End of Life Planning and Care for Heart Failure Patients

Summary for the Heart Failure End-of-Life Planning and Care Task Group

February 2010
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Executive Summary

The challenge
Heart failure (HF) is a progressive disease of the heart muscle that is highly debilitating and is associated with a five-year mortality rate (approximately 50%), worse than many forms of cancer. Currently, about 400,000 Canadians are living with HF and 50,000 new cases are diagnosed each year. It has been projected that as the population ages, the number of people with HF and associated hospital visits will continue to increase. This trend has serious implications for both our healthcare system and the quality of life of thousands of Ontarians.

Over the past several years, the Heart and Stroke Foundation of Ontario (HSFO) has consulted with patients, families and healthcare professionals about the needs of patients with HF. It is evident that despite important strengths in cardiovascular care in Ontario, there are significant gaps and weaknesses in the sort of care available for people with HF. To improve the continuity and quality of care, reduce the healthcare burden, and improve the quality of life for patients and their families, Ontario needs to adopt a systematic approach that supports patients, their families and healthcare providers in planning and implementing chronic disease management that is patient-centered, inclusive of co-morbidities, and designed to address end-of-life issues, including advanced care planning and end-of-life care.

End-of-life care provision will require the involvement of an interprofessional and interdisciplinary healthcare team in various care settings, including the community, hospitals and outpatient settings. So end-of-life issues can be managed effectively, discussions about advanced planning should begin as early as possible in the disease process, when the patient is fully capable of participating in the decision-making process and reevaluated when appropriate.

What is needed
Addressing these objectives and improving HF care will require:

- The education of patients, families, primary care providers and HF specialists and teams.
- A clear understanding of the roles, responsibilities and expectations of different care providers.
- Improved communications between care providers, particularly when there are co-morbidities and multiple specialists.
- Links between HF and hospice/palliative care providers and programs.
- Training for home and hospice/palliative care providers on HF support and management and support from HF specialists and teams.
- Greater flexibility in the entry requirements for hospice/palliative care, including recognition of the often unpredictable prognosis of HF patients.

Ontario has both significant strengths and weaknesses concerning end-of-life planning and care for those with HF. Engaging all stakeholders in moving forward, defining the key principles for end-of-life care for HF patients, and identifying a model or models appropriate for Ontario will help the province to move forward and improve the quality and continuity of care.
Recommendations

It is time to build on the momentum of work within the cardiology and hospice/palliative fields, as well as a grassroots call for change, to improve HF care in Ontario. To promote change and improvement, the HSFO’s task group recommends:

1. Identifying and activating HF champions in all Local Health Integration Networks (LHINs). Champions could then provide support to their respective LHINs and develop collaborative relationships with local Hospice/Palliative End of Life Care Networks.
2. Engaging Ontario’s hospice/palliative care system and encouraging them to more fully embrace the needs of people with HF.
3. Educating and activating care providers to address end-of-life planning and care issues with their patients with HF (e.g., making available educational opportunities and a package of resources) at appropriate points in the care process.
4. Outreach to Family Health Teams and Community Health Centres to help them develop or implement a HF management framework or approach.
5. Educating patients and families about HF and the issues they need to consider.
6. Encouraging LHINs to ensure that the needs of individuals with HF are addressed as they work to enhance end-of-life planning and care.
7. Proposing that the Ministry of Health and Long-Term Care support systems changes and provide resources that would help to reduce or eliminate barriers to end-of-life care for patients HF.
End of Life Planning and Care for Heart Failure Patients

Even though he lived in a major Canadian city and had been seen at a specialized heart failure clinic, my father did not have a “good” death but one characterized by suffering, confusion and frustration – for him and his family. For two months, he lingered in an acute cardiac ward, coming to the realization that he was dying despite the fact that none of his care providers – not even his cardiologist – were willing to talk to him about it. He was just down the hall from his outpatient heart failure clinic but there was no communication between the two units and the acute ward staff seemed perplexed about how to care for him and frustrated by his failure to “get better.” My mother and I did our best to advocate for him but we felt helpless and ineffectual, and for two months we watched him suffer needlessly. Ultimately, five days before he died, he was transferred to a palliative unit and received the sort of care he had needed for far too long. Dying with dignity should not be reserved for only cancer patients.

Heart failure (HF) is a progressive disease of the heart muscle that can be caused by infection or injury (e.g., following a heart attack). HF is the only cardiovascular disease to be increasing in prevalence and poses a significant challenge for our healthcare system. HF is highly debilitating disease and reduces a person’s ability to perform daily activities as well as his/her quality of life. Most Canadians do not realize that HF has a higher mortality rate than many forms of cancer. End-stage HF patients can experience many of the same physical, emotional and care challenges as other palliative patients. However, few hospitals or HF services are organized to address end-of-life planning and care. This gap can result in significant medical and psychosocial challenges for patients, families, caregivers and care providers.

Scope of the problem
The number of Canadians who will require palliative care for end-stage heart failure is not only significant but will increase in the future. Currently, approximately 400,000 Canadians are living with heart failure and 50,000 new cases are diagnosed each year. The annual mortality from heart failure can range between a low of 5% to a high of 50%, with an average estimated to be about 10% per year. Approximately half (40% to 50%) of patients die within five years of diagnosis.

Mortality is only part of the problem. Within one year of being discharged from hospital alive, one in five with a diagnosis of HF is readmitted at least once. Frequent hospitalizations are not only costly for our healthcare system, but reflect the poor quality of life of many people with HF. It has been projected that the number of HF hospitalizations will increase up to three-fold over the next 40 years, due in part to an aging population and a growing number of people with HF.

We know that HF has a high mortality rate, that fewer Canadians are dying in hospitals and that organized palliative care can be beneficial. Guidelines have been released that advocate for the integration of a palliative care approach within HF treatment (e.g., in Canada, the US, the UK and Australia). However, end-of-life planning and palliative care remains a neglected part of the continuum of care for HF patients in Ontario.
HF management needs

A systematic review published in 2006 determined that many of the management issues in the care of end-stage patients are similar for HF, cancer and AIDS patients. In this review, the most common symptoms for HF patients were documented as:

- Fatigue (69-82% of patients)
- Pain (63-80%)
- Breathlessness (60-80%)
- Anxiety (49%)
- Nausea (17-48%)
- Confusion (18-32%)
- Depression (9-36%)

Other symptoms that have been documented include loss of functional independence, gait/walking difficulties, falls, constipation, incontinence, and/or anorexia. The symptom burden also includes psychosocial and spiritual challenges posed by living with a chronic, fatal illness involving frequent hospitalizations, altered self-image and dependency.

Patients with HF have a range of symptoms affecting their quality of life, some of which are not classically associated with cardiovascular disease. As a result, some symptoms may not be recognized by care providers and either not treated or undertreated. In one study, it was estimated that only about 4% of HF patients receive palliative care.

Informal interviews of practitioners working in a variety of cardiac settings in 2008 by the Heart and Stroke Foundation revealed that there is no cohesive strategy for the care of end-stage HF patients. Communication between outpatient clinics (where heart failure patients are typically managed), various specialists who may be treating different co-morbidities, and inpatient units (where end-stage patients are often subsequently admitted) tends to be sub-optimal. Furthermore, few outpatient clinics or inpatient units have formal or even informal linkages with palliative care programs.

HF also poses unique challenges. Many HF patients are managed by primary care providers who may be knowledgeable about the patient and family but cannot be expected to be expert in management of this complex disorder. Moreover, primary care providers may not be comfortable discussing end-of-life issues with patients and reluctant to initiate such conversations or to make referrals to hospice/palliative care programs. This reluctance may mirror the fact that some primary care providers and patients view end-of-life planning as a sign of “giving up” and hospice/palliative care as oriented around pain management (e.g., for cancer patients) rather than supportive care.
Unlike cancer patients, HF patients may experience an unpredictable and lengthy pattern of decline, punctuated by crises and “rescues” through hospitalization and/or specialist intervention. A considerable proportion of HF patients, perhaps between 30% and 40%, die suddenly or unexpectedly from cardiac arrest. The prognostic uncertainty created by the uneven pattern of decline and improvement can make it difficult for patients and healthcare providers to know or accept when long-term planning or end-of-life-care discussions are appropriate. A 2002 comparison of lung cancer and HF patients, for instance, found that HF patients had a poorer understanding of their illness and prognosis and fewer health services, leaving them more isolated and with fewer opportunities for making end-of-life plans.19

The 2009 revised American College of Cardiology and American Heart Association HF guidelines20 have mapped out the stages in the development of heart failure, and the recommended therapy by stage, as shown in the following diagram.

Source: Figure 1 in Jessup et al, 2009 Guidelines Focused Update on Heart Failure20
Stages in the Development of Heart Failure/Recommended Therapy by Stage. ACEI indicates angiotensin-converting enzyme inhibitors; AB, angiotensin II receptor blocker; EF, ejection fraction; FHx CM, family history of cardiomyopathy; HF, heart failure; LVH, left ventricular hypertrophy; and MI, myocardial infarction.

As shown in this algorithm, Stage D is defined as refractory HF requiring specialized interventions. During this stage, Class 1 recommendations include clinical interventions (identification and control of fluid retention), the consideration of treatment options such as referral for cardiac transplantation or specialized HF programs, and end-of-life planning. Recommendation 4 states: “Options for end-of-life care should be discussed with the patient and family when severe symptoms in patients with refractory end-stage HF persist despite application of all recommended therapies.” As well, Recommendation 5 states: “Patients with refractory end-stage HF and implantable defibrillators should receive information about the option to inactivate the defibrillator.”

The position of the HSFO task force differs from that of the ACC/AHA guidelines in that the task group believes that -- because of the unpredictable nature of HF -- end-of-life discussions should not wait until symptoms are severe. The HSFO task group also recognizes not all people with HF are referred to specialized care, particularly for hospice/palliative care. Those few that are referred to hospice/palliative care tend to come through various routes (e.g., through a referral from a family practitioner, cardiologist, hospital service, etc.) and as a result may have different care needs. For example, some patients referred by primary care providers due to a medical crisis are subsequently “rescued” by a HF team or specialist. When the immediate crisis is resolved, the patient is no longer considered eligible for hospice/palliative care and end-of-life planning may be “shelved” as no longer required.

During a 2009 Heart&Stroke Clinical Update presentation on HF care\textsuperscript{21}, none of the practitioners in the workshop (25% internists, 19% hospitalists, 25% family practitioners, 13% nurse practitioners and 19% allied health care workers) felt that the issue of prognosis should be discussed during the time of HF exacerbation requiring hospitalization. In contrast, 62% felt that prognosis should be discussed after optimization of HF treatment, usually after about three months. However, healthcare practitioners demonstrated serious concerns about talking to HF patients about their prognosis. 47% indicated they thought it could frighten patients and make them think they are dying and 33% agreed that “they will think I am giving up on them and there is nothing more to do.” As well, there was diverse opinion on who should initiate such conversations although a third (36%) thought it should be the family doctor, 50% thought it should be some sort of HF specialist (specialist, cardiologist/internist or advanced practice nurse) and 14%, a palliative care physician or nurse. When asked the availability of palliative care services for HF patients in their region, 43% said they were easily accessible but 29% said they didn’t know and 21% said they weren’t available, with 7% saying they were available but limited.

Although the Clinical Update audience is not a representative sample of healthcare providers, it is nevertheless disturbing to see that almost half (47%) are reluctant to discuss prognosis for fear of frightening their patients with HF.
Lack of planning can have unanticipated and often distressing consequences. One American study reported that even among HF patients with do-not-resuscitate orders, only 45% had talked with their doctors about deactivating their implantable cardioverter defibrillators (ICDs). Over a quarter of patients received at least one shock in the last month of their life, with 30% receiving a shock in the last minutes of life. In some cases, multiple shocks were reported, to the distress of next of kin who witnessed them.22

A qualitative, grounded-theory study of 20 HF patients in Hamilton found that although patients wanted messages balanced whenever possible with hope, they also wanted to know the truth about their condition and what the future was likely to hold. Moreover, patients preferred to have such conversations initiated by the healthcare providers and wanted them to occur while they still had the cognitive capacity to process and respond appropriately.23 Ironically, there is also evidence that patients may be more receptive to talking about their prognosis and implications for care planning during periods of disease exacerbation or crisis -- the very time at which clinicians may be more reluctant to broach these topics.24,25

Given the often unpredictable prognosis for HF, finding the “right time” for this discussion is not easy and individual clinicians may vary in their ability to engage in this sort of sensitive and open conversation.

**Calls for HF end-of-life care**

There is a growing call for improved end-of-life planning and care for HF patients. The 2006 Canadian Cardiovascular Society Consensus Conference on heart failure recommended: 26

- Approaching patients early in the heart failure disease process to discuss advanced medical directives and reviewing these decisions regularly and after any change in the patient’s condition.
- Encouraging patients to identify substitute decision-makers.
- Where possible, discussing with patients their end-of-life wishes (a living will).
- Balancing quantity and quality of life, especially as patients near the end of life, when the physician should readdress the goal of therapy and focus on quality of life.
- Routinely re-evaluating psychosocial issues.
- Evaluating the coping ability and burden of caregivers of patients with advanced heart failure.

End-of-life care is also included as an important part of the continuum of care in the recommendations of the Canadian Heart Health Strategy and Action Plan, specifically when discussing cardiovascular services and interprofessional clinical guidelines.27

**What is required?**

HF patients in Ontario need a systematic approach to long-term planning that is patient-centered and takes into account all patient physical and mental comorbidities and potential end-of-life and hospice/palliative care needs and preferences. Like patients with other life-threatening diseases, such as cancer, Alzheimer’s disease or end-stage renal disease, as early as appropriate in the disease process, when fully capable of advanced planning, every HF patient needs to make plans for the future. This includes planning for 1) life with HF, 2) the end-
of-life stage or process, and 3) if it is required, the sort of end-of-life care they would want. These discussions need not be sequential and can occur in different settings and be held with different types of healthcare professionals. Moreover, as the patient’s situation changes or new treatments become available or are offered, previous decisions should be reviewed and reevaluated to determine if they are still appropriate and continue to reflect the patient’s preferences.

1. **Planning for life with HF:** The discussion about what the future may bring should begin at the time of diagnosis, determined by the patient’s current health status and preferences. The patient needs to understand the diagnosis of HF (what it is and what it means for both him/herself and the family) and how to live in the present with HF. Training for HF self-management should begin as soon as possible and care navigators or case managers should be involved to assist the patient. Such discussions can occur in different settings: as part of hospital discharge planning, during consultation with a HF team or specialist, or in the primary care setting. The primary care provider should be a key player in such discussions, because of his/her intimate knowledge of the patient and the family.

2. **Planning care when heart failure progresses:** At this stage, the patient needs to understand the probable prognosis and course of the disease. Advanced care planning is a key component of the work required at this stage.

3. **Planning for care as end-of-life approaches:** Because of the relatively high rate of unexpected death, not every patient with HF will live to require end-of-life care. For those who do, it is important that planning be made before the patient is in crisis. In order to make informed decisions, education on the types of services offered by hospice/palliative care programs, as well as their availability and requirements, is required.

**What do we need to ensure HF patients have access to appropriate planning?**

In order to ensure that HF patients have an opportunity to make all three types of planning, we need an agreed-upon approach to patient-oriented care, including:

- Education of patients and families regarding the need for planning.
- Education of primary care providers about HF management, when to make referrals, and the need for HF and end-of-life planning, including tools to support them in initiating and holding these sensitive discussions.
- Education and tools for HF specialists and teams.
- A clear understanding of the roles, responsibilities and expectations of all members of the interdisciplinary/interprofessional care team.
- Improved communications between care providers so as to optimize continuity of care for HF patients (e.g., breaking down the silos of primary care, specialists, hospital and ambulatory clinic settings).
- Links between HF and hospice/palliative care providers and programs so there is greater awareness on both sides of the issues faced by patients with HF, patient needs, what services hospice/palliative services can play, and their respective roles in planning and care.
- Training for home and hospice/palliative care providers on the management of HF support.
- Greater flexibility in the entry requirements for home care.
• Hospice/palliative care services that recognize the often unpredictable prognosis of HF patients.
• Support from HF specialists and teams for home and hospice/palliative care services attending to HF patients, as well as for families and caregivers.

**Current strengths in Ontario**

Ontario has a number of strengths when it comes to addressing end of life issues for other conditions, particularly cancer, and in providing high quality acute and chronic cardiovascular care. It is time to bring together stakeholders, share ideas and chart a new path for HF patients that ensures optimal quality of life across the entire continuum of care, including end of life.

Strengths in Ontario that should be leveraged include:

• An increasing arsenal of treatment options for HF management.
• A province-wide system for coordinated home care services managed through a network of Community Care Access Centres.
• A system of community support services available through a variety of organizations around Ontario.
• A growing emphasis in primary care on hospice and palliative care and delivery by interdisciplinary teams.
• Grassroots support for improvement in HF hospice and palliative care, as evidenced by the Heart and Stroke Foundation’s initiative.
• An End-of-Life Care Network that supports excellence in hospice and palliative care, including workshop learning experiences focusing on patients with HF.
• A commitment to the development of a comprehensive model for hospice and palliative care.

Management of HF patients may be offered in a number of different settings. Within each category, some may practice in accordance with standardized orders and care maps, whereas others may not. The most common models are:

• Private primary care practices in which there may be relatively few HF patients.
• Primary care physicians who offer HF clinics and, due to larger numbers, may have greater familiarity with HF than the typical primary care provider.
• Nurse led clinics, in which the nurse(s) is constant but individual physicians practice according to their individual style, with little or no consistency in practice behaviours.
• Partial service HF clinics which do not offer transplantation but have a champion physician and nurse.
• University-based, full-service HF clinics which offer transplantation.

Other means of delivering care to HF patients may include:

• Telemedicine -- TV, telephone or Internet-based consultation.
• Cardiac rehabilitation programs.
• Shared care -- an approach in which specialists are brought into primary care practices to improve communications, consultation and mentoring.
• Home care services – Community Care Access Centres (CCACs) provide nursing, rehabilitation and home services for HF patients.
Each model and setting offers different opportunities for providing end-of-life planning. To proceed, however, we need to clearly define and describe the roles and responsibilities of practitioners within each model for end-of-life planning and care and provide them with appropriate tools and supports for this activity.

**Limitations**

At the same time, we must recognize that the current environment in Ontario also has a number of significant limitations or weaknesses when it comes to end-of-life care for HF patients. There is no system to ensure that end-of-life care and planning are routinely incorporated into the care of all HF patients. Moreover, palliative and hospice care is not adequately covered in many medical school and nursing curricula.

Barriers to integrating end-of-life planning and care into HF treatment may come from a number of different sectors. For example, a 2007 review of palliative care for heart failure patients in England identified five types of challenges, all of which may exist in Ontario.²⁸

<table>
<thead>
<tr>
<th>Type/Source of Challenge</th>
<th>Issues</th>
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<tbody>
<tr>
<td>Cardiology-related</td>
<td>• Misperceptions of what palliative care provides</td>
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<td></td>
<td>• Reluctance to “hand over” patients as HF progresses</td>
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<td></td>
<td>• Dominance of the medical model</td>
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<td></td>
<td>• Denial of death</td>
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<tr>
<td>Palliative care-related</td>
<td>• Lack of CHF knowledge</td>
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<td></td>
<td>• Cancer focus</td>
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<td></td>
<td>• Funding streams that are specific to cancer</td>
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<tr>
<td>Patient-related</td>
<td>• Resistance to palliative care due to misperceptions and stigma</td>
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<tr>
<td>Disease-related</td>
<td>• Uncertain prognostication</td>
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<td></td>
<td>• Difficulty of deciding whether an exacerbation/acute event is salvageable</td>
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<tr>
<td>Organizational/team-related</td>
<td>• Conflict of interdisciplinary perspectives on patient care</td>
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<td>• Debate over who should have “difficult” conversations with CHF patients</td>
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<td>• Lack of collaboration between community and hospice teams, including access to patients when they are in a different sector</td>
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<td></td>
<td>• Lack of key worker to case manage/coordinate care</td>
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<td>• Lack of funding</td>
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A scan of the Ontario landscape by the members of the End of Life Planning and Care Task Group convened by the HSFO found:

- The needs of patients with HF may be complex, especially if there are other comorbidities (e.g., renal disease, diabetes). Many of our existing cardiac services, such as rehabilitation programs, are not designed to meet the needs of these patients. The following example from the practice of one of the members of the HSFO task group shows some of the challenges that may be encountered.
80 year old patient with a history of HF and EF [ejection fraction] of 25%. History of moderate Alzheimer’s/mixed dementia. On Lasix 40 mg a day, Ramipril 2.5 mg a day and Aricept (for dementia). Lives at home with his wife. The HF has been stable. He is frail and has had a few falls. The main problem is wandering. He gets up to urinate 5 or 6 times every night. He is so tired and confused that he wanders out the front door of the house and she has to chase him down. She is burning out and wants to place him. We reduced the Lasix and he takes it after lunch (goes to bed relatively volume depleted from the Lasix and thus makes less urine at night). That helps a bit but he still gets up a lot. Therefore, we got rid of the Aricept (slowly). There are no adverse cognitive consequences from doing so. However, because Aricept makes his bladder twitchy, going off of it almost completely eliminates the nocturnal voiding. As a result, he sleeps better. She sleeps better. He is actually less confused. His HF stays stable. We avoided nursing home placement for two years until he died of an acute HF exacerbation.

- Access to specialized HF management and end-of-life and hospice/palliative care services can vary across the province. For example, a 2005 retrospective chart review found that even when a rural hospital provided adequate care for HF patients, there was considerable room for improvement.29
- There is no province-wide tracking of HF patients or services, so we lack good data on care volumes or needs.
- Most HF clinics are focused on ambulatory patients and are not structured to support planning throughout the continuum of care, including end-of-life.
- Many patients move between separate and fragmented services (e.g., outpatient vs. inpatient care), none of which has accountability for end-of-life planning or care.
- Many patients with HF and their families do not understand the disease, what to expect or their care options. Furthermore, prognostic uncertainty and interactions with clinicians focused upon treatment and “rescue” may make it difficult for patients and families to broach the topic of end-of-life planning.
- There is no consistent protocol for end of life in home care for HF and few resources to help patients and families either plan for the future or cope with crises. In many cases, calling 9-1-1 often becomes the fall-back, irregardless of patient values or wishes.
- Existing palliative care services may not be sufficient to meet the need in Ontario, even for oncology patients. Moreover, the structure and entry requirements of many palliative care programs mean they may not be appropriate for patients with end-stage HF.
- Care providers working in hospice and palliative care may lack the training or experience to provide the highest quality end-of-life care for patients with HF. One estimate has been that approximately 95% of all palliative care patients in Toronto have a diagnosis of cancer, with the remaining 5% consisting of patients with HF, end-stage renal disease, and other diseases. These figures are echoed by data from the UK, which found that people with non-malignant conditions constitute only 5% to 8% of those cared for in hospital daycare and in-care facilities.30 Obviously, the small volume of non-oncology patients has ramifications for the level of familiarity and expertise of care providers with HF symptom management.
- Qualitative research in the UK has highlighted the tensions that can emerge between the “‘non-invasive’, holistic approach focusing on quality of life issues characteristic of palliative care specialists and what they see as the “invasive” approach of cardiology-
based HF services. Bridging these approaches may require negotiation and a focus upon what best serves the individual patient.

Opportunities for improvement
The opportunity exists to apply the lessons learned from cancer and other jurisdictions to the growing number of people dying from HF and other non-malignant illnesses in Ontario. In Canada, a National Framework for Advance Care Planning has been developed based upon the recognition that:

- Each person is intrinsically valued, unique and has the moral right to autonomous decision-making.
- Life and the natural process of death provides opportunities for personal growth and self-actualization.
- Caregivers enter into a therapeutic relationship with patients and families based on mutual respect for one’s inherent dignity and integrity.
- It is important to address individuals’ (patients’) and families’ suffering, expectations, needs, hopes and fears.
- Advance care planning is only facilitated when the patient and family is prepared to accept it.
- Advance care planning should be guided by quality of life as assessed by individuals for themselves.

Both the draft Advance Care Planning in Canada National Framework and the CHPCA’s environmental scan are based upon the belief that end-of-life care must be guided by respect for the individual, accessibility and high quality (safe, ethical and effective care that is knowledge- and research-based), and must be adequately resourced.

The current Canadian model for hospice/palliative care, as outlined by the CHPCA, starts early in the disease process (see figure). It recognizes a shift in focus from disease treatment and therapy aimed at modifying the disease, to a phase of hospice/palliative care designed to relieve suffering and/or improve or maintain quality of life. It has also been adapted from the traditional palliative/hospice care model to demonstrate the uneven and sometimes repeated pattern of decline, crisis and recovery that may continue for several years or may resolve unexpectedly in sudden death.

Source: Adapted from A Model to Guide Hospice Palliative Care, 2002. The Canadian Hospice Palliative Care Association.
Future directions

It is important that the needs of HF patients be recognized when developing advanced care, hospice and palliative policies and services. A system of care must be developed that is flexible and addresses the common needs of all end-of-life patients, as well as the unique challenges posed by HF. It is time to build on the momentum of changes and developments, including the release of the Canadian Heart Health Strategy and Action Plan, and improve HF care in Ontario. There are three priorities: 1) engaging stakeholders in moving forward, 2) defining the key principles for end-of-life care for patients with HF, and 3) identifying a model or models appropriate for Ontario.

1. Engaging all stakeholders in moving forward

Stakeholders must be brought together from the worlds of primary care, cardiology, geriatrics, internal medicine and palliative care (e.g., the Hospice Association of Ontario, Ontario Palliative Care Association, Palliative Care Consultants Network, Ontario Community Support Association and hospital palliative/end-of-life care networks within the LHINs), as well as patients and families. What are the roles of different care providers and how can they better communicate to reduce duplication and ensure continuity of care? A key target will be the LHINs, because of their role in care coordination and ensuring patient-centred care.

2. Defining the key principles for end-of-life care for patients with HF

The Canadian Hospice Palliative Care Association (Appendix I) has identified their key principles for end-of-life care, which align with those put forward by the Ontario Health Quality Council. Conversations between HF care providers and end-of-life care specialists are needed to determine if those principles are adequate for dealing with HF or whether there are additional issues or concepts that must be addressed.

3. Identifying a model or models appropriate for Ontario

What “made in Ontario” solution could be used to ensure there is improved access to appropriate end-of-life care for patients in Ontario with HF? Pilot projects such as shared-care palliative programs in Kitchener-Waterloo and Niagara may provide insights and templates. As was the case with stroke, system changes may be needed to support best practices. Although stakeholders can advocate for change, this sort of system-level change requires the involvement and commitment of provincial and regional health decision makers.

Task Group Recommendations

Recommendations made by the task group to move forward and support the priorities it identified include:

1. Identifying and Activating HF Champions: HF champions should be identified in all LHINs. HF champions can consist of healthcare providers with expertise in HF diagnosis and management, as well as patients and families who have experience of the disease process. Once identified, the HSFO is willing to share information and facilitate the
orientation of champions (e.g., through teleconferences). Key tasks of the champions would be to:

- Introduce themselves and offer their support to their local LHIN.
- Develop a collaborative relationship with their local Hospice Palliative/End of Life Care Network.
- Participate in End of Life Networks Setting the Stage for Change workshops, which focus on HF.

2. **Engaging Ontario’s Hospice/Palliative Care System:** The hospice/palliative care system in Ontario needs to be encouraged and supported to embrace the needs of people with HF. Tactics to support this objective include:

- Forward the HSFO’s task group statement to all Ontario Hospital/Palliative End of Life Care Network, the Provincial Consortium for hospice/palliative care, the Ontario College of Family Physicians, the Ontario Association of CCACs and the Canadian Palliative Care Physicians’ Association.
- Prepare a package for End of Life Care Networks on HF hospice/palliative needs.

3. **Educating and Activating Care Providers:** Physicians, hospitalists, CCACs and other healthcare and service providers should be encouraged to work with individuals with HF to address end-of-life planning and care issues as appropriate. Some of the key messages identified by the HSFO task group for HF and hospice/palliative care providers are summarized in Appendix II. Supports for care providers could include:

- Providing educational opportunities, such as at the Canadian Cardiovascular Congress (Canadian Cardiovascular Society), HSFO’s Heart&Stroke Clinical Update, and other professional meetings or conferences.
- Education and other supports to help interprofessional teams, especially those in primary care, effectively collaborate and cooperate in providing patient-centred HF care.
- Preparing a package for healthcare providers with resources such as care paths, prognostication and symptom management tools, as well as resources for professional and patient education.

4. **Outreach to Family Health Teams and Community Health Centres:** As part of their commitment to primary care reform and patient-centred care, family health teams (FHTs) and Community Health Centres (CHCs) should develop HF management frameworks or approaches.

5. **Patient and Family Education:** HSFO will seek partners for the development and distribution of HF resources for patients and their families. A draft of some of the key messages for patients and families coping with a HF diagnosis are provided in Appendix III.

6. **Activating LHINs:** Encouraging LHINs to ensure that the needs of individuals with HF are addressed as they work to enhance End of Life Planning and Care.

7. **Ministry Support:** Asking the Ministry of Health and Long-Term Care to ensure that the level of resources for End of Life Care is adequate to provide services for individuals with HF and that the barriers to accessing End of Life Care for HP patients are eliminated. For example, healthcare providers need time to receive training on HF hospice/palliative care issues and management, as well as time to conduct such conversations with patients and families.
By incorporating end-of-life planning and care, there is an opportunity to make substantive changes and improvements in the management of patients with HF and to support their families. Engaging all stakeholders in moving forward, defining the key principles for end-of-life care for HF patients, and identifying a model or models appropriate for Ontario will improve the quality and continuity of care for Ontarians with HF.
Appendix I: Canadian Hospice Palliative Care Association Values and Guiding Principles

Values
All hospice palliative care activities recognize and support the following values:

V1. The intrinsic value of each person as an autonomous and unique individual.
V2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
V3. The need to address patients’ and families’ suffering, expectations, needs, hopes and fears.
V4. Care is only provided when the patient and/or family is prepared to accept it.
V5. Care is guided by quality of life as defined by the individual.
V6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.

Guiding Principles
The following principles guide all aspects of hospice palliative care:

GP1. Patient/Family Focused. As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

GP2. High Quality. All hospice palliative care activities are guided by:

- The ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality.
- Standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline.
- Policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines.
- Data collection/documentation guidelines that are based on validated measurement tools.

GP3. Safe and Effective. All hospice palliative care activities are conducted in a manner that:

- Is collaborative.
- Ensures confidentiality and privacy.
- Is without coercion, discrimination, harassment or prejudice.
- Ensures safety and security for all participants.
- Ensures continuity and accountability.
- Aims to minimize unnecessary duplication and repetition.
• Complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

GP4. Accessible. All patients and families have equal access to hospice palliative care services:

• Wherever they live.
• At home, or within a reasonable distance from their home.
• In a timely manner.

GP5. Adequately Resourced. The financial, human, information, physical and community resources are sufficient to sustain the organization’s activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization’s activities.

GP6. Collaborative. Each community’s needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

GP7. Knowledge-Based. Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

GP8. Advocacy-Based. Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association’s model to guide hospice palliative care.

GP9. Research-Based. The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.
Appendix II: Key Messages for Care Providers

For leaders in hospice/palliative care

- Patients with HF suffer from many of the same symptoms as other patients facing the end of life, such as fatigue, pain, breathlessness, anxiety, nausea, confusion and depression.
- Patients may experience an unpredictable and lengthy pattern of decline.
- Medicine has a limited ability to predict the prognosis for an individual HF patient.
- Given that cardiology focuses on active treatment, a cardiac care team may feel ill-equipped to help with end-of-life planning and care and so would benefit from input/consultation to assist with these issues.
- Be aware that medical practitioners may be concerned that discussing end-of-life issues may suggest to patients that they are giving up on them.
- HF patients may appear reluctant to discuss end-of-life planning and care. Patients who have had an acute episode and have been “rescued” (e.g., returned to a better level of functioning and quality of life) may feel this may happen again.
- Choices of treatment options may change according to how the patient feels at the time.

For HF champions

- In developing your education for patients think about the three important phases:
  - planning for life with HF
  - planning for the end-of-life stage
  - planning for end-of-life care.
- Engaging hospice/palliative care practitioners earlier helps to address issues before they become problems. This can help with symptom control. Many of the symptoms are in areas outside the dominant focus of cardiac care (e.g., depression, anxiety, confusion).
- End-of-life planning is not a single conversation. Patients and family members may be looking for professionals to initiate such discussions, so whenever possible try to create such opportunities.
- Find out about hospice/palliative care resources in your area.
- It may be helpful to talk of HF as a life-limiting illness and the value of an advanced care plan.
- One way to talk about issues is to explain that we hope for the best but prepare for the worst.
Appendix III: Key Messages for Patients and Families

- HF is a life-limiting illness.
- Treatment is available to manage HF and hopefully you will enjoy years with few symptoms.
- The pattern of this disease is very unpredictable and will vary from person to person and over time.
- It is important for you and your family to think ahead about your future needs and to prepare an advanced care plan.
- You should expect your care provider to be as truthful and helpful as possible. You may ask to discuss HF issues at any time.
- You may find it helpful to talk with healthcare providers who focus on palliative care. You may ask for a referral to this sort of program or type of care provider.
- Planning before there is a crisis can help to prevent suffering.
- The important thing is to talk about your values and what you want for yourself.
- Your family and loved ones need to understand your wishes so they may speak for you if there is a crisis.
- An advanced care plan should be developed, reviewed and shared with your family and your healthcare providers.
References

1 Kostuk WJ. Congestive heart failure: what can we offer our patients? CMAJ 2001;165:1053-5.


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