☐ **No** ☐ **Not sure**

5. Decision-Making and Support

Who I Trust:

If I become unable to make decisions for myself, I trust the following person to speak for me:

Name:

Relationship:

Contact:

Have I spoken with this person about my wishes?

☐ **Yes** ☐ **No**

Do I want this person legally appointed as my decision-maker?

☐ **Yes** ☐ **No** ☐ **Not sure yet**

Other people I want involved in my care:

People I do not wish to be involved:

This will be respected wherever possible and in line with safety and care needs.

6. Other Wishes and Reflections

This space is for anything not already covered that you want others to know:

Risks vs. Values Worksheet

Purpose

This worksheet is designed to support thoughtful, relational conversations about risk, values, and dignity in care.

It can be used for self-reflection, with your support network, or during times of uncertainty. It helps you explore the risks you may be facing, what could happen if those risks aren't managed, and how significant that impact might be for you.

This process can highlight different perspectives - such as what your care team might prioritise compared to what feels most important to you. For example, your team may focus on medical stability, even if you've had difficult experiences with medical care in the past. You might feel that the emotional distress of a hospital admission outweighs the physical risks of not going.

The tool helps clarify competing concerns, uncover hidden assumptions, and centre your own values - especially when recovery isn't the only or current goal. In longstanding eating disorders, risk is often present, but not all risk means danger or hopelessness. This worksheet can help you and your team respond with care and intention, rather than react out of fear.

1. Clarifying the Decision or Concern

What decision, situation, or care pathway are we exploring?

Why does it feel difficult or unclear for me?

Who is involved or affected by this decision?

2. Mapping Risks and Harms

Type of Risk or Harm	Examples or Concerns	Impact On	Level of Concern (Low/Medium/High)
Physical Health			
Emotional Distress			
Therapeutic Relationship			
Autonomy / Rights			
Family / Carer Impacts			
Cultural / Identity Safety			
Other (e.g. spiritual distress, housing loss, stigma)			

3. Exploring Value and Meaning

What matters most to me?

What could be lost or harmed if I engage in a standard eating disorder care approach?

4. Context and Caution

What past experiences might be shaping how I am perceiving the risks I am facing?
(e.g., a clinician may have high anxiety after a negative outcome, individuals may recall trauma from previous care experiences, or I may have felt pressured in the past).

Am I reacting from fear, grief, or other emotions?

Have I considered how this decision (whichever choice is made) will impact my relationships and supports?

Am I responding from fear, bias, or pressures from professionals more than from my own values and ethics?

5. Shared Reflection and Next Steps

Are there ways to meet safety needs while still honouring my values and voice?

Have I named and shared responsibility for the decision or plan?

☐ **Yes** ☐ **No**

What will be documented (e.g. care notes, advance planning, handover summaries), and how will it be communicated with transparency and care?

Who will follow up - and when?

What supports are needed for me moving forward?

Care Collaboration Summary Sheet

Purpose

This summary sheet helps document:

- Who is currently involved in the your care
- What agreements have been made
- What the next steps are
- It supports clarity, transparency, and continuity - especially during transitions, care
- planning reviews, or shared decision-making processes.

This sheet is a working document. It can (and should) be updated as care evolves.

1. Who Is Involved?

Name of person receiving care:

Carer or family member(s) (if involved):

GP or primary medical contact:

Psychiatrist:

Dietitian:

OT, or allied health professional:

Peer Worker or other community support:

Other key supports or services (e.g., housing, community, NDIS, advocacy):

2. What Has Been Agreed ?

Current goals or focus of my care:

Key harm reduction, ACP (Advance Care Planning), or comfort-focused decisions made:

My priorities, the teams priorities - want to avoid (e.g., coercion, re-traumatisation, loss of trust):

Shared language or relational approaches agreed to (e.g., “supporting safety” instead of “enforcing compliance”):

3. What Happens Next?

Date of next check-in, care review, or team meeting:

Person(s) responsible for checking in and following up:

Any outstanding referrals, documents, or coordination actions (e.g., ACP updates, medical reviews, peer support connection):

Plan if care becomes uncertain or distress increases:

Closing Reflection

With your consent, this summary can be shared across your care team, supporters,
and relevant services.

It is not a contract. It is a living tool designed to support shared understanding and accountability.

Revisit and update regularly to ensure it remains aligned with the your evolving needs, preferences, and circumstances.

Using This Summary Sheet Well

The following practices can help ensure the Care Collaboration Summary is used ethically and relationally - keeping my voice, values, and evolving needs at the centre of care.

Lead with Relationships	This summary is a guide for conversation, not a checklist. Begin with genuine connection and shared purpose.
Centre My Voice	Use my own words wherever possible. If a care goal or value is documented, it should reflect what matters to me - even if the language is different from what the care team might use.
Review Together, Not in Isolation	Whenever possible, review the completed summary with me, ensuring I feel ownership and understanding.
Update Transparently	Care goals, team roles, and agreements can and will shift. Updates should be invited openly rather than treating the document as final or fixed.
Use for Connection, Not Compliance	This tool is about keeping care aligned and person-led, not about rigidly enforcing expectations.
Reflect on Gaps	If coordination breaks down, name it. Use those moments to guide improvement and collaboration, not just individual response.

Optional Resources: Recovery Is Always an Option

This workbook centres your dignity, your voice, and what matters most to you - even if recovery isn't the current goal. But recovery is always an option.

You have the right to explore harm reduction and recovery-oriented pathways at different times, or even alongside each other. There's no single "right" way forward - just what's right for you, in this moment.

If you feel curious about recovery or want to explore what support could look like - now or later - here are some resources that may help:

- **Recovery & Wellness Workbook for Eating Disorders**
- **The Eating Disorder Recovery Journal: Creative Activities to Keep Yourself Well**
- **Eating Disorder Recovery Journal**
- **Inspiring Recovery**
- **Break Free from ED**
- **Navigating Long-standing Eating Disorders**

You can use these resources on your own, with a support person, or as part of future care planning. There's no pressure, only the invitation to stay connected to what matters most for you.

There's no single way forward, only the path that feels possible right now.

Take what's useful, leave what isn't, and know that support can look different over time.

Glossary

These definitions reflect the context of eating disorder care and advance care planning, including person-led, trauma-informed, and dignity-based approaches. Some terms have been drawn from the National Eating Disorder Strategy 2023 - 2033 and the National Palliative Care Strategy 2018 with adaptation to support practical, values-led use.

Term	Description
Advance Care Planning	Advance care planning is care planning that prepares for future healthcare needs by identifying and articulating the person's personal values, beliefs, and healthcare preferences. It enables individuals to make decisions about the health care they would or would not like to receive in the future if they became seriously ill and were unable to communicate preferences or make treatment decisions (Advance Care Planning Australia, 2024).
Advance Care Directive	An advance care directive documents a person's preferences for future healthcare and may include a record of their values, life goals, preferred outcomes and directions for future care and treatments.
Autonomy	Autonomy refers to a person's right and capacity to make informed, uncoerced decisions about their own life and care. In healthcare, respecting autonomy means acknowledging the individual's values, preferences, and choices, even when these differ from clinical recommendations - provided they have the capacity to decide (Beauchamp & Childress, 2019).
Capacity	Capacity refers to a person's ability to make informed decisions about their own care. While legal definitions vary across Australian states and territories, capacity is generally understood as the ability to understand relevant information, appreciate the consequences of a decision, and communicate a choice. In the context of mental health and eating disorders, assessing capacity should include consideration of trauma, relational context, and fluctuating cognitive or emotional states - and must not be conflated with agreement to treatment. *Note: For jurisdiction-specific details, refer to local mental health laws. This Guide includes Victorian principles as one case study*
Compassionate Communities Frameworks	A framework which extends care beyond clinical settings and promote shared responsibility, relational support, and community connection, especially in contexts of complexity, loss, or life-limiting illness (Dumont et al., 2022; Bakelants et al., 2023).

Complex	In a trauma-informed context, “complex” refers to circumstances, needs, or presentations that involve multiple, intersecting factors - such as trauma history, co-occurring conditions, systemic disadvantage, and relational or psychosocial distress. Complexity is not simply about diagnostic difficulty or service fragmentation; it recognises the impact of structural and relational adversity, and the need for care that is flexible, nuanced, and person-led (Sweeney et al., 2016).
Co-occurring/ Co-existing conditions	Refers to the presence of two or more conditions or experiences at the same time. In the context of eating disorders, this often includes co-occurring or co-existing mental health challenges such as anxiety, depression, trauma-related disorders, or substance use. These conditions may interact in complex and compounding ways, affecting care needs and recovery pathways (SAMHSA, 2016).
Dignity of Risk	People have the right to make informed choices, even when those choices involve uncertainty or perceived risk *(Mental Health and Wellbeing Act, 2022).* An understanding that autonomy, growth and development often require an element of risk, and that allowing some level of risk shifts the focus to collaborative support, rather than coercive (Marsh & Kelly, 2018).
Disordered Eating	Disordered eating encompasses eating behaviours and patterns that fall between ‘normal’ eating and an eating disorder, generally including symptoms and behaviours of eating disorders at a lower frequency or level of severity. Restrictive, compulsive, irregular and/or inflexible eating behaviours and patterns may be considered disordered eating and are a risk factor for the development of an eating disorder.
End of Life	End of life refers to the stage in a person’s life when they are living with an advanced, progressive, and life-limiting condition, and where death is likely within a period of months, weeks, or days. It may be brief or prolonged and includes the physical, emotional, social, and spiritual support needed during this time.
Enduring Power of Guardianship	An Enduring Power of Guardianship is a legal document that allows a person to appoint someone they trust to make personal, lifestyle, and health-related decisions on their behalf, if they lose decision-making capacity in the future. The appointed guardian may be authorised to make decisions about medical care, living arrangements, and other non-financial matters, depending on the powers granted (ALRC, 2014). In Australia, the scope and legal process for EPGs vary by state and territory. In Western Australia, for example, EPGs are governed by the *Guardianship and Administration Act 1990 (WA)* and must be made while the person has full capacity.
Evidence-based Practice	An approach to practice and decision-making that relies on the best available evidence. Evidence-based practice involves the integration of research evidence, clinical expertise, and person values and perspectives, to inform care.

Family/supports and Community	An individual who provides care, support, or advocacy for someone experiencing an eating disorder. This may include family members (e.g., parent, child, partner, grandparent), friends, or members of the broader community. It is important to recognise that cultural and relational contexts vary and that extended family, chosen family, and community networks often play vital roles, particularly within Aboriginal and Torres Strait Islander communities and other cultures.
Grief	Grief is a natural response to loss, encompassing emotional, cognitive, social, and physical reactions. While traditional models - such as the five stages of grief - may describe common themes (e.g., denial, anger, bargaining, depression, acceptance), grief does not follow a fixed path or timeline. Each person's experience is unique, shaped by their relationship to the loss, cultural context, personality, and available support.
Harm Reduction	Harm reduction is a pragmatic, person-centred approach that seeks to minimise risk and support safety, dignity, and engagement - especially when treatment is declined, not accessible, or no longer effective. In the context of longstanding eating disorders, harm reduction can include medical monitoring, flexible therapeutic goals, and relational support, without requiring recovery as a precondition for care. (Birch, Downs & Ayton, 2024).
Life-limiting Illness	A life-limiting illness, also known as a terminal illness, is a condition or disease that has little or no prospect of cure and is likely to cause death at some point in the future.
Lived Experience of an Eating Disorder or Disordered Eating or Body Image Concerns	An individual who has previously or is presently experiencing an eating disorder (whether diagnosed or undiagnosed), disordered eating or body image concerns.
Longstanding Eating Disorder	A descriptive term used to refer to individuals who have been living with an eating disorder for a prolonged period - often alongside significant health, social, or treatment-related challenges. This term acknowledges the ongoing nature of the experience without implying hopelessness or permanence.
Mental Health Law	A framework of legislation that governs the assessment, treatment, and rights of individuals experiencing mental illness. These laws differ across Australian states and territories, with each jurisdiction having its own Mental Health Laws outlining legal criteria for involuntary treatment, decision-making capacity, and safeguards. In this Guide, mental health law is referenced in the context of ethical care, capacity, and systemic obligations.
National Safety and Quality Health Service Standards (2021)	The National Safety and Quality Health Service Standards aim to protect the public from harm and to improve the quality of health service provision. The Standards provide guidance as to the level of care consumers can expect from health services (Australian Commission on Safety and Quality in Health Care, 2021).

Palliative care Principles	Palliative care principles refer to a holistic approach to care that prioritises quality of life, dignity, and relief of suffering for individuals living with serious or life-limiting conditions. These principles include person-centred care, respect for autonomy, comfort, open communication, and support for emotional, spiritual, and psychosocial needs. They are relevant across the care continuum - not only at end of life - and can be applied alongside therapeutic, harm reduction, or community-based approaches (Palliative Care Australia, 2018; World Health Organization, 2020)
Person-centred Care	Person-centred care is an approach that respects, acknowledges and responds to a person's preferences, needs, and values. It treats individuals as human beings rather than conditions to be treated or cured, and it includes the person, along with their families, carers, and supports in all care and decision-making processes (Australian Commission on Safety and Quality in Health Care, 2021).
Person-led Care	Person-led care builds on person-centred principles by placing the individual in a leading role - actively guiding the direction, pace, and priorities of their care journey. This approach is especially important when navigating trauma, complexity, or longstanding health conditions. Person-led care honours autonomy and seeks to rebalance traditional power dynamics in healthcare and support systems (Sweeney et al., 2016).
Recovery	A subjective state defined by an individual that reflects personal goals and perspectives. For some people experiencing eating disorders, recovery may signify overcoming the thoughts, feelings, beliefs and behaviours associated with the eating disorder, resulting in improved physical and psychological wellbeing. For others, recovery may reflect a dynamic process of moving towards or maintaining a subjective state of wellbeing or quality of life.
Relational Authority	Relational authority refers to the influence, insight, and trust that emerge through sustained, authentic relationships - particularly when legal documents (such as an Advance Health Directive or Enduring Power of Guardianship) are absent or limited. In the context of care, it recognises the knowledge held by those who have walked closely alongside a person - such as family, peer workers, or long-term supporters - whose relational understanding can guide values-aligned decisions. This concept is grounded in relational ethics, which values interdependence, trust, and the situated knowledge that emerges through meaningful human connection (Hirsch , 2023).
Relational Ethics	Ethical decisions are grounded in the quality of the relationships involved. It involves deep listening, being present and responsive, collaborative decision making and building authentic connections (Pollard, 2015).
Severe and Enduring Eating Disorder	A 'severe and enduring eating disorder' may refer to an eating disorder that exhibits prolonged duration, however this is not a diagnostic term and there is currently no consensus definition. Further research into criteria and preferred terminology is needed.

Shared Decision-Making	Shared decision-making is a transparent, collaborative process that includes the person receiving care, their family or carers (if appropriate), and health professionals. It respects the individual's values and preferences while integrating clinical knowledge and cultural or lived experience expertise (Advance Care Planning Australia, 2022).
Specialist Palliative Care Services	Services provided by a multidisciplinary team of clinicians who have specialist skills, competencies, experience and training in palliative care. These services may provide direct care to patients with complex palliative care needs, and/or provide consultation services to support non-specialist clinicians to provide palliative care.
Spiritual Care	Spiritual care involves recognising and responding to the needs of the human spirit when people are facing trauma, illness, or grief. This may include the need for meaning, connection, faith, hope, or a sense of peace. Spiritual care can be religious or non-religious and is shaped by the person's own beliefs, values, and culture. It may be provided by a chaplain, spiritual adviser, cultural healer, or by trusted people within the person's community or care team (Royal College of Psychiatrists, 2020).
Stepped System of Care for Eating Disorders	The stepped system of care for eating disorders depicts the full continuum of coordinated, evidence-based services that should be available and increase or decrease in intensity according to a person's changing needs (NEDC, 2023).
Substitute Decision-maker	Someone that an individual trusts to make healthcare decisions on their behalf if they become unable to do so. They may be appointed as part of an advance care planning directive.
Terminal Illness	A condition that is expected to lead to death, typically within a relatively short time frame. In palliative care, "terminal" often refers to the final stage of a life-limiting illness, where curative treatment is no longer effective or appropriate, and the focus shifts to comfort and quality of life (Australian Commission on Safety and Quality in Health Care, 2021).
Trauma-Informed Practice	An approach to care that recognises the widespread impact of trauma, prioritises emotional and psychological safety, and avoids re-traumatisation. It emphasises choice, trust, collaboration, and cultural humility in every aspect of support (Blue Knot Foundation, n.d.).

References

Full references for tools and frameworks are included in The Holding Hope Guide.