# Holding Complexity: trauma, illness, and continuity in care at the end of life

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## KEYWORDS
Supportive care; Trauma-informed care; Health inequity; Mental health; Chronic disease

## EXECUTIVE SUMMARY
Harley is a 40-year-old man living with advanced COPD, trauma, and significant social disadvantage. His care highlights the complexity of delivering palliative care principles in advanced non-malignant chronic disease, where physical symptoms, mental health, stigma, literacy, and geographical isolation intersect. Through a transdisciplinary supportive care model with embedded psychiatry, care was adapted to prioritise trust, safety, and continuity. Despite recurrent crises, including suicidality and overdose, engagement was sustained. Outcomes demonstrate that consistent, trauma-informed care can reduce risk, strengthen connection, and support legacy-making.

## INTRODUCTION
People living with advanced non-malignant chronic disease often experience layered complexity beyond physical illness. Mental health conditions, trauma histories, stigma, low health literacy, and social isolation intersect, creating barriers to care access and continuity. Traditional models designed for more predictable and linear disease trajectories often struggle to respond to this level of complexity.

This case study explores how a transdisciplinary Supportive Care for Chronic Disease (SCCD) model, enhanced by embedded psychiatry, can respond to these intersecting needs. It demonstrates how care can remain present, adaptive, and person-centred, even when risk escalates and engagement fluctuates.

## YEAR CASE STUDY WAS IMPLEMENTED
2024 to 2026

## CASE STUDY DETAIL
### The specific issue being addressed
Harley is a 40-year-old man living alone in a small upstairs unit, physically and socially separated from the outside world. He lives with advanced COPD alongside PTSD, depression, and anxiety. His history includes incarceration, substance use, and significant childhood trauma. He is unable to read or write, relying on others to interpret the information that shapes his care. His primary supports, his father and stepmother, live an hour away, creating a fragile connection between stability and crisis.

Harley's situation reflects intersecting layers of complexity. Mental health needs sit beneath and alongside physical illness. A history of substance use influences clinical decision-making, particularly around medication access. Low health literacy limits navigation of care systems. Geographic separation reduces immediacy of support. Together, these factors contribute to disengagement, unmet need, and escalating risk.

### Approach developed to address this issue
Care was delivered through the Supportive Care for Chronic Disease (SCCD) program, a transdisciplinary model integrating palliative care principles early in advanced non-malignant chronic disease. Embedded psychiatry (SCCD+) enabled concurrent management of mental health, trauma, and physical illness.

The approach centred on adapting care to Harley, rather than expecting him to adapt to the system. Communication shifted away from written instruction toward supported, verbal engagement. Trust-building became a primary clinical task. Risk was not treated as a reason to withdraw care, but as a signal to intensify it. Protective factors such as family, pets, and identity were actively identified and reinforced.

Continuity, flexibility, and trauma-informed practice underpinned all care delivery.

### Summary of activities and their implementation

Engagement began by meeting Harley where he was, both physically (via telehealth) and emotionally. Early care addressed breathlessness and nutrition, while opening space for conversations about fear, safety, and what mattered most.

Over time, small but meaningful shifts emerged. Harley began engaging more consistently, attending appointments with his stepmother and connecting with embedded psychiatry. Practical supports including mobility aids, housing advocacy, and income assistance made day-to-day life a little easier. Re-engagement with activities such as motorbike riding restored a sense of autonomy and identity.

This progress was not linear. Periods of deterioration followed, marked by medication cessation, withdrawal, and escalating psychological distress. During these times, the team intensified rather than reduced care. Safety planning was enacted, follow-up increased, and coordination across services strengthened. When trauma resurfaced and risk escalated, this resulted in a coordinated inpatient mental health admission.

As his physical condition progressed, care complexity increased. Discussions around breathlessness, dying, and control emerged alongside challenges related to substance use history and prescribing decisions. Despite repeated crises including overdose and suicidality, the team stayed. Even within instability, opportunities for legacy-making remained, with Harley identifying goals such as reconnecting with family and engaging in valued experiences.

## Summary of outcomes and measurable impacts of the activities

The most significant outcome was sustained engagement in the context of high complexity and risk. Harley remained connected to care despite repeated crises, representing a critical shift from expected patterns of disengagement.

There was evidence of increased insight and self-protective behaviour, including distancing from harmful influences and seeking support during distress. Family involvement strengthened, reducing isolation and improving continuity. The system responded effectively to acute crises through coordinated, compassionate intervention.

Importantly, this model of care supported the emergence of future-oriented thinking. Alongside expressions of despair, Harley articulated goals, relationships, and experiences that mattered to him. The coexistence of hope and distress reflects a meaningful outcome in advanced disease.

## The extent to which the activity is scalable and ease of adoption by other services / organisations

This type of care is scalable because it relies on principles rather than high-cost infrastructure. Embedding psychiatry even at low fractional capacity enables significant impact within existing systems. The approach is adaptable across metropolitan, regional, and rural settings and integrates with primary and specialist care.

Its transferability lies in its focus on continuity, flexibility, and trauma-informed care, all are capabilities that can be developed across services managing complex chronic disease populations.

## Important lessons learnt and critical success factors

This case demonstrates that continuity of care is most critical when risk is highest. Services must be equipped to respond to complexity by leaning in, not stepping back. Mental health and trauma are central to advanced non-malignant chronic disease care and must be addressed alongside physical illness.

Stigma, particularly related to substance use, can shape how care is both provided and received, in subtle but significant ways and requires active recognition. Health literacy barriers demand system-level adaptation rather than patient compliance.

Most importantly, this case highlights that hope and despair can coexist. The role of care towards the end of life is to hold both, maintaining connection even when outcomes are uncertain.

## Other comments/information

Harley’s story reflects the non-linear reality of advanced non-malignant chronic disease. It demonstrates that the value of supportive and palliative care lies not only in clinical outcomes, but in the ability to remain present, especially when complexity is at its peak. In this context, care is not defined by resolution, but by continuity.