TICKING OFF THE BUCKET LIST - MANAGING CHRONIC ILLNESS IN THE COMMUNITY

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KEYWORDS

Supportive Care Service, Multidisciplinary Team, person centred care. Supportive care, Palliative care, Quality of Life, Chronic non-malignant life-limiting illness, Advanced Care Planning

EXECUTIVE SUMMARY

This is a case study of PA who was reviewed by the Supportive Care Service (SCS) between August, 2024 and April, 2026. PA was a 75-year-old gentleman with a long history of interstitial lung disease. He had a very supportive ex-wife and his main goal was to remain at home for as long as possible.

PA had led an active life and had run his own insurance business for many years. Adjusting to living with a chronic illness had been difficult but PA continued to keep mentally busy and aimed to always have something to look forward to.

This case study highights the importance of an interdisciplinary team in caring for patients in the community who have complex non-malignant conditions. It also demonstrates how different community teams can work together for the greater good enabling person centred care and achieving patient goals.

INTRODUCTION

There is increasing recognition of the substantial physical and psychological symptom burden experienced by individuals living with advanced non-malignant disease. Despite this, access to specialist palliative care for this population remains disproportionately low.

An Australian study found that although most patients die from non-malignant conditions, they access palliative care far less than patients who die from cancer. This highlights the persistent and clinically significant gap in equitable access to palliative care for patients with chronic, non-malignant disease,

In response to this disparity, the New South Wales Government initially allocated time-limited funding to the Southeastern Sydney Local Health District to support the development of a community-based model of care for individuals with late-stage degenerative and chronic conditions. The primary objective of this initiative was to enhance patient wellbeing and maintain independence by enabling individuals to remain at home for as long as possible.

Consequently, the Supportive Care Service (SCS) was established at St George Hospital in April 2023. The SCS adopts a multidisciplinary team approach, comprising a palliative care consultant, Clinical Nurse Consultant (CNC), Physiotherapist (PT), Occupational Therapist (OT), Social Worker (SW), pharmacist, dietitian, Speech Pathologist (SP), psychologist, administrative support, and intellectual disability palliative care CNC to deliver coordinated, patient-centred care across the disease trajectory.

This funding has since been secured on an ongoing basis, reflecting sustained health system commitment to addressing unmet palliative care needs in this population.

Our case study demonstrates the work that our supportive care service does. We tell the story of Mr PA who was able to remain in the comforts of his own home until the end of his life.

YEAR CASE STUDY WAS IMPLEMENTED

August 2024 – April 2026

CASE STUDY DETAIL

PA was a 75-year-old man living with his supportive ex-wife. They had 2 adult sons. He was diagnosed with interstitial lung disease (ILD) in 2019 and was managed with home oxygen therapy and Pirfenidone. He also had severe obstructive sleep apnoea requiring overnight CPAP with entrained oxygen. Over time, PA experienced a gradual functional decline due to worsening breathlessness, eventually becoming housebound and increasingly dependent. He was referred to the Supportive Care Service (SCS) in August 2024, at which point he was still able to mobilise short distances with a walker and attend appointments with oxygen.

PA had completed a New South Wales Advance Care Directive, stating that he would find life unacceptable if he could no longer communicate or perform basic self-care. He expressed a clear preference to remain at home at the end of his life. He focused on meeting important life goals which helped to give his life meaning and purpose.

SCS played a key role in managing PA's symptoms in the community, including fatigue, breathlessness, fluid overload, and low mood. Care was delivered through a multidisciplinary approach. As his condition progressed, he developed right heart failure, which was managed in collaboration with the Hospital in the Home (HITH) team. To address significant fatigue, SCS arranged an iron infusion, which improved his energy levels and enabled him to complete a personal goal of writing children's books for his grandchildren. He collaborated with his son who illustrated the books.

A range of allied health and community services supported PA at home. Occupational therapy provided a recliner chair and wheelchair to improve safety and mobility within the home. A stairlift was installed to overcome the environmental challenges of the long, sloping driveway which became increasingly difficult as his oxygen needs increased. The Respiratory Coordinated Care Program (RCCP) supported management of his CPAP therapy, while Speech Pathology (SP) provided strategies to manage dry mouth and thick secretions causing distress, particularly overnight. Social Work (SW) assisted with care coordination and supported the ex wife as her caregiving responsibilities increased. The government home-based dental service facilitated a necessary tooth extraction, reducing pain and discomfort.

PA identified a number of personally meaningful end-of-life goals (his Bucket List), that included watching the Canterbury-Bankstown Bulldogs game at the commencement of the season and he also expressed a strong desire to hold his newborn granddaughter. PA achieved both of these goals.

As his condition deteriorated, PA required admission to the Palliative Care Unit (PCU) for symptom management and respite. Following discharge, he was linked with the Community Palliative Care Team (CPCT) for ongoing home-based care. Despite these supports, PA experienced a fall at home, leading to readmission and subsequent transfer to an acute hospital, where he died peacefully surrounded by family.

This case highlights that while disease progression in advanced ILD cannot be reversed, symptom control and quality of life can be significantly improved through coordinated, patient-centred care. Identifying and prioritising what mattered most to PA was paramount; remaining at home and achieving personal goals . The involvement of multiple services, including SCS, HITH, RCCP, allied health and CPCT, enabled a holistic approach addressing physical, emotional, and practical needs.

Ultimately, this case demonstrates the importance of multidisciplinary collaboration in palliative care and reinforces that supporting patient autonomy, dignity, and encouraging 'bucket list' goals can be as important as managing clinical symptoms.