Holding Hope WORKBOOK

For People who Care For, Love or Support Someone 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.

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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.

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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).

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Before You Begin

If you are reading this, you may be someone who cares deeply - walking alongside a person who is living with a longstanding eating disorder. That care might take many forms: quiet presence, fierce advocacy, practical support, or simply continuing to show up despite the uncertainty.

This workbook has been created with you in mind.

We know that families, partners, and close supporters often carry invisible burdens. You may have felt left out of conversations, unsure where to turn, or caught between wanting to help and not knowing how. You may be holding grief, frustration, fear - or moments of connection and hope that others don't always see. All of this belongs here.

These pages are not here to offer simple answers, nor to assume that your role or relationship is easy to define. Instead, they are designed to support reflection, to invite grounded conversation, and to gently guide decision-making when things feel complex or heavy. They sit alongside The Holding Hope Guide - a resource written for everyone involved in this space - but this workbook speaks directly to the people who love and care in ways that often go unrecognised.

We also acknowledge that not everyone is in a close or active caregiving role - and that for some, relationships may be strained, fractured, or marked by trauma. If you are reading this with distance or hesitation, your presence is still valid. You do not have to be "everything" to be someone who matters.

You'll find tools in this workbook that explore what care can look like, how to navigate uncertainty, and how to care for yourself while walking alongside someone else. These tools are not here to judge or direct, but to support thoughtful, values-based choices - whether in moments of crisis, quiet reflection, or shared planning.

We hope this resource can offer something practical, something steady, and something human. Most of all, we hope it affirms that your care, your questions, and your presence matter.

With appreciation,

Shannon Calvert and the NEDC Project Team

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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 care for, love or support someone with a longstanding eating disorder.

The experiences of families and supporters are crucial when considering alternative care pathways. Some tools are specifically designed to include your perspective in a respectful and considered way. The tools may support deeper understanding, shared planning, and meaningful involvement in care aligned with the individual's wishes.

This workbook offers thoughtfully designed tools to support families and carers in providing safe, respectful, and person-centred care. It recognises the carer's journey as uniquely complex and honours the diverse experiences that shape each individual's path.

Each tool can be used in a way that suits your circumstances-whether for personal reflection, in collaboration with a loved one affected by a longstanding eating disorder, or alongside health professionals and support networks.

These resources are not checklists or formal assessments. They are meant to be revisited, adapted, and used flexibly over time. Each person's experience is different, and these tools are here to reflect and respect that.

You are welcome to:

- Photocopy or print individual tools from the workbook
- 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

Whenever possible, we encourage using this workbook in partnership - whether with a trusted health professional, peer worker, family member, or care coordinator. These tools are most powerful when part of a respectful, ongoing collaboration that honours every voice and role in the care process.

Access the Holding Hope Guide here

Reflecting on Our Beliefs, Values and Hopes as Loved Ones: Worksheet

Supporting care with curiosity, understanding and compassion

Purpose

This worksheet invites families, carers, and loved ones to gently explore how our own beliefs, experiences, and hopes may shape the way we understand and support someone living with a longstanding eating disorder.

It is not about blame or having the right answers. It is about holding space for the complexity of care - especially when things feel uncertain, difficult, or outside the boundaries of what we hoped for.

These questions are here to support reflection, not judgment. They may bring up discomfort, sadness, or relief. There is no need to complete them all at once. Use them in your own time, or talk them through with someone you trust.

You are doing something incredibly difficult. Taking time to reflect is not a sign of failure - it is a sign of care.

This worksheet may be helpful when:

- You feel unsure what is right or helpful
- You feel torn between safety and respecting choice
- You are worried your own emotions or history may be influencing your reactions
- You want to pause and reflect on how to support in ways that feel more aligned with what matters most

You may also wish to revisit this worksheet throughout your journey, especially when care decisions feel complex or emotionally charged.

1. Holding Onto Hope

What have I been hoping for most - and why does that matter to me?

Have I found it difficult to accept that progress might look different from full recovery?

Have I been able to talk with my loved one about what hope looks like for them?

2. Understanding Reactions and Emotions

Do I feel helpless, anxious, or frustrated when my loved one refuses support or care?

Are there times I have reacted out of fear or urgency rather than reflection?

How do I usually respond when I feel powerless to make things better?

3. Reflecting on Past Experiences

Have my past experiences with health care, trauma, or loss shaped the way I see this situation?

Are there aspects of my loved one's story that feel especially familiar or painful to me?

Could these past experiences be affecting how I perceive risk, safety, or what's possible?

4. Considering Different Perspectives

Have I had the chance to listen deeply to how my loved one feels about their care - including what has helped or harmed?

Are there times I have struggled to understand their choices, even if they made sense to them?

Do I recognise that people can want support - but not always in the way we expect?

5. Language and Meaning

Have I found myself using language like “refusing,” “manipulating,” or “not trying hard enough”?

How might I reframe this in a way that feels more compassionate or person-centred?

Have I acknowledged the strength it takes to survive and speak up - even when it feels hard to hear?

6. Values in Tension

Are there times when my values (e.g. safety, independence, honesty) feel in tension with my loved one’s values or choices?

Have I been able to name this tension - and talk it through with support?

Am I holding myself to unrealistic expectations about what I should be able to fix, know, or control?

7. Moving Forward with Care

What do I need to feel more supported in my carer/supporter role?

Are there ways I can stay connected to my loved one while also looking after my own wellbeing?

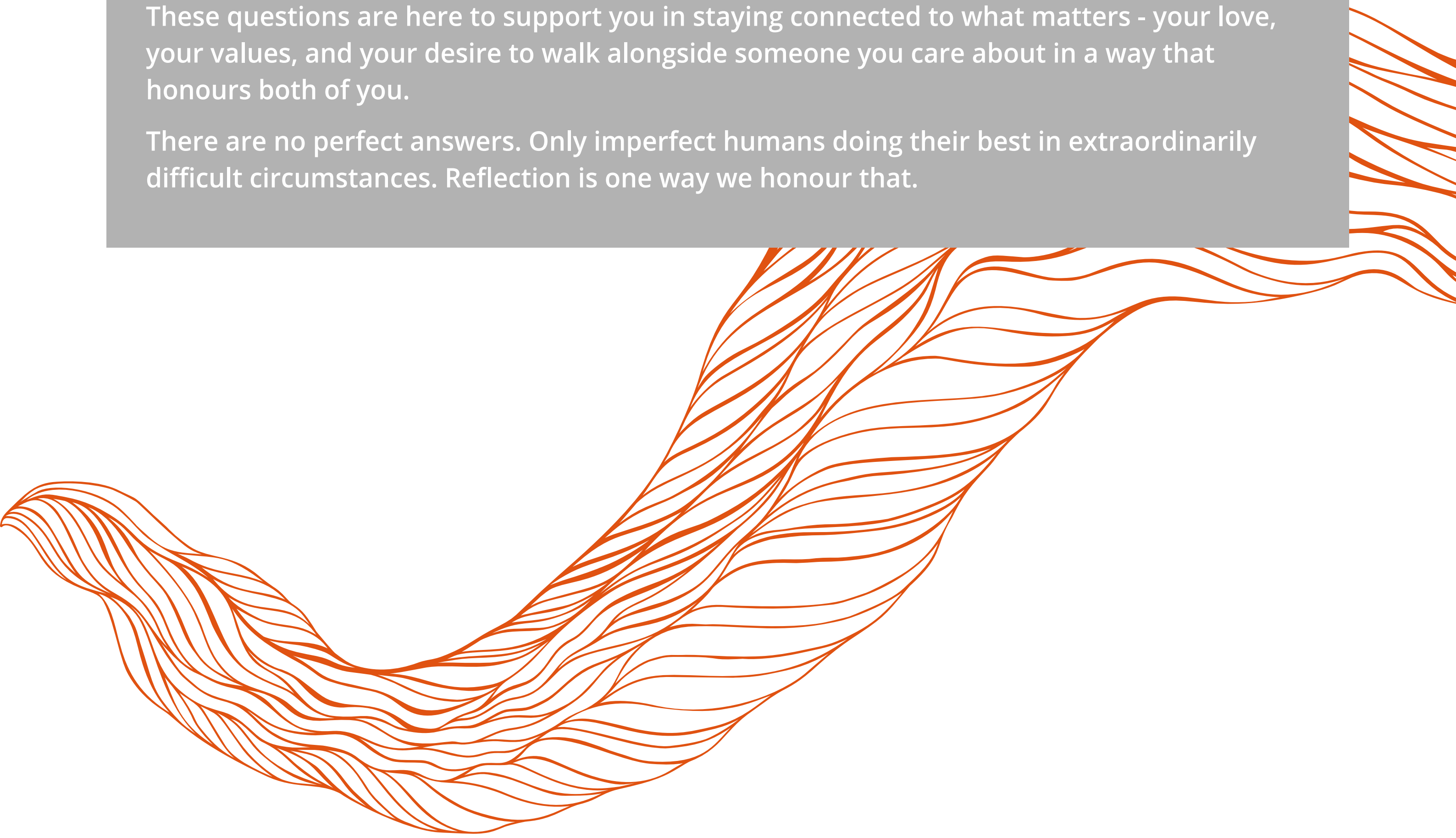
What would compassionate support look like - for both of us - even when we see things differently?

Closing Reflection

You are not expected to carry this alone.

These questions are here to support you in staying connected to what matters - your love, your values, and your desire to walk alongside someone you care about in a way that honours both of you.

There are no perfect answers. Only imperfect humans doing their best in extraordinarily difficult circumstances. Reflection is one way we honour that.



Family Supporter Reflection Tool

Purpose

This tool is designed to help you reflect on your experience, role, and needs in supporting someone whose relationship with care and recovery may be complex.

You can complete it privately, with support, or bring it into care planning conversations if you wish.

Remember:

- You are not expected to have all the answers
- You do not need to be perfect to be present
- Your care matters - and so does your wellbeing.

This tool is not about saying the right thing - it's about making space for what's real, even if it's uncertain, contradictory, or hard to put into words.

If you need support, consider reaching out to:

- Eating disorder carer peer services
- Mental health carer support lines
- Culturally specific or faith-based carer organisations
- Professionals involved in the care planning process who can listen without judgement.

1. Your Relationship and Role

What is your relationship to the person you are supporting?

What does "support" look like for you right now? (e.g. emotional, practical, advocacy)

Has your role changed over time? In what ways?

2. Your Hopes and Fears

What do you most hope for - in their care, or in their life more broadly?

Are there fears you carry - and how do they affect you?

Are there particular situations that feel hard to navigate - emotionally, practically, or relationally?

3. What You've Seen and Experienced

How long has the person you care about been affected by an eating disorder?

What kinds of treatment or support have they had - and what was helpful or harmful?

Have you noticed times where they were most connected or able to engage?

Are there recurring challenges in the system that have made their journey more difficult?

4. Your Needs and Boundaries

Do you feel heard and respected by services or professionals?

What kind of support do you need to stay steady in your role? (e.g. respite, emotional support, clear communication)

Are there any boundaries you need to set to protect your own wellbeing?

Is it difficult to say "I don't know what to do"? Is there anyone you can safely say that to?

5. Navigating Care Conversations

Do you feel included in care conversations? Is it in a way that feels supportive and appropriate? Are there things you wish professionals understood about your perspective, culture, or experience?

If Advance Care Planning or harm reduction approaches are discussed, what thoughts or concerns come up for you?

Are you clear on what your role is - and what it's not expected to be?

6. Supporting Autonomy and Connection

Are you able to stay connected with your loved one, even if you don't agree with their choices?

What helps you honour their autonomy without feeling like you are abandoning them?

What have you learned about balancing stepping in with stepping back?

7. Personal Reflection or Message

This space is for you - to reflect, write, or speak from the heart.

You might want to write a message to yourself, to the person you support, or to their treating/care team

Examples:

“I’m scared, but I also trust that my role isn’t to control everything.”

“I love ________ and I want to be part of their care, but I need help too.”

“It’s hard to watch how worn down they’ve become by their experiences in the system. I hope we can work together to build something more supportive.”

“I want to feel like our reality is heard - not just assumed. That’s how trust begins.”

When care gets complex, love and fear often sit side by side.

This tool is not about fixing the person you care for - it’s about staying connected, grounded, and clear in your role.

You are part of the circle of care - and your experiences matter.

Family Version: Advance Care Planning Companion Tool

Purpose

This tool is to support you - as a loved one - to share insights, concerns, and reflections when your family member is considering changes to their care. It may be especially useful when formal legal documents (such as Advance Health Directives) are not yet in place, but your role remains significant.

This tool is not a legal document. It is a relational and ethical resource that can guide shared understanding and support meaningful care planning alongside your loved one.

1. What I Understand About My Loved One's Wishes

What has your loved one shared - in words or actions - about the kind of care they want or don't want?

Are there specific care experiences or settings they've clearly expressed wanting to avoid or revisit?

What do you believe matters most to your loved one in terms of dignity, comfort, and safety?

2. What I'm Hoping For in This Process

What would respectful involvement look like for you?

What kind of support do you need to stay steady and included - without being over-responsible?

Are there specific fears or concerns you'd like to name - even if you don't have all the answers?

3. Examples of Ways I Can Support My Loved One

Tick any that feel true for you:

- ☐ **Emotional or relational support**
- ☐ **Practical care (e.g. transport, meals, attending appointments)**
- ☐ **Cultural or spiritual advocacy**
- ☐ **Communication with services**
- ☐ **Quiet presence or companionship**
- ☐ **Other:**

4. Personal Message or Reflection

You may wish to write a short note to your loved one, to their care team, or simply to reflect on this moment. This is your space.

Reminder:

Your care, insight, and presence matter. Even without formal authority, you bring vital relational knowledge and advocacy that can guide ethical, values-based care planning.

This tool can be shared in meetings, appointments, used in supervision, or included in care documentation with you and your loved one's consent.

Risks vs. Values Worksheet

Purpose

This worksheet supports reflective, relational conversations about risk, value, and dignity in care. It helps clarify competing concerns, surface hidden assumptions, and centre the person's values - particularly when risk is present, but recovery is not the only or current goal. In longstanding eating disorders, risk is often present - but not all risk signifies danger or hopelessness. This tool helps teams respond thoughtfully rather than reactively.

Use this tool in self-reflection, with your own supports or at times of uncertainty.

It does not replace clinical or legal frameworks - but aims to strengthen ethical clarity and relational integrity.

1. Clarifying the Decision or Concern

What decision, situation, or care pathway is being explored?

Why does it feel difficult or ethically unclear?

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 my loved one?

What could be lost or harmed if my loved one engaged in a standard eating disorder care approach?

What could be protected, upheld, or honoured by shifting to an alternative care pathway?

4. Context and Caution

What past experiences might be shaping how I am perceiving the risk my loved one is facing? *(e.g. a clinician may have high anxiety after a negative outcome, individuals may have previously been able to stay in the community when a similar thing happened, carers may be recalling a traumatic event)*

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

Have I considered how this decision (whichever choice is made) will impact the relationship I have with my loved one?

Am I responding from fear, bias, or pressures (from myself or others) rather than from shared values and ethics?

5. Shared Reflection and Next Steps

Are there ways to meet safety needs while still honouring my loved one’s voice and values?

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

☐ **Yes** ☐ **No**

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

Who will follow up - and when?

What supports am I and/or our family/friends going to need moving forward

Scenario Walk-Through Tool

Purpose

This tool helps you map the possible outcomes of a difficult decision about your loved one’s care or circumstances, alongside emotional, relational, and ethical impacts. It is designed to support clearer thinking and foster shared accountability. You may use it for self-reflection, with your own supports, or in conversations with the care team. This tool is not about finding a perfect or risk-free path - it is about navigating complexity with care, courage, and integrity.

1. Defining the Scenario

What decision or situation are we currently facing?

Why does this feel difficult, risky, or ethically complex?

Who is involved - and who might be affected (including our families, friends, community, culture, or beliefs)?”

2. Exploring Possible Pathways

For each potential course of action, consider:

Option	Brief Description	Likely Outcomes	Emotional/ Relational Impacts	Ethical Considerations

Prompting Questions for Each Row:

- **Option: What are the possible actions or pathways?**
- **Brief Description: What does this option involve practically?**
- **Likely Outcome: What are the realistic clinical or care outcomes?**
- **Emotional / Relational Impacts: How might this affect trust, safety, grief, connection?**
- **Ethical Considerations: Which values (e.g., autonomy, dignity, justice) are being upheld or compromised?**

3. What We're Carrying

What personal fears, assumptions, hopes, or loyalties are shaping my thinking?

Am I reacting from urgency, fear, guilt, grief, or compassion?

Am I holding moral distress, responsibility, or unresolved past experiences that may be influencing this moment?

4. Integrity and Intentions

What would it mean to act with integrity here - even if the outcome remains uncertain?

How do I want to show up for my loved one - regardless of which pathway is chosen?

What individual or collective supports might help us move forward with clarity and care?

Closing Reflection

Decisions in complex care often evolve. This tool can be revisited as situations shift, or new information emerges.

Acting with care is not about finding certainty - it is about staying aligned with values, humanity, and relational trust at every step.

Understanding Ethical Decision-Making in Care: Worksheet

What helps guide decisions when things feel uncertain?

Purpose

When a loved one is unwell - especially with a longstanding illness - the decisions made by care teams can feel confusing, upsetting, or even at odds with what you hoped for.

This worksheet is here to help you understand how ethical decisions are made in healthcare settings - and to reflect on how your voice and values might also be considered within this process.

It does not assume you are responsible for decisions. But it does recognise that you are deeply affected by them - and that your insight, concern, and compassion matter.

You may wish to use this worksheet:

- To reflect after a difficult appointment or case conference
- When a care decision feels unclear, distressing, or unexpected
- When you want to better understand how values and ethics are considered
- To prepare questions or reflections to bring to a care team or clinician

This tool can be read alone or shared with a support worker, advocate, or health professional. It is offered with deep respect for the role you are carrying.

1. What’s Happening?

What decision, change, or care plan is being discussed - and are there parts I disagree with or find challenging? Why?

What do I know about how this decision was made - and was I given the opportunity to be involved or informed as a carer?”

What has my loved one said or shown about what matters most to them - and how can my perspective as a carer also be included and respected in this process?”

2. What Do Ethical Care Teams Try to Balance?

Care teams are often trying to weigh up many things at once - including:

- **Safety (avoiding harm)**
- **Autonomy (respecting the person’s right to choose)**
- **Dignity (preserving self-worth and values)**
- **Engagement (staying connected, not forcing compliance)**
- **Equity (considering culture, identity, access, and systemic barriers)**

Does it seem like the team is trying to balance these? Have any been prioritised or overlooked?

Do I feel that ethics - not just rules or protocols - are guiding this decision?

Do I see any values in tension - for example, safety versus dignity, or risk versus trust?

3. What’s Being Missed or Left Out?

Whose voice has been included in this process?

Has my loved one been supported to express their views, even if they are unwell or distressed?

Have I had a chance to share what I know - not just about symptoms, but about what matters to them as a person?

4. Emotional Layer

Have I been able to name how I feel - fear, sadness, frustration, guilt - and be heard without blame?

Do I understand how the team is managing their own emotions, fears, and responsibilities?

Do I feel that these emotional layers are being acknowledged in a caring and respectful way?

5. Clarity, Care and Communication

Has the team communicated their reasoning clearly - including what was considered, what's being tried, and why?

Do I know how the plan will be followed up, and who to speak to if things change or I have questions?

Do I feel included and informed, even if I am not the decision-maker?

Closing Reflection

Not every decision will feel right to everyone. Sometimes, even when ethics guide the process, the outcomes still feel heartbreaking or uncertain.

Care Collaboration Summary Sheet

Purpose (Carer/Family version)

This summary sheet provides a shared record of your loved one's care, including:

- Who is currently involved in their care
- What agreements have been made
- What the next steps are

It is designed to support clarity, transparency, and continuity - especially during transitions, care planning reviews, or shared decision-making processes. This is a working document, intended to evolve as care needs and circumstances change, and to ensure that carers, family, and supporters are included and informed.

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 care (in the person's own words where possible):

Key harm reduction, Advance Care Plans, or comfort-focused decisions made:

Priorities for what the person - and the team - 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

This summary can be shared (with the person's consent) across their 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 person's 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 the person's 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 the Person's Voice	Use yours and your loved one's own words wherever possible. If quoting a care goal or value, honour its meaning - even if it doesn't match language used by the care team.
Review Together, Not in Isolation	Whenever possible, review the completed summary with your loved one, ensuring they feel ownership and understanding.
Update Transparently	Care goals, team roles, and agreements can and will shift. Invite updates 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.

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 promotes 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
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.).

Note: References for tools and frameworks are included in The Holding Hope Guide.