

Dying of heart failure: how do we improve the experience?

Similar to many other high income nations, Australia continues to report improving life expectancy for most, though not all, of our population.¹ Chronic heart failure (CHF) was the ninth leading cause of death in 2021, when a single cause of death was considered.² However, for most people with CHF, particularly older people, CHF is not an isolated illness. Instead, for many people, CHF is one of several conditions they live with and manage day-to-day. Not surprisingly then, data from 2019 show that the total number of deaths increased fourfold when CHF was considered as an associated, not single, cause of death.³

Despite the improvements afforded by multiple pharmacological, surgical and interventional developments in heart failure, the goal of therapy remains delayed disease progression for many. Cognisant of this reality, recent heart failure guidelines all highlight the important role of palliative care.⁴⁻⁶ Palliative care is defined by the World Health Organization as an approach that improves the quality of life for people and their families, when faced with life-threatening illness. This is achieved by recognising and addressing physical symptoms, psychosocial issues, and spiritual or existential challenges.⁷ Palliative medicine in Australia is a relatively new medical specialty, formally recognised in 2005.⁸ Globally, the palliative care workforce remains underpowered for the community's needs.⁷ In recognition of this issue, both the European⁹ and American⁵ guidelines highlight the need to adopt a palliative approach, whereby elements of palliative care, such as recognising and managing difficult symptoms (eg, severe chronic breathlessness), are delivered by the usual treating team (ie, by non-palliative care specialists). Referral to specialist palliative care clinicians is thereby reserved for people with more challenging or complex care needs. For a palliative approach to be successfully delivered, non-palliative care clinicians, both specialists and general practitioners, must feel empowered and competent in recognising the needs of patients and their informal carers, in managing symptoms and providing holistic support, and in delivering this concurrently with active disease-directed care for CHF.⁹⁻¹¹

The *MJA* recently published an article regarding the imperative of reframing palliative care.¹² The rationale was to improve and broaden uptake, and the authors highlighted that evidence exists for earlier palliative care introduction in the patient journey with a focus on multidisciplinary delivery, making palliative care “everyone’s business”.¹² For this to happen successfully, health care professionals across all specialties need to attain competency and comfort with conversations about dying. Further clarity is also needed around when and why referral is required, and an appreciation of what can be achieved by a local upskilled usual care team and what requires specialist palliative care referral or input. A recent Delphi study exploring referral criteria provides an excellent starting point for

CHF clinicians and services to address local needs in a systematic manner.¹³ The authors suggested a number of criteria as potential important triggers for initiating specialist palliative care referral. Despite requiring validation, these are helpful considerations in clinical care and were summarised as:

- symptoms of advanced disease;
- requirement for advanced heart failure therapies;
- hospital utilisation burden;
- clinician estimation of reduced life expectancy (less than six months);
- symptom burden and/or distress; and
- requirement for specific outcomes such as decision making or discussion at the request of the patient, family or care team.

Many older Australians with CHF are primarily managed by their general practitioner, often with input from a variety of specialists, including cardiologists, general physicians, geriatricians, renal physicians, and respiratory physicians — a reflection of the associated disease burden. Of all these subspecialty physician groups, until recently, only cardiology was lacking training regarding end-of-life care and/or palliative care in the advanced training curriculum.^{14,15} As of 2024, the Royal Australasian College of Physicians advanced training curriculum for cardiology now also includes this important aspect of care. The curriculum discusses palliative care as appropriate for terminal care, to support decision making around treatment goals, and as part of the multidisciplinary care of older people. This is an improvement from the previous curriculum, but we would contend that the focus and importance is too narrow.¹⁶ Indeed, the concept of focusing not on prognostication as the tool to guide referral to palliative care, but on broad needs, may require a significant commitment to self-education for the profession. To date, cardiology has enjoyed a strong evidence base for therapeutic interventions with much trial data providing evidence on the hard endpoint of mortality. To provide high quality palliative care, cardiology must focus beyond this outcome to also consider the patient experience and priorities.¹⁷ This may necessitate a significant shift in the approach to disease management and research focus for the profession. Moreover, with heart failure therapies reducing heart failure hospitalisations, an unanticipated challenge may be the need to provide assessment and care pathways, including palliative care, outside the traditional inpatient model of referring to another treatment team in the acute setting.

In addition to holistically addressing challenging physical symptoms, psychosocial issues and existential challenges over the last years of life, palliative care aims to improve end-of-life care and enable people to die well in their place of choice.¹⁸ In 2014, a Grattan Institute report, *Dying well*, concluded that 70% of

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Australians wished to die at home,¹⁹ thus requiring delivery of end-of-life care at home. Although similar proportions are reported internationally, the report highlighted that people dying in the United States, New Zealand, France and Ireland were more than twice as likely to die at home than in Australia. Detailed data regarding location of death are not currently available locally; however, a 2021 report collating several data sources²⁰ described that most deaths in Australia (88%) occurred in adults aged over 65 years, and in Victoria and Queensland (2016–2017), 50% of deaths in this age group occurred in hospital and 36% in aged care.²⁰ As such, it appears likely that most people with CHF are not dying at home. It is likely that the lower numbers of people dying at home reflects, at least in part, Australian palliative care workforce issues and current cancer-focused service models. Further, there may be consequences of smaller family sizes, less multigenerational households, and perceived family or carer burdens. To improve this and extend the care of people dying with heart failure, there will need to be concomitant expansion of the responsible workforce (“everyone’s business”) and the adoption of models that include people with diseases with different trajectories and timelines to those of cancer.

Although discomfort with discussing death may underlie clinician reluctance, we found that waiting until the terminal admission in heart failure resulted in low documentation of people participating actively in discussions about their own death (18%).²¹ This represents a potential missed opportunity for the dying person²² and places a significant load on their family, who may feel the responsibility of making decisions on their behalf. Notably, recent data support that end-of-life discussions have benefits for reducing complicated grief and depression in subsequently bereaved caregivers.¹⁷ A recent systematic review²³ of effective communication in palliative care, from the perspectives of patients and their caregivers, concludes by noting their appreciation of health care professionals who pay attention to concerns beyond strictly medical issues. Means of facilitating engagement with existential issues by clinicians have been described.²⁴

Recent evidence supports the concept of patient-centred care by a coordinated primary care team, with demonstrated improvements in depression and health-related quality of life measures.²⁵ This also accords with patient and carer values.²⁶ Nevertheless, no Medicare Benefits Schedule (MBS) item is currently available for palliative care provision by clinicians other than those with specialty training in palliative medicine. In addition, the time required to properly engage in a palliative approach by participation in respectful conversations that explore and contextualise the impact and priorities of the disease for that individual patient likely further dissuades clinician engagement. As such, it is difficult to envisage that all clinicians will embrace this discussion and care opportunity as their responsibility and as “everyone’s business”. Given the current focus on primary health care²⁷ and Medicare reform in Australia, the possibility exists to embed a needs-based palliative approach

into heart failure management. The focus on referral triggers being in response to a particular need, rather than a phase of the disease or clinical prognostication, reflects the variable trajectory and difficulty in anticipating the disease course in heart failure. Indeed, the 2020 European Association for Palliative Care Taskforce position statement on palliative care for people living with heart failure recommends the introduction of palliative care early in the disease.⁹ It appears most likely that extending a coordinated primary care team approach, typically with a consistent, known and trusted general practitioner, will deliver best care to people dying with chronic disease.²⁸

Adoption of a palliative approach to CHF care, supported by multidisciplinary community-based teams can make the wish to die at home a reality for more people in the community.²⁹ Such a model, integrating a palliative approach within existing cardiology care, has improved outcomes for Canadians with heart failure.²⁹ Those authors described home-based care, delivered by palliative care physicians and nurse practitioners, with primary care clinicians. Importantly, cardiologists remained involved. Their model demonstrated a significant reduction in hospital-based death (28% compared with 69% receiving traditional models of care). Moreover, they documented the reality and feasibility of changing care goals along the illness course, with the involvement of palliative care. Interviews with health care professionals highlight facilitators (ongoing professional education, shared care, effective communication within the team) as well as barriers (apprehension of cardiologists to introduce palliative care and lack of access to community-based health care workers).²⁹

To apply these learnings to the Australian health care landscape, we suggest that:

- All health care students and advanced medical trainees (irrespective of specialty) receive training in key domains of palliative care, including recognising, assessing and managing challenging physical (eg, pain, breathlessness etc) and psychological (eg, low mood, anxiety etc) symptoms, and communication skills. Focusing on improving quality of life by addressing patients’ and carers’ needs is critical.
- General practitioners should be recognised for the essential role they play in caring for older Australians, with evolution of the MBS to support prolonged consultations to discuss the impact and care needs of chronic life-limiting disease, end-of-life wishes, and care options, including dying at home.
- Nurse practitioners and community-based nurses are highly trained and well placed to deliver both heart failure and palliative care. Their importance as part of a multidisciplinary team aiming to deliver care at home is paramount.²⁹
- Giving priority to codesigned research that examines people’s preferences for care in late-stage chronic disease and what is required to achieve these preferences.

- Transitioning the existing workforce of cardiologists to being an essential part of the multidisciplinary team providing a palliative approach is required, underpinned by education, research (ideally codesigned with consumers), and tracking implementation.
- Professional and societal expectations need to evolve, embracing the notion that achieving a good death may be an excellent outcome in chronic disease.

These six priorities aim to achieve changes in care delivery, attitude and experience. A patient-centred approach is of central importance in the development of new models of care.

In conclusion, we hope the identification of these six priorities can result in changes in care delivery which are focused on a patient-centred approach. Achieving a new model of care for people dying with heart failure will require health care professionals to develop new skills and to engage with the needs of patients and their families and carers. The implementation of this model of care, and the assessment of its benefits, should focus on prioritising quality of life and the care experience as the most important endpoints.

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