

# Approach to advanced heart failure at the end of life

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## Abstract

**Objective** To outline symptom management in, as well as offer a home-based protocol for, patients with advanced heart failure (HF).

**Sources of information** The terms *palliative care* and *heart failure* were searched in PubMed and relevant databases. All articles were reviewed. The specific medical management protocol was developed by the “HeartFull” collaborative team at the Temmy Latner Centre for Palliative Care in Toronto, Ont.

**Main message** Educating patients about advanced HF and helping them understand their illness and illness trajectory can foster end-of-life discussions. Home-based care of patients with advanced HF that includes optimizing diuresis can lead to improved symptom management. It is also hoped that it can reduce both patient and health care system burden and result in greater health-related quality of life for patients with advanced HF.

**Conclusion** This article provides an overview of how to manage common symptoms in patients with advanced HF. The home diuresis protocol with guidelines for oral and intravenous diuretic therapy is available at [CFPlus](#).\*

## Stratégie face à l'insuffisance cardiaque avancée en fin de vie

### Résumé

**Objectif** Expliquer la prise en charge des symptômes et offrir un protocole à domicile à cet effet aux patients souffrant d'insuffisance cardiaque avancée.

\*The **Temmy Latner Centre for Palliative Care protocol for home diuresis** is available at [www.cfp.ca](#). Go to the full text of the article online and click on the **CFPlus** tab.

### EDITOR'S KEY POINTS

- Unpredictable trajectories and the lack of obvious transition points in disease progression can make conversations about advance care planning with patients with advanced heart failure (HF) quite challenging. Educate patients about the uncertainty associated with HF and draw the trajectory of HF while explaining the variable nature of the illness and that each decompensation is a time when death is possible. With a better understanding of the illness and its trajectory, patients can be better prepared for end-of-life decisions.
- This approach for assessment, management, and monitoring of patients with advanced HF at the end of life includes the following: set up a collaborative team, have a monitoring plan to detect exacerbations early, assess and manage symptoms, continue HF medications when possible, and have a plan to manage exacerbations.
- The home-based protocol for diuresis that this team has developed is used only when patients' goals of care include being at home and focusing primarily on comfort. The protocol is initiated when patients experience a worsening of symptoms attributed to advanced HF.

### POINTS DE REPÈRE DU RÉDACTEUR

- Les trajectoires imprévisibles et l'absence de points de transition évidents dans l'évolution de la maladie peuvent compliquer considérablement les conversations concernant la planification préalable des soins avec des patients souffrant d'insuffisance cardiaque avancée. Il importe d'informer les patients à propos de l'incertitude entourant l'insuffisance cardiaque et de dessiner pour eux la trajectoire de l'affection, tout en leur expliquant la nature variable de la maladie et le fait que chaque décompensation puisse être un moment où le décès peut survenir. En comprenant mieux la maladie et sa trajectoire, les patients peuvent être davantage préparés à prendre des décisions en fin de vie.
- Cette stratégie pour évaluer, prendre en charge et surveiller les patients souffrant d'insuffisance cardiaque avancée en fin de vie comporte les éléments suivants : former une équipe de collaborateurs, dresser un plan de monitoring pour détecter sans délai les exacerbations, évaluer et prendre en charge les symptômes, poursuivre la pharmacothérapie pour l'insuffisance cardiaque, si possible, et établir un plan pour prendre en charge les exacerbations.
- Le protocole de diurèse à domicile élaboré par cette équipe n'est utilisé que si les objectifs du patient en matière de soins incluent de rester à la maison et sont axés surtout sur le confort. Le protocole est entamé lorsque se produit une aggravation des symptômes du patient attribués à l'insuffisance cardiaque avancée.

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**Sources de l'information** Les expressions en anglais *palliative care* et *heart failure* ont servi à une recension dans PubMed et d'autres bases de données pertinentes. Tous les articles ont fait l'objet d'une revue. Le protocole de prise en charge médicale en question a été élaboré par l'équipe de collaborateurs «HeartFull» du Centre de soins palliatifs Temmy Latner à Toronto, en Ontario.

**Message principal** L'éducation des patients à propos de l'insuffisance cardiaque avancée pour les aider à comprendre leur maladie et sa trajectoire peut faciliter les discussions en fin de vie. Les soins à domicile aux patients souffrant d'insuffisance cardiaque avancée qui comportent une diurèse peuvent améliorer le contrôle des symptômes. Il est à espérer que la stratégie puisse réduire à la fois le fardeau du patient et le système de santé, et se traduire par une meilleure qualité de vie sur le plan de la santé chez les patients atteints d'insuffisance cardiaque avancée.

**Conclusion** Cet article offre un aperçu de la prise en charge des symptômes communs chez les patients souffrant d'insuffisance cardiaque avancée. Le protocole de diurèse à domicile, de même que des lignes directrices pour une thérapie diurétique tant par voie orale qu'intraveineuse se trouvent en anglais dans **CFPlus\***.

*You have come to the hospital to visit your patient Frank—a 78-year-old man with congestive heart failure (HF), hypertension, and diabetes—who was admitted with a decompensation of his HF. For 4 days he received intravenous (IV) administration of furosemide. Now Frank is responding well to diuresis and is almost ready for discharge. Unfortunately, this is his third admission this year for decompensated HF. Each time he has needed IV furosemide.*

*Frank lives alone in a small apartment. His wife of 54 years passed away last year. He has a daughter who lives in the same city but is quite busy with her family. He has 3 grandchildren.*

*Frank's medical history includes the following: ischemic cardiomyopathy (New York Heart Association class IV), ejection fraction of 20%, a previous myocardial infarction, coronary artery bypass grafting, atrial fibrillation, hypertension, type 2 diabetes, and chronic kidney disease. Several years ago he received a cardiac resynchronization therapy (CRT) device with defibrillation. Frank takes the following medications: 25 mg of metoprolol twice daily, 25 mg of captopril 3 times daily, 2.5 mg of warfarin daily, an 80-mg oral dose of furosemide twice daily, 10 mg of isosorbide dinitrate 3 times daily, 500 mg of metformin twice daily, 20 mg of rosuvastatin daily, 150 mg of ranitidine daily, and multivitamins daily.*

*You know that Frank has been struggling with symptoms of his advanced HF for the past year. He has*

*shortness of breath with minimal exertion. He has peripheral edema. He also describes anorexia and fatigue. He gets quite anxious when he is short of breath.*

*You have tried to discuss his illness with him and to start advance care planning; however, he has been reluctant to discuss the future.*

*When you see him in the hospital this time, he asks you why he feels this way and why he has to keep coming to the hospital.*

## Sources of information

The terms *palliative care* and *heart failure* were searched in PubMed and relevant databases. All articles were reviewed. The specific medical management protocol was developed by the "HeartFull" collaborative team (created by J.A. and S.M.) at the Temmy Latner Centre for Palliative Care in Toronto, Ont, as there is a gap in the literature around medical management of patients with HF at the end of life. The "HeartFull" model was developed collaboratively by cardiology, palliative care, and primary care specialists, as well as using community resources, and it provides education modules and therapeutic guidelines for diuresis in the home.

## Main message

**Heart failure prevalence.** Approximately 500 000 Canadians have congestive HF. More than 50 000 new patients are diagnosed each year and more than half of new cases occur in people older than age 80.<sup>1</sup> Approximately 50% of patients with HF die within 5 years of diagnosis.<sup>2</sup> The condition is responsible for a high burden of hospitalization for symptoms that are currently difficult to manage in the ambulatory setting.<sup>3-5</sup>

**Definition of advanced HF.** The Heart Failure Society of America defines *advanced HF* as "those patients who have advanced, persistent HF with symptoms at rest despite repeated attempts to optimize pharmacologic and nonpharmacologic therapy," as shown by 1 or more of the following factors: frequent hospitalizations ( $\geq 3$  per year), chronic poor quality of life with inability to accomplish activities of daily living, need for intermittent or continuous intravenous support, or consideration of assistive devices as destination therapy.<sup>6</sup>

**Pathophysiology and symptom burden.** Damage to ventricular function results from numerous causes, including myocardial ischemia or infarction. Decreased left ventricular function (LVF) leads to symptoms of forward HF (low output), which causes confusion, fatigue, anorexia, and renal dysfunction. Decreased LVF also leads to backward pressure (high filling pressure) on the cardiopulmonary system resulting in dyspnea, ascites, liver congestion, and peripheral edema. Additionally, decreased LVF causes a cascade of neurohormonal

mediators such as the renin-angiotensin-aldosterone system, the sympathetic nervous system, and tumour necrosis factor. These neurohormonal mediators sustain and increase damage to the ventricles, which sets up a vicious cycle whereby decreased LVF causes neurohormonal changes that worsen LVF. This explains why HF medications ( $\beta$ -blockers, angiotensin-converting enzyme inhibitors [ACEIs], angiotensin II receptor blockers) are effective. They work by decreasing the effect of the neurohormonal cascade, limiting the effect on ventricular damage and improving symptoms. These not only improve symptoms but also decrease mortality.<sup>7</sup> In addition to symptoms of dyspnea, fatigue, and confusion, patients with advanced HF experience pain, anorexia, depression, and anxiety. Numerous studies show that patients with end-stage HF experience symptoms similar to patients with cancer at the end of life.<sup>7</sup>

**Challenges in palliating end-stage HF.** There are several additional challenges in caring for those with non-malignant illnesses such as HF compared with caring for patients with an oncologic illness. Models of palliative care, developed primarily for those with oncologic illness, need to be adapted to acknowledge these challenges, as an increasing number of patients being referred for palliative care have non-malignant illness such as HF, chronic obstructive pulmonary disease, and dementia.

One of these challenges includes the trajectory of HF being much more variable and unpredictable than the trajectory for most oncologic illnesses. There are few reliable prognostic indicators that predict when patients are entering the end phase of their illness. **Figure 1**<sup>8,9</sup> presents a trajectory comparison between a patient with end-stage HF and that of a patient with cancer. For patients with HF, the trajectory is often stable for a period of time, and as their disease progresses, they experience repeated decompensations with return to near baseline function and health.<sup>8-11</sup> This is in contrast to the somewhat more predictable trajectory for patients with cancer at the end of life, where there is generally a steady decline in function in the last 3 months of life.<sup>12</sup> In the absence of prognostic indicators and with the variability in function, health care practitioners should focus on the needs and goals of this patient population rather than solely on prognosis.

A second challenge in caring for patients with end-stage HF is that patients and caregivers often lack understanding of the terminal nature of HF.<sup>10,11,13</sup> While the reasons for this are unclear, there are several possibilities. First, there are no obvious time points or events that clearly herald the transition from active care to palliative care. Unlike chemotherapy for the patient with cancer, therapy for HF does not lose efficacy or stop. Medications used to treat chronic HF are the same as medications used to palliate end-stage HF.<sup>12</sup> Additionally,

there are fewer diagnostic approaches that definitively illustrate disease progression (compared with computed tomography and magnetic resonance imaging in oncology). For patients with cancer, these transition points can provide an opportunity for health care providers to discuss disease progression and for patients to gain understanding of their illness.

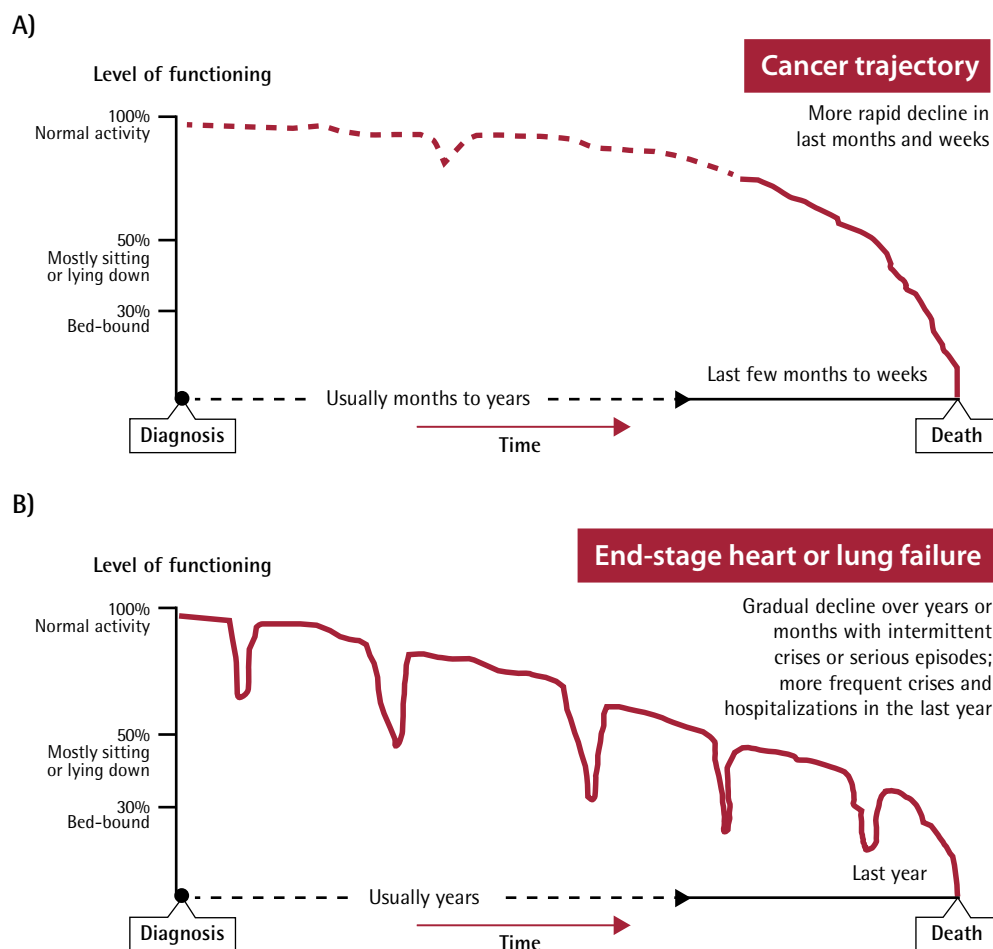
Thus, in the care of patients with HF, the unpredictable trajectories and the lack of obvious transition points in disease progression can make conversations about goals of care, values, and advance care planning with these patients quite challenging.<sup>11,14-16</sup>

From our experience, it is useful to begin by educating patients and caregivers about the natural history of HF. By drawing the trajectory of HF (**Figure 1**)<sup>8,9</sup> for patients and caregivers, you can explain the variable nature of the illness and explain that each decompensation is a time when death is possible. You can explain that the diuresis and other management during a decompensation is an attempt to regain previous function; however, at some point that will not be possible. This can help patients and families better understand the variable trajectory and the uncertainty associated with HF. Once a patient has a better understanding of the illness and illness trajectory, you can begin to discuss his or her values and goals for the future and prepare for end-of-life decisions. **Box 1** provides examples of how to begin these discussions with patients. Recognizing that these conversations need to occur repeatedly can improve patient understanding.<sup>7,13</sup> Also, whenever possible, include the patient's caregivers in these conversations.

For more information about advance care planning discussions, visit the Speak Up Campaign website, [www.advancecareplanning.ca](http://www.advancecareplanning.ca), for tools and resources; this campaign is an important initiative to help physicians support their patients during this time. Articles by Ahluwalia et al<sup>17</sup> and Sudore and Fried<sup>18</sup> are also good resources for advance care planning discussions.

*You spend time explaining to Frank the ups and downs of the HF trajectory and, in fact, when you draw the trajectory for him he realizes that this is the nature of the illness and not something that he is doing wrong. You tell him that when he gets home from the hospital it would be a good time to have a discussion about the future and how he wants his care going forward.*

*A few weeks later he comes to your office with his daughter for a conversation regarding his goals of care. During the discussion he tells you that he now understands that he is nearing the end of his life and he does not want to prolong this phase. He wants to stay home as long as possible and avoid hospitalizations and further investigations. He wants you to focus on his comfort. He is not afraid of dying but wants to make sure he does not suffer from pain or symptoms. Given these expressed*

**Figure 1. Illness trajectories: A) Cancer trajectory vs B) end-stage heart or lung failure trajectory.**

Reproduced with permission from Pallium Canada.<sup>8</sup> Adapted with permission from Lunney et al.<sup>9</sup>

values and goals, you recommend against cardiopulmonary resuscitation and defibrillation. You explain that his cardiac device needs to be reprogrammed to avoid shocks at the end of life. Frank thinks (as do many patients) that he needs the defibrillator all the time to live.

**Implantable cardiac defibrillator (ICD) deactivation.** Many patients with HF are treated with specialized cardiac devices. These devices function as pacemakers, and the pacemaker might have additional functions such as cardiac resynchronization therapy (CRT) or a defibrillator or both. Some patients have a device that functions only as an ICD. A CRT pacemaker coordinates the contractions of both the right and the left ventricle and improves heart function, improving the quality of life and symptoms for many patients. Defibrillation is another function that is part of some, but not all, implantable pacemaker devices, which means the device is programmed to detect

malignant arrhythmias and provide an electric shock to restore normal rhythm. Some devices only provide defibrillation; these are known as *implantable cardiac defibrillators*. A CRT pacemaker can be equipped to provide defibrillation; this device is then called a *cardiac resynchronization therapy defibrillator*.

It is important to know that the defibrillator function of any implantable device is independent from pacing or resynchronization therapy. The defibrillator itself can be deactivated and the patient can continue to receive the symptom improvement therapy from CRT. Defibrillator deactivation is important when patients want to focus on comfort, as the defibrillator might provide electric shocks to the patient at the end of life, which can be distressing and uncomfortable.

There are often many opportunities to discuss the need for and use of the ICD. This can be a challenging conversation because patients and caregivers might



### Box 1. Examples of introductory statements when discussing goals and values with patients and preparing for end-of-life decisions

Examples of introductory statements include the following:

- "Have you and your family ever talked about what might happen in the future with your health?"
- "Would it be okay to talk about what might happen in the future with your health?"
- "Do you have any worries or fears about the future? Or perhaps about a time in the future when medications will not help you return to your current health?"

Based on your patient's readiness to have these discussions, you can get more specific about values, goals, and planning:

- "If during a decompensation, we start to see that the medications are not going to help make you feel better and that you are approaching the end of your life, then we would want to know more about how you want us to focus on your comfort. Some patients might want to be at home as long as possible; others might want to be cared for in a hospice or palliative care unit. Tell us what you would want"
- "It is good for us to talk about that time now, so that we learn what is important to you and we can help you and your family make good decisions for you"

have misconceptions about the ICD. **Table 1** addresses some of these patient misconceptions.

For more information on ICD deactivation, the Cardiac Care Network<sup>19</sup> and BC's Heart Failure Network<sup>20,21</sup> provide guidelines and algorithms.

### Collaborative approach to care of advanced HF

The following is an outline of our collaborative approach to care for patients with advanced HF. We have developed this approach through collaboration with cardiology, palliative care, and primary care specialists, as well as using community resources. While we acknowledge that all of these elements might not be achievable in every situation, they can be adapted where possible by others.

**1. Set up a collaborative team for your patient.** Whenever possible, collaborative models of care are important in the care of these patients. The collaborative team can include a primary care physician who is available for home-based care, an internist or cardiologist to support the primary care physician in decisions regarding HF therapy, and a palliative care physician to support the management of complex medication regimens in the patient's home.<sup>5,22-24</sup> Pathways of communication between caregivers and members of the team, which might include remote access for cardiology or palliative care support, should be established.<sup>16</sup> Depending on the community of practice, different versions of this collaborative model can be constructed.

**Table 1. Patient misconceptions about ICDs**

MISCONCEPTION	EXPLANATION
I will always be dependent on the ICD and will die as soon as it is deactivated	The ICD delivers an electric shock only during a serious arrhythmia; it does not work continuously. If the patient is dependent on a pacemaker and his or her ICD has the pacemaker or CRT function, reassure them that the defibrillator function is independent of these functions. The defibrillator can be deactivated without affecting other functions
Deactivation of the ICD requires surgery or is painful	ICD deactivation is a noninvasive procedure and is not painful
Deactivation of the ICD can be done from my home	ICD deactivation is done in the clinic that placed the device; therefore, it is important to deactivate an ICD before the last hours or days of life. In an emergency, an ICD can be deactivated by placing a ring magnet on the patient's chest. This only deactivates the ICD temporarily—while the magnet is on the chest
CRT—cardiac resynchronization therapy, ICD—implantable cardiac defibrillator.	

**2. Have a monitoring plan to detect exacerbations early.** Daily monitoring of the patient's weight and symptoms can help detect exacerbations in the early stages. Work with patients and caregivers to establish a red flag marker (ie, weight increase of 2 kg, increased peripheral edema, or increased dyspnea) that will indicate an oncoming exacerbation and initiate the protocol described below. Ensure patients and families know whom to call; with many people involved in care, this can get complicated. Give family members 1 contact number for someone who is available to respond within hours rather than days.

**3. Assess and manage symptoms.** Patients experience a multitude of symptoms, including anxiety and depression. You can use the Edmonton System Assessment Scale<sup>25</sup> to systematically assess common symptoms. A full discussion of the management of various symptoms (eg, pain, nausea, anorexia) is outside the scope of this article; however, brief guidance is provided in **Table 2**.<sup>26,27</sup> Also, pay attention to the patient's caregivers who are often elderly with their own comorbidities.

**4. Continue HF medications.** As described earlier, HF medications such as  $\beta$ -blockers and ACEIs help with

**Table 2. Management of various symptoms of advanced HF**

SYMPTOM	MANAGEMENT
Pain	<ul style="list-style-type: none"> <li>• Where possible, treat root cause of pain (eg, antianginal agents for ischemic chest pain)</li> <li>• For mild pain, prescribe acetaminophen</li> <li>• For moderate to severe pain, use opioids as first-line therapy; titrate dose for adequate relief</li> <li>• Avoid NSAIDs owing to possible fluid retention, GI bleeding, and renal failure</li> <li>• Consider complementary medicine options (eg, physical therapy, massage therapy, hydrotherapy, acupuncture, mindfulness meditation)</li> </ul>
Fatigue	<ul style="list-style-type: none"> <li>• Remember that causes are multifactorial: volume overload, myopathy and cachexia, pain, dyspnea, sleep-disordered breathing, depression, anxiety, iron deficiency</li> <li>• Acknowledge fatigue and consider strategies for energy conservation</li> <li>• Using intermittent methylphenidate might be appropriate if tolerated; monitor BP and HR, but HF is not a contraindication to using methylphenidate</li> </ul>
Insomnia	<ul style="list-style-type: none"> <li>• Remember that causes are multifactorial: dyspnea, anxiety, fear of dying in sleep, pain, sleep-disordered breathing</li> <li>• Recommend sleep hygiene practices</li> <li>• Using zopiclone might help but it increases risk of falls in older patients</li> </ul>
Nausea	<ul style="list-style-type: none"> <li>• Discontinue medications that might be causing nausea</li> <li>• Consider a 10-mg oral dose of domperidone 3 times a day or a 10-mg subcutaneous or oral dose of metoclopramide 3 times a day to improve gut motility</li> </ul>
Anorexia and cachexia	<ul style="list-style-type: none"> <li>• Optimize HF therapy: ACEIs and carvedilol have demonstrated favourable effects on metabolism and cachexia<sup>26</sup></li> <li>• High-energy nutritional supplements might be useful for malnutrition but there is no evidence that clinical outcomes are improved.<sup>26</sup> Also, they can be very expensive for families</li> <li>• Avoid dexamethasone for appetite stimulation, as it promotes sodium and fluid retention</li> </ul>
Constipation	<ul style="list-style-type: none"> <li>• Prevention is important: use a stimulant (eg, senna) or an osmotic agent (eg, PEG 3350 in low quantity: 17 g in 250 mL of fluid) or a combination of both</li> <li>• Do not use fibre if patient is not able to drink sufficient fluid to keep stool soft. With insufficient fluids, fibre can be more constipating</li> <li>• Lactulose causes cramps and distention and is less favoured</li> <li>• Ensure laxative is included when opioids are prescribed for dyspnea</li> </ul>
Depression	<ul style="list-style-type: none"> <li>• Use low-dose SSRIs as first-line therapy; however, they can induce fluid retention and hyponatremia if there is renal insufficiency. Onset of effect is 1–2 wk or longer, which is a disadvantage at the end of life</li> <li>• Recommend cognitive-behavioural therapy, spiritual support, mindfulness-based training, and dignity therapy; these interventions for depression in people with HF are not supported by RCT evidence<sup>27</sup></li> </ul>
Anxiety	<ul style="list-style-type: none"> <li>• Recommend interventions that might help enhance patient's sense of control (eg, support groups, HF education)</li> <li>• For patients who do not respond to these interventions, consider short-acting benzodiazepines (eg, lorazepam); however, use caution when considering benzodiazepines for elderly patients</li> </ul>

ACEI—angiotensin-converting enzyme inhibitor, BP—blood pressure, GI—gastrointestinal, HF—heart failure, HR—heart rate, NSAIDs—nonsteroidal anti-inflammatory drugs, PEG—polyethylene glycol, RCT—randomized controlled trial, SSRI—selective serotonin reuptake inhibitor.

symptoms and decrease mortality.<sup>28,29</sup> Try to maintain these medications. If symptomatic hypotension occurs, try staggering doses of medications. If that does not work, begin decreasing the number of medications the patient takes to find a dose combination he or she can tolerate. There is not complete agreement on the order of medication reduction in this patient population; however, the following presents the general agreement.

*First:* If the patient has hypotension, stop calcium channel blockers.

*Second:* If hypotension continues, consider stopping  $\alpha$ -blocking medications next.

*Third:* Try to maintain the  $\beta$ -blocker and the ACEI if possible; however, often the doses will need to be reduced.

*Fourth:* Whether or not to continue anticoagulation is often a concern. Currently, this decision is best made

on an individual basis with each patient. Exploring the patient's values and goals, as well considering the burden associated with anticoagulation therapy, usually leads to a satisfactory decision.

*Fifth:* Finally, review all your patient's medications, as there are often other medications that can be eliminated at this time, such as cholesterol-lowering agents.

**5. Have a plan to manage exacerbations.** Currently there are no published guidelines for home-based diuresis, and family physicians and palliative care physicians are not commonly trained in escalation of oral doses or intravenous administration of diuretics. Therefore, through collaboration and expert consultation, we adapted a protocol for inpatient escalation of intravenous diuresis<sup>30</sup> for use in the home environment.

**Home diuresis protocol.** The protocol for home diuresis that we developed provides stepwise guidelines for assessment, management, and monitoring. It is used only when patients' goals are for comfort-oriented care. Their goals are such that they wish to remain at home, make comfort a priority, and avoid hospitalizations. The protocol is initiated when patients experience a worsening of symptoms attributed to HF. This protocol is available at **CFPlus**.\*

Home-based care of patients with advanced HF that includes optimizing diuresis can lead to improved symptom management and possibly a decreased number of hospitalizations. In turn, we hope it can reduce both patient and system burden and result in greater health-related quality of life for patients with advanced HF.

*With this plan you have been managing Frank at home for the past 4 months. He has had follow-up with his cardiologist for ICD deactivation. He has required 2 escalations of his furosemide dose, and in both cases doubling his oral dose for 5 days was sufficient. He has become weaker over this time and spends most of each day in bed. He is relieved to be at home. You have discussed transfer to a palliative care facility in the near future, as he does live alone and might not have sufficient supports as his illness progresses.*

## Conclusion

This article describes a collaborative approach to care for patients with advanced HF. Home-based care of patients with advanced HF that includes optimizing diuresis can lead to improved symptom management and possibly a decreased number of hospitalizations. 🌿

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## Contributors

All of the authors of this manuscript are responsible for the reported findings. All participated in the concept and design; analysis and interpretation of the data; drafting or revising or making intellectual contributions to the content of the manuscript; and approving the manuscript submitted for publication.

## Competing interests

None declared

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