Holding Hope GUIDE

A collaborative, ethical guide for supporting dignity, choice, and person-centred care in longstanding eating disorders.

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.

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

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About the National Eating Disorders Collaboration (NEDC)

NEDC is a national sector collaboration dedicated to developing and implementing a nationally consistent, evidence-based system of care for the prevention and treatment of eating disorders. NEDC is funded by the Australian Government Department of Health, Disability and Aging. Over the past decade, NEDC has created a large body of comprehensive, evidence-based information and resources that establish standards for the prevention and treatment of eating disorders. NEDC implements these standards in system-building projects, workforce development and consultation.

To inform its work, NEDC engages a broad range of stakeholders, including people with lived experience of eating disorders and their families and supports, clinicians, researchers, and other experts. NEDC also provides expert consultation and guidance on evidence-based provision of eating disorder services to policymakers and national, state/territory and regional health, mental health and community organisations. NEDC's work is led by National Director Dr Sarah Trobe and Chair Professor Phillipa Hay, and a Steering Committee of national sector leaders and experts. NEDC's contract is administered by the Butterfly Foundation on behalf of the Commonwealth Government.

Learn more about NEDC's work at www.nedc.com.au

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About the Author
Shannon Calvert

Lived Experience Educator & Advisor

Shannon Calvert is a lived experience specialist with extensive expertise in eating disorders, mental health, suicide prevention, and palliative care. Her work spans both government and non-government sectors, where she has held advisory, consultancy, and leadership roles across policy, clinical education, research, and systems reform.

As an educator and advisory consultant, Shannon is known for her ability to support multidisciplinary teams with a strong focus on trauma-informed care, ethics, and lived experience leadership. She facilitates co-designed partnerships that shape evidence-informed policies, research initiatives, and educational programs that reflect the needs of people most impacted by complex care.

Shannon's dedication to this work is deeply personal. She has lived with, and survived a longstanding eating disorder while navigating complex trauma and chronic health conditions. Alongside her own experience, she has provided peer-informed support to others navigating similar paths. Her role as a carer for her mother through end-of-life also profoundly shaped her commitment to compassionate, values-led care across the lifespan.

Shannon is committed to advancing ethical, person-centred approaches that honour lived experience as both expertise and leadership. Through her work, she champions the development of sustainable, compassionate models of care, particularly for those often marginalised in traditional systems. She continues to advocate for sector-wide change that balances clinical insight with human dignity and supports the wellbeing of both individuals and the workforce that cares for them.

Acknowledgment and Dedication

This Guide has emerged from years of dialogue, reflection, and community input - shaped by those who generously contributed to the original Holding Hope Discussion Paper (2023), and those who have since engaged in ongoing conversations that helped transform its ideas into practice. We honour the lived and living experiences that have guided every stage of this work, and the dedicated colleagues across disciplines who have walked alongside - including peer workers, clinicians, researchers, policymakers, and supporters. Your honesty, critique, care, and hope have informed the Guide's tone, content, and direction.

We are especially grateful to the diverse reviewers who brought insights across psychiatry, nursing, psychology, dietetics, counselling, academia, research ethics, palliative care, service design, and the invaluable insights drawn from lived and diverse experiences.

Your willingness to question, reflect, and collaborate has strengthened the depth, clarity, and relevance of this resource.

Dr Adaeze Bradshaw
Clinical Director & Consultant Psychiatrist
Lincolnshire Partnership NHS Foundation Trust (LPFT NHS)

Megan Bray
Director & Accredited Practicing Dietitian
Collective Health Co

Dr Sophie Davison
Chief Psychiatrist
Australian Government Department of Health, Disability and Aging

Dr Anthea Fursland
Clinical Psychologist
The Swan Centre

Professor Phillipa Hay
Chair of Mental Health; Academic Psychiatrist
Western Sydney University

Laura Kiely
Accredited Practicing Dietitian; Gestalt Psychotherapist; PhD Candidate
Western Sydney University

Dr Randall Long
A/Prof Randall Long
Senior Consultant Psychiatrist; Head of Unit; Senior Lecturer
Statewide Eating Disorder Service & Consultation Liaison Psychiatry Service
Flinders University

Gabriel Lubieniecki
Credentialed Eating Disorder Clinician;
Lived Experience Advocate; PhD Candidate
Western Sydney University
The Swan Centre

A/Prof Andrea Phillipou
Associate Professor / Principal Research Fellow in Eating Disorders
Head, SWAN Research Group
Orygen / Centre for Youth Mental Health
The University of Melbourne

Anna Rose (née Millichamp)
Accredited Practicing Dietitian, PhD Candidate;
Senior Sessional Teaching Fellow
Bond University

Dr Jacinta Tan
Retired Consultant Child & Adolescent Psychiatrist; Clinical Academic and Medical Ethicist
Imperial College London
My Lighthouse Ltd

Dr Vicki Tsianakas
Lecturer; Medical Anthropologist
King's College London

Special Dedication

This Guide is dedicated to every individual, family member, carer, and supporter whose life has been shaped by a longstanding eating disorder.

It is for those who have sought care and found it wanting. For those who have been brave enough to ask for something different. For those who have quietly endured when systems could not meet them with compassion.

It is also for those whose lives were lost, and whose memory continues to guide and ground this work. Though your names may not be written on these pages, your stories are held within every section of this Guide. Your experiences, and the enduring love and advocacy of those who carry your legacy, have not been forgotten.

To the professionals who have walked alongside with open hearts and open minds - who have made space for relational care, questioned rigid pathways, and placed dignity at the centre, your courage and commitment are recognised and deeply valued.

This document exists because of you all. It is built from the conversations, reflections, and collective efforts of many. With reverence and responsibility, we honour what you've lived, what you've offered, and what you continue to teach.

We carry both deep gratitude and heartfelt dedication to those whose lives were shortened by this illness, and to the families, friends, and communities who hold their memory with enduring love. Their stories, courage, and advocacy continue to guide this work with profound responsibility.

In Loving Memory and Deep Appreciation

Katie and the Bennett family, especially her mother, Ellen Bennett, and her fearless advocacy at KMB for Answers.

Kasey and the Piekunka family, especially her sister Kym Piekunka, for her bold and passionate advocacy through 'Resilient Siblings.'

Emilee and the Mazur family, especially Jack and Linda and their tireless work with The Emilee Connection.

Caitlin and her exceptional mother, Faye.

Katie, and the Brauman family, especially her mother, Sarah.

Sally and the family and friends who stood beside her.

Chloe, and the Tupper family, whose legacy is held dearly in her art 'A Life Within Stillness: Illuminating Severe Enduring Anorexia Nervosa'.

To my mother, who believed in me during my darkest hours: though she is no longer with me, her love, courage, and unwavering faith sustained me for nearly forty years. It is through our shared struggles, and the lessons I've learned from others, that this work has come to life.

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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A note on language

The language used in this Guide reflects a careful effort to balance established terminology in clinical, academic, and service contexts with the evolving preferences and lived experience insights emerging from the field.

We primarily use the term ‘longstanding eating disorder’ to describe experiences where an eating disorder has significantly and negatively impacted a person’s physical, emotional, and social wellbeing over a prolonged period of time, often in the face of extensive treatment histories, system limitations, and unmet needs.

We acknowledge the common use of the term ‘severe and enduring eating disorder’ (SE-ED) in academic literature and some service models. While that term has been foundational to the literature base, many individuals and communities have expressed concern about the implications of ‘severe and enduring’ - particularly when it feels deterministic or exclusionary (Lubieniecki et al., 2025). For that reason, we have chosen to use the term ‘longstanding’ throughout this, while recognising the overlap and ongoing conversations about language in this space.

We also acknowledge that the term ‘complex’ appears throughout this Guide. It is commonly used in healthcare to describe layered presentations or systemic barriers, but we recognise it can carry unintended implications, especially when used to define a person rather than a context. Our intention is not to label individuals as ‘complex cases,’ but rather to reflect the clinical, relational, and ethical complexity that arises when longstanding illness intersects with trauma, service fatigue, or competing perspectives. We have sought to use this term carefully and sparingly.

Importantly, this Guide does not restrict its relevance to one diagnosis (such as anorexia nervosa), nor does it assume that all individuals have received a formal diagnosis. It is written for and with individuals whose experience of an eating disorder, regardless of type, has persisted over time, caused significant distress or deterioration, and been compounded by system-based barriers to care, recovery, and quality of life.

In addition to recognising distress, this Guide also values the concept of maturity of experience, the insight, clarity, and lived wisdom that many individuals bring after navigating illness, treatment, and healthcare systems over time. This maturity is often overlooked in traditional models of care and deserves to be named and respected.

We also recognise that language is not neutral. It shapes how care is offered, how people are seen, and how power is held. Where possible, we have chosen terms that are humanising, person-led, and reflective of the diversity of those most affected.

As the field continues to evolve, we remain committed to listening and adapting. This is a contribution to the broader conversation about how we speak to, with, and about those who live with longstanding eating disorders.

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Key considerations

- The Glossary (see page 110) provides definitions and context for terms that may be unfamiliar, ambiguous, or contested
- The term ‘longstanding eating disorder’ is used to reflect impact, duration, and systemic experience, not to imply fixedness or futility
- Where terminology from the literature or diagnostic frameworks is referenced (e.g., “SE-ED”), it is contextualised with care
- Above all, the Guide is written to centre the human experience, not just clinical descriptors, and to make space for reflection, growth, and continued dialogue across roles and sectors

This document is written in Australian English, which may include spelling and terminology variations from other forms of English, such as American English.

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Foreword

Honouring the humanity at the heart of care

In developing this Guide, I extend my deepest compassion to everyone whose life has been impacted by a longstanding eating disorder. This work builds on the Holding Hope Discussion Paper (2023) and continues its call not just for better understanding, but for better care.

This Guide is more than just a resource; it reflects the power of listening to those navigating complexity and risk, to those who support them, and to those working to create meaningful change within the systems they are part of. It is written in response to the many individuals and families who have felt unnoticed, unsupported, or abandoned, not because their stories were unclear but because our systems have not yet evolved to support them effectively.

We recognise that not all journeys are linear. Not all suffering can be resolved through standard care, and not everyone is treated with dignity when their needs fall outside conventional models. This Guide is for those challenging moments - when care becomes complex, outcomes are uncertain, and, although recovery may not be the immediate goal, relationship, comfort, and humanity still matter.

This is not about choosing one model of care over another; it is about rejecting the notion that if recovery is out of reach, care must end. It is about acknowledging the heartbreak that occurs when people pass away, not only from illness but also from exclusion. It calls for a response rooted in humility, not blame or withdrawal, but presence, reflection, and action.

This work has been shaped by the courage of those who sought something different. It has been informed by the insights of individuals, families, peer workers, clinicians, and community members who arrived, not with easy answers, but with open hearts and open minds.

Thank you to the individuals who generously shared their lived experiences. To the families who advocated through grief and love, your voices resonate throughout these pages. To the professionals willing to embrace uncertainty and adapt their practices, your integrity makes this work possible.

My hope is that this Guide reaffirms that care can be principled, practical, and personal, even when the future is uncertain. It aims to support ethical, trauma-informed, and person-centred responses for those whose experiences have often been marginalised in care. Furthermore, it offers a pathway forward for services striving to accompany people with honesty, adaptability, and compassion.

This document is not about giving up; it is about showing up, with tools, reflection, and care that honours the individual in front of us.

I extend my sincere thanks to the National Eating Disorders Collaboration (NEDC) for entrusting me with the responsibility of leading this work. Their principled leadership, commitment to integrity, and deep care for the sector continue to shape progress across our shared landscape.
It has been a privilege to develop this resource in partnership with an organisation that consistently seeks to understand and respond to the evolving needs of our community.

With gratitude,

Shannon Calvert

Methodology and Development

The Holding Hope Guide builds upon the foundation established by the original Holding Hope Discussion Paper (2023). The Discussion Paper combined a structured literature review with insights from lived experiences and sector consultations to investigate the relevance of palliative care in the context of longstanding eating disorders.

This Guide represents the next phase of that work. It not only deepens the ethical and conceptual considerations discussed in the original paper but also translates these insights into practice through a flexible, tool-based resource. It reflects an evolving landscape of dialogue, experimentation, and care across the fields of eating disorders, mental health, and palliative care.

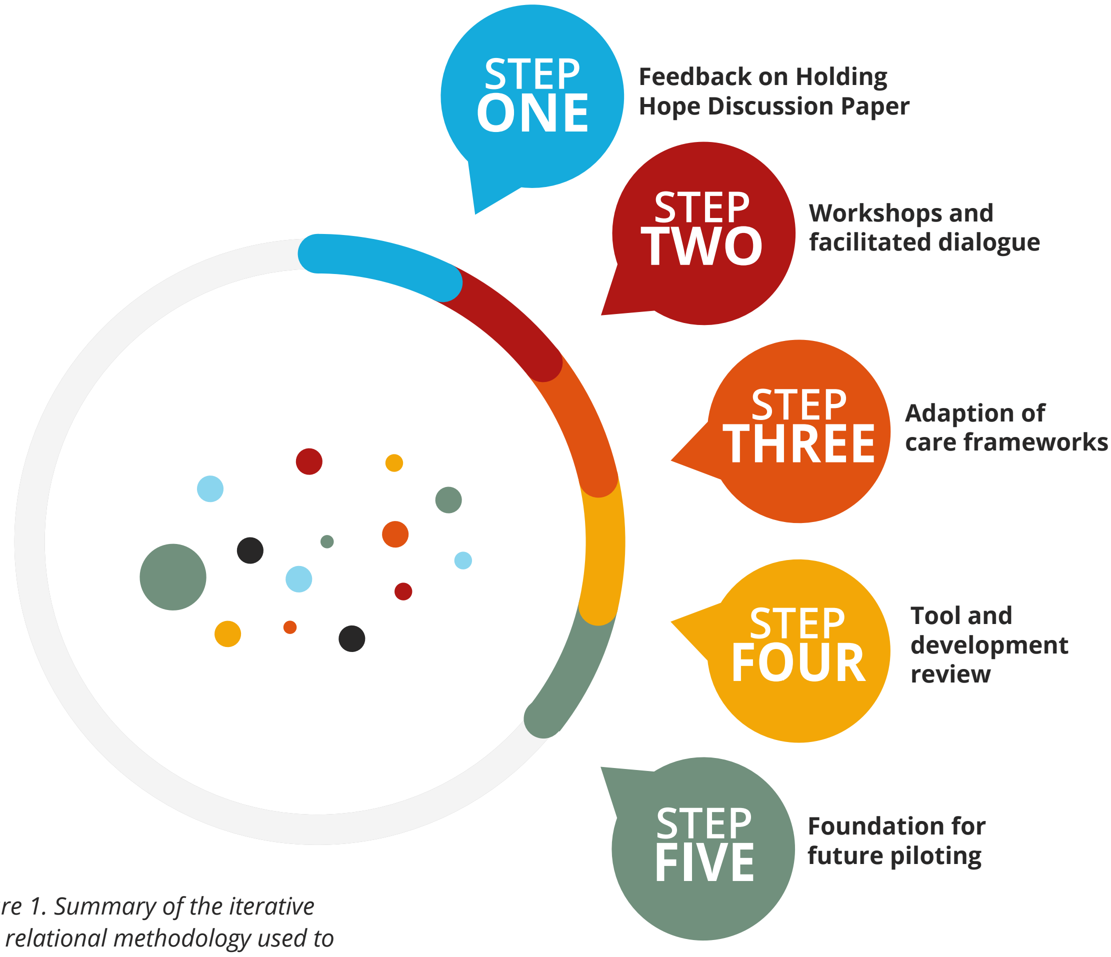

Figure 1. Summary of the iterative and relational methodology used to develop this Guide

An iterative and relational process

Rather than adopting a linear or fixed model, the development of this Guide followed an iterative, relational process. It has been shaped through dialogue, critical reflection, and repeated cycles of feedback, grounded in real-world experience and evolving care needs. This process was informed by:

- Ongoing feedback and reflection following the release of the initial Holding Hope Discussion Paper (2023).

- An updated literature review building on that completed for the Holding Hope Discussion paper, incorporating recent research and additional relevant publications to inform the Guide.
- Workshops and facilitated dialogues, including those at national and international forums such as the ANZAED 2024 Conference, where clinicians, carers, and peer workers engaged with the discussion paper and contributed critical reflections.
- Tool development grounded in practice, from self-reflection worksheets to co-reflection and supervision tools, allowing for adaptation to diverse needs and contexts.
- Collaborative review processes, including feedback from individuals with lived and living experience, carers, health professionals, researchers, peer workers, and both government and non-government organisations.

Laying the foundations

This pilot provides a structured foundation for implementation in community, clinical, and peer-led settings. Its true value will be determined by those who engage with it: individuals, families, carers, and teams. Their feedback, challenges, and insights will shape what needs to be strengthened, adapted, or reimagined over time.
A diverse group of stakeholders across academia, clinical practice, peer work, policy, and lived experience will be invited to critically review and explore the Guide in use. This co-reflective process is essential to ensuring that the tools remain relevant, inclusive, and capable of evolving in response to real-world complexity.

Understanding the evidence

While research evidence is incorporated throughout the Guide where it exists, the development of this Guide is primarily grounded in anecdotal evidence shared with the author through hours of consultation. These contributions reflect lived experience, practice-based wisdom, and the kinds of personal reflections that are often absent, overlooked, or devalued by traditional research methodologies.

In developing this Guide, we have sought to share power with people with lived experience by allowing for different modes of engagement and knowledge sharing that are self-determined and of greatest meaning to those with lived experience, allowing us to integrate lived experience and research evidence to provide rich and nuanced perspectives on this topic. The available research evidence on longstanding eating disorders is also limited due to the absence of large-scale rigorous studies with this population.

We acknowledge the strengths and limitations of this but encourage readers to acknowledge the importance of anecdotal evidence and hearing the voices of those who have lived through this journey. These essential perspectives deepen our understanding, help reframe assumptions, guide ethical practice, and inspire more humane and responsive approaches to care.

SECTION 1:
Introduction & Purpose of the Holding Hope Guide

1.1 Introduction

The National Eating Disorders Collaboration (NEDC) is committed to improving the lives of all Australians impacted by eating disorders. This work focuses on supporting a coordinated, evidence-informed system of care that enables early intervention, comprehensive treatment, and long-term recovery.

At the same time, we recognise that individuals living with longstanding eating disorders and their loved ones often face ongoing and complex challenges that extend beyond current service design.

This Guide was developed in direct response to that reality. It reflects a shared commitment to compassion, integrity, and equity in the context of complexity. This work aims to broaden the care landscape - not by replacing evidence based recovery-focused care, but by expanding how meaningful, person-led support can be provided when recovery is not currently possible, accessible, or aligned with the individual's goals. We hold both hope and honesty. We remain committed to learning, evolving, and working together to ensure that no one is left behind.

1.2 About this Guide

This Guide is a reflective, person-centred resource designed to support compassionate, ethical, and values-aligned care for people living with longstanding eating disorders. It is not a clinical guideline, treatment protocol, or set of prescriptive standards.

It offers adaptable tools, prompts, and planning frameworks which are designed to be used in conjunction with professional care. This guide may be particularly helpful when typical treatment approaches may no longer be effective, accessible, or aligned with the person's needs. It draws on clinical, ethical, academic, and lived experience perspectives to support dialogue, decision-making, and collaborative planning in complex care contexts.

This Guide is intended to be used alongside a person's broader care team, recognising that clinical responsibility remains with qualified health professionals. It is not a substitute for evidence-based care, but a companion when care needs to be reimagined or extended.

For current clinical standards and national guidance, readers are encouraged to refer to ANZAED's Clinical Practice and Training Standards (Heruc et al., 2020).

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WHY “HOLDING HOPE”?

As expressed in the original Holding Hope Discussion Paper:

“Holding Hope” serves as a reminder of the foundational reasons why we are in this field, regardless of our roles. Ultimately, it is about seeing and hearing the person beyond their diagnosis and disorder - about our collective commitment to support and honour the humanity of those most deeply impacted.”

Building on this foundation, Holding Hope is more than a title, it is a guiding philosophy that threads through every page of this Guide. It reflects the complexity of working alongside people living with longstanding eating disorders, where hope is not always linear, and where suffering is often met with silence or arises in moments when systems were unable to respond with compassion.

To hold hope is to stay present - not by insisting on a singular outcome, but by honouring the dignity, voice, and humanity of the person in front of us, even when recovery feels uncertain or out of reach.

This phrase symbolises the intention to act with courage, empathy, and ethical clarity in the face of discomfort, disagreement, or grief. It speaks to our willingness to create care pathways that are principled and person-led - even when they challenge conventional frameworks.

Whether we are health care professionals, peer workers, carers, advocates, or community members, Holding Hope reminds us why we do this work. It calls us back to the core of ethical care: to see the whole person beyond their diagnosis, to walk alongside them without abandonment, and to co-create care that reflects respect, safety, and belonging.

In a field shaped by urgency and intensity, Holding Hope is an invitation to slow down, reflect, and act with integrity - even, and especially, when the answers are not simple.

What This Guide Is and Is Not

To support clarity and shared understanding, the following table outlines what this Guide offers, and what it does not.

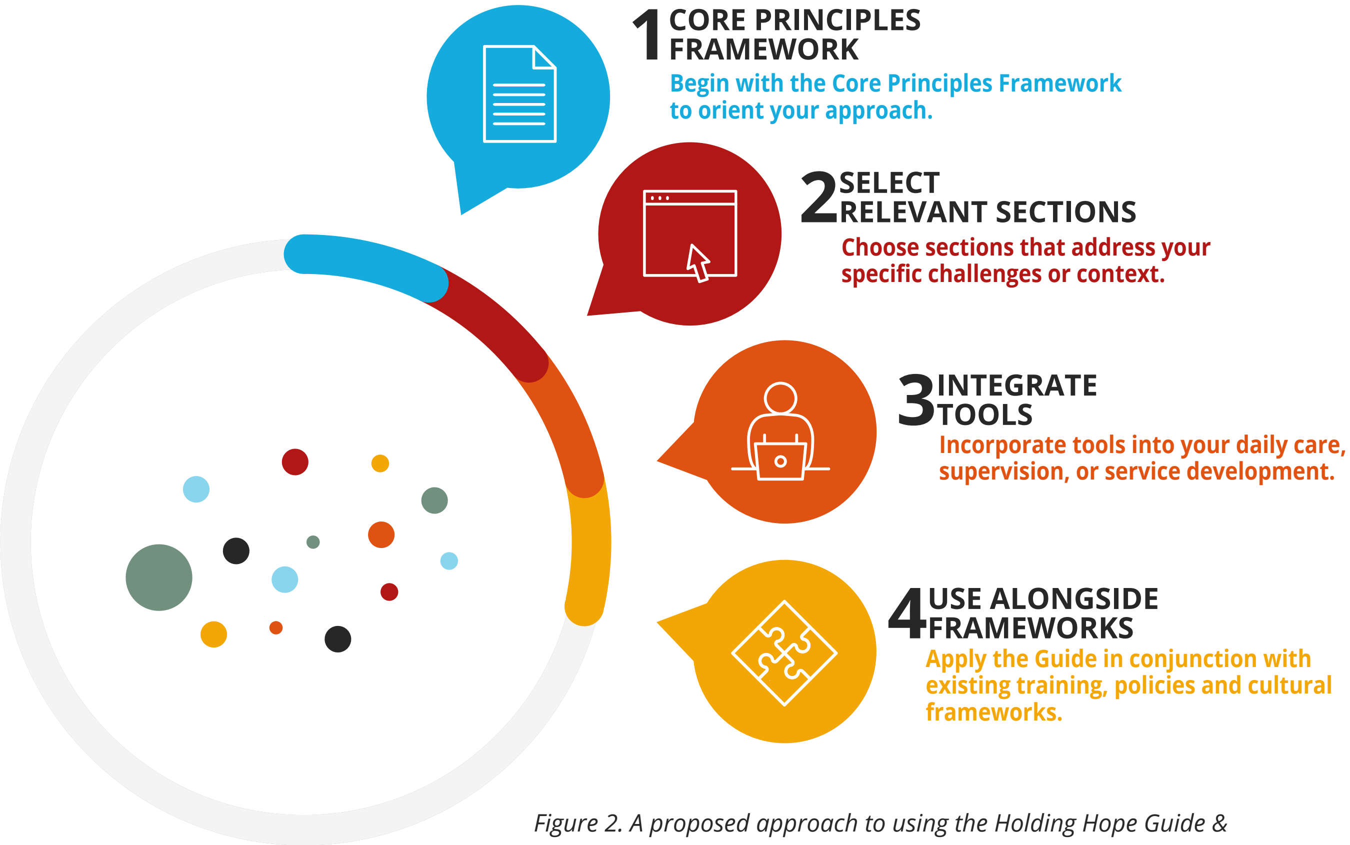
This Guide is:	This Guide is not:
A practical, trauma-informed resource that supports ethical, values-aligned care across diverse settings.	A clinical practice guideline that stipulates formal recommendations for the diagnosis or treatment of longstanding eating disorders.
A framework to support reflection, planning, and decision-making when traditional recovery models are not effective, accessible, or aligned with the person's needs.	A tool to determine eligibility, readiness, or treatment compliance for people with longstanding eating disorders.
A collection of adaptable tools - including care templates, conversation guides, checklists, vignettes, and communication strategies - designed to support person-led dialogue.	A replacement for evidence-based treatment.
A values-driven resource to support clinicians, peer workers, families, and services in navigating complexity together.	A prescriptive or one-size-fits-all model of care.
A daily anchor for reflection and practice.	A purely theoretical exploration.
An offering of possible pathways for people experiencing longstanding eating disorders.	Guidance for the initial response or treatment of eating disorders that are newly diagnosed or not considered to be "longstanding" (acknowledging that this is an ambiguous term).

Table 1. What this Guide Is and Is Not

Note: Unlike clinical guidelines, which provide structured recommendations for diagnosis and treatment, this Guide offers flexible and reflective resources to support ethical care planning, particularly when standard approaches may not meet the needs of those with longstanding or complex experiences.

1.3 How to use this Guide

This Guide can be used in the ways that directly suit your role, context, and priorities. Start where it matters most to you or the person you're supporting. The infographic below offers one suggested path, but the tools can be adapted for direct care, planning, reflection, or advocacy, whether individually or collaboratively.



1 CORE PRINCIPLES FRAMEWORK

Begin with the Core Principles Framework to orient your approach.

2 SELECT RELEVANT SECTIONS

Choose sections that address your specific challenges or context.

3 INTEGRATE TOOLS

Incorporate tools into your daily care, supervision, or service development.

4 USE ALONGSIDE FRAMEWORKS

Apply the Guide in conjunction with existing training, policies and cultural frameworks.

Figure 2. A proposed approach to using the Holding Hope Guide & Workbooks

How to use the Guide across roles

This Guide has been shaped with and for the diverse communities of people navigating the complexities of care including those receiving it, those providing it, and those walking alongside. The table below outlines some suggested uses of the guide across different roles. Whatever your starting point, the Guide is designed to be used flexibly - as a source of support for care planning, reflection, supervision, advocacy, or systemic change.

Health Professionals	May find tools to anchor complex care conversations, support reflective practice, and strengthen ethical reasoning in day-to-day decision-making.
Lived and living experience	May use it to clarify personal values, express care preferences, and co-create plans that reflect what matters most.
Carers and supporters	May find guidance for staying connected, communicating with services, and reflecting on their role in supportive and safe ways.
Multidisciplinary teams and service leaders	May use the Guide to embed trauma-informed and rights-based models of care, enhance supervision, support ethical service delivery and cohesive whole team/service responses to complex, longstanding eating disorder experiences.

1.4 Accessing the Tools: Supporting usability and flexibility

To support ease of use, this Guide is accompanied by three separate workbooks which include a series of tools. These workbooks are organised by audience:

- Consumers: For People With a Longstanding Eating Disorder
- Carers: For People who Care For, Love or Support Someone With a Longstanding Eating Disorder
- Workforce: For the Workforce Supporting People With a Longstanding Eating Disorder

Whilst each workbook is tailored with these audiences in mind, there may be tools in other workbooks that resonate with you. As with this entire Guide, the workbooks can be used flexibly, picking and choosing which tools do and don't work for you. They are not prescriptive, linear workbooks, but a space to dip in and out of resources that feel suitable for your context.

1.5 Core principles of the Holding Hope Guide

These principles are not aspirational, they are essential to delivering safe, ethical, and person-centred care in the context of longstanding eating disorders.

While not drawn from a single source, the principles reflect a synthesis of widely recognised, evidence-informed models and values, including those from trauma-informed care, harm reduction, supported decision-making, recovery-oriented practice, palliative care, and human rights-based approaches. It is also shaped by the voices and priorities of those with lived and living experiences of longstanding eating disorders.

These principles do not replace clinical standards, ethical codes of conduct, or service-specific requirements. Instead, they serve to guide practice in contexts where complexity, uncertainty, and deeply individualised needs require more relational, ethical, and person-led approaches.

PRINCIPLE	WHAT IT MEANS IN PRACTICE
Person-led (informed by person-centred care)	Care is guided by the individual's values, priorities, and lived context, not solely by diagnosis, service protocols, or program eligibility. While informed by recognised person-centred care frameworks, this approach places a stronger emphasis on personal agency, shared decision-making, and ethical responsiveness to the person's own goals and definition of meaningful care (Australian Commission on Safety and Quality in Health Care, 2021).
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).
Trauma-informed and harm reduction-oriented care	Trust, safety, and reduced harm take precedence over compliance, coercion, or narrow clinical goals (Blue Knot Foundation, n.d.; Hudy, 2024).
Recovery is possible, not prescribed	A meaningful life can include progress, setbacks, and personal definitions of healing.
Cultural and contextual humility	Care must be culturally safe, identity-aware, and responsive to marginalisation (Center for Substance Abuse Treatment, 2014; Royal Australian and New Zealand College of Psychiatrists [RANZCP], 2023)
Shared decision-making	Planning is transparent, collaborative, involving the person, their family or substitute decision-maker, health professionals, and where appropriate, lived and cultural expertise. This approach supports care that aligns with the person's values, preferences, and goals (Advance Care Planning Australia, 2024).
Connection over compliance	Relationships are prioritised as the foundation for engagement, safety, and continuity of care.
Ethically reflective and evidence-informed	Care is grounded in critical reflection, learning, and evolving knowledge, not static assumptions about care (Australian Commission on Safety and Quality in Health Care, 2021).
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).

Table 2. Core Principles Framework for care in the context of longstanding eating disorders

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Guiding Frameworks

The development of this Guide was shaped by recognised frameworks that support ethical, person-centred, and context-responsive care. These frameworks were not applied prescriptively but have been adapted to inform the structure, tone, and tools of the Guide. They reflect a combination of evidence-informed approaches drawn from palliative care, mental health, disability rights, and trauma-informed practice. They align with recognised system standards and frameworks, including:

Palliative Care Principles	These principles emphasise dignity, holistic support, and quality of life, particularly when curative or recovery-focused goals may no longer be realistic or aligned with the person's wishes (World Health Organisation [WHO], 2020).
Advance Care Planning	Planning for future healthcare, which promotes autonomy, early conversation, and shared planning between individuals, families, and care teams (Advance Care Planning Australia, 2024)
Harm Reduction	An approach that offers pragmatic ways to reduce harm, sustain engagement, and support dignity when safety cannot be guaranteed or treatment is declined (Birch et al., 2024).
Compassionate Comunities' 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 lifelimiting illness (Bakelants et al., 2023; Dumont et al., 2022).
National Safety and Quality Health Service Standards (2021)	• Standard 1 (Clinical Governance) • Standard 2 (Partnering with Consumers) • Standard 5 (Comprehensive Care)
Shared Decision-Making Models	• Ottawa Decision Support Framework (Stacey et al., 2020) • Elwyn Three-Talk Model (Elwyn et al., 2015) • Advance Care Planning Australia (2024) - values-based, person-led decision-making
Trauma-Informed Practice Guidelines	• Blue Knot Foundation (n.d.) - Trauma-informed principles for complex care • Substance Abuse and Mental Health Services Administration (SAMHSA; 2014) - Six key principles of trauma-informed approaches • RANZCP (2020) - Position statement on trauma-informed care in mental health settings
Human Rights-Based Approaches to Health, Autonomy, and Decision-making	• The United Nations Convention on the Rights of Persons with Disabilities (2008) • The Australian Human Rights Commission (n.d.) • The WHO (2017) - QualityRights initiative and person-centred care guidelines

Table 3. Guiding Frameworks

These frameworks provide a scaffold, but the ethical orientation of this Guide is what connects practice to meaning and care to humanity.

1.6 Lived experience narratives

Listening to lived and living experiences is essential to understanding longstanding eating disorders - not as abstract conditions, but as deeply human experiences. Through extensive consultations, several themes emerged that give voice to this reality, which this Guide seeks to honour.

These insights are embedded throughout the Guide to ensure that care is informed by both academic evidence and experience-based knowledge, including lived experience evidence. This approach recognises that lived experience is not a case study to be analysed but a legitimate and essential form of evidence that must shape the systems, services, and decisions that affect people's lives (Lumby, 2024). As Conti, Rhodes and Adams (2016) emphasise in their call to "listen in the dark," the stories of people living with longstanding eating disorders often resist resolution and certainty, yet they are essential to ethical, responsive care.

Listening to these narratives, even when they are complex or confronting, allows us to see the whole person and the reality they carry.

"It wasn't that I didn't want help, I just needed the help to look different"

"After so many admissions, I knew the drill - but none of it spoke to what I actually needed"

"We were told to just hang in there. But services stopped showing up. We felt completely alone"

"Being called non-compliant made me stop trusting. I wanted care, but I needed it on terms that felt safe"

1.7 A framework for recognition, not exclusion

This Guide avoids rigid definitions or eligibility cut-offs to understand the experiences of people with longstanding eating disorders. Instead, teams are invited to consider the questions below.

This approach opens the door to more personalised, ethical, and adaptive care - where the depth of a person's history is honoured, and their future is shaped with them, not for them.

CONSIDER

What has the person been through?

**What care have they received?
How has it shaped their experience?**

What are they asking for? How are we responding?

Why recognition matters

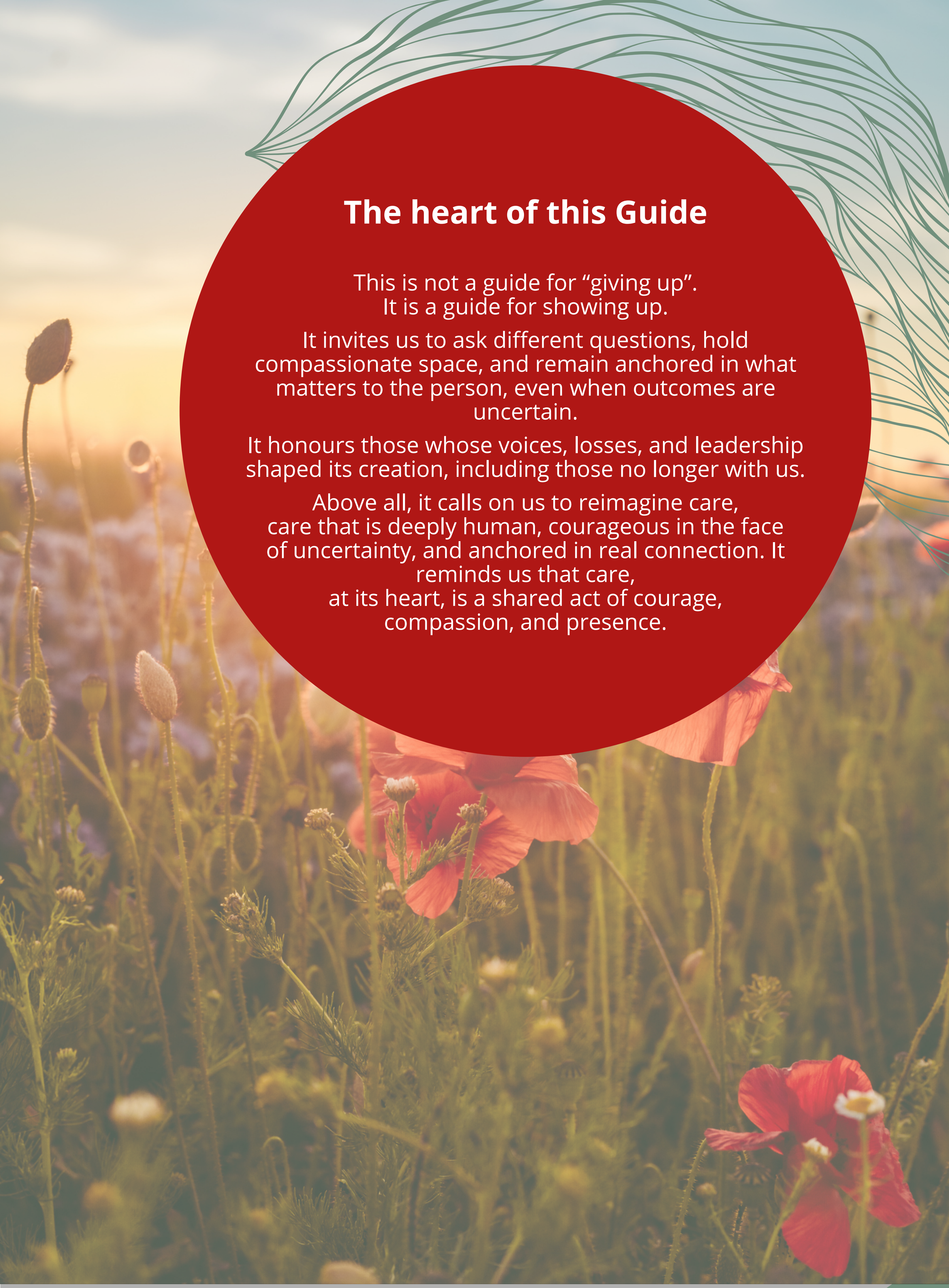
People with longstanding eating disorders can be excluded from services due to the duration of their illness, diagnostic labels, or assumptions about their motivation to engage with treatment. This exclusion can lead individuals to feel unseen and further harms them by making the unique experiences of those with longstanding eating disorders less recognised in both clinical and social settings. The following 5 practice points support the ongoing recognition, centering and validation of the lived experience journey and are central to Holding Hope in practice, and in health care more broadly.

Centring lived experience	Recognise the significance of the lived and living experience and the persons current context
Challenge stereotypes	Disrupt narratives of "non-compliance" or hopelessness.
Create space for innovation	Open paths for alternative approaches such as harm reduction, palliative care, and peer support models.
Acknowledge impact	Recognise the physical and emotional costs of chronic engagement with services.
Validate experience	Affirm the full spectrum of each individual and their loved

A note on service capacity and system constraints

We recognise that not all services or systems are currently resourced or equipped to offer adaptive models such as palliative or harm-reduction-informed care. Capacity constraints, policy limitations, and workforce demands are real and valid challenges.

The purpose of this section, and the Guide overall, is not to assign blame but to offer practical tools and ethical considerations for working with complexity within the realities of our health systems. Wherever possible, a flexible approach to care that is guided by trauma-informed principles, collaborative planning and respect for human dignity can reduce harm and foster continuity, even in resource-limited contexts.



The heart of this Guide

This is not a guide for “giving up”. It is a guide for showing up.

It invites us to ask different questions, hold compassionate space, and remain anchored in what matters to the person, even when outcomes are uncertain.

It honours those whose voices, losses, and leadership shaped its creation, including those no longer with us.

Above all, it calls on us to reimagine care, care that is deeply human, courageous in the face of uncertainty, and anchored in real connection. It reminds us that care, at its heart, is a shared act of courage, compassion, and presence.

SECTION 2:
Understanding Longstanding Eating Disorders

2.1 Introduction and purpose

This section provides foundational context for understanding longstanding eating disorders, particularly for readers who may be less familiar with the clinical, social, and systemic issues involved. It outlines key concepts, language, and approaches used throughout this Guide, and offers a high-level orientation to the complexity, misinterpretations, and ethical tensions that often arise in longstanding eating disorder care.

Readers seeking a comprehensive overview of the clinical, lived experience, and systemic context are encouraged to refer to the original Holding Hope Discussion Paper (2023).

2.2 Language, legitimacy, and lived reality

An intentional effort has been made throughout this Guide and the accompanying workbooks to use language that is relational, respectful, and grounded in lived experience. Clinical terminology appears only when necessary and is framed within a broader person-led, trauma-informed, and rights-based lens. Language is not neutral. The terms we use shape how people are seen, supported, and invited into care, particularly in situations where diagnostic definitions may not reflect the person's full reality.

Key affirmations that underpin language choices:

- A person's diagnosis does not define their legitimacy or worthiness of care
- People of any body size, diagnosis, or background can be profoundly impacted by eating disorders, even when they do not meet traditional diagnostic criteria or are excluded from typical care pathways
- The term 'longstanding eating disorder' is used in this Guide to reflect lived reality, not failure, futility, or chronicity

Relevant terms such as complexity, person-led care, recovery resistance, harm reduction, and palliative care (in the context of eating disorders) are further defined in the Glossary.

In this Guide, the terms person-centred and person-led are both used intentionally and with distinction:

Person-centred care	Refers to collaborative, respectful care that aligns with the individual's goals and values. It is a principle embedded in many health frameworks.
Person-led care	Acknowledges that in contexts of complexity, trauma, or longstanding experience, individuals may need to set their

Both approaches are critical to dignity-based care (Abimbola, 2023) and may be used at different points in the care journey.

2.3 Complexity and gaps in care

People living with longstanding eating disorders often experience complexity across physical, psychological, social, and systemic dimensions. These experiences are shaped by more than duration; they reflect histories of harm, repeated treatment attempts, and prolonged disconnection from responsive care.

Common lived realities may include:

- Ongoing physical health complications (e.g.,, cardiac, gastrointestinal, endocrine, or bone conditions) (Hambleton et al., 2022)
- Co-occurring mental health or neurodivergent experiences (e.g.,, PTSD, suicidality, OCD, autism) (Kinnaird et al., 2018; Cobbaert et al., 2024; Udo et al., 2019)
- Trauma histories, including previous experiences of coercive or inadequate treatment (Day et al., 2024)
- Social and relational strain, family fatigue, and loss of trust in services (Mac Donald et al., 2023)
- Structural disadvantage (e.g.,, disability, housing or income insecurity, marginalisation) (Burnette et al., 2024)

At a system level, many people encounter care pathways that are not equipped to meet the complexity of their needs. Services are often organised around recovery-focused or crisis-response models, which, while well-intentioned, may inadvertently exclude those requiring longer-term, relational, or adapted approaches. Interpretations of engagement, such as perceptions of "non-compliance" or "treatment resistance," may unintentionally contribute to disconnection or reduced access to care.

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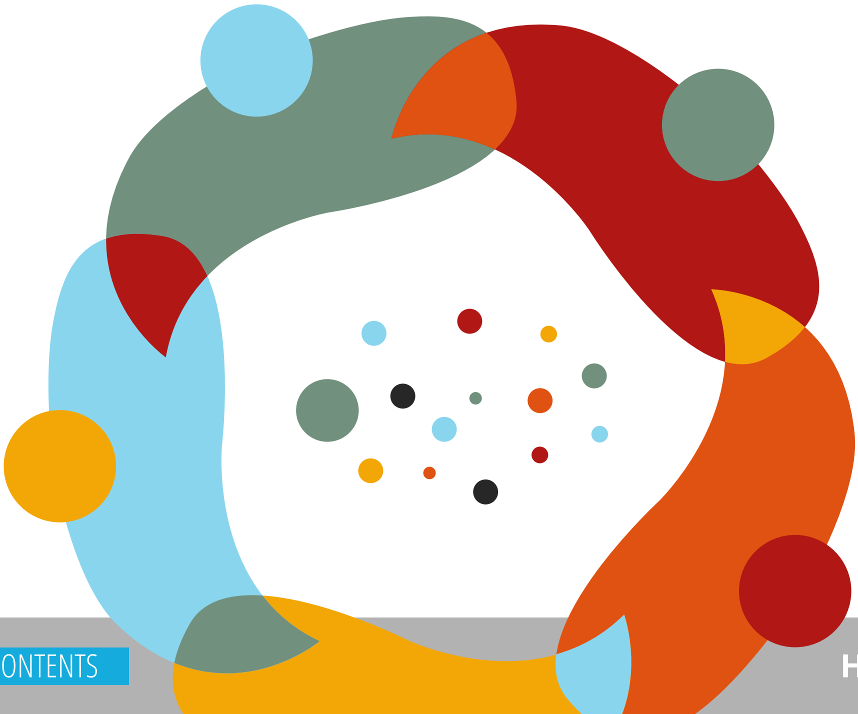
Common systemic limitations include:

- Eligibility thresholds based on BMI, diagnosis, or perceived readiness to recover (Broomfield et al., 2017; Musolino et al., 2016)
- Fragmented or disconnected care between mental health, medical, disability, and palliative systems
- Gaps in community-based, harm-reduction, respite, or palliative options
- Misalignment between needs and prevailing treatment models (Moberg, 2025)
- Geographic and financial inequities (Flavel et al., 2016; Mulders-Jones et al., 2017)
- Lack of knowledge or resources required to respond to cultural and identity-specific needs
- Limited support for carers or chosen supporters, especially in complex or long-term care (Treasure et al., 2016)

These challenges are not the fault of individuals, whether those seeking care or those providing it. They reflect the broader pressures experienced across health and community systems, including resource constraints, limited-service integration, and variable access pathways. They cannot be resolved by any one person working alone. Instead, addressing them requires collective effort, supported by reflective practice and regular supervision. Acknowledging these realities openly enables teams to move beyond blame or frustration and toward more ethical, flexible, and person-centred models of support.

Adapting models to reflect an individual's lived context, values and goals allows for the centring of personhood and affirms dignity, even when care is complex



2.4 Treatment models for longstanding eating disorders

For individuals living with longstanding eating disorders, a small number of evidence-based models have been developed or adapted to prioritise autonomy, emotional safety, and quality of life. These models have focused adapting treatments for long standing anorexia nervosa and include:

Specialist Supportive Clinical Management Severe and Enduring Anorexia Nervosa (SSCM-SE)	SSCM is a flexible, person-centred approach developed as a control condition in clinical trials but has been shown tobe effective in its own right (McIntosh et al., 2005 ; Solmi et al., 2021). SSCM-SE has been adapted for the treatment of longstanding anorexia nervosa and aims to support individuals to identify their own goals with a focus on the therapeutic alliance and combines clinical support to focus on quality of life improvements without prescriptive treatment targets. Preliminary research has shown SSCM is associated with meaningful improvements in the treatment of longstanding anorexia (Kiely et al., 2022, Touyz et al., 2013). SSCM may also be applicable in the treatment of other longstanding eating disorder diagnoses other than anorexia, however this has yet to be evaluated.
Integrated Enhanced Cognitive Behavioural Therapy (I-CBTE)	I-CBTE is a structured, multidisciplinary model that integrates Enhanced CBT with medical, dietetic, and psychosocial support (Ibrahim et al., 2022). I-CBTE is designed to provide coordinated care across inpatient and outpatient settings and has been applied in some services to support individuals with longstanding anorexia. It emphasises early engagement, shared decision-making, and sustained continuity of care. Limited research has investigated the efficacy of I-CBTE, but preliminary evidence from case studies suggest it may be associated with meaningful symptom reduction for individuals with longstanding and complex anorexia (Ibrahim et al., 2022; Viljoen et al., 2024).
Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)	MANTRA is a manualised model that incorporates motivational work,emotion regulation, interpersonal reflection, and cognitive flexibility. While MANTRA was originally developed for adults withanorexia nervosa, it has been adapted in some services for group based delivery or use in more complex, enduring presetations (Startup et al., 2021).
Cognitive Behavioural Therapy for Severe and Enduring Anorexia Nervosa (CBT-SEAN)	CBT-SEAN (Touyz et al., 2013) is a modified version of the CBT-AN protocol developed by Pike et al. (2003) in which weight gain and recovery from core eating disorder symptoms are not assumed treatment priorities. Instead, treatment goals are set collaboratively and weight gain is encouraged but is not the primary focus of therapy. CBT-SEAN also focusses on motivational enhancement and quality of life as primary treatment goals (Touyz et al., 2013). CBT-SEAN has been associated with meaningful improvements in social functioning and eating disorder symptoms, and appears acceptable to participants with a retention rate of 85%.

Table 3. Guiding Frameworks

It is essential to explore all treatment options and therapeutic pathways to give each person the best chance for recovery or support. However, it is equally important to assess whether the individual has the necessary resources and access to engage with these options. This includes the availability of trained clinicians, a genuine offer of treatment (not just theoretical eligibility), cost considerations, and physical and psychological readiness to participate.

Ethical care involves recognising what is possible within the person's context and capacity, and co-creating plans that reflect both clinical expertise and lived experience.

2.5 Clarifying misunderstood concepts in longstanding eating disorder care

This section addresses common questions and concerns about key concepts referenced in this Guide that relate to care for longstanding eating disorders. This includes harm reduction, person-led care, autonomy, and palliative care. These clarifications are not intended to replace clinical, legal, or policy guidance. Rather, they are intended to support informed, respectful dialogue and help reduce fears or misinterpretation in complex care planning.

Does harm reduction mean endorsing or enabling disordered behaviours?

Harm reduction does not condone or encourage disordered behaviours. It is a practical, trauma-informed approach that aims to reduce physical, psychological, and relational harm in situations where full recovery is not currently accessible, or the person is not ready to engage in traditional treatment. Harm reduction sustains engagement and safety and can prevent re-traumatisation or crisis escalation.

Refer to Russell et al (2019) for more information.

Can people with eating disorders refuse treatment?

Adults who are assessed as having decision-making capacity have the legal right to refuse treatment, even if their choice involves risk. This right is grounded in human rights principles and applies across all health conditions.

Capacity should be assessed fairly, recognising that disagreement or distress does not equal incapacity - and that communication shaped by trauma or neurodivergence must be understood in context.

Refer to Russell et al (2019) for more information.

Is person-led care a risk to safety?

Person-led care (aligned with person-centred principles) can enhance safety when implemented with structure, transparency, and support. It strengthens therapeutic relationships and reduces disengagement or escalation, particularly for those with prior negative or coercive treatment experiences.

Safety includes emotional, relational, and cultural dimensions, not only physical risk.

Refer to Australian Commission on Safety and Quality in Health Care (2011) for more information.

Is Palliative care the same as Hospice Care?

Palliative care is not limited to end-of-life settings. It can be introduced at any stage of a life-limiting condition and may be used alongside curative or other treatments. Its focus is on quality of life, symptom relief, and aligning care with what matters most to the person. According to Palliative Care Australia, it "aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness."

Hospice care, in contrast, is both an approach to end-of-life care and a type of specialist service often delivered in a designated facility. While all hospice care is palliative, not all palliative care is hospice. Hospice services typically provide high-quality care focused on comfort, dignity, and symptom management for people approaching the end of life.

Refer to Palliative Care Australia, 2021; Palliative Care Australia, 2016

Does palliative care mean giving up?

Palliative care is not about surrender, it is about refocusing care on what is achievable, meaningful, and respectful. For some individuals, this may include reducing pain, maintaining comfort, preserving relationships, or upholding dignity in the face of uncertainty or limited treatment options.

It can coexist with harm reduction, peer support, spiritual care, and psychosocial interventions. Palliative care is about supporting people to live as well as possible, on their own terms.

Can someone be forced to receive palliative care?

Palliative care is a voluntary and consent-based approach. While it may be raised as a care option, it should only be pursued with the person's agreement (or that of their legal decision-maker). Informed, shared decision-making is central to ethical palliative care.

Refer to the National Palliative Care Strategy 2018.

Can a person change their mind to withdraw from receiving palliative care?

Preferences and needs may evolve over time. A person can withdraw from palliative care at any point and explore alternative or recovery-focused treatment approaches. Flexibility and compassion must remain central to all care planning conversations.

Refer to the National Palliative Care Strategy 2018.

SECTION 3:
Foundational Care Approaches

3.1 Introduction and purpose

This section outlines the essential values and practices that underpin all aspects of care explored in this Guide. It offers a shared foundation for working with individuals living with longstanding eating disorders, particularly when recovery is uncertain, non-linear, or not currently the person's goal.

These approaches are not aspirational ideals; they are the foundations of ethical care - principles such as autonomy, relational engagement, shared responsibility for risk, and a commitment to dignity, meaning, and cultural safety. That is, they represent the minimum standard for dignity-centred, trauma-informed, and person-led support. They reflect a commitment to relationships, autonomy, and context, even in complexity.

Foundational ethical principles include:

- Respect for autonomy
- Commitment to relational engagement
- Shared responsibility for risk
- Upholding dignity and meaning
- Cultural and emotional safety
- Non-abandonment and continuity

These principles inform not only clinical decisions, but also how teams show up, stay present, andremain accountable when care becomes ethically or emotionally challenging. They sit alongside they foundations of ethics in health care (beneficience, non-maleficence, justice and autonomy), which are expanded upon in Section 4.

3.2 Quality of life and ethics of care

When recovery is not the current focus, quality of life becomes a primary goal of care. This does not mean giving up on hope, it means anchoring care in what the person finds most meaningful, manageable, and sustaining at that point in their journey.

Quality of life goals may include (WHO, 2012):

We recognise that not all services or systems are currently resourced or equipped to offer adaptive models such as palliative or harm-reduction-informed care. Capacity constraints, policy limitations, and workforce demands are real and valid challenges.

- Physical comfort and symptom relief
- Emotional regulation and relational safety
- Connection to nature, creativity, or spirituality
- Reduced distress during medical procedures or transitions
- Opportunities for social contribution, work, or cultural connection

Achieving quality of life goals should not be seen as "less than" recovery, they are part of ethical, person-centred care.

Health-related quality of life reflects a person's perceived physical, mental, and social wellbeing in relation to their health status, daily functioning, and capacity to engage with who matters most to them (WHO, 2012)

3.3 Dignity of risk: Shared decision-making in context

A central concept within trauma-informed and rights-based care is the principle of dignity of risk - the right to make informed decisions, even when those decisions involve uncertainty or potential harm. This principle is increasingly recognised in national trauma-informed frameworks and aligns with values of autonomy and supported decision-making. As outlined in Section 23 of the *Mental Health and Wellbeing Act (2022),* individuals have the right to take reasonable risks. It refers to a person's right to make choices about their life, including decisions others may view as unsafe, as long as they have the capacity to do so. It acknowledges that autonomy, identity, and growth often require exposure to risk (Australian Aged Care Quality and Safety Commission, 2024).

DIGNITY OF RISK ➔ Refers to a person's right to make choices about their life, including decisions others may view as unsafe, as long as they have the capacity to do so. It acknowledges that autonomy, identity, and growth often require exposure to risk (Australian Aged Care Quality and Safety Commission, 2024).

Ethical care means recognising the difference between:

Risk to someone	This refers to situations where risk is imposed on a person without their active involvement, often with good intentions, but without shared understanding or consent. These decisions are typically made for someone, rather than with them. In practice, this can feel disempowering, particularly for individuals with a history of coercion or disconnection in care.
Risk with someone	This reflects a relational, trauma-informed approach where risk is explored collaboratively. It involves open dialogue, consent, and trust, allowing the person to meaningfully engage in decisions that affect them. It recognises that safety also includes emotional and cultural dimensions, and that autonomy and growth often involve tolerable levels of uncertainty or vulnerability.

In the context of longstanding eating disorders, this distinction helps to move beyond binary notions of ‘safe’ or ‘unsafe’ care. It opens space for conversations like:

- “What does meaningful risk look like for you right now?”
- “How can we stay connected, even when we don’t agree?”
- “What supports your sense of agency in this decision?”

This framing invites a shift from protective control to respectful partnership, one that honours a person’s readiness, identity, and humanity.

Upholding the principle of dignity of risk requires services and professionals to:

- Avoid assuming that all risk must be eliminated
- Remain engaged, even when care goals diverge from clinical expectations
- Share risk transparently through reflective practice, team accountability, and dialogue with the person and their supporters
- Provide opportunities for support, supervision and reflective practice to assist the workforce in navigating these situations and any counter-transference that may arise

Risk-taking is not always a sign of deterioration. It may reflect agency, boundary-setting, survival strategies, or clarity about what a person can and cannot bear.

Allowing for risk may indicate agency, resilience, or boundary-setting, not only deterioration. Where risk cannot be eliminated, it must be ethically shared, transparently acknowledged, and relationally navigated (Cribb & Entwistle, 2011).

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In trauma-informed contexts, risk-taking can also be understood as a response shaped by lived experience including behaviours developed to preserve emotional safety, autonomy, or a sense of control, especially after past experiences of coercion or disempowerment. When risk cannot be avoided, it must be ethically shared, relationally held, and openly documented.

3.4 Person-led, relational, cultural and trauma-informed care

Person-led and relational practice

Person-led care centres the individual as the expert in their own life. It acknowledges that meaningful care cannot be imposed; instead, it must be co-created based on what the person defines as helpful, tolerable, or aligned with their goals. Person-led care may include:

- Flexible goals tailored to the person's context, values, needs, and readiness.
- Respect for refusal, ambivalence, or conditional engagement.
- Validation of insights and priorities that might not align with traditional medical models.

This approach is not passive or "hands-off." Person-led care is active, skilled, and deeply relational. It may involve adjusting the pace of engagement, co-authoring care plans, responding to sensory or cultural preferences, or recognising partial engagement as a valid and meaningful step.

Relational care emphasises that trust, presence, and connection are often more therapeutic than any single intervention (Tieu & Matthews, 2024). It requires:

- Time, consistency, and humility
- The ability to acknowledge and repair any ruptures in the therapeutic relationship
- A willingness to remain engaged, even when outcomes are uncertain or non-linear

Together, person-led and relational care shift the focus from "How do we fix this?" to "How do we support this person in a safe, ethical, and authentic way?"

Cultural and trauma-informed practice

Care must actively respond to each person's identity, culture, history, and lived experience. Cultural and trauma-informed practice are not adjuncts - they are central to ethical, effective, and person-centred care (Blue Knot Foundation, n.d.; RANZCP, 2023).

This section aligns with the NEDC Eating Disorder Safe Principles (NEDC, 2024) and builds on trauma-informed frameworks developed by the Victorian Centre of Excellence in Eating Disorders (CEED, 2024), First Nations health organisations (e.g.,, NACCHO, Lowitja Institute), and lived experience-led communities (e.g.,, Reframing Autism, n.d.)

Cultural safety in practice

Cultural safety is defined by the person receiving care, not by the practitioner (Williams, 1999; Nursing Council of New Zealand, 2011). Cultural safety requires:

- Attention to the impacts of colonisation, racism, migration, and systemic inequality (Dudgeon et al., 2014; AIATSIS, 2020)
- Services to partner with community-led organisations and cultural leaders wherever possible
- Services to provide access to and normalise the use of interpreters, peer workers, and cultural liaisons
- Normative assumptions about health, food, and recovery to be questioned and re-framed (NEDC, 2024)
- Examination of how Western ideals of food, body image, and health shape treatment approaches and goals and can exclude or harm those from diverse communities

Trauma-informed practice in context

Trauma-informed care acknowledges the prevalence of trauma and its profound impact on health, identity, and care engagement. Many individuals with longstanding eating disorders have experienced multiple forms of trauma, including medical harm, coercion, neglect, or institutionalisation (Blue Knot Foundation, n.d.; CEED, 2024).

Trauma-informed care involves (Mental Health Coordinating Council, 2018):

- Recognising the high prevalence of traumatic experiences and that trauma may shape how a person communicates, relates, or engages with care
- Fostering relationships where disclosures of trauma are possible, without expectation, and responding to disclosures appropriately and sensitively
- Promoting safety in all interactions, including emotional, relational, cultural, and environmental safety
- Using collaborative language that’s easy to understand and supports informed choice
- Understanding that coercive and involuntary interventions can lead to traumatisation or re-traumatisation and seeks to uphold the principles of transparency, collaboration, and mutuality and maximises opportunities for choice and control
- Recognising that cultural and trauma-informed care both ask us to relinquish assumptions, centre lived realities and respond to the whole person, not just the clinical presentation.

3.5 Spiritual and existential considerations

Many individuals navigating longstanding illness, including eating disorders, reflect on spiritual or existential questions. These may relate to identity, purpose, grief, mortality, legacy, or simply the search for meaning. As recognised in palliative and person-centred care frameworks, allowing space for this type of meaning-making is not only appropriate, but also essential to supporting the whole person (Puchalski et al., 2009; WHO, 2020).

Spirituality is defined broadly and does not necessarily involve religion. It may include:

- Cultural, ancestral, or kinship traditions
- Nature, creativity, ritual, or silence
- Formal religious beliefs
- Personal philosophies, values, or inner frameworks

In the context of longstanding eating disorders, these themes often arise in response to chronic uncertainty, accumulated loss, or questions about the future. While they may emerge more explicitly in end-of-life or palliative contexts, they are relevant across all stages of care and deserve to be met with dignity and presence.

Spiritual and existential care is not outside the scope of general healthcare or mental health practice. As the WHO and palliative care frameworks have long affirmed, spiritual support is a legitimate domain of quality of life, particularly when suffering extends beyond the physical (WHO, 2020).

Professionals and supporters can engage in this space by:

- Listening without seeking to solve, minimise, or redirect
- Asking permission before exploring spiritual concerns or beliefs
- Offering access to chaplaincy, cultural leadership, or peer-based spiritual support where appropriate
- Respecting silence, ambiguity, or a person's desire not to discuss existential themes

As Puchalski et al. (2009) highlight, spiritual care is not about having answers, it is about bearing witness, facilitating connection, and making space for what matters most to the individual.

Final reflection

**Foundational care does not begin with diagnosis or a treatment plan.
It begins with a relationship, values and presence.**

This section reminds us that ethical is not just what we do, it is how we do it. With courage. With humility. And with the unwavering belief that every person is worthy of safety, respect and dignity no matter where they are in their care journey.

Before You Begin Section 4: A Gentle Reiteration and position Statement

The intent of Section 4 is not to advocate for or against any specific treatment setting, hospital admission, or use of mental health laws. These decisions are highly individual and shaped by clinical, legal, ethical, cultural, and relational considerations.

Instead, this section offers a principled foundation for approaching difficult decisions in ways that uphold dignity, minimise harm, and keep the person, their values, history, and humanity, at the centre of care.

For many people with longstanding eating disorders, the ability to express preferences or participate in decision-making can fluctuate. At times, the eating disorder may become so dominant that it restricts the person's own voice, making it harder to speak from personal values rather than from the illness. When this occurs, care may need to be guided for the person. Decisions of this nature should never fall to a single clinician alone. Shared deliberation, collective responsibility, and transparent communication help ensure alignment and protect the person from the consequences of fragmented or unilateral decision-making.

A trauma-informed, rights-based approach requires careful attention to what feels unsafe, overwhelming, or distressing for the individual, not based on assumptions or generalisations, but grounded in their lived reality. Trauma is defined by the person. Exploring whether the distress arises from the person's own experience or from the eating disorder's resistance can support clearer, more compassionate decision-making.

For people with lived or living experience reading this section: Your voice matters deeply. Your insights into what supports trust, engagement, safety, and dignity lie at the heart of ethical care. This section does not diminish your autonomy. Its purpose is to protect it by ensuring that when the illness overwhelms your ability to speak from your own values, your support team remains committed to honouring who you are, not what the eating disorder demands.

It is also important to recognise that acute and involuntary care environments vary widely across states, regions, and services. Where possible, treating teams should seek to understand the nature of the setting being considered, including its resources, cultural and trauma-informed capacity, and any relevant history of previous experiences within that service. This preparation supports transparency, reduces unexpected harms, and allows for collaborative planning with those who will be involved. When acute care is the only available option, naming concerns openly, preparing early, and approaching the process collectively can reduce distress and help maintain a sense of dignity and partnership, even when the circumstances are challenging.

Our hope is that the principles in this section support teams, individuals, and their loved ones, to navigate uncertainty together. When approached collaboratively and with humility, even the hardest decisions can be made in ways that reduce harm, maintain connection, and provide steadier pathways toward safety, stability, and support.

This section exists to guide that shared process: to support care that is compassionate, coherent, and ethically grounded, especially in the moments when the way forward feels most challenging.

SECTION 4:
Navigating Ethical & Legal Complexity in Care

4.1 Introduction

Ethical and legal decision-making in the context of longstanding eating disorders is rarely linear or clear-cut. These decisions are not only clinical, they are emotional, relational, and often deeply moral. They frequently arise at moments of uncertainty, emotional strain, or disagreement, and are influenced not only by systemic barriers and structural inequities but also by team dynamics and individual values.

Shannon and the NEDC team wish to thank Simon Katterl for his expertise and consultation around the development of this section.

How do I use this section?

This section is designed for clinicians, multidisciplinary teams, peer workers, and system leaders supporting individuals where care is complex, ethically charged, or has legal or human rights implications. It offers a grounding point to maximise opportunities to provide ethical, reflective, and person-led care and invites practitioners to slow down, ask critical questions, and honour the full humanity of the person in situations where mental health laws are used. It complements the tools in the workbooks, which support collaborative dialogue and shared reflection.

We suggest:

- Revisiting Section 3: Foundational Care Approaches if you are newer to values-based or trauma-informed practice
- Integrating these ethical considerations into supervision, care planning, and cross-disciplinary dialogue
- Using this section as a compass, not a rulebook, to navigate complexity together.

4.2 Ethical decision-making in context

Supporting people with longstanding eating disorders often means holding space for profound ethical tension between autonomy and duty of care, risk and trust, hope and realism. These tensions rarely come with easy answers and often emerge in moments of deep uncertainty.

Ethical decision-making in this context cannot rely on static policies or a simple risk matrix. It calls for emotional honesty, shared responsibility, and humility, especially when trust is fragile and power imbalances are present. It requires open communication and critical reflection on the role of systems, the limits of certainty, and the meaning of relational safety.

The tools in the workbooks are designed to support this process, helping teams to:

- Identify and name tensions in values, roles, and perspectives
- Centre the person's voice, even when communication is limited
- Weigh the relational risks of action and inaction
- Maintain transparency and foster mutual trust across decisions

Uncertainty cannot be removed, but it can be navigated collaboratively, allowing decisions to be made with integrity, care and accountability.

Some of the most common dilemmas include:

Should we intervene when someone refuses care?

How do we support someone when their stated wishes don't match their actions?

When does support cross the line into coercion?

How do we balance physical safety with the person's right to choose?

What does dignity mean when traditional recovery is no longer the person's goal?

In moments of ethical uncertainty, we invite you to pause and ask:

Have we centred this person's voice, not just their diagnosis or risk profile?

Are we responding with transparency, humility, and compassion?

Are we staying with the complexity, or trying to resolve it too quickly?

Are we walking with this person, or acting upon them?

Have we listened deeply, explored and understood their internal conflicts and struggles which might be contributing to difficulties?

4.3 Core ethical dimensions

Ethics is an inherent and inseparable part of clinical care. Professional conduct often focuses on upholding the four core ethical principles beneficence, nonmaleficence, autonomy, and justice (Varkey, 2021). In an attempt to support individuals navigating the ethical issues involved in the treatment of longstanding eating disorders, Jamieson et al. (2024) explored these issues and offered tools to support reflective practice when decisions feel contested or unclear:

Voice and Relational Authority	• Who holds decision-making authority in this situation - and why? • Are we recognising the person's voice, even if it shows up as refusal, fatigue, or silence? • Are we honouring insight from families, carers, or peers?
Equity and Justice	• How do intersecting factors - diagnosis, weight, culture, disability, neurodivergence, class, gender identity - shape access to care? • Are we naming and addressing structural injustice, such as weight bias in healthcare or systemic racism?
Risk and Shared Responsibility	• Are we focusing only on clinical risk? Or are we considering emotional, relational, and systemic risks? • Are we willing to share the weight of risk and uncertainty with the person and their broader support network?
Autonomy and Human Rights	• Are we treating capacity and consent as static checkboxes, or as dynamic, culturally grounded processes? • Are we upholding human and legal rights even under institutional or policy pressures? • Are we attuned to how eating disorders can subtly affect decisionmaking capacity? • Have we clearly distinguished between the decisions where capacity may be compromised and those where it remains intact? • Are we supporting and enhancing a person's ability to make choices and exercise autonomy, without placing them with responsibilities that feel overwhelming or burdensome?
Hope and Realism	• Are we creating space for and valuing alternative forms of hope - such as • hope for comfort, connection, or dignity? • Are we transparent about prognosis, without withdrawing services or presence from the person in need? • Are we helping people to hold hope whilst also balancing the awareness of the realities of their health concerns?

Table 5. Core Ethical Dimensions

Important note:

While the questions above are intended to foster ethical reflection and compassionate, person-centred care, it is crucial that such reflection occurs within legal boundaries. Ethical reasoning must not supersede legal obligations, particularly in cases involving coercion, forced treatment, or deprivation of liberty. Services and professionals must ensure their actions are both ethically defensible and legally sound.

Common ethical dilemmas in practice

When decisions feel contested or unclear, these five core ethical dimensions offer a reflective foundation. They are informed by lived experience, clinical insight, real-world dilemmas and ethical inquiry.

We encourage readers to consult the original paper Jamieson et al. (2024), 'Navigating the Ethical Complexities of Severe and Enduring Eating Disorders' for a more comprehensive exploration of these dimensions.

The following scenarios have been developed to support reflection. They are based on practicebased experience and apply the above core ethical dimensions.

Scenario	Ethical Considerations
A person repeatedly refuses nasogastric refeeding whilst being medically at risk.	• Balancing a person's right to make their own decisions with the clinician's responsibility to ensure safety and wellbeing • Respect for informed refusal • Considerations around decision making capacity • The need to critically consider what the least restrictive option of care is
A family seeks a palliative care plan, which may include access to hospice or community-based support, but the team is uncertain whether these service would accept the referral, or if there is an eligibility criteria that may not align with the longstanding eating disorder experience	• Navigating uncertainty around prognosis and care eligibility • Supporting the family to balance hope with realistic planning • Understanding the difference between curative goals and comfort-focused care • Exploring ethical tensions between clinical definitions and person-centred needs • Fear of "giving up" or prematurely shifting away from active treatment
A clinician is reluctant to shift away from symptom reduction goals (e.g.,, weight restoration, adherence to meal plan, or no longer meeting diagnostic criteria) despite the person's consistent desire to change focus.	• Exploring how care goals can shift from fixed clinical targets to priorities defined by the person receiving support • Identifying whether the need of the clinician or the needs of the client are being prioritised/ considered • Exploring the implications of continuing to pursuing symptom reduction vs those offered by meaningful engagement (as defined by the client)

A carer expresses burnout and moral distress over repeated hospital admissions.	• Identifying and valuing the relational impact • Balancing the need to reduce harm with the responsibility to offer care that is realistic, respectful, and sustainable for everyone involved
A team proceeds with involuntary treatment despite significant family or peer opposition.	• Balancing the legal authority to intervene with the potential harm it may cause to trust, connection, and therapeutic relationship • Being responsible for how authority is exercised, including its impact on trust, autonomy, and the person’s experience of care

Table 6. Common Ethical Dilemmas in Practice

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4.4 Tools for ethical reflection and practice

Ethics cannot be reduced to a checklist, as care is rarely that simple. Instead, the tools in this section support transparent, relational, and values-driven decision-making. Designed for use across a range of settings, including multidisciplinary teams, clinical and peer supervision, case reviews, and conversations with families and communities, they foster thoughtful reflection, collaborative dialogue, and a shared sense of ethical accountability. This is especially vital when care deviates from conventional or linear pathways.

Table 3 summarises the ethical reflection tools included in this Guide.
Full versions and guidance for use can be found in the accompanying Workbooks.

Values-Based Practice (VBP) (Fulford et al., 2012; Woodbridge & Fulford, 2004)

VBP practice invites stakeholders, including the individual, family, peer workers, and clinicians, to reflect on how they each understand and prioritise values such as safety, dignity, autonomy, trust, and hope. It is especially helpful when people's values appear in tension or when teams feel ethically "stuck."

Example for use: During team discussions where care planning has stalled due to conflicting perspectives on safety vs. autonomy.

Workbook	Tools
For the Workforce Supporting People with Longstanding Eating Disorders	Values-in-Practice Check-In Sheet Reflective Practice & Role Alignment Framework

DILEMA Framework

Adapted from Jamieson et al. (2024) the DILEMA model supports structured ethical reasoning when facing complex dilemmas. It prompts a shift away from binary thinking and towards collaborative, person-led responses.

D	Define the dilemma
I	Identify values and voices
L	Look at legal, cultural, and relational considerations
E	Explore options, risks, and uncertainties
M	Map shared responsibilities and limits
A	Act with accountability, adaptability, and care

Example for use: When a person declines a recommended intervention and the team is divided on whether to escalate care.

Workbook	Tools
For the Workforce Supporting People with Longstanding Eating Disorders	Ethical Decision-Making & Dialogue Prompts
	Mental Health Laws Ethical Reflection Tool

Bias Reflection Tool (Chapman et al., 2013; Jamieson et al., 2024)

This tool surfaces unconscious assumptions that may influence care - including beliefs about compliance, risk, prognosis, or capacity. It supports ethical clarity and team alignment, particularly when teams feel divided or reactive.

Example for use: When assumptions about someone's capacity or motivation may be shaping care responses.

Workbook	Tools
For the Workforce Supporting People with Longstanding Eating Disorders	Bias Reflection Tool

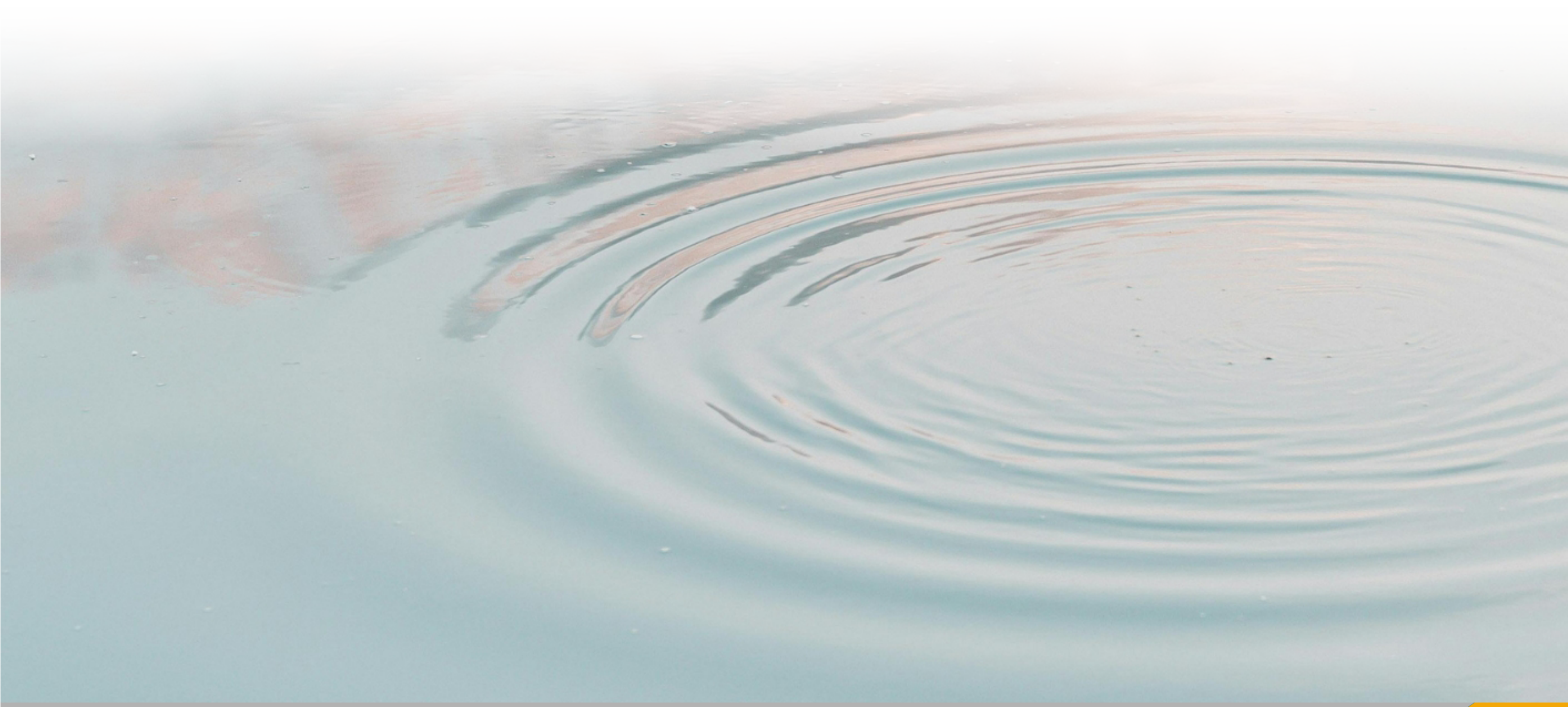
Ethical Dialogue Tools (Delany et al., 2024; Haan et al., 2018)

The Ethical Dialogue Prompts and Worksheet support open, honest conversations in care planning, team meetings, or joint sessions with individuals and families.

They emphasise shared humanity, respect for uncertainty, and collective sense-making.

Example for use: In a meeting with a family where different understandings of risk or recovery are present.

Workbook	Tools
For the Workforce Supporting People with Longstanding Eating Disorders	Ethical Decision-Making & Dialogue Prompts
	Mental Health Laws Ethical Reflection Tool



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Risk and Suicidality Framework (Australian Psychological Society, 2025; Suicide Prevention Australia and Mental Health and Suicide Prevention Research and Education Group, 2022)

This framework differentiates between types of distress (e.g.,, passive risk, active suicidality, trauma-driven behaviours) and helps teams plan ethically, not reactively. It supports trauma-informed and relationally grounded responses to risk, especially when defaulting to hospitalisation or other escalation strategies are being questioned.

Example for use: When exploring alternatives to hospital admission for a person experiencing deep distress but not active suicidality.

Workbook	Tools
For the Workforce Supporting People with Longstanding Eating Disorders	Risk vs. Values Worksheet
For People Who Care For, Love or Support Someone with a Longstanding Eating Disorder	Risk vs. Values Worksheet
For People with a Longstanding Eating Disorder	Risk vs. Values Worksheet
For the Workforce Supporting People with Longstanding Eating Disorders	Capacity & Voice Consideration Prompt Sheet

Table 7. Tools to Support Ethical Reflection

These tools are most effective when used alongside:

- **Reflection and care planning templates**
- **Clinical supervision and co-reflective practice**
- **Diverse input from the person, loved ones and multi-disciplinary professionals**
- **A commitment to ethical humility and shared learning**

4.5 Facilitating ethical conversations

Ethical care requires more than good intentions - it requires space. Space to pause, to listen, and to reflect, particularly when care decisions are complex, uncertain, or emotionally charged.

This is especially true in the context of longstanding eating disorders, where ethical tensions often arise alongside trauma histories, systemic constraints, and differing perspectives on risk, readiness, or responsibility (Day et al., 2024; Mac Donald et al., 2023; Musolino et al., 2016).

Facilitated ethical conversations create room for emotional honesty, shared accountability, and deeper understanding, not just of what should be done, but of what matters most, to whom, and why.

When thoughtfully guided, these conversations can:

- Slow the pace of decision-making when time and context allow
- Surface assumptions, biases, and emotional dynamics that may otherwise remain hidden
- Support relational repair, reduce moral distress, and clarify shared values
- Ensure the person's voice, whether expressed directly, through relationships, or via prior planning, remains central to care

They are most effective when:

- A trusted facilitator or reflective team member helps guide the process
- Psychological safety is prioritised, especially in multidisciplinary environments
- The goal is not consensus, but deeper ethical clarity and mutual respect

These conversations may be helpful in settings such as:

- Multidisciplinary care meetings involving disagreement or uncertainty
- Clinical or peer supervision
- Case reviews where distress, rupture, or perceived risk is present
- Service-wide reflection or system recalibration

4.6 Legal considerations and the role of mental health laws

In Australia, when a person is assessed as experiencing a psychiatric illness and fulfills further criteria (including a risk to self and others or a lack of decision-making capacity), mental health laws allow for involuntary mental health treatment in a hospital or in the community (RANZCP, 2017a). Whilst the specific criteria which must be met to provide involuntary treatment vary across the states and territories (RANZCP, 2017b, see Table 3 below), they are designed to preserve life and enable urgent intervention (Department of Health and Aged Care, 2013).

Many mental health laws contain principles that are influenced by the 1991 United Nations Principles for the Treatment of Persons with Mental Illness and the Improvement of Mental Health Care (RANZCP, 2017a; United Nations, 1991), which emphasise the right to be treated in the least restrictive manner, that valid consent for treatment must be sought (with allowances for exceptions), that individuals are informed of their rights, and that care respects the humanity and dignity of people.

This means that providers must do everything practical to provide treatment on a voluntary basis and within the least restrictive environment and manner (e.g., within the community where possible).

Similarly, the United Nations Principles stipulate that involuntary seclusion and physical restraint practices are employed when it is the only means available to prevent immediate or imminent harm to the "patient" or others, but some laws allow for these practices to be used for the prevention of nuisance, absconding or property damage (RANZCP, 2017a).

These principles are also influenced by the UN Convention on the Rights of Persons with Disabilities (CRPD; 2006), which has been interpreted to shift the system away from the use of substitute decision-making approaches to supported decision-making approaches. However, many of Australia's current mental health laws have been critiqued as being incompatible with the CRPD's emphasis on supported decision-making and non-coercive care (Maylea, 2023; Gill et al., 2020).

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Table 1. Involuntary Treatment Criteria in Australian mental health laws - Adapted from Royal Australia and New Zealand College of Psychiatrists

Involuntary Treatment Criteria in Australian mental health laws – Adapted from Royal Australia and New Zealand College of Psychiatrist

	ACT Mental Health Act 2015	NSW Mental Health Act 2007	NT Mental Health and Related Services Act 1998	QLD Mental Health Act 2016	SA Mental Health Act 2009	TAS Mental Health Act 2013	VIC Mental Health and Wellbeing Act 2022	WA Mental Health Act 2014
Mental Illness	The person has a mental illness or mental disorder, and	The person is suffering from mental illness and, owing to that illness, there are reasonable grounds for believing that care, treatment and control of the person is necessary:	The person has a mental illness and as a result of the illness; because of the absence of involuntary treatment, is likely to:	The person has a mental illness; Because of the person's illness, the absence of involuntary treatment, or the absence of continued involuntary treatment, is likely to result in:	The person has a mental illness and because of that mental illness, the person requires treatment for	The person has, or appears to have, a mental illness and without treatment, the mental illness will, or is likely to seriously harm:	the person has mental illness; and because the person has mental illness, the person needs immediate treatment to prevent:	the person has a mental illness for which the person is in need of treatment and because of the mental illness, there is:
Harm	Is doing, or is likely to do serious harm to themselves or some else or	For the person's own protection from serious harm or the protection of others from serious harm and	cause serious harm to himself or herself or to someone else or	imminent serious harm to the personal others or	The persons own protection from harm (where the physical or mental and including harm involved in the continuation/deterioration of the person's condition)or to protect others from harm and	safety of the person or others or	(i) serious deterioration in the person's mental or physical health; or (ii) serious harm to the person or to another person; and	A significant risk to the safety of the person or another or a significant risk of serious harm to the person or to another or
Need for care	Is suffering, or is likely to suffer, serious mental or physical deterioration and	N/A	suffer serious mental or physical deterioration and	the person suffering serious mental or physical deterioration.	The person has impaired decision making capacity relating to the appropriate treatment of the person's mental illness;	the persons health and	if the person is made subject to a temporary treatment order or treatment order, the immediate treatment will be provided to the person; and	a significant risk to the health of the person and
Psychiatric treatment	Treatment/care/support is likely to reduce the harm or deterioration (or its likelyhood) or result in an improvement in the person's condition and	N/A	The person requires treatment that is available at an approved treatment facility and	N/A	N/A	the treatment will be appropriate and effective in terms of the outcomes referred to in section 6 (1) [see additional criteria] and	N/A	Treatment in the community cannot reasonably be provided to the person and
No less restrictive environment	The treatment, care or support cannot be adequately provided in another way that would involve less restriction of the freedom of choice and movement	no other care of a less restrictive kind that is consistent with safe and effective care, is appropriate and reasonably available to the person.	There is no less restrictive means of ensuring that the person receives the treatment and	The main objective of the Act are to be achieved in a way that is the least restrictive of the rights and liberties of a person who has a mental illness.	There is no less restrictive means than an impatient treatment order [I tio] of ensuring appropriate treatment of the person's illness will stop	The treatment cannot be adequately given except under a treatment order.	there are no less restrictive means reasonably available to enable the person to receive the immediate treatment.	The person cannot be adequately provided with treatment in a way that would involve less restriction.
Additional criteria	The above criteria must be satisfied before a mental health order can be made for a person with decision making capacity (DMC), who refuses treatment, care or support, the harm or deterioration must be so serious that it outweighs the right to refuse. If a person lacks DMC and refuses treatment, care or support, the only criteria that applies is the existence of a mental disorder or illness. Separate criteria apply to forensic psychiatric treatment orders	In considering whether a person is a mentally ill person, the continuing condition of the person, including any likely deterioration in the person's condition, and likely effect of any such deterioration, are to be taken into account	the person is not capable of giving informed consent to the treatment or has unreasonably refused to consent to the treatment.	The person does not have capacity to consent to be treated for the illness.	In considering whether there is no less restrictive means than an ITO of ensuring appropriate treatment, consideration must be given, amongst other things, to the prospects of the person receiving all necessary treatment on a voluntary basis or in compliance with a community treatment order.	[i] the person does not have DMC [ii] the treatment will: prevent/remedy mental illness; Or manage/alleviate it where possible; Or reduce the risks that persons with mental illness may pose to themselves or others; Or monitor and evaluate the person's mental state.	N/A	(i) the person does not demonstrate the capacity to make a treatment decision about the provision of treatment (ii) Decisions regarding ICT must be made with reference to guidelines published by the chief psychiatrist

Whilst mental health laws generally refer to the provision of involuntary psychiatric treatment, the initial focus of compulsory treatment orders is often to help restore decision-making capacity, giving time for a person to make a decision, gather information and the involvement of appropriate decision-making supports (Department of Health and Aged Care, 2013).

In the context of eating disorders, this may involve addressing nutritional malnourishment and its associated impacts on decision-making capacity (Elzakkers et al., 2016; Guillaume et al., 2015).

What does "least restrictive" care mean?

In most mental health laws, there is a duty to provide the least restrictive treatment to a person possible. This requires that clinicians:

- **Always seek to prioritise autonomy and choice for consumers, avoiding coercion wherever possible.**
- **Treatment should always start in the way that is least intrusive on a person's rights and autonomy and only increase as it is required under mental health laws.**
- **Any restrictions should be proportionate to the risk and be applied for the shortest time possible.**

Involuntary treatment in the context of longstanding eating disorders raises profound ethical dilemmas - particularly when trust is fragile, histories of trauma are present, or recovery goals are contested.

The layered nature of these dilemmas is illustrated in the case study that follows.

Learning through a lived experience...

The Human Impact of Ethical Decisions: A Case

A coronial inquest in Western Australia examined the death of a young woman with a longstanding eating disorder. Despite clear and repeated requests from her family to receive palliative care at home, an involuntary admission proceeded based on medical risk and clinical concern. She died shortly thereafter in hospital.

The inquest highlighted:

- The mismatch between relational authority and clinical perspectives
- Systemic gaps in non-coercive care options
- A lack of coordinated pathways for individuals no longerseeking recovery-based interventions
- The profound impacts these experiences have on people with an eating disorder, and their support systems

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Note: This example draws from a publicly available coronial inquest in Western Australia. No identifying details have been included. Every effort will be made to seek permission to reference the case more directly in future editions, in keeping with the trauma-informed and relational values that guide this work. We acknowledge the courage and advocacy of the family, and of those who cared for and supported this individual, and hope this Guide contributes in some small way to the change they sought on behalf of their loved one.

Experiences of Involuntary Treatment

Involuntary treatment can be one of the most ethically complex decisions in care for eating disorders. Its impacts can be profound for individuals, loved ones, and clinicians alike (Katterl et al., 2023; Krieger et al., 2021; Jankovic et al, 2011; Rienecke et al., 2023). Caregivers have reported feeling a mixture of guilt and relief in response to involuntary admissions, and that services responded to, rather than prevented crises (Jankovic et al, 2011). Clinicians also face moral distress when navigating these decisions as involuntary treatment can adversely impact the therapeutic relationship (Saya et al. 2019, Wyder et al. 2015) - requiring clinicians to balance duty of care, legal obligations, institutional expectations, and a deep desire to do what is right. These are not failures of intent, but reflections of systemic gaps and ethical complexity (Laureano et al., 2024).

Those with lived experience of involuntary treatment and restrictive practices report distress surrounding the lack of control they feel, significant disruptions to education, employment and relationships, and that the treatment felt coercive or punitive (Lubieniecki, McGrath, & Sharp, 2025; Rienecke et al., 2023). Some do, in retrospect, acknowledge that involuntary treatment was beneficial and required (Rienecke et al., 2023). However, individuals who continue to struggle with their eating disorder following involuntary treatment, tend to view their experiences of involuntary treatment more negatively (Rienecke et al., 2023), highlighting the complexity and diversity of experiences.

National Mental Health Consumer and Carer Forum (2020) position statement maintains that involuntary treatment and other restrictive practices (like restraint and seclusion) are avoidable and preventable, and that rates of involuntary treatment remains too high.

In ratifying the CRPD, the Commonwealth government stated that it interprets the convention to permit the use of involuntary treatment so long as it was a last resort and subject to safeguards (CRPD, 2006; United Nations, 1991). Consequently, there are circumstances where involuntary care may be deemed essential and permitted, and for some it can be helpful to include this in proactive crisis planning.

When delivered in trauma-informed, appropriately resourced settings, mental health laws can play a vital role in:

- Providing temporary safety during periods of acute risk
- Supporting individuals who feel overwhelmed or ambivalent in making decisions
- Allowing time for re-evaluation of care, treatment goals and pathways
- Offering life-saving interventions that reconnect a person with hope, care, and possibility
- When there is loss of capacity and the team are acting in the best interests of the person, for example, to prevent death

However, there are significant challenges when the broader system is not equipped to hold that responsibility. Despite being enacted with protective intent, individuals may be transferred into environments that:

- Lack eating disorder knowledge and/or trauma-informed training
- Are under-resourced to offer therapeutic engagement or continuity of care
- Do not provide clear transitional pathways or consistency across teams or jurisdictions

This can be particularly distressing for those who have experienced restrictive practices, prolonged hospitalisation, or previous experiences of harm in care (Dawson et al., 2021; Lubieniecki, McGrath, & Sharp, 2025). In such cases, involuntary treatment may inadvertently:

- Contradict a person's clearly expressed values and preferences
- Disrupt relational safety or therapeutic engagement (Saya et al. 2019, Wyder et al. 2015)
- Re-enact trauma or reinforce disconnection (Lubieniecki, McGrath, & Sharp, 2025)
- Impact family and carer wellbeing, particularly when communication is fragmented

Decisions involving Mental Haelth Acts need to be:

Decisions involving Mental Health Laws need to be:

- **Made collaboratively, with the person, trusted others and care team**
- **Documented transparently, with clear rationale and follow up**
- **Reviewed through a team-based, ethical lens - not left to one person alone**
- **Paired with opportunities for relational repair and supported reflection**
- **Proactive and guided by the persons values - including Advance Care Planning, relational authority summaries, and reflective supervision, which can reduce reliance on crisis-driven responses**
- **Guided by the legal requirements in each state or territories mental health laws**

IT IS IMPORTANT TO...

understand the current context of care and whether the receiving service is equipped to provide trauma-informed, eating disorder treatment under the jurisdiction of the law. The intent to preserve life must be weighed against the potential for further psychological or relational harm. These dilemmas are not binary. They require careful, collaborative consideration of both clinical need and the broader system's capacity to uphold safety, dignity, and appropriate care

See the Mental Health Laws Ethical Reflection Tool in the Workforce Workbook for structured guidance when working through these decisions. There are many facets that contribute to how, when and why mental health laws (such as enacting compulsory treatment) may be used, these include:

- **Pressure:** From systems/organisations, families and loved ones, colleagues or other health professionals and patients, for a particular outcome
- **Fear:** From clinicians, families and loved ones, colleagues or other health professionals and patients around what could happen with or without the use of mental health laws
- **Care and hope:** From clinicians, families and loved ones, colleagues and other health professionals for this patient and what they wish the outcome could be

Using these tools in practice

These reflective questions and practice prompts support values-based decision-making when involuntary treatment is being considered. They can be used in supervision, case reviews, or ethical discussions to examine whether care aligns with a compassionate, trauma-informed approach - or whether coercive patterns may be emerging.

Ethical questions for teams to consider - Reflective prompts

- Are we prioritising life and medical risk or outcomes over relational trust - and at what cost?
- Have we genuinely explored harm reduction, respite, or collaborative decision-making?
- Are we interpreting distress or refusal as incapacity?
- Have we considered the person’s cultural, neurodivergent, or trauma-informed context?
- Have we given time and space for the person and their chosen supports to have their perspective heard?
- Have we assessed the risks and considered how compulsory treatment may alter them?
- Have we documented our rationale and explored all reasonable alternatives?
- Have loved ones, peer support workers, or patient advocates been included in the care planning?
- How will this decision affect future trust, engagement, and wellbeing?
- Have we reviewed this case through ethical or interdisciplinary supervision?
- Regardless of capacity, has the team explained the rationale for using mental health laws to intervene, and discussed it with the person, allowing them to share their views?
- Have we explored ways to support the person to optimise their capacity or have autonomy over other aspects of their experience?

Compassionate Application	Coercive Application
Decisions are guided by the person’s previously expressed values or as outlined in Advance Care Planning, with thoughtful explanation when this isn’t feasible	Disregards the person’s clearly expressed preferences and does not provide a clear and compassionate explanation of why mental health laws are being used.
Initiated in response to acute, life-threatening risk with efforts to minimise harm and with as much advanced discussion as possible	Initiated abruptly to manage institutional risk or practitioner discomfort and ignores the need to form and maintain compassionate and supportive therapeutic relationships
Accompanied by honest communication, relational support, and follow-up repair	Delivered without transparency, explanation, or relational consideration

• Includes family, peers, or cultural advocates where appropriate • Seeks to preserve dignity and reduce trauma • Applied with clinical humility and ethical review • Time-limited, with regular review and clear exit points	• Excludes trusted supporters or fails to seek input around cultural considerations • Results in fear, humiliation, shame or re-traumatisation • Applied without space for reflection or consideration of alternate pathways • Open-ended, prolonged, or defaulted to repeatedly

Table 9. Ethical Considerations and Applications

4.7 Recognising relational authority when legal documents are absent

Many individuals do not have formal legal documents, such as an Advance Health Directive (AHD) or Enduring Power of Guardianship (EPG). An AHD allows the person to express their treatment preferences in advance, but it is not legally binding. In contrast, an EPG appoints another person to make decisions on their behalf when they are no longer able to, and while legally enforceable, it does not always reflect the person's expressed wishes.

In these situations, the knowledge, observations, and insights of those who have walked closely alongside the person, including families, carers, peer workers, and trusted supporters - can offer essential context about the person's values, preferences, communication style, and historical responses to care. These perspectives can be understood as a form of relational authority, which draws upon relational ethics (Hirsch, 2023).

Relational authority refers to influence that arises through trust, empathy, and genuine connection, rather than formal position or legal power. It is earned over time through consistent care, integrity, and shared experience. In healthcare contexts, relational authority can foster trust, increase collaboration, and support ethical care decisions, particularly when formal documents are absent or contested (Mukherjee & Thomas, 2022; Tomaselli et al., 2020).

Recognising relational authority is increasingly supported by national frameworks, co-designed guidelines, and clinical practice initiatives. For example, the NSW Health Family and Carer Rights and Responsibilities (2023) affirms the right of families and carers to be heard, respected, and meaningfully involved in decisions impacting the person they support.

Recognising relational authority does not replace legal or clinical decision-making frameworks - and there can be circumstances where the person's wishes and those of their supporters diverge.

However, when relational authority is overlooked, services may risk:

- Not aligning care with the person's authentic values, priorities, and life context
- Inadvertently contributing to distress, grief, or moral injury to those who have provided critical support
- Missing opportunities for trust-building, continuity, and more compassionate care
- Failing to access insights, resources, and advocacy held by those in a position of relational authority

PRACTICAL GUIDANCE FOR TEAMS	
Focus Area	**Practical Applications**
1 Begin planning early and relationally	• Support the person to name trusted supporters, even informally • Create care summaries or values statements that reflect both personal and relational perspectives • Use the Advance Care Planning tools and Care Collaboration Summary Sheet to document shared understanding *(see Workbook for People with Longstanding Eating Disorders)*
2 Centre relational insight, even without legal tools	• Ask: "What has this person previously expressed and who knows them best?" • Record the perspectives of loved ones and peer workers with equal care • Validate family (including chosen family) knowledge as part of ethical care planning
3 Use involuntary pathways only with transparency and accountability	• Engage ethical or clinical supervision before applying mental health laws • Clearly document why less restrictive options were not viable • Maintain open communication with families and supporters, even when views diverge
4 Acknowledge systemic constraints honestly	• Be transparent about resource gaps, funding limitations, or policy challenges • Involve service leaders or advocates to support compassionate planning • Avoid using the absence of legal documents as justification to exclude relational voices

Table 10. Practical Guidance For Teams

Documenting relational insight when legal directives are absent

This section outlines how teams can document meaningful insights provided by trusted supporters, particularly when no formal legal documents are in place. Doing so helps ensure that decisions remain person-centred, trauma-informed, and ethically grounded.

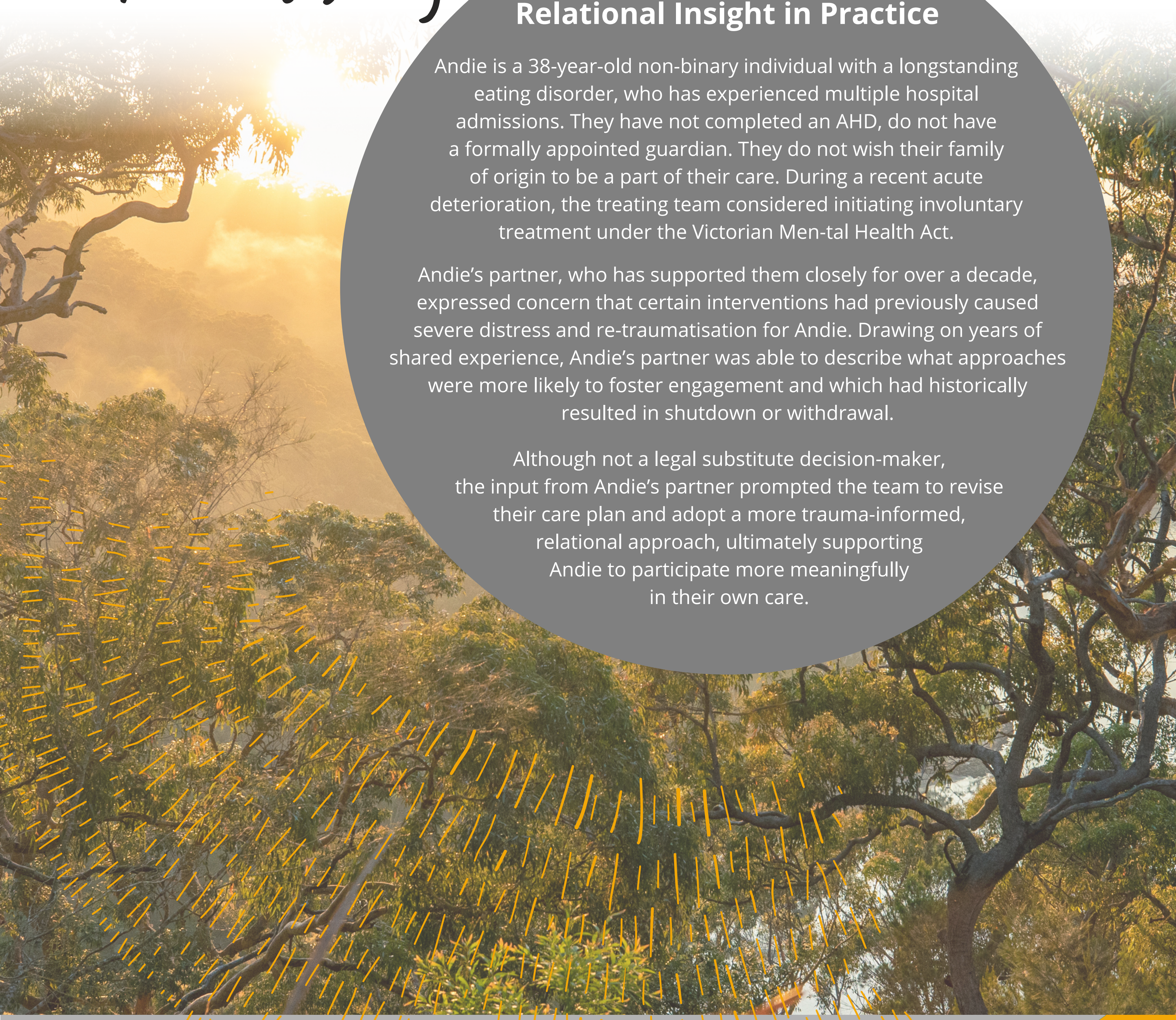
Documenting relational insight can:

- Support continuity and relational trust across care settings
- Guide future decision-making and avoid repeated harms
- Reduce conflict by making individuals values, boundaries, and history visible

Consider recording the following:

- The person’s known care preferences, in their own words
- Shared understanding of values by family, peers, or carers
- Past treatment experiences and outcomes (including trauma or success)
- Identified care boundaries (e.g., expressed wish to avoid use of physical restraint or tube feeding)
- Trusted contacts for future planning or crises
- Any informal or partial planning conversations held to date

Andie’s Story...



Vignette-
Relational Insight in Practice

Andie is a 38-year-old non-binary individual with a longstanding eating disorder, who has experienced multiple hospital admissions. They have not completed an AHD, do not have a formally appointed guardian. They do not wish their family of origin to be a part of their care. During a recent acute deterioration, the treating team considered initiating involuntary treatment under the Victorian Men-tal Health Act.

Andie’s partner, who has supported them closely for over a decade, expressed concern that certain interventions had previously caused severe distress and re-traumatisation for Andie. Drawing on years of shared experience, Andie’s partner was able to describe what approaches were more likely to foster engagement and which had historically resulted in shutdown or withdrawal.

Although not a legal substitute decision-maker, the input from Andie’s partner prompted the team to revise their care plan and adopt a more trauma-informed, relational approach, ultimately supporting Andie to participate more meaningfully in their own care.

4.8 Advance Health Directive & Enduring Powers of Guardianship

Why these tools matter in the context of longstanding eating disorders

Individuals with longstanding eating disorders often experience periods of medical deterioration, emotional distress, or decision-making overload, especially after years of treatment, trauma, or system fatigue. Advance care planning tools such as AHD's and EPG's (or their equivalents) are not only relevant at the end of life, but they also offer proactive, respectful ways to ensure a person's values and care preferences are honoured, particularly when capacity fluctuates or when care decisions become ethically or clinically challenging.

They can help reduce distress in times of crisis, clarify the person's voice in advance, and provide guidance to families and health professionals when the person may not be able to speak for themselves.

Importantly, these are not just legal documents, they are also relational tools. They invite thoughtful, collaborative conversations well before a crisis, and reinforce trust, shared understanding, and values-based care.

Advance Health Directives

Allow a person to clearly record what treatments they would or would not want in the future, including preferences about hospitalisation, refeeding, sedation, palliative care, or end-of-life decisions (Australian Department of Health, Disability, and Aging, 2025).

Enduring Power of Guardianship

An Enduring Power of Guardianship (or equivalent decision-making arrangement) enables a person to appoint someone they trust to make personal, health, or lifestyle decisions on their behalf if they lose capacity. Rules and terminology vary across Australian jurisdictions (Australian Government Carer Gateway, n.d.).

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Advanced Health Directives and Enduring Powers of Guardianship may be especially helpful when:

The individual wishes to clearly state what care they do or do not want in the future

Previous experiences of coercion or harm make it difficult to re-engage in care without clear boundaries

There is concern that future decisions may be made without the person's voice being central

The person prefers a specific family member, peer worker, or advocate to help represent their wishes

Table 4 outlines how Advanced Health Directives and Enduring Powers of Guardianship can be used.

Table 11. How to use Advanced Health Directives and Enduring Powers of Guardianship

When documented early and shared transparently, these tools can:

- Prevent coercive or rushed decision-making in moments of crisis
- Ensure that care aligns with the person's long-term values and cultural context
- Reduce the emotional and ethical burden placed on clinicians and families
- Uphold the individual's dignity, even when they are at their most vulnerable

Practical Tips for Implementation:

- Encourage early completion of AHD's and nomination of guardians before crisis
- Involve loved ones and peer workers in the process (with consent)
- Store documents accessibly (e.g.,, My Health Record, GP)
- Use relational authority when legal tools are incomplete

Limitations and Cautions:

- In some jurisdictions, AHD's may be overridden under specific mental health legislation, particularly if the person is made involuntary.
- Service systems may vary in their willingness or capacity to honour unconventional preferences.
- The voice of a legal guardian may be privileged over relational or cultural knowledge.

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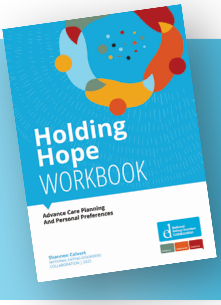
Note on Terminology: terminology and legal processes for advance care planning tools vary across Australian states and territories. Readers are encouraged to consult their relevant public rustee, guardianship authority, or local health department for specific legal guidance.



TOOLS IN THE WORKBOOKS THAT SUPPORT CARE PLANNING

ACP Snapshot Summary Sheet - LIVED EXPERIENCE WORKBOOK
Comfort-Focused Care Planning Tool - LIVED EXPERIENCE WORKBOOK
Mental Health Laws Ethical Reflection Tool - WORKFORCE WORKBOOK
Care Coordination Toolkit - WORKFORCE WORKBOOK

4.9 Considerations for capacity assessments

Decision-making capacity plays an important role in determining the care someone will receive. Mental health laws require individuals to have capacity to give informed consent for treatment and the principles which determine whether someone has capacity differ by state and territory (see Table 2 below).

Table 12. Relevant Mental Health Legislation by State and Territory

State/Territory	Relevant Mental Health Legislation	Support services
Australian Capital Territory	ACT Mental Health Act 2015	Legal Aid ACT
New South Wales	NSW Mental Health Act 2007	Mental Health Advocacy Service
Northern Territory	NT Mental Health and Related Services Act 1998	Community Visitor Program Northern Territory
Queensland	QLD Mental Health Act 2016	Legal Aid Queensland
South Australia	SA Mental Health Act 2009	SA Health - Advocacy, complaints & appeals
Tasmania	TAS Mental Health Act 2013	Advocacy Tasmania
Victoria	VIC Mental Health and Wellbeing Act 2022	Independent Mental Health Advocacy
Western Australia	WA Mental Health Act 2014	Mental Health Advocacy Service

The principles set out in the *Mental Health and Wellbeing Act (2022)* are summarised in Table 13 and are explored in more detail below to highlight the considerations relevant to decisions about capacity assessments in the context of eating disorders.

Table 13. Victorian Principles of Capacity - s. 87(2) Mental Health and Wellbeing Act 2022

State	Principles
Victoria	The Mental Health and Wellbeing Act 2022 principles state that: • The capacity to give informed consent is specific to the decision that needs to be made. • It should be presumed that a person has capacity to give informed consent. • A person's capacity to give informed consent may change over time. • It should not be assumed that a person lacks capacity to give informed consent based only on their: - age - appearance - condition - behaviour • A decision that a person lacks capacity to give informed consent should not be made purely because they make a decision that could be considered unwise. • Consideration must be given to whether the person may be enabled to give informed consent by providing them with appropriate supports. See s. 87(2) - *Mental Health and Wellbeing Act (2022)*

As demonstrated in the *Mental Health and Wellbeing Act Vic (2022),* capacity is decision-specific, it must be assessed in relation to a particular decision at a particular time. It is not global: a person may have capacity for one decision but not another. Capacity may also fluctuate, especially in the context of eating disorders, where medical instability, distress, or relational dynamics can influence cognitive clarity and insight.

Importantly, the law requires that individuals be supported to participate in decision-making, and that assumptions are not made based solely on age, appearance, condition, behaviour, or perceived risk. A decision considered "unwise" is not grounds for determining incapacity. Nor should capacity be conflated with agreement or compliance.

Appropriate supports in the context of longstanding eating disorders may include trauma-informed communication, culturally safe engagement, and the presence of trusted supporters or advocates. These supports are not only legally relevant but ethically necessary, particularly where trust in systems has been eroded.

Autonomy should not be viewed solely as a legal threshold, but also as a dynamic and relational experience. It is shaped over time by consistent relationships, emotional readiness, and the felt safety of care environments. These factors must be considered alongside legal and clinical frameworks when navigating complex decisions (Jamieson et al., 2024).

4.10 Understanding capacity through an ethical lens

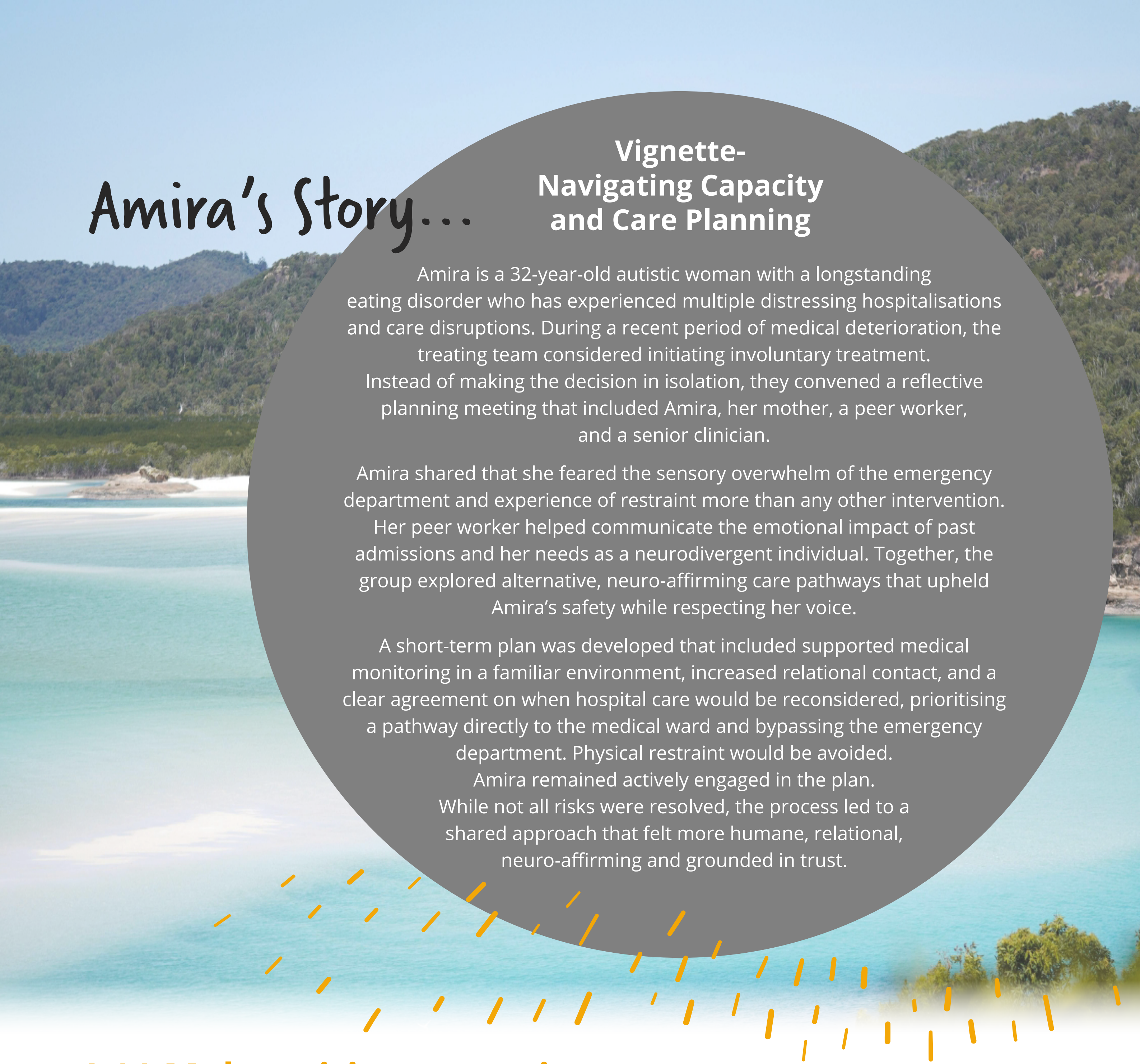
While legislation outlines the formal criteria for determining decision-making capacity, ethical practice in real-world care settings often demands a broader, more nuanced understanding. Particularly in the context of longstanding eating disorders, relational, cultural, and trauma-informed factors may shape how individuals express choice, understand risk, or engage in care. These considerations are not substitutes for legal thresholds but are essential to delivering care that is respectful, person-led, and ethically sound. The table below introduces practice reflections grounded in core ethical principles, such as respect for autonomy, nonmaleficence, and beneficence (Beauchamp & Childress, 2019) and explores how they apply when supporting capacity and decision-making in complex situations.

Practice reflections to support ethical and relational approaches to capacity:

These principles can guide ethical reflection alongside statutory requirements when working with complexity, uncertainty, or perceived risk.

Principle	Practice Insight
Disagreement is not incapacity	A person declining treatment may still possess full decision-making capacity
Context matters	Capacity can shift depending on environment, relational safety, fatigue, or perceived threat
Communication varies	Neurodivergent, trauma-affected, or culturally grounded ways of expressing choice must be recognised and respected
Relational insight has value	Families, peer workers, or cultural advocates may help interpret preferences based on care history
Risk tolerance varies	Acceptance of risk may reflect informed decision-making - not denial or pathology
Autonomy includes the right to make decisions	If capacity is intact, such decisions must be respected - even when involving high risk
Ethical decisions are best made collectively	Shared reflection between the person, trusted supporters, and professionals promotes transparency and person-led care.

Table 14. Practice Reflections on Capacity



Amira's Story...

Vignette- Navigating Capacity and Care Planning

Amira is a 32-year-old autistic woman with a longstanding eating disorder who has experienced multiple distressing hospitalisations and care disruptions. During a recent period of medical deterioration, the treating team considered initiating involuntary treatment.
Instead of making the decision in isolation, they convened a reflective planning meeting that included Amira, her mother, a peer worker, and a senior clinician.

Amira shared that she feared the sensory overwhelm of the emergency department and experience of restraint more than any other intervention. Her peer worker helped communicate the emotional impact of past admissions and her needs as a neurodivergent individual. Together, the group explored alternative, neuro-affirming care pathways that upheld Amira's safety while respecting her voice.

A short-term plan was developed that included supported medical monitoring in a familiar environment, increased relational contact, and a clear agreement on when hospital care would be reconsidered, prioritising a pathway directly to the medical ward and bypassing the emergency department. Physical restraint would be avoided.
Amira remained actively engaged in the plan.
While not all risks were resolved, the process led to a shared approach that felt more humane, relational, neuro-affirming and grounded in trust.

4.11 Malnutrition, capacity, and ethical assumptions

Malnutrition and medical instability, particularly when prolonged, can affect cognitive processes such as concentration, insight, decision-making, and emotional regulation capacity (Elzakkers et al., 2016; Guillaume et al., 2015). However, a specific diagnosis, such as a longstanding eating disorder or low weight, should not be used in isolation as an indicator of compromised decision-making capacity *(Mental Health and Wellbeing Act 2022 (Vic).* Making assumptions based on diagnosis or body weight can undermine person centred care, erode trust, and compromise ethical obligations to assess capacity on an individualised basis (Elzakkers et al., 2016).

While nutritional compromise may influence cognition, the legal test as to whether a person with a longstanding eating disorder has decision-making capacity will rest on whether certain criteria are met.

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For example, in the *Mental Health and Wellbeing Act (2022)* this turns on whether a person can:

a. Understand the information they are given for the purpose of deciding whether or not to consent; and
b. Remember that information; and
c. Use or weight that information in deciding whether or not to consent; and
d. Is able to communicate the decision the person makes by speech, gestures or any other means.

Therefore, a person who experiences changes in their cognition as a result of malnutrition is still required to have their capacity tested on these criteria, or others set out in their jurisdiction's mental health laws. Refusal of refeeding or hospitalisation should not automatically be interpreted as incapacity, or disengagement. Similarly, it does not mean someone does not wish to get help, just perhaps not this particular type of help. In some situations, refusal may represent a reasoned, values-based decision shaped by deep knowledge of a person's own history and limits. This does not suggest that refusal is without risk or that care teams should withdraw concern. Rather, it highlights the need for careful, dialogue about what matters to the person, how capacity is assessed, and how support can be offered without repeating past harms (Elwyn, 2022).

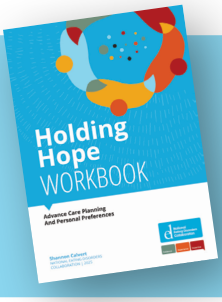
At the same time, the effects of severe and prolonged malnutrition on cognition and exacerbating core eating disorder symptomology and insight must be taken seriously (Phillipou, Rossell, & Castle, 2018). Previous cases of capacity assessments have argued that core eating disorder symptomology such as fear of weight gain mean individuals are "incapable of weighing the advantages and disadvantages of eating in any meaningful way" (Boyle, 2019). Therefore, the challenge lies in distinguishing when a person's decision reflects an enduring expression of values and when it may be shaped or distorted by acute physiological or psychological compromise.
Where capacity is compromised, this does not negate the need for compassion or ethical reflection. Even in cases where involuntary care is required, efforts should still be made to reduce coercion, preserve trust, and document the person's known values to guide future decisions.

Capacity assessments should be:

- Individualised to the person's situation and history
- Contextualised within trauma-informed, neuro-affirming and culturally safe frameworks
- Supportive, not punitive, with efforts made to adapt communication and reduce coercion wherever possible.

Questions to consider when assessing capacity:

- Does the person understand the information relevant to their decision?
- Can they consider the potential consequences in light of their own values and life context?
- Are they making decisions free from overwhelming distress, coercion and lack of perceived choice, such as due to their intense eating disorder cognitions? (e.g., “my eating disorder just won’t let me say yes to this support”)
- If doubt exists, have we made efforts to support capacity through trusted relationships, peer input, or adapted communication, before considering involuntary pathways?
- How has the eating disorder shaped this person’s identity, values, beliefs, and decision-making, and has this now become an authentic part of who they are, rather than pathology?



TOOLS IN THE WORKBOOKS THAT SUPPORT THESE PRINCIPLES

Capacity & Voice Consideration Prompt Sheet - WORKFORCE WORKBOOK
Ethical Decision-Making & Dialogue Prompts - WORKFORCE WORKBOOK
Individual Values and Goals Worksheet - LIVED EXPERIENCE WORKBOOK

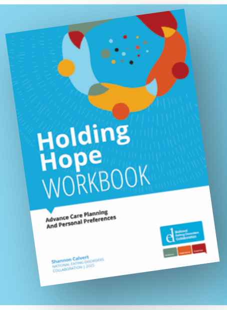
4.12 Considerations around suicidality

Mental health risk and suicidality are often interpreted through a binary lens, present or absent, crisis or safety. In practice, distress exists on a continuum. This is particularly relevant in the context of longstanding eating disorders, where risk may present as ambivalence, resignation, despair, or existential pain (Jobes, 2023; Westermair et al., 2024).

Reduced intake, physical deterioration, or emotional withdrawal may arise from exhaustion, hopelessness, or a loss of meaning, not necessarily a wish to die (Jobes, 2023). Suicidal thoughts can emerge from the burden of persistent symptoms, emotional fatigue, or the perception that no viable care options remain (Izquierdo et al., 2023; Westermair et al., 2024).

It is important to recognise that suicide is a leading cause of death among people with eating disorders. Individuals with anorexia nervosa are up to 31 times more likely, and those with bulimia nervosa 7.5 times more likely, to die by suicide compared to the general population (Preti et al., 2011). While escalation procedures are legally mandated in many services, they do not always equate to increased safety. In some cases, well-intentioned interventions may intensify distress, particularly if they are experienced as controlling, invalidating, or retraumatising (Hawton et al., 2022), especially when historical service experiences, cultural contexts, and relational dynamics shape a person's sense of safety and trust (Westermair et al., 2024).

These realities call for a paradigm shift, from crisis-driven responses to relational, person-centred approaches that prioritise connec-tion over control. Integrating nu-anced, ongoing discussions of suicidality into everyday care cre-ates space to understand meaning, explore context, and reduce reliance on reactive escala-tion. Ethical care isn't always about finding the perfect solution, it's about showing up, staying connect-ed, and being present with the per-son, especially when things are com-plex or uncertain. In moments when hope is fragile, anchoring support in the individual's values, history, and sense of agency may offer a path toward safety and dignity. While such approaches may not eliminate suffering, they can reduce the des-pair that makes life feel unliveable.



TOOLS IN THE WORKBOOKS THAT SUPPORT THESE PRINCIPLES

Harm Reduction Planning Template - LIVED EXPERIENCE WORKBOOK
Mental Health Laws Ethical Reflection Tool - WORKFORCE WORKBOOK
What Matters to Me? - LIVED EXPERIENCE WORKBOOK
Crisis & Transition Planning Template - Appears in all three workbooks, with slight adaptations to suit each audience

SECTION 5:
Adaptive Pathways in Care

5.1 Introduction and purpose

Not every individual with a longstanding eating disorder will find healing within conventional recovery frameworks. Many have complex health needs, have lived through trauma, or experience ambivalence that shapes how - or whether - they can engage with treatment. Others have tried, repeatedly, and found these models of care don't quite fit their needs.

This section introduces adaptive care pathways for individuals and the role of care coordinators.

Adaptive care pathways include harm reduction, respite care, palliative care and comfort-oriented advance care planning.

These are not a substitute for recovery. Rather, they are an extension of care that prioritises quality of life, safety, and relational trust, particularly when distress is high or readiness for change is low. They can be something that is dipped in and out of when the need arises, with people returning to more typical pathways, or for some, they might be a more consistent approach to care.

5.2 The role of a care coordinator

Care coordination refers to the deliberate organisation and facilitation of care activities between multiple service providers to ensure the person receives integrated, ap-propriate, and person-centred sup-port across time and settings (Deliv-ering High-Quality Cancer Care, 2013; World Health Organization, 2016). The role has been widely recognised in chronic disease management, mental health, and palliative care as essential to improving outcomes, reducing fragmentation, and strengthening continuity of care (Khanna et al., 2022; NSW Mental Health Commission, 2020).

Given the fragmentation that often exists in eating disorder service systems, particularly in longstanding and enduring presentations, the established model of care coordination, as used in other areas of healthcare, offers a valuable, trauma-informed, and person-centred approach that warrants broader adoption. National frameworks in Australia, such as the National Palliative Care Coordination Program and models promoted by the NSW Agency for Clinical Innovation, illustrate how dedicated care coordination roles can enable seamless, relational, and home-based support across complex care journeys (ACI, 2022; Palliative Care Australia, 2024).

Care for individuals with longstanding eating disorders is often non-linear, involving a mix of acute, community, psychosocial, and informal supports. Systems may be reactive and siloed, with no single professional holding a complete view of the person's needs, risks, or preferences. As a result, individuals and families are frequently left to coordinate support themselves, especially during periods of disengagement, transition, or crisis.

A care coordinator, whether a nurse, social worker, peer worker, counsellor, case manager, or another trusted professional, can act as a relational bridge. Their role is not simply to navigate systems, but to foster connection, clarify roles across services, and hold shared accountability. Importantly, they walk alongside the person, not above them, grounded in trust, continuity, and presence.

While care coordination is not yet widely embedded in eating disorder services, its relevance is clear. Embedding this role offers a compassionate way to reduce system burden, avoid preventable crises, and honour the lived realities of those navigating long-term, intersecting care needs.

When care is coordinated, it becomes:

Continuous
Rather than episodic

Connected
Rather than isolated

Collaborative
Rather than coercive

Core responsibilities of a care coordinator

A care coordinator holds important responsibilities:

Care coordinator responsibilities	
Map the person's care team and support network	Advocate for the person's goals,rights, values and intersectional needs
Facilitate communication between services	Guide navigating care options and pathways
Support transitions, referrals, and follow-up	Have a strong, trusting relationship with the person and their support network
Identify service gaps or care/treatment breakdowns	

Table 15. Care Coordinator Responsibilities

When might a care coordinator be needed?

A designated coordination role is especially helpful when:

- The individual has experienced repeated disengagement, discharge, or hospitalisation
- The care approach is shifting (e.g., toward harm reduction or palliative care)
- There are co-occurring medical, psychiatric, or disability-related needs
- Families are overwhelmed, unsupported, or carrying care responsibilities alone
- Communication between services is fragmented, and shared responsibility is not clearly established
- Legal documents, advocacy needs, or ethical dilemmas require coordination.

Clarifying the role of a care coordinator

The role and responsibilities of a care coordinator can sometimes be misunderstood.

Key challenges and considerations for care coordinators include:

Role ambiguity	Care coordination is often informally assigned or misunderstood across settings, leading to confusion about who is responsible for what.
Lack of clarity	Without defined responsibilities, coordination can become contested, duplicated, or neglected.
Resource constraints	Staff may feel unable to “own” the role without protected time, support, or recognition.
System fragmentation	Individuals and families are often left to bridge service gaps alone during times of distress.
Opportunity for impact	Even when a formal role doesn’t exist, embedding coordination principles can reduce harm and improve outcomes.
Rapidly evolving situations	When the physical and mental state of someone is rapidly shifting, care providers are making reactive or time sensitive decisions and engaging the care coordinator gets left behind.

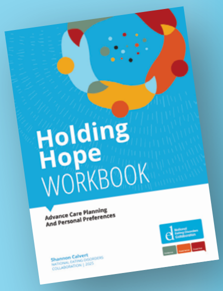
Table 16. Challenges and Considerations

Care coordinators centre the person, strengthen the team around them, and bring shared accountability to systems that often default to fragmentation.

The table below highlights the difference between relational, person-centred coordination and more transactional or misunderstood versions of the role.

An effective care coordinator is:	A care coordinator is not:
Relational - builds trust and safety	A case manager who controls access to care
Organised - maintains clarity across timelines and responsibilities	A substitute for clinical treatment
Person-centred - listens and adapts to what matters most	A “fixer” responsible for outcomes
Trauma-informed - anticipates distress and responds with care	A gatekeeper or final decision-maker
Proactive - prevents breakdowns before they escalate	Someone who carries sole responsibility for outcomes
Networked - knows local systems, resources, and advocates	A clinician working in isolation from the broader care team

Table 17. Effective Care Coordination



TOOLS IN THE WORKBOOKS THAT SUPPORT THESE PRACTICES

Service-Level Care Coordination Checklist: Workforce Supporting People with Longstanding Eating Disorders

Mapping and planning templates for shared care (Advance Care Planning Companion Tool, Shared-Decision-Making Map, Crisis & Transition Planning Template): For People with Longstanding Eating Disorders and the Workforce Supporting People with Longstanding Eating Disorders

Checklists for transitions, Advance Care Planning, and ethical decision-making: For People with Longstanding Eating Disorders, the Workforce Supporting People with Longstanding Eating Disorders, People Who Care For, Love or Support Someone with a Longstanding Eating Disorder

5.3 Harm reduction in longstanding eating disorders

Harm reduction refers to policies, programs, and practices that aim to reduce the negative consequences of behaviours that pose risk, while supporting individu-als to enhance safety, dignity, and self-determination (Mar-latt, 1996). It recognises that requir-ing abstinence from eating disorder behaviours, or working to-wards full symptoms centered re-covery, as a condition of care, can be exclusionary. Instead, it promotes access,But en-gagement, and compassion. Individ-uals are supported to "come as they are," receive non-judgmental care, and collaboratively determine what is manageable, safe, or meaningful at a given point in time (Birch, Downs, & Ayton, 2024).

While historically applied in the con-text of substance use, harm reduc-tion principles are increasingly recognised as both rele-vant and necessary in the field of eating disorders - particularly for those with a longstanding illness (Gilmartin et al., 2025; Marcolini et al., 2024).

Harm reduction offers a relational, values-aligned approach that prioritises quality of life, safety, and autonomy, especially when full recovery is not currently desired or possible. It does not abandon hope; it reframes it through presence, flexibility, and trust. Harm reduction holds space for what is possible now, offering care that is principled, person-led, and grounded in the realities of each individual's life and context.

What Harm Reduction Involves

Harm reduction strategies aim to prevent deterioration, reduce risk, and enhance wellbeing, even when symptom elimination is not the immediate goal. Such strategies rely on therapeutic relationships built on trust, transparency, and shared decision-making (Birch, Downs, & Ayton, 2024). Within eating disorder settings, these approaches may support sustained engagement with care, minimise medical and psychological harm, and preserve connection for individuals who might otherwise disengage entirely.

When informed by ethical and evidence-based principles, harm reduction in longstanding eating

Individualism	• Tailored care plans aligned with the person's goals, values, and readiness • Collaborative goal-setting focused on what feels realistic and meaningful
Pragmatism	• Medical monitoring (e.g., electrolytes, cardiac risk) to address immediate safety • Psychosocial support that validates emotional needs and honours lived experience • Development of safety and coping strategies that extend beyond symptom managing or reduction • Inclusion of family or supporters (where appropriate) to strengthen relational scaffolding
Incrementalism	• Gradual behaviour support in place of enforced eradication • Nutritional strategies that are flexible, adaptive, and honour bodily autonomy and individual needs and preferences

Accountability without Termination	• Harm minimisation techniques (e.g., safer practices, emergency planning) • Ongoing review with openness to adapt goals and strategies over time • Support for self-reflection without punishment, such as discharge, for setbacks or plateaus

Table 18. Harm Reduction Concepts

This practical, adaptive, and rela-tional approach reflects growing calls for a broader spectrum of care responses in the treatment of longstanding eating disorders. Harm reduction enables continued engagement even when recovery is not the stated goal, help-ing to build trust and create opportunities for future change (Birch, Downs, & Ayton, 2024). Through a collaborative approach, individuals, their sup-ports, and care providers can agree on certain safety parameters - including crisis stabilisation plans if needed.

Examples of harm reduction strategies and approaches

- Getting medical stability to a reasonable and sustainable point of functioning, rather than seeking full weight restoration
- Finding a life worth living, whilst having an eating disorder
- Finding an individual's own sustainable "base line"
- Increasing the safety of eating disorder behaviours
- Focussing on the eating disorder behaviours a person feels motivated to work on, rather than prioritising reducing symptoms as outlined in manualised treatment
- Use of respite care to provide planned moments of relief and break from the rigors of care, treatment or recovery
- Use of palliative care supports to ease physical and emotional discomfort
- Focussing support on co-existing conditions, such as depression or suicidal ideation
- Open and transparent discussion about the consequences and risks of eating disorder behaviours that are ongoing.

Why transparency matters in the context of harm reduction

Open and honest conversations about harm reduction are essential to ethical practice. They help reduce fear or confusion, clarify the intention behind care plans, and support individuals and families to remain engaged without unrealistic expectations.

Transparent conversations:

- Strengthen therapeutic trust and reduce shame
- Promote informed consent and shared decision-making
- Clarify that harm minimisation is not avoidance or neglect
- Reduce stigma and help supporters offer appropriate care
- Prepare everyone involved for the non-linear nature of recovery
- Reinforce that stabilisation, dignity, and continued connection are valid outcomes

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This approach aligns with the ethical principles of autonomy (respecting a person's right to make decisions), beneficence (promoting wellbeing), and non-maleficence (avoiding harm) (Beauchamp & Childress, 2019). These values are also enshrined in the Australian Charter of Healthcare Rights, which highlights the importance of respect, dignity, informed decision-making, and non-coercive support (Australian Commission on Safety and Quality in Health Care, 2020).

Implementation and provider readiness

Offering harm reduction in longstanding eating disorder contexts requires skill, consistency, and a readiness to stay with uncertainty.

Key elements include:

- Training in trauma-informed care and shared risk planning
- Willingness to tolerate uncertainty and complexity
- Clear communication and consistency across multidisciplinary teams
- Documentation that reflects and respects the person's values, boundaries, and care preferences.

What Harm Reduction Is Not

Harm reduction is not passive or permissive. It is not the absence of care or "colluding" with the eating disorder. Nor is it incompatible with recovery.

Instead, it is an active, ethical practice grounded in relational safety, shared responsibility, and realistic goals. It meets people where they are - and helps keep them engaged, safer, and more connected to support.

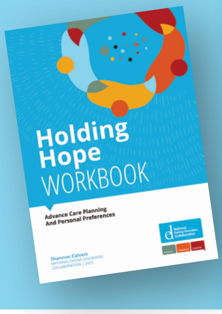
The Victorian Centre of Excellence of Eating Disorders (CEED) harm reduction resource offers a synthesis of current evidence-informed harm reduction frameworks and guidance to support clinicians in integrating harm reduction alongside evidence-based treatment.

Honouring the complexity of the lived experience

Each experience of harm reduction is vastly different. For some, it happens alongside treatment and recovery focussed actions, for others it is a pause before returning to treatment and for certain individuals, it is the main pathway of care they wish to pursue. Making the decision to move towards a harm reduction approach can be a complex journey for the person who is living it. There may be a nuanced blend of relief, excitement, grief, fear or a sense of hopelessness or abandonment. All these experiences and feelings are allowed to be present and need the time and space to be expressed and explored. The most important part is that people are not left to feel alone in these emotions, that they feel confident they have a choice of if, how, when and why they engage in a harm reduction approach. Equally, the experience of being a carer or supporter in these circumstances is not to be forgotten or overlooked. Those who have been on this journey with their loved one for some time will have their own complex responses. They, too, deserve compassion, acknowledgement, and support as they navigate the emotional landscape of witnessing change, managing uncertainty, and holding hope. Open dialogue, mutual understanding, and shared decision-making can provide vital connection points, reminding everyone involved that healing, in whatever form it takes, is a collective process.

Harm reduction in practice

> "Even though Katie was still very unwell, the care plan she developed with her treating team made a noticeable difference. Knowing there was an agreement in place - one that supported her to stay out of hospital if she kept up with regular meals and medical checks eased a lot of her anxiety. She really gave it her all. It was the hardest I'd ever seen her try, and with that came a quiet confidence that she could keep going. I started to see glimmers of her smile again. We began to shift focus, noticing the small, meaningful parts of her life beyond the eating disorder - the little gems that gave her hope."
>
> **- Katie's Peer Mentor**



TOOLS IN THE WORKBOOKS THAT SUPPORT HARM REDUCTION

Harm Reduction Planning Template - LIVED EXPERIENCE WORKBOOK

Co-Reflection & Ethical Debriefing Prompts - WORKFORCE WORKBOOK

Crisis & Transition Planning Template - In ALL THREE WORKBOOKS, with slight adaptation to suit each audience

Capacity & Voice Consideration Prompt Sheet - WORKFORCE WORKBOOK

FAMILY SUPPORTER REFLECTION TOOL - CARER WORKBOOK

Final Note: Hope Through Flexibility

Harm reduction acknowledges that while recovery remains a possibility, it cannot be the only benchmark of care. For those living with longstanding eating disorders, it offers a life-affirming, dignity-led path - one that maintains hope through flexible, ethical and compassionate care and can at times offer a reprieve from the pressures and intensity of treatment and recovery focussed activities.

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5.4 Respite care - A harm reduction strategy

For individuals living with longstanding eating disorders, the demands of traditional treatment -including refeeding, behavioural compliance, and intensive therapy can become inaccessible, misaligned with lived priorities, or even harmful. Many are left navigating physical discomfort, emotional fatigue, and service disengagement without appropriate alternatives.

In this context, respite care offers a compassionate and temporary form of support. It is not focused on clinical correction or symptom eradication, but on reducing pressure, preserving trust, and restoring emotional, relational, and physiological capacity - for both individuals and those who support them. It is a strategy centred on presence, relief, and quality of life.

What is respite care?

Traditionally, respite care refers to short-term support provided to relieve a primary carer. Respite is “someone else stepping in to take over a carer’s role for a short time” (Carer gateway, n.d). It is a space for rest and recovery.

However, its principles can also be extended to individuals themselves, particularly when they are experiencing treatment fatigue, fear, or distress in the face of ongoing clinical expectations.

In this broader interpretation, respite care becomes a low-pressure, harm-reducing intervention that prioritises presence, relief, and ethical engagement, particularly when full recovery is not the immediate goal. It aligns with compassionate approaches that value relational support, collective responsibility, and non-clinical responses to distress (Abel, 2018; Birch, Downs, & Ayton, 2024).

Respite care in the Australian context

While there is growing recognition of the need for flexible models of care, formal respite care options specific to eating disorders remain limited across Australia. Where these options do exist, they are often locally adapted and impacted by resource constraints and variable service readiness.

This Guide does not assume that respite care is widely available. Rather, it seeks to legitimise and normalise this approach as a valid form of ethical, trauma-informed care and to offer guidance for its implementation where opportunities arise.

These gaps also highlight the need for equitable service development, particularly for individuals in regional areas, marginalised communities, or without informal advocacy supports.

Core principles and practical applications of respite care

Respite care in the context of longstanding eating disorders is typically defined by:

- Short-term admissions (e.g., 3 -14 days)
- Low-pressure goals, such as hydration, rest, or pain management
- Optional nutritional support, offered without coercion
- Trauma-informed planning, acknowledging past harms and fears

- Respect for autonomy and identity, including cultural, gendered, and lived experience considerations
- Collaborative exit planning, linked with community or outpatient follow-up (Jamieson et al., 2024)

Importantly, respite care is not a sign of failure. It is a relational, person-led strategy that creates space to re-engage with care in a way that honours the person's circumstances, capacity, and current priorities.

What can we learn from existing models of care?

Internationally and locally, several services have developed respite-style or harm-reducing care models tailored to people with longstanding eating disorders. These models provide examples of relational continuity, flexible care goals, and person-led planning.

Examples of respite-style care models	
Sweden	The Stockholm Centre for Eating Disorders has developed a **case management** approach for individuals with longstanding eating disorders. This model offers structured outpatient support that **prioritises autonomy, continuity**, and **harm reduction**, with the goal of **reducing hospitalisations** and **preserving trust** (Molin et al., 2016).
Netherlands	A **collaborative care model** has been developed using mixed-methods research to support individuals with severe and enduring anorexia nervosa. This model centres on **shared decision-making** and **flexible treatment planning**, including **negotiated goals** that do not assume full recovery. It **promotes emotional stabilisation** and **relational continuity** as therapeutic outcomes (van den Eijnde-Damen et al., 2024).
United Kingdom	NHS Trusts have introduced proposed care pathways for individuals with longstanding eating disorders. These include **short inpatient admissions** and **structured interventions** that de-emphasise symptom elimination in favour of building **relational trust, reducing physical risk**, and **supporting quality of life** (Reay et al., 2022).
Australia	RenourishTM is a unique approach to supporting the medical stability of people with eating disorders. Rather than refeeding occurring under distressing and sometimes coercive circumstances, the Renourish team offers planned, voluntary, time limited refeeding hospital admissions to support a return to medical stability (Queensland Physician Care, n.d.). Please note that at the time of publication, this program is on hold.

Table 19. Examples of Respite-Style Care Models

These examples highlight that respite care can be embedded within case management, outpatient, or inpatient settings when guided by harm reduction and trauma-informed principles. They demonstrate that doing less with intention and integrity can often lead to more sustained engagement.

Respite care is not a regression, it is a deliberate pause

It acknowledges that amidst complexity and chronicity, rest, relief, and presence are protective and meaningful forms of care. When offered with clarity and compassion, respite care can reduce emergency admissions, prevent deterioration, and rebuild the relational trust that is essential for future engagement.

As the need for flexible care grows, respite care options remind us that ethical practice isn't always defined by intensity - but often by attunement.

5.5 Palliative care - Important considerations and realities

Palliative care remains poorly understood, inconsistently applied, and often inaccessible for individuals living with longstanding eating disorders. This section offers guidance on what palliative care is, and is not, and how its principles can be applied ethically and respectfully in this context.

This is not about withdrawing care. It is about reshaping care in alignment with the person's values, clinical reality, and lived experience. Whether or not someone meets formal eligibility criteria for palliative care, its core principles - dignity, comfort, connection, and choice remain deeply relevant and ethically necessary (Treem, Yager, & Gaudiani, 2023).

When should palliative care be considered?

Palliative care can be offered alongside recovery oriented treatment, psychosocial support, harm reduction strategies, recovery and community or peer-based care. It does not require a terminal diagnosis and may be appropriate at any stage of a life-limiting condition where complexity, chronicity, or distress is present. It reframes care around quality of life, offering new ways to engage ethically, even when standard treatments are no longer viable (Calvert, 2023; Treem et al., 2023).

Palliative care may be appropriate when:

- Extensive, evidence-informed treatment has not led to meaningful or sustained improvement
- The person is experiencing progressive medical decline (e.g.,, cardiac risk, chronic pain, disability, or severe fatigue)

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- Access to treatment has become inaccessible, retraumatising, or no longer aligned with the person's goals
- The person has clearly and consistently declined further intensive or recovery-focused treatment (Downs et al., 2023; Phillipou et al., 2023; Westermair et al., 2021)

Where does 'terminal' care fit within palliative care? Palliative care is a broad approach that can be introduced at any stage of a life-limiting condition long before a person is considered terminal. While terminal care refers specifically to care provided during the final stage of life, palliative care includes a much wider set of principles that support comfort, dignity, and quality of life across the course of illness (Australian Commission on Safety and Quality in Health Care, 2021; Palliative Care Australia, 2018).

In the context of longstanding eating disorders, recognising this distinction is essential. Many individuals may benefit from palliative approaches without being near end-of-life. Limiting access to palliative care only when a person is considered terminal can delay meaningful support, increase suffering, and reinforce the false belief that values-led care is only appropriate when recovery is no longer possible (Treem, Yager, & Gaudiani, 2023; Yager, Gaudiani, & Treem, 2022).

Common challenges to eligibility

Access to palliative care in the context of eating disorders remains limited and inconsistently integrated into service systems. There is ongoing lack of clarity and consensus in both psychiatric and palliative care settings (Yager, Gaudiani, & Treem, 2022).

- Inconsistent definitions of "life-limiting" in the context of eating disorders
- Limited extension of palliative models beyond cancer or aged care
- Variable clinician training or confidence in applying palliative approaches in mental health
- Systems that continue to frame recovery as the only acceptable outcome (Downs et al., 2023; Phillipou, 2023)

Understanding uncertainty around end-of-life definitions

In longstanding eating disorders and other non-linear or complex conditions, defining when a person is nearing the end of life can be especially difficult. The term "terminality" occasionally appears in academic discourse to describe this uncertain space where curative treatments are no longer helpful, but formal end-of-life criteria may not be met. However, this term is not currently defined in major palliative care glossaries or widely used in clinical guidelines. Some international terminology has since been reconsidered and retracted, reinforcing the need for careful, person-centred language and an emphasis on life-limiting illness rather than diagnostic labels (Gaudiani, 2025).

Instead, clinicians and teams are encouraged to consider the broader context of life-limiting illness, where goals of care may need to shift toward comfort, quality of life, and dignity, even in the absence of a clear prognosis. This includes:

- Recognising progressive decline without formal end-of-life designation

- Engaging in ethical conversations about transitioning to palliative approaches
- Clearly documenting rationale for any shift in goals of care.

For guidance on this, see:

- Australian Commission on Safety and Quality in Health Care (2021). National Consensus

What is palliative care?

Palliative care is a holistic, person-centred approach that supports individuals living with serious or life-limiting illness (WHO, 2020). Its focus includes:

- Relief from physical, psychological, emotional, and spiritual suffering
- Promoting wellbeing, meaning, and connection
- Prioritising quality of life - not merely prolonging it
- Respecting autonomy and aligning care with personal values

Palliative care is NOT

- It is **not** the same as end-of-life or hospice care
- It is **not** a sign of failure by the person, their family, or the service
- It is **not** about giving up on care but about realigning care
- It does **not** mean withdrawing support, hope, or presence

Embedding palliative care principles

Even when formal access to palliative care services is unavailable, its principles can - and should - be embedded in everyday care planning.

These principles align with internationally recognised definitions of palliative care, which emphasise quality of life, holistic psychosocial and spiritual support, and relief of suffering (WHO, 2020; Palliative Care Australia, 2018; Quill & Abernethy, 2013). Importantly, these principles are not limited to specialist teams - they can be meaningfully enacted by generalist, community, and mental health providers.

Rather than being confined to a single section, palliative principles are interwoven throughout this Guide - reflected in its planning tools, reflective prompts, and approaches to harm reduction, supervision, and adaptive care.

Palliative care principles include:

Supporting comfort, function, and emotional regulation

Managing pain and physical symptoms

Reducing treatment-related trauma

Holding space for meaning making and reflection

Maintaining relational connection and trust

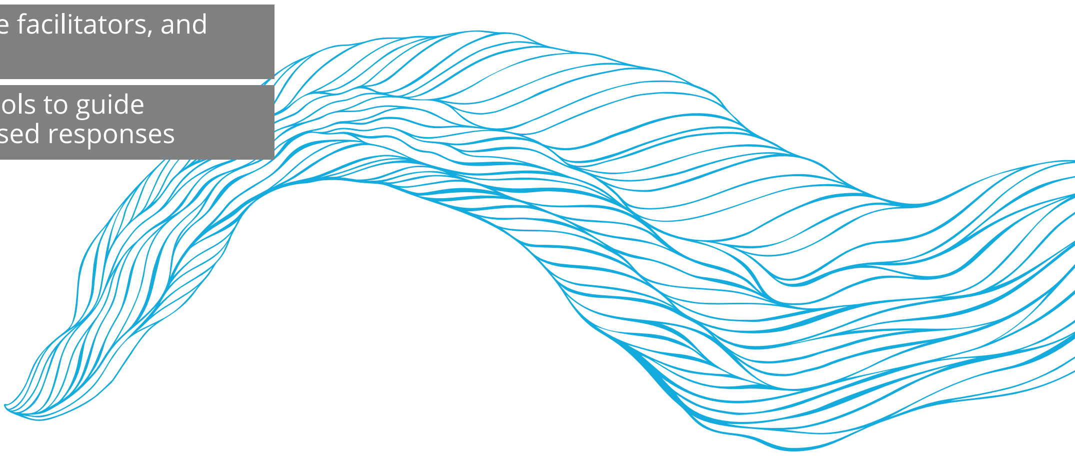
Real-World considerations

In practice, access to palliative care for individuals with longstanding eating disorders is shaped by systemic, interpersonal, and cultural factors, including:

- Service constraints (e.g., funding, eligibility, geographic access)
- Clinician discomfort or limited training
- Misconceptions that palliative care equals “giving up”
- Lack of specific palliative models for mental health
- Stigma and fear around naming care as comfort-focused
- Medico-legal concerns that create uncertainty and risk for clinicians and services
- Limited expertise in navigating adaptive care for eating disorders
- Lack of suitable supervision and reflective practice opportunities for clinicians
- Families needing the most support at this stage, but receiving the least

Palliative care is often seen as the domain of specialists, leaving many professionals feeling unprepared to apply its principles in mental health or eating disorder settings. This highlights broader gaps in education, service design, and cross-sector collaboration. As a result, care can become difficult to navigate, especially when typical treatment approaches have been exhausted or are no longer appropriate.

For Health Professionals and Care Teams considering Palliative Care options	**For Individuals and their loved one’s considering Palliative Care options**
Be honest about what is possible and what is not	You have the right to shape your care, even when options feel limited
Don’t wait for a crisis to initiate palliative discussions	Comfort-based care is still care and does not need justification
Use supervision to explore fears, bias and moral distress	It is okay to name fatigue, fear, grief, or a desire for peace
Frame palliative care as compassionate realignment, not failure	You are not alone and your experience matters
Involve peer workers, reflective facilitators, and cultural guides in planning	
Use ethical decision-making tools to guide discussion and reduce fear-based responses	



Practical reflections and considerations

Palliative-aligned care may focus on presence, comfort, connection, and meaning - whether through symptom relief, shared reflection, or gentle companionship. These are not “lesser” forms of care. They are acts of profound attentiveness, grounded in humanity, dignity, and compassion.

In real-world practice, this might include:

- Slowing the pace of conversations to allow emotional processing
- Sitting with uncertainty without requiring immediate change
- Working flexibly with families and loved ones
- Responding to sensory, cultural, or spiritual needs
- Remaining present when others have stepped back

For individuals with longstanding eating disorders, palliative-aligned care recognises that healing does not always mean recovery. It reframes care not as a set of interventions to be completed but as an ongoing, relational commitment to dignity, safety, and meaning.

This approach is not about stepping back - it is about staying alongside. It affirms that even in the absence of cure - comfort, connection, and presence remain possible and necessary.

5.6 Advance care planning

Advance care planning is a voluntary, person-led process that enables individuals to reflect on and communicate what matters most in their care - particularly in the context of future uncertainty, medical deterioration, or potential loss of decision-making capacity (Sudore et al., 2017).

It is not a legal document, but a values-based and relational approach to planning. Advance care planning helps ensure that future care decisions remain grounded in a person’s goals, boundaries, and lived experience - even when they may not be able to speak for themselves. It supports shared understanding, ethical responsiveness, and continuity across clinicians, services, and support networks (Brinkman-Stoppelenburg et al., 2014).

Why and when to begin advance care planning

Advance care planning is most effective when initiated early - before a crisis of health or capacity arises. For individuals with longstanding eating disorders, it may be especially relevant:

- During periods of relative stability
- When care goals begin to shift (e.g.,, toward harm reduction or comfort-focused care)
- Following distressing or coercive treatment experiences
- As part of routine, values-based planning with trusted professionals

These shifts in care may arise after multiple treatment attempts that have not led to sustained benefit. A 2020 systematic review of interventions for (what is clinically termed) severe and enduring eating disorders (SE-ED) found that overall evidence quality is low and outcomes inconsistent (Kotilahti et al., 2020). Acknowledging this complexity can help ensure future decisions are guided by the person's voice - not just clinical indicators or assumptions (Jamieson et al., 2024).

What does advance care planning look like?

Advance care planning conversations can explore a wide range of preferences and priorities, including:

- Views on hospitalisation, refeeding, or involuntary treatment
- Identification of trusted supporters (formal or informal)
- Cultural, spiritual, sensory, or environmental needs
- Boundaries around care practices that have caused harm or distress
- Reflections on what quality of life means to the person

These insights can be shared verbally, captured in an advance care planning workbook, or summarised in the clinical file - always with informed consent and collaborative input.

How can advance care planning complement legal documents?

While not legally binding, advance care planning can guide care when formal legal documents are absent, ambiguous, or under review. It complements, but does not replace:

- Advance Health Directives (AHDs): Legally recognised documents that specify consent to or refusal of specific medical treatments
- Enduring Powers of Guardianship (EPGs): Formal appointments of substitute decision-makers if a person loses capacity

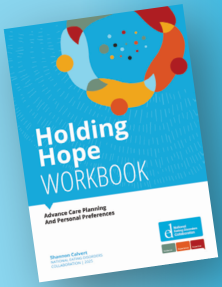
Advance care planning adds ethical depth by capturing values, boundaries, and relational considerations that legal tools may not reflect. It is especially useful in multidisciplinary settings where tensions or dilemmas arise (White et al., 2017).

How can advance care planning support palliative care principles?

Advance care planning is particularly important when care goals begin to centre on dignity, comfort, and quality of life. Even without formal palliative referral, these conversations often align with palliative frameworks (Calvert, 2023) and can clarify:

- What comfort and dignity mean to the individual
- What types of care are welcome or declined
- Who the person wants involved in decision-making or support

Advance care planning is not about limiting options, it is about creating space for honest, values-aligned care. Whether used early, during transitions, or in preparation for future uncertainty, it offers a foundation for ethical, person-led planning.



TOOLS IN THIS GUIDE THAT ADVANCE CARE PLANNING

Advance Care Planning Workbook - LIVED EXPERIENCE WORKBOOK
Advance Care Planning Snapshot Summary Sheet - LIVED EXPERIENCE WORKBOOK
Family Version: Advance Care Planning Companion Tool - CARER WORKBOOK
Comfort-Focused Care Planning Tool - LIVED EXPERIENCE WORKBOOK
Mental Health Laws Ethical Reflection Tool - WORKFORCE WORKBOOK
Care Coordination Toolkit & Planning Checklist - WORKFORCE WORKBOOK

Final Reflection…

Adaptive Pathways in Care

There is no single pathway through longstanding eating disorders and no one definition of healing. For some, traditional recovery frameworks may feel possible and hopeful. For others, particularly those who have faced repeated distress, trauma, or system gaps, different approaches are needed. Care does not end when recovery is uncertain. Harm reduction, respite, care coordination, palliative-aligned support, and Advance Care Planning all offer legitimate, ethical, and person centred responses to complexity. These are not “second-best” options - they are evidence-informed strategies rooted in compassion, dignity, and respect.

By slowing down, listening closely, and staying alongside, even when the path is unclear, we uphold what matters most: safety, autonomy, connection, and the possibility of meaning within and beyond the eating disorder.

Choosing any of these pathways can always be a detour on the way to recovery, or they can be a chosen, self-determined alternative.

Adaptive pathways in care are the opening of a door, when it feels as though all others have closed.

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CONTENT CONSIDERATION

A note before you read

This section features a series of fictional case vignettes, meticulously crafted composite narratives designed to mirror the multifaceted realities of patient care. Although the characters within these stories are not actual individuals, the situations and challenges they encounter are rooted in real-life experiences, clinical knowledge, and the systemic challenges that have been identified across various healthcare settings.

The scenarios covered in these vignettes encompass:

- The complexities of advanced illness and associated medical risks
- The implications of involuntary treatment and the role of legal intervention
- The emotional turmoil of family distress and the process of anticipatory grief
- The nuanced and sensitive issues surrounding end-of-life care, particularly in the context of eating disorders

These narratives are not intended to upset or disturb readers. Rather, they serve to:

- Demonstrate the practical application of the tools provided in this guide
- Acknowledge and honour the difficult choices that families and healthcare professionals are often required to make
- Foster reflection, facilitate ethical discussion, and enhance the quality of care planning

Readers may find the content challenging or may see reflections of their own experiences within these stories. They are presented not as definitive answers but as a means to encourage deep engagement with the intricate nature of care. It is crucial to approach these scenarios with an understanding of the need for clarity, thoughtful preparation, and compassionate planning in delivering care.

SECTION 6:
Case Vignettes and Applications

6.1 Bringing the Guide to life

Care is rarely simple. It is shaped by systems, beliefs, emotions, histories, and by the real, raw complexity of human lives. The fictional vignettes in this section were created to bring that complexity into view. Each one illustrates how the tools and principles in the Holding Hope Guide can be applied in different contexts: where clarity is lacking, hope feels distant, or systems are strained.

Every day, across services and communities, people are living stories just like these:

- Adults too unwell to speak for themselves, without documented care preferences
- Parents watching their children deteriorate, knowing they cannot intervene
- Clinicians trying to do the right thing in systems that limit their options
- People with lived experience being asked to trust again, without knowing if they'll be heard

This section honours those realities. And it holds hope that by offering practical tools, shared language, and ethical clarity, no one individual, family, or professional has to navigate this alone.

6.2 How this section is structured

Each vignette follows a consistent format which includes:

- A short context introducing the person's situation, care setting, and relational environment
- A section on how the Guide could support care, with clear examples of tools and decisions
- A reflection and outcome, not always a resolution, but a shift in tone, trust, or direction
- A tool summary table outlining which Guide tools were used, who used them, and how
- References to the relevant workbooks where those tools can be found

The stories present a variety of perspectives, including those of individuals, families, clinicians, care teams, and support workers. They were crafted with compassion and respect, honouring both the individuals living these experiences and the professionals who support them. These scenarios highlight the challenging realities faced by many individuals, families, and healthcare providers (see

Vignette Index below for more detail). Each vignette aims to encourage thoughtful engagement with the ethical, relational, and practical aspects of care.

We hope these stories offer more than just hypothetical examples. We aim for them to inspire dialogue, provoke discomfort, spark inspiration, and cultivate the collective courage to approach care differently.

Vignette Index and Key Themes

Vignette	Narrative Focus	Key Themes
Emma	Reclaiming voice and direction when care feels overwhelming	Suicidality driven by treatment fatigue; harm reduction planning; relational trust; shared boundaries
Leila	Creating space for support, trust, and small beginnings	Short respite admission for hydration and symptom relief; harm reduction in hospital; ethical flexibility and MDT alignment
Jonah	When harm reduction gives way to comfort and clarity	Harm reduction no longer sufficient; transition to palliative care; coordinated planning; family voice
Marcus	Exploring options with honesty, choice, and ethical care	Young adult agreeing to trial one final evidence-based treatment; ethical discomfort about age; planned review point and autonomy
Samira	Sustaining connection when recovery is not the goal	Disengagement in recovery but continued engagement in therapeutic support; clinician reflection; capacity; non-coercive alignment
Anna	Relational trust and gentle re-entry after system disconnection	Family helplessness when person refuses all care; sister uses the Guide to rebuild trust; reduced fear, increased safety
Elena	Planning for dignity and peace in the face of uncertainty	Lack of documentation nearly leads to forced treatment; post-crisis shifts to ACP, AHD, and palliative planning; death at home with dignity

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Vignette: Emma

Reclaiming voice and direction when care feels overwhelming

Context

Emma is 29 years old and has lived with anorexia nervosa (restricting subtype) for over a decade. She has experienced multiple treatment episodes, many of which involved refeeding and inpatient admissions under the Mental Health Act. While Emma has physically survived these interventions, she describes them as emotionally traumatic and overwhelming.

After her most recent discharge, Emma shares with her peer worker that she feels exhausted, disconnected, and increasingly suicidal, not because she wants to die, but because she “can’t face being made to survive like this again.” Her family is deeply concerned. Her psychiatrist feels pressure to act protectively, while Emma’s GP is uncertain about next steps.

Emma has also expressed: “I don’t want to live like this. I don’t want to die, but I can’t keep doing this kind of ‘living’.”

She is open to trying a different approach but only if her autonomy is respected. Her psychologist convenes a care meeting involving Emma, her GP, parents, a social worker, and a peer worker. Together, they explore whether harm reduction and shared planning could offer a safer, more sustainable alternative to crisis-driven responses.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Individual Values and Goals Worksheet	Emma (with peer worker)	Helped Emma identify tolerable and meaningful aspects of life (creative work, family time, autonomy). This grounded future planning in her values.
Harm Reduction Planning Template	Emma, team, family	Shifted care focus from weight targets to reducing medical crises, supporting sleep and hydration, and avoiding forced treatment.

Bias Reflection Tool	Psychiatrist	Enabled reflection on internalised fears about risk and reframe of harm reduction as valid and person-led.
Ethical Decision-Making & Dialogue Prompts	MDT	Supported ethical reflection and reframing of 'non-escalation' as a values-aligned decision, not neglect.
Family Voice in Care Planning Template	Emma's sister (with team)	Brought relational insight into Emma's preferences and needs, improving shared understanding within the team.
Scenario Walk-Through Tool	Team	Explored outcomes of re-admission vs. home-based support, enabling informed, collaborative decision-making.
Crisis & Transition Planning Template	Emma, peer worker, psychologist	Mapped crisis response preferences, contacts, language cues, and alternatives to emergency services callouts.

Reflection and Outcome

Emma's care team shifts focus from inpatient admissions and weight-based targets to coordinated, community-based harm reduction. A shared plan built on her own values and limits is signed and shared across providers, including her GP, emergency services (if required), and family. The clarity of this plan offers Emma a new kind of safety: one that respects her autonomy without withdrawing support.

She begins weekly contact with her peer worker and re-engages in short, focused sessions with her psychologist and dietitian. The tone of these interactions is different now, less urgent, more collaborative. For the first time in a long time, Emma feels that she is being asked what she wants, rather than what she is willing to endure.

She rediscovers her creative expression, starts painting again, and begins work on a personal zine for others navigating similar experiences. These activities are not framed as treatment milestones but as meaningful anchors in her day-to-day life.

Although Emma's physical health remains fragile, her distress reduces, and she no longer expresses active suicidality. When asked how she's feeling, she tells her peer worker: "I still don't know if I want to stay but I feel like I can breathe again. That's something."

Her care team continues to meet regularly and remains flexible, aligned in tone and in approach. There are no false promises of recovery, no pressure to shift course, at this stage only commitment to staying present with Emma, wherever she is.

This shift from control to collaboration changes the quality of her care relationships. Emma no longer feels like a problem to be solved. She feels seen, heard, and held in a way that makes continuing feel possible. Even in the absence of a clear outcome, hope becomes tangible - not as an expectation, but as an offering

Vignette: Leila

Creating space for support, trust, and small beginnings

Context

Leila is a 41-year-old woman with a long history of anorexia nervosa (binge-purge subtype) and significant trauma related to her earlier inpatient admissions. Two years ago, she was discharged from a specialist eating disorder service after falling below the program's minimum BMI threshold and missing several appointments during a mental health crisis. Despite this, she had previously engaged well with care and was actively trying to stay connected to support. However, since her discharge, accessing coordinated care has been challenging.

Leila has maintained weekly contact with a trusted private dietitian and has recently formed a meaningful connection with a peer mentor through a local mental health service. These two relationships have become her primary sources of support, and they are the only services she actively trusts.

Recently, when Leila presented to her GP with signs of dehydration, chest pain, and severe fatigue, she expressed a deep fear of hospital admission, recalling past experiences of refeeding, restraint, and disempowerment. Understanding her history, her GP proposed a different approach: a short, planned respite admission focused solely on hydration, rest, and comfort-based care.

Initially, the hospital team was hesitant. Leila's presentation was deemed "outside scope," and there were concerns about ethical risk, resource use, and professional expectations. However, a small, cross-disciplinary team was formed, including the GP, hospital psychiatrist, dietitian, peer worker, and an occupational therapist. This team aimed to explore how care could be safely and ethically delivered while respecting Leila's autonomy and establishing clear boundaries.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Harm Reduction Planning Template	Leila, dietitian, peer worker	Outlined Leila's care preferences, including IV hydration, no weighing, and access to a quiet space.
Comfort-Focused Care Planning Tool	Leila, peer worker, OT	Clarified that the admission would centre on symptom relief and sensory regulation, not weight gain.
Ethical Decision-Making & Dialogue Prompts	GP, psychiatrist, MDT	Facilitated a pre-admission discussion about ethical risks, clinical limits, and team alignment.
Care Collaboration Summary Sheet	GP, post-discharge team	Documented learnings from the admission and outlined follow-up roles and continuing community supports.

Reflection and Outcome

Leila completes a three-day respite admission. She receives IV hydration and symptom monitoring without psychiatric intervention, weight measurement, or nutritional expectations. The hospital's occupational therapist provides brief support to help create a calming sensory environment - including comfort-focused positioning, soft lighting, noise reduction strategies, and access to soothing tactile items. These small adjustments help Leila feel grounded and less hypervigilant in a setting that would previously have triggered distress.

Importantly, there is no pressure to change, comply, or engage beyond what feels tolerable. Leila listens to music, rests, and meets briefly with the unit dietitian to discuss hydration strategies and food textures, not targets, metrics, or goals. Staff gently check in but never push. Boundaries are clear, care is consensual, and Leila's preferences are actively upheld.

After discharge, Leila tells her peer worker: "I didn't feel safe because they tried to fix me. I felt safe because they didn't."

This admission does not reverse Leila's illness, nor is that the intent. Instead, it represents a critical shift: a hospital experience that is non-threatening, validating, and built on collaboration. For Leila, who had previously associated clinical care with coercion and loss of control, this becomes a turning point.

The impact of this experience ripples outward. Leila resumes weekly sessions with her dietitian, now with greater trust and emotional presence. Her GP remains an active and supportive figure. The peer worker continues to meet with her regularly. Leila has also expressed tentative openness to considering a referral to a psychologist, who would work alongside her GP and dietitian within the parameters of her care plan. The hospital's allied health team, initially unsure, requests follow-up training in adaptive care and trauma-informed planning.

For the first time in years, Leila begins to describe her healthcare experiences using words like "safe," "seen," and "heard." This moment doesn't resolve her illness, but it reframes her relationship with care, not as something done to her, but something possible with her. It becomes the beginning of a new kind of safety.

Vignette: Jonah

When harm reduction gives way to comfort and clarity

Context

Jonah is a 47-year-old neurodivergent man living with a longstanding eating disorder. His eating disorder experience has changed a lot over the years, at times aligning with a binge eating disorder diagnosis, and other times aligning with atypical anorexia. He previously worked in education and remains closely connected to his older sister, who has long served as both advocate and emotional anchor in his care.

Over the past decade, Jonah engaged with multiple inpatient and outpatient treatments. While he initially hoped for recovery, these experiences increasingly felt disempowering and did not align with his needs. Two years ago, he asked his treating team to stop focusing on refeeding, citing physical trauma, spiritual distress, and burnout. With support from his psychiatrist and GP, a structured, neuroaffirming harm reduction plan was introduced.

For a time, this approach brought stability. Jonah maintained minimal oral intake, relying on foods that catered to his sensory sensitivities, engaged in check in appointments with a community nurse and peer mentor, and accessed planned respite admissions for hydration and symptom relief at his preferred hospital. His sister and care team helped preserve trust and relational continuity.

However, in the past six months, Jonah's health has significantly declined. Now largely bed-bound, he is experiencing cardiac complications, extreme fatigue, and difficulty engaging in care planning. While his voice has softened, his values remain clear.

The harm reduction plan, once stabilising, no longer feels sustainable. The care team is left with a compassionate and complex question: What now, when further intervention may cause harm and what accompaniment may be the most ethical care left to offer?

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Comfort-Focused Care Planning Tool	MDT and Jonah	Helped reframe care around symptom relief, dignity, and peaceful support, rather than harm prevention or clinical goals.

Ethical Decision-Making & Dialogue Prompts	Psychiatrist and team	Supported team reflection on grief, fear of 'giving up,' and ethical tensions. Enabled consensus to honour Jonah's values without initiating futile interventions.
Advance Care Planning Tool	Jonah and Psychiatrist	Documented Jonah's refusal of forced treatment and his wishes for comfort-oriented care.
Advance Care Planning Snapshot Sheet	GP and legal advocate	Summarised Jonah's directives and made them accessible across services, including emergency and hospital settings.
Advance Care Planning Tool (Family Version)	Jonah's sister	Helped her articulate what Jonah feared, what brought him comfort, and what had historically caused harm.
Family / Supporter Reflection Tool	Sister and social worker	Provided relational insights and clarified support needs and boundaries from a family perspective.
Care Collaboration Summary Sheet	Hospital social worker	Facilitated referrals to palliative services, coordinated at-home medical support, and confirmed that refeeding would not be reinstated unless explicitly requested by Jonah.

Reflection and Outcome

Jonah passed away peacefully at home, surrounded by his sister, a palliative nurse, and a peer mentor who had supported him throughout his care journey. In the final week of his life, Jonah spoke little but remained present. His sister later shared that on the day before he passed, he appeared unusually light and even playful, as if he had found a quiet sense of peace.

There were no final attempts to refeed, no emergency admissions, and no forced interventions. Instead, his final days were marked by presence, honesty, and gentle care.

While his earlier harm reduction plan, which had included minimal but regular oral intake, symptom monitoring, and access to respite admissions, had supported a period of stability and trust, it was no longer clinically sufficient. After careful review, the treating team agreed that further refeeding attempts would be medically futile and carried a high risk of both physical deterioration and psychological harm. This decision was not made lightly but emerged through ongoing ethical dialogue and consensus within a supported multidisciplinary team.

Jonah retained full decision-making capacity and had clearly and consistently expressed his preferences in partnership with his sister and care providers. His advance care planning documents were completed voluntarily, with insight and intent, and were honoured across all settings.

In the final phase of his illness, the team's role shifted, from trying to reverse decline, to walking alongside it with compassion, clarity, and continuity. Jonah's care highlights the importance of remaining present and attuned, even when recovery is no longer possible or ethically supportable given the risks and circumstances.

Vignette: Marcus

Reclaiming voice and direction when care feels overwhelming

Context

Marcus is a 28-year-old man who has been living with bulimia nervosa since his mid-teens. Over the years, he has engaged in multiple outpatient therapies, eating disorder interventions, and completed two inpatient admissions. Despite these efforts, he reports no meaningful or lasting benefit. He now experiences significant physical fragility and social withdrawal and has been disengaged from formal services for over a year, citing treatment fatigue and trauma from previous refeeding experiences. He is deeply stuck in the binge and purge cycles but doesn't see how re-engaging in treatment could possibly help.

Recently, Marcus shared with his GP that he is "tired of trying" and has been thinking about "not wanting to do this anymore." Although not actively suicidal, he describes a deep sense of emotional and physical exhaustion that makes continued treatment feel untenable. His GP, who knows him well, becomes concerned. She acknowledges his distress but also grapples with an ethical dilemma: is it too soon to consider a non-treatment pathway for someone so young?

She refers Marcus to a community psychiatrist and care coordinator, who convene a multidisciplinary case review. The team explores difficult but necessary questions:

1. What constitutes "evidence-based" care in longstanding eating disorders?
2. Have Marcus's past treatments been sufficient to consider alternative pathways?
3. Is it ethical to push for more intervention or to support a harm reduction or non-treatment plan in a man not yet 30?

The team is divided. Some are hopeful that adapted models, such as SSCM, might help; others worry about repeating cycles that cause harm. The psychiatrist suggests pausing - not to "give up," but to consider shifting from a goal of cure to one of care, from pressure to partnership. Marcus agrees to try SSCM, with additional considerations around harm reduction, relational safety and Marcus's own measures of progress.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Ethical Decision-Making & Dialogue Prompts	Psychiatrist and MDT	Initiated reflection on treatment futility, age-related assumptions, and ethical tensions around risk and precedent.

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Ethical Decision Reflection Aid	MDT	Helped clinicians surface and name value conflicts, bias, and internal discomfort about non-linear care decisions.
Individual Values and Goals Worksheet	Marcus (with psychologist)	Facilitated a pre-admission discussion about ethical risks, clinical limits, and team alignment.
What Matters to Me Tool	Marcus	Supported exploration of identity, meaning, and what makes life feel tolerable or worth engaging with.
Harm Reduction Planning Template	Marcus, therapist, MDT	Structured a treatment trial with protective supports (hydration, emotional safety, regular check-ins).
Advance Care Planning Tool	Marcus and care coordinator	Documented a shared agreement: if the treatment trial is not beneficial, Marcus may choose to return to a palliative-aligned approach.
Care History & Service Access Audit Tool	Care coordinator	Identified gaps in trauma-specific care and longstanding illness models, which informed next steps.

Reflection and Outcome

Three months into trialing SSCM, Marcus remains ambivalent but engaged. He has not required hospitalisation, maintains hydration, and continues weekly therapy.

There has been no major physical change, but something quieter is unfolding. Marcus no longer feels alone in his care. He describes feeling less guarded and more open to reflection. His therapist notes subtle shifts, small moments of curiosity and trust. Marcus is not focused on recovery, but on exploring what else might be possible when care doesn't feel conditional.

This is the first time Marcus has felt like a co-author in his care. He is not being "given another chance" on someone else's terms. He is being offered time, space, and informed choice.

The upcoming four-month review will serve as a collective check-in, not a performance review. Whether Marcus continues treatment or opts for a palliative-aligned approach, the team will support him with consistency and clarity.

Later, his psychiatrist reflects: "I thought we had to choose between treatment or palliative care. What we needed was to slow down and create a middle ground."

Marcus's story challenges the binary framing of eating disorder care. It shows that for younger adults with longstanding illness, dignity, flexibility, and honest partnership are not endpoints, they are foundations. The door hasn't been closed. It has simply been widened.

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Vignette: Samira

Sustaining connection when recovery is not the goal

Context

Samira is a 58-year-old woman living with anorexia nervosa (binge-purge subtype). She has a long and complex history of engagement with mental health services, including multiple inpatient admissions, psychiatric reviews, and community treatment programs spanning over three decades. Her medical history includes osteoporosis, arrhythmia, and past suicide attempts. She lives alone, has no formal support network, and is highly articulate, with a background in academia.

Over the years, Samira has become increasingly withdrawn from structured services, citing burnout and emotional harm from care experiences that felt coercive or misaligned with her values. She describes a deep ambivalence, not about life itself, but about a system that repeatedly demanded compliance without meeting her where she was.

Despite stepping back from formal care, Samira maintains monthly contact with a psychologist she trusts, one of the few clinical relationships she continues to accept. During a recent review, she shared calmly:

“I don’t want to recover. I’ve made peace with that. But I’m not trying to intentionally die, but I am okay if that happens, I just don’t want to give up the anorexia, it’s only thing that makes life feel manageable.”

The psychologist was caught off guard. Unsure whether to escalate, withdraw, or continue, they wrestled with ethical concerns: could ongoing support without a recovery goal be seen as enabling or negligent? Conversely, would withdrawing care amount to abandonment?

The psychologist took the dilemma to their supervisor, however in supervision they were advised to refer Samira to the local area mental health team. This felt counter intuitive to the psychologist, and they felt that it would likely contribute to retraumatising Samira and destroy the relational trust. The psychologist reached out to a colleague who they thought might offer a different perspective. Together, they explored whether support grounded in presence, rather than progress, could be ethically and clinically sustained.

Samira remains cognitively clear, emotionally articulate, and fully capable of participating in shared decision-making. Her refusal of recovery-focused care is not impulsive or avoidant, it is consistent, considered, and communicated with clarity.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Reflective Practice & Role Alignment Framework	Psychologist	Helped reflect on scope, responsibility, and values tension.
Bias Reflection Tool	Psychologist and colleague	Surfaced assumptions about non-recovery and ethical discomfort.
Values-in-Practice Check-In Sheet	Samira and Psychologist	Clarified goals, expectations, and role boundaries.
Harm Reduction Planning Template	Samira, Psychologist, GP	Outlined a care plan focused on sustainability and choice.
Capacity & Voice Consideration Prompt Sheet	Psychologist and colleague	Explored cognitive clarity and trauma-informed understanding of capacity.
Scenario Walk-Through Tool	Psychologist and colleague	Explored ethical trade-offs of continuing vs exiting care.

Reflection and Outcome

Six months later, Samira is still physically unwell but has become more emotionally stable. She continues to have monthly sessions with her psychologist, with the focus shifted away from progress. Samira describes her psychologist as “the only one who doesn’t ask me to be someone else.” She occasionally reaches out to her general practitioner for symptom support and has resumed writing poetry, a creative outlet she had abandoned years ago.

Her eating habits remain irregular, and she has made it clear that she is not pursuing weight gain or specific nutritional goals. However, she is no longer experiencing suicidal thoughts. While her life hasn’t undergone a complete transformation, it feels more tolerable, less defined by fear and more grounded on her own terms.

Her therapy sessions focus on emotional regulation, creative dialogue, and quiet connection, all grounded in relational safety. The psychologist documents insights and reflective themes from their sessions and maintains regular supervision to ensure ethical oversight. The psychologist has since found professional networks and supervision that is more aligned with their approach and the needs of Samira.

For Samira, this therapeutic relationship offers rare support without added pressure. For the psychologist, it means letting go of outcome-based thinking and returning to the value of being present.

During a recent supervision session, the psychologist reflected, “I stopped measuring success in terms of weight restored or appointments kept. I started measuring it in trust. And she’s still here.”

Samira, the GP and the psychologist agree to continue support with clear boundaries and regular reviews. No interventions are forced, and no progress is assumed. However, the connection and its inherent dignity remain central to their approach.

Vignette: Anna

Relational trust and gentle re-entry after system disconnection

Context

Anna is a 31-year-old woman living with anorexia nervosa and long-standing trauma related to previous admissions. Several years ago, she was placed under the Mental Health Act for involuntary treatment - an experience she describes as “dehumanising” and something she’ll “never go through again”. Since then, she has disengaged from all formal health services.

Anna has had to return to living at home with her mother as she was unable to continue living independently. She is visibly malnourished, and refuses even basic medical check-ins. Her mother, Helen, has tried repeatedly to encourage her to visit a GP or re-engage with treatment, but Anna becomes withdrawn or distressed whenever care is mentioned. Friends have also expressed concern, some have called Helen in tears, unsure what to do.

After speaking with a carer advocate, Helen is told that if she genuinely believes Anna’s life is in danger, the only available option is to contact mental health triage or emergency services. But Helen knows that this would likely retraumatise her daughter and risk permanent disconnection. She has witnessed firsthand what her daughter has experienced when placed under a treatment order and she cannot bear to see it happen again.

Desperate but determined not to harm her daughter’s trust, Helen turns to Anna’s sister, Lucy - a nurse living interstate. Lucy has distanced herself from Anna’s care in the past, as she has found it overwhelming, but she agrees to support Helen and begins researching alternative frameworks and stumbles across the Holding Hope Guide. Together, she and Helen explore whether there is any way to offer care that isn’t clinical control, and whether the Guide’s tools might allow for a different kind of conversation.

Helen and Lucy have both been deeply affected by Anna’s eating disorder. Helen has often taken the lead in trying to re-engage services, driven by worry and maternal instinct. Recently Lucy has begun to reach out more and has provided a calm point of connection for Anna, where she isn’t the person with anorexia, but rather the sister. Together, Helen and Lucy carry the emotional weight of watching their Anna suffer, and it is their shared love that anchors the decision to try a different path.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
What Matters to Me	Anna with Lucy's support	Helped begin non-clinical reflection and create space for safety-based care goals.
Individual Values and Goals Worksheet	Anna	Identified daily priorities and boundaries that centred around safety, trust, and autonomy.
Harm Reduction Planning Template	Helen	Supported emotional clarity and helped reduce escalation rooted in fear.
Care Coordination Toolkit	Lucy and local providers	Aligned gentle, voluntary supports that respected Anna's autonomy while offering backup care.
Scenario Walk-Through Tool	GP and ethics panel	Helped prepare for ethical responses if Anna's condition deteriorated and she continued to refuse formal care.

Reflection and Outcome

Anna does not pursue treatment. She does not seek weight restoration. But she begins attending monthly GP visits, on her terms for symptom management and basic medical support. She has pain relief options for ongoing GI issues, regular phone contact with Lucy, and a written list of things that help her feel calm and safe, which she occasionally updates when she feels ready.

Her mother, Helen, describes the shift not in medical outcomes, but in emotional climate:

“We didn't save her. But we stopped scaring her. And I think that's why she's still here.”

For the first time in years, Anna is choosing to remain connected - not because anyone told her to, but because the conditions of care no longer felt like a threat. The family shifted from urgency to presence, and in doing so, re-established a foundation of trust.

The local mental health team remains contactable, with Anna's consent, and a harm reduction plan remains active in the background. Lucy later delivers a webinar for clinicians, sharing how the Guide helped their family reframe care, not as a fixed goal, but as a relationship built on dignity and time. Helen and Lucy both remain consistently present, checking in without pressure and creating space for Anna to feel supported rather than observed. Their united, grounded presence becomes part of the quiet web that holds her. The family has not solved Anna's condition, but they have shifted the relational climate in which she is living it.

Vignette: Elena

Planning for dignity and peace in the face of uncertainty

Context

Elena was a 36-year-old woman living with longstanding anorexia nervosa (restricting subtype), shaped by more than two decades of illness and repeated traumatic experiences in care. She was introspective, musically gifted, and fiercely intelligent. But her trust in the health system had eroded after years of involuntary admissions, nasogastric feeding, and treatment approaches that left her feeling invisible and controlled.

Over time, Elena made it clear to her family, her GP, and the few clinicians she still allowed into her life - that she no longer wished to pursue hospitalisation, weight gain goals, or refeeding protocols. She had tried these interventions many times, with courage and intent. But they had come to feel more like endurance than healing. She described her stance not as a wish to die, but as a wish to stop surviving under siege. She wanted peace, presence, and a different relationship with care.

Her parents, Sofia and Mark, understood. They were deeply grieving, but grounded. They had watched Elena fight and fall through years of treatment that too often left her depleted rather than empowered. “If she could have recovered,” they often said, “she would have. She tried everything.”

Elena’s GP struggled to understand this and felt that Elena did not have capacity to make this decision. The GP called a meeting with Elena’s parents and the other professionals Elena had some engagement with, but Elena was excluded. The GP proposed an urgent psychiatric review and felt that Elena needed involuntary treatment to weight restore her and assist with restoring decision-making capacity. Sofia and Mark felt frustrated that Elena was excluded from a discussion about her own care, and that her wishes were not being respected. They felt the GP was placing blame on them for “giving up” on their daughter. The other clinicians felt conflicted and could sense this clear divide in opinions.

One night, whilst at home, Elena collapsed, and her mother called an ambulance. As emergency staff began preparing for potential admission under the Mental Health Act, Sofia and Mark watched in fear, feeling powerless to intervene. A junior nurse, uncertain but listening, hesitated and dedicated time to hearing Elena’s preferences and listening to Sofia and Mark. The nurse advocated for Elena to receive some support to stabilise her physically, under the condition that Elena followed up with her GP the next day. Elena was allowed to return home. It was a close call. Too close.

Feeling helpless and unsure what to do, Elena reached out to a mental health advocacy group and was assigned an independent advocate, who sent her the Holding Hope Guide, and helped Elena, Sofia and Mark understand the options and document Elena’s preferences. This helped open up a candid conversation with the GP about what Elena truly needed.

Workbook Tools in Practice

Tool	Used by	Purpose and Impact
Advance Care Planning Tool	Elena, advocate and GP	Documented clear care preferences and values.
Advance Health Directive (AHD)	Elena and advocate	Formalised refusal of future forced treatment.
Advance Care Planning Snapshot Sheet	GP and social worker	Ensured consistent communication across providers.
Comfort-Focused Care Planning Tool	Elena, palliative nurse, family	Clarified home-based care priorities
Family / Supporter Reflection Tool	Sofia and Mark	Helped process grief, clarify boundaries and role

Reflection and Outcome

Elena died seven weeks later, peacefully, at home. She was in her own bed, surrounded by her parents, sister, and a small circle of people who had honoured her voice. Soft music played, the same playlist she had helped compile and candles were lit around the room. There were no sirens. No restraints. No forced interventions. Just calm. Just presence.

Although Elena’s cognitive clarity fluctuated in her final days due to malnutrition, her preferences had been clearly documented during a period of stable decision-making. Her refusal of further hospitalisation or forced treatment was developed with her GP and family, and reflected values expressed over many years. Legal tools, including an AHD and EPG, enabled her care team to honour those wishes when she could no longer speak for herself. The alignment of her prior expressions, clinical consensus, and family insight created a strong ethical foundation and prevented retraumatisation at a vulnerable time.

Her death, while deeply painful, did not feel like a failure of care. It felt like care finally aligned with her values. Everyone involved, from the GP to the palliative nurse to her parents, knew what she had asked for. And for the first time, those wishes were protected.

After her passing, Sofia shared: “Losing Elena is the hardest thing I have ever lived through. But we did not lose her to the system. We lost her holding our hands.” Mark added: “If we hadn’t written it down… if we hadn’t used the Guide… she would have died in hospital. And I don’t think we would have recovered from that.”

Elena’s story highlights the importance of clear, values-led planning. What could have been a retraumatising emergency became a supported transition shaped by dignity and trust.

Since her death, her care team has revised practice. The GP now initiates early planning conversations, and the social worker offers training on supported decision-making and guardianship. Elena’s story, though heartbreaking, has become a quiet catalyst for change.

Her care did not rest on compliance or cure. It rested on accompaniment, trust, and the right to be supported without being overruled.

6.3 Closing Reflections

The vignettes in this section are fictional but deeply grounded in real-world dynamics. Each scenario offers a different window into how care might shift ethically, practically, and relationally when we move from a prescriptive model toward one of shared understanding. There is no singular pathway through longstanding eating disorders. But across these stories, a common thread emerges: dignity is not defined by recovery alone, and care does not begin or end with compliance.

The tools in this guide can support teams, individuals, and families in navigating complex care decisions with more confidence and compassion by centring lived values, clarifying legal protections, and fostering ethical reflection. These stories are not templates, they are invitations to pause, listen more deeply, and walk alongside, even when certainty is out of reach.

SECTION 7:
Implementation Support

7.1 Introduction

This Guide is not a fixed protocol or rigid framework. It is a living resource designed to evolve through dialogue, reflection, and responsive use in real-world settings.

Whether you are a clinician, peer worker, GP, service leader, carer, advocate, or educator, this section offers practical strategies for integrating the Guide into everyday contexts. It encourages using the tools with flexibility, responsiveness, and relational intent adapting them to suit the people, settings, and systems you work within.

7.2 Bringing the Guide into services

You do not need a major service redesign to begin using the Guide. Many tools can be introduced gradually through care planning meetings, reflective discussions, or even a single conversation.

These examples demonstrate how the Guide can support ethical, transparent, and person-led care even in small starting points:

Examples of practical integration:	
Case consultations or team reviews:	Use the Ethical Decision-Making & Dialogue Prompts or Risk vs. Values Worksheet to support complex decisions
Crisis and transition planning:	Use the Crisis & Transition Planning Template to collaboratively map responses and safety considerations.
Advance care planning:	Introduce the Advance Care Planning Tool, Snapshot Summary Sheet, or Family/Carer Version to guide structured, person-led discussions.
Service development:	Reflect on intake, engagement, and discharge processes using the Core Principles Framework and Service-Level Care Coordination Checklist.

The Guide supports:

- Flexibility across inpatient, community, peer-led, palliative, disability, and primary care settings.
- Transparency in documenting decisions with accountability and compassion.
- Ethical alignment by inviting teams to examine power, bias, and systemic assumptions.

7.3 Supporting workforce reflection and supervision

Sustainable, ethical care relies on reflective practice and emotional safety, particularly in high-intensity or ethically complex work. This Guide acknowledges that reflective supervision, peer support, and clear role boundaries are critical to workforce wellbeing.

Examples of application in supervision:	
Individual or team reflection	Use the Reflective Practice & Role Alignment Framework or Values-in-Practice Check-In Sheet to explore alignment, burnout, or role strain.
Debriefing after distress	Apply the Co-Reflection & Ethical Debriefing Prompts or Team Reflection & System Learning Prompts to support shared learning after challenging episodes.
Multidisciplinary or cross-role supervision	Use the Bias Reflection Tool to surface unconscious beliefs and support values-led care.

Guiding supervision principles:

- Affirm cultural and identity safety
- Acknowledge power dynamics and organisational influence
- Support both peer-led and clinically aligned reflective structures

7.4 Embedding the Guide in systems, training, and policy

Beyond individual use, the Guide offers a foundation for aligning organisational policies, training, and service culture with person-led, rights-based care. Its values and tools are designed to align with - not replace - existing quality and safety frameworks.

Applications include:

Area	Use of the Guide
Policy development	As an ethical foundation for harm reduction, non-admission protocols, advance planning, or end-of-life care pathways.
Staff training	Integrated into onboarding, workforce development, or professional learning programs (including the lived experience workforce).
Cross-sector engagement	Fostering shared language and relational principles across mental health, disability, aged care, palliative, and primary care sectors.

Use the Guide to:

- Centre dignity and autonomy in care models.
- Support documentation and communication consistency.
- Align service responses with relational and rights-based principle

7.5 Implementation reflection checklist

Below are practical questions your team or service might use to begin or deepen implementation:

- Have we trialled the Guide with one individual or team case this month?
- Are we integrating the tools into team meetings, care reviews, or reflective practice?
- Are any of our policies in tension with the Guide's principles?
- Are we supporting staff to use the Guide reflectively, not just practically?
- Have we invited feedback from people with lived experience who are engaging with the tools?
- Is there a nominated champion or facilitator helping guide implementation across the team or service?

7.6 A living resource

This Guide does not offer final answers. It offers a place to begin, an invitation to co-create, reflect, and act with courage, even when the way forward is uncertain.

Each time you return to these tools, whether during care planning, a quiet moment of supervision, or a brave team conversation, you are helping shape what ethical, person-led care can look like.

You are not expected to use this Guide perfectly. You are invited to use it with honesty, adaptability, and compassion.

Adapt it. Translate it. Share it. Challenge it. Let it grow where care is most needed.

**Holding Hope
is not the conclusion.
It is the foundation.
The real change happens in what
we build beyond these pages
- in relationships restored,
voices uplifted, systems reimagined,
and lives made more liveable.**

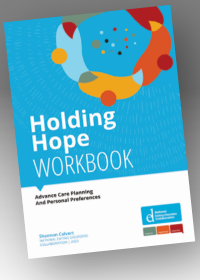
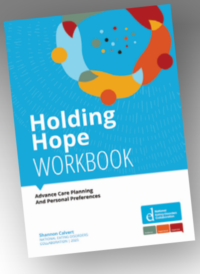
**We are all part of the chapters
that unfold after this one
- toward a future where dignity,
trust, and quality of life
are not ideals,
but realities.**

SECTION 8:
Using the Workbooks

8.1 Overview of the Workbooks

Each workbook aligns with the needs of the workforce, those with living experience, or those who are carers and supporters. Core themes of the Holding Hope Guide are included, along with practical tools, templates, and reflection prompts.

These workbooks were developed to enhance the practical application of the Holding Hope Guide across diverse care contexts. While some tools are role-specific, many are relational, designed for shared planning, ethical dialogue, and collective care across personal and professional boundaries.

Workbook Title	Overview
Holding Hope Workbook: **For the Workforce Supporting People With Longstanding Eating Disorders** 	• Supports clinicians, peer workers, service leaders and multidisciplinary teams to explore roles, values, bias and support ethical decision making and reflective practice. • Encourages compassionate, person-centred care for individuals with enduring eating disorders who seek alternatives to traditional recovery-focused approaches. • Promotes collaborative dialogue and values-based care planning that respects lived experience, autonomy, and diverse definitions of quality of life. • Provides tools and guidance for navigating complex clinical decisions and system challenges with empathy and integrity • Highlights the importance of reflective practice, team support, and ongoing learning in responding to non-recovery pathways with ethical sensitivity.
Holding Hope Workbook: **For People With a Longstanding Eating Disorder** 	• Invites individuals to reflect on their experiences, values, and personal definitions of well-being outside conventional recovery frameworks. • Encourages self-exploration and storytelling as powerful tools for insight, validation, and empowerment. • Provides structured exercises to support emotional safety, clarify goals, and strengthen voice and autonomy in care planning. • Promotes thoughtful dialogue with care providers and support networks around identity, choice, and alternative care pathways. • Reinforces dignity, respect, and hope by focusing on quality of life and meaningful relationships.

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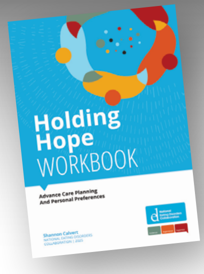
Holding Hope Workbook: **For People who Care For, Love or Support Someone With a Longstanding Eating Disorder**



- Includes tools for bias reflection, care audits, supervision prompts, communication aids, and cross-team planning.
- Helps loved ones reflect on their role, emotional responses, and personal values in supporting someone navigating non-recovery-focused care.
- Encourages open dialogue, active listening, and co-creating care pathways that prioritize autonomy, dignity, and meaningful life experiences.
- Supports caregivers in balancing hope with realistic expectations and developing sustainable ways to offer support without burnout.
- Validates the complexity of caring and promotes shared learning through guided reflection.

Note: These workbooks are not diagnostic tools or compliance checklists. They are trauma-informed, relational resources designed to uphold dignity, strengthen communication, and make space for values-based decision-making. Each tool invites thoughtful use and adaptation, not rigid completion and may be used collaboratively or individually.

While these resources were developed in the context of longstanding eating disorder care, their relevance often extends to broader areas of health, mental health, and complex care. We encourage services, teams, and communities to adapt, reflect on, and contribute to their ongoing development.

8.3 How to use the workbooks

The workbooks can be:

- Used independently or alongside the main Holding Hope Guide
- Adapted to suit individual roles, preferences, and contexts
- Shared digitally, printed, or used in supervision, team development, or family conversations
- Revisited over time as care needs shift or new questions emerge

8.4 Workbook tool index

The following table provides an at-a-glance reference for all tools included in the workbooks. Each entry lists the tool name, the workbook it appears in, and its page number for easy navigation.

Tool
WORKFORCE ***(For the Workforce Supporting People With Longstanding Eating Disorders)***
Values-in-Practice Check-In Sheet
Reflective Practice & Role Alignment Framework
Care History & Service Access Audit Tool
Language in Practice: A Prompt Sheet for Ethical and Relational Communication
Risks vs. Values Worksheet
Family Voice in Care Planning Template
Scenario Walk-Through Tool
Bias Reflection Tool
Ethical Decision-Making & Dialogue Prompts
Mental Health Laws Ethical Reflection Tool
Capacity & Voice Consideration Prompt Sheet
Advance Care Planning Snapshot Summary Sheet
Co-Reflection & Ethical Debriefing Prompts
Team Reflection and System Learning Prompts
Care Collaboration Summary Sheet
Care Coordination Toolkit & Planning Checklist
Care Coordination Service Self-Assessment
LIVED EXPERIENCE ***(For People With a Longstanding Eating Disorder)***
Individual Values and Goals Worksheet
What Matters to Me?
Crisis & Transition Planning Template
Care History & Service Access Audit Tool
Advance Care Planning Workbook
Advance Care Planning Snapshot Summary
Harm Reduction Planning Template
Comfort Focused Care Planning Tool
Risks vs. Values Worksheet
Care Collaboration Summary Sheet

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CARER ***(For People who Care For, Love or Support Someone With a Longstanding Eating Disorder)***

Family / Supporter Reflection Tool

Family / Supporter Version: Advance Care Planning Companion Tool

Risks vs. Values Worksheet

Scenario Walk Through Tool

Care Collaboration Summary Sheet

Ethical Deicions Making Tool

Bias Reflection Tool

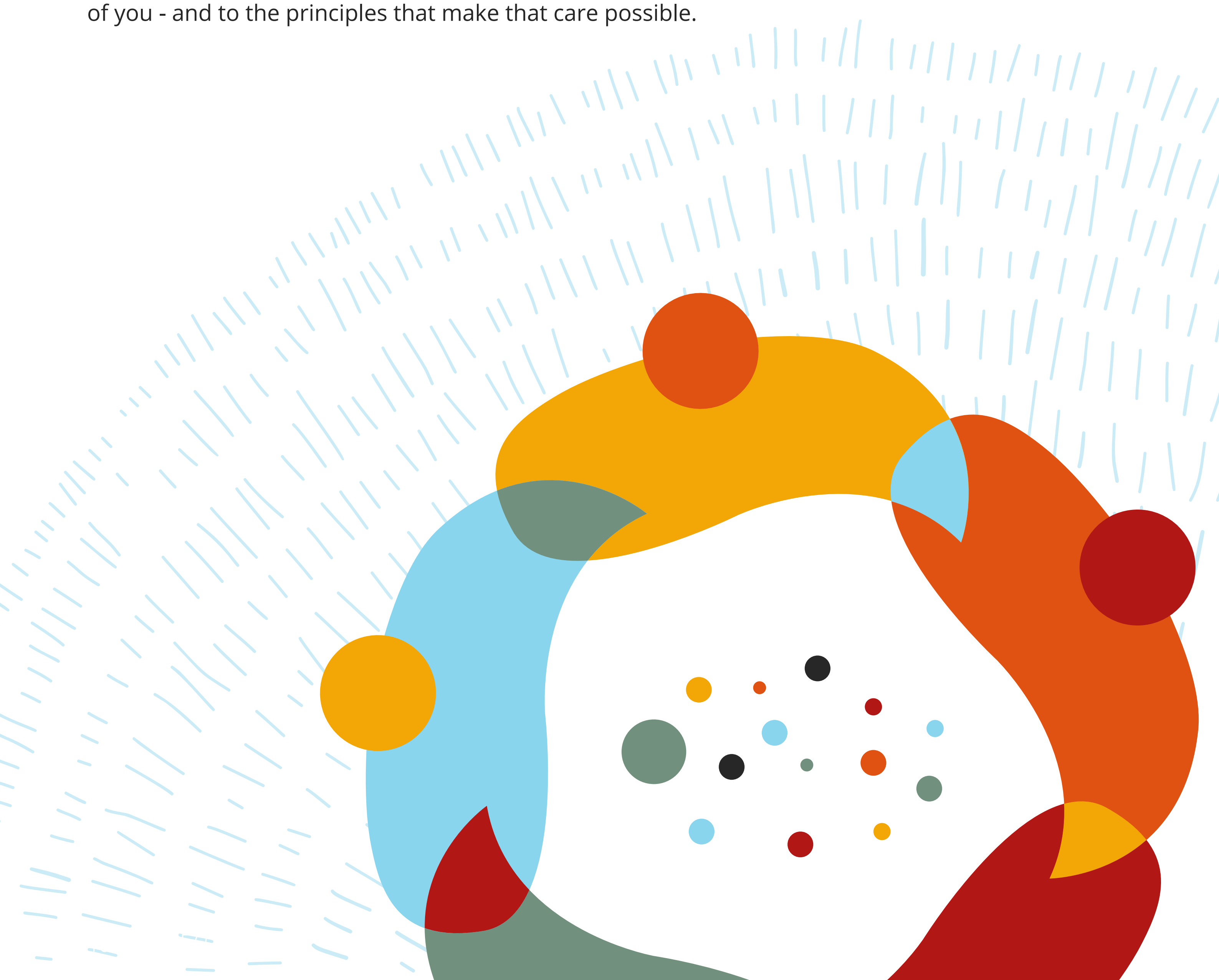
SECTION 9:
Closing Reflections

There is no single path through complexity - but there are ways to walk it together.

This Guide is not a prescription. It is an offering - a practical, principled resource that invites deeper listening, ethical courage, and shared care. It is grounded in lived experience and built for the real-world tensions many of us face: when clarity is elusive, when support is limited or fragmented, and when care must be reimagined, not abandoned.

Whether you are holding space for another or seeking support yourself, we hope this Guide reminds you: that dignity matters, that presence is powerful, and that even when recovery is not the destination, care still matters deeply.

You do not need to have all the answers. You only need to remain connected to the people in front of you - and to the principles that make that care possible.



Glossary

Key terms below are taken from the National Eating Disorder Strategy 2023 - 2033 and the National Palliative Care Strategy 2018. While many of the terms below have broader usage, they have been defined in relation to eating disorders and longstanding eating disorders

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 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	Recovery is a personal and subjective process defined by the individual. For some, it may involve reducing the impact of the eating disorder and experiencing improvements in physical, psychological, or social wellbeing. For others, recovery may be an ongoing journey of strengthening safety, connection, meaning, and quality of life in ways that align with their values and circumstances. This Guide recognises that recovery is not linear and does not follow a single pathway; each person's experience and definition should be supported and respected. (Hirsch, 2023)
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.).

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