What matters most? Transforming care in advanced non-malignant chronic disease

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Key Words

Supportive care; non-malignant chronic disease; early palliative care; transdisciplinary model; carer support; embedded psychiatry

EXECUTIVE SUMMARY

People living with advanced non-malignant chronic disease frequently experience crisis-driven care and have complex and often unmet physical, psychosocial, and psychiatric needs. The Hunter New England Local Health District (HNELHD) Supportive Care for Chronic Disease (SCCD) service integrates palliative care principles into outpatient chronic disease management through an allied health-led, transdisciplinary model, enhanced by embedded psychiatry. Informed by a randomised controlled trial, the model achieves sustained reductions in emergency presentations (59%), admissions (73%), and bed days (67%), without detriment to symptom burden or quality of life. This scalable model improves outcomes for patients, carers, and health services.

INTRODUCTION

People living with advanced non-malignant chronic disease in the last two years of life experience high symptom burden, psychosocial complexity, and fragmented care, often resulting in repeated crisis-driven hospital use. Despite this, access to structured supportive and palliative care remains limited.

The *Liver Life* Randomised Controlled Trial (HNELHD, 2021) demonstrated that an allied health-led, transdisciplinary supportive care model—integrating early palliative care principles and running in parallel to standard outpatient chronic disease care—reduced emergency department presentations and unplanned hospital admissions for advanced liver disease patients by 66%, alongside improved patient and carer experience and significant cost savings. This work was recognised with the ACHS Quality Initiative Award in Clinical Excellence and Patient Safety and the ACI HNE Rural Innovation Award (2022).

In response, the NSW Ministry of Health funded the establishment of Supportive Care for Chronic Disease (SCCD) service in 2022. This scalable model now extends across chronic disease specialty groups including heart failure, motor neurone disease, Parkinson's disease, chronic obstructive pulmonary disease (COPD), advanced liver disease, and for First Nations populations, embedding person-centred, transdisciplinary care alongside existing treatment pathways.

HIGHLIGHTS

• Care guided by patient/carer measures, centred on “what matters most”
• 59% fewer ED visits; 73% fewer admissions; 67% fewer bed days
• Outcomes sustained for ≥6 months post-program
• No decline in symptoms or quality of life despite reduced acute care
• ~$875k saved in one year (~$19,855 per patient)

METHODOLOGY/PROCESS

Model of Care
SCCD is a 12-week, allied health-led transdisciplinary program delivering holistic care across clinical, psychosocial, functional, and existential domains. Care is guided by a structured Supportive Care Bundle integrating assessment, shared care planning, and coordination across hospital, community, and primary care.

Patient and Carer-Centred Approach
Validated patient and carer-reported measures are embedded in real time to identify unmet need and guide tailored interventions. This ensures care is anchored in what matters most to patients and carers.

Evaluation Approach
Health service utilisation was measured per patient per week across pre-, during, and post-program periods.

Changes in patient-reported outcomes were analysed using Bayesian linear mixed-effects models, accounting for repeated measures. Bayes Factors were used to determine evidence for change over time in symptom burden (Integrated Palliative Outcomes Scale – IPOS) and quality of life (Euro(EQ)-5D-5L).

Post program evaluation surveys completed by patients, carers and clinicians provided qualitative evidence on the feasibility and acceptability of the program.

Implementation and Scale
The model is delivered through partnerships with chronic disease specialty services and scaled across a geographically diverse health district using hybrid (in-person and virtual) care. Implementation science principles support transferability across disease groups and settings.

RESULTS/OUTCOMES

Service-wide outcomes (2024/25) demonstrate sustained and scalable impact with consistency across chronic disease specialty groups:

· Emergency department presentations reduced by 59% (0.11 → 0.05 per patient/week)
· Admissions from ED reduced by 73% (0.07 → 0.02 per patient/week)
· Unplanned bed days reduced by 67% (0.51 → 0.17 per patient/week)
· Reductions sustained for ≥6 months post-program

· 99 ED presentations and 579 bed days avoided, equating to $874,950 in savings (~$19,855 per patient) over a 9-month period

Crucially, Bayesian analysis demonstrated decisive evidence of no change in patient-reported outcomes, indicating stability in symptom burden and quality of life despite reduced acute care use and expected decline due to the terminal nature of disease:

CONCLUSION

The HNELHD Supportive Care for Chronic Disease service demonstrates that early integration of palliative care principles—within a transdisciplinary, patient-driven model —can transform care for people living with advanced non-malignant chronic disease without compromising symptom burden or quality of life. By embedding patient and carer-reported measures, strengthening continuity across care settings, and addressing both clinical and psychosocial complexity, this model delivers sustained reductions in acute care use alongside improved experience of health care. Its scalability, transferability, and alignment with value-based care position SCCD as a leading model for system-wide transformation in life-limiting non-malignant chronic disease care.

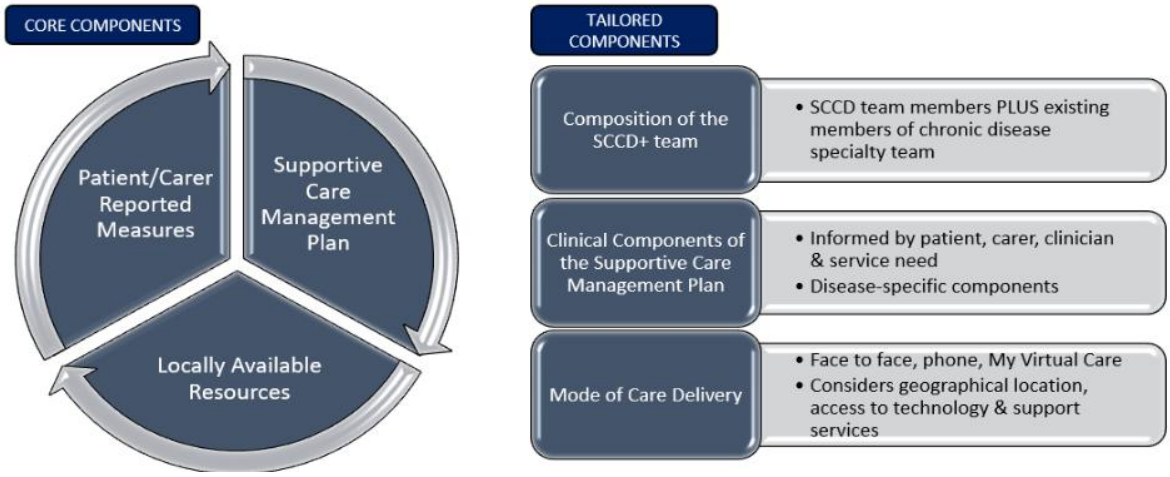

Figure 1. Core versus Tailored Components of the Supportive Care Bundle



Figure 2. SCCD Domains of Care

Patient or Carer-Reported Measure	Appointment 1.	Appointment 2.	Carer only appointment	Appointment 3.	Appointment 4.
Integrated Palliative Outcomes Scale (IPOS)	X	X		X	X
EuroQol (EQ-5D-5L)	X	X		X	X
Malnutrition Screening Tool (MST)	X				X
EAT-10	X				X
Carer Experience Scale (CES)	X		X		X
Carer Support Needs Assessment Tool (CSNAT)	X		X		X

Figure 3. SCCD program schedule of measures