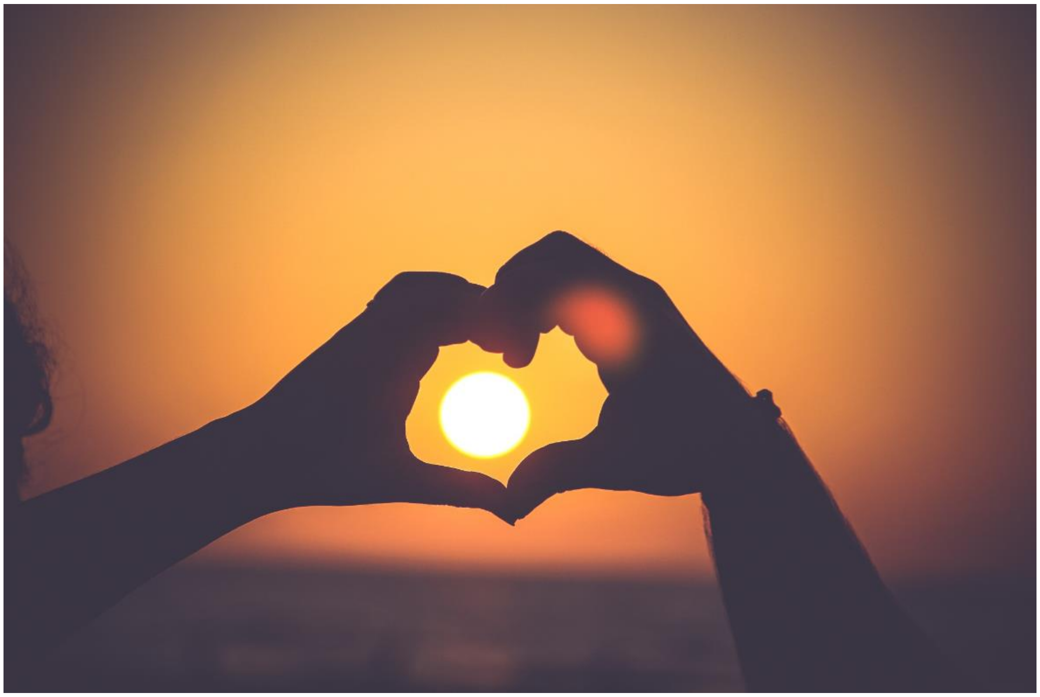
WHAT REALLY MATTERS NOW

NOTES FOR LIVING WITH ADVANCED HEART FAILURE



A Comprehensive Resource for People Who have Advanced Heart Failure and the Carers who Support Them

Shared Care Supportive Cardiology Project

SharedCare
Partners for Patients

British Columbia

doctors of bc

island health

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HONOURING THE TERRITORY

This document was created on the territories of the ləkʷəŋən (Lekwungen)-speaking peoples, also known as Victoria, BC, Canada. Our intention is to learn and respect each individual's preferences and priorities as they move through their life's journey, in sickness and in health. In honouring the territories and the Indigenous Peoples of this land, we commit to caring for all people in a good way.

ABOUT THIS GUIDE

This guide has been developed to help to improve the care and quality of life you experience in living with advanced heart failure. Informed by interviews, advice and reviews by patients living with heart failure, this guide offers information to support your day-to-day living and to assist you in planning, adapting and understanding this stage in your life journey.

Whether you read this booklet cover to cover or review different sections at different times, please use this guide in whatever way it serves you best. We encourage you to share a copy of this booklet with close members of your circle of care.

ACKNOWLEDGEMENT

This Supportive Cardiology Project is funded in partnership by Doctors of BC and the BC government through the Shared Care Committee. We would also like to acknowledge the significant in-kind support provided throughout the project by multiple programs and departments of Island Health.

The *Shared Care Supportive Cardiology Project* was co-created by health care professionals and patient representatives. We are deeply grateful for the consideration of everyone who contributed their thoughts, perspective and experience in the development of this guide. We wish to particularly thank all the patients and their family members who kindly shared their experiences living with advanced heart failure. Their stories guided us throughout the creation of this document.

Our shared intention is to ensure you have all the information you need to recognize and adapt to the changes in your health, have important conversations with your family and your care team and to live each day as fully as possible.

CHAPTER 1: Information for People with Advanced Heart Failure

SUPPORTING THE TRANSITION

This booklet focuses on supporting you in the transition from chronic heart failure with minimal or easily managed symptoms to a more symptomatic, difficult to manage stage known as advanced heart failure. The information is intended to help you and your family recognize the signs that indicate your condition is changing and help you adapt as well as possible to living with advancing heart failure through to the end of life.

Our hope is:

- for you to feel empowered to raise all topics important to you as your symptoms progress;
- to help you feel prepared and confident during discussions with your health care team;
- to support your active participation in decision-making; and
- to ensure what matters most to you is heard, understood and respected.

> ***"Don't sugar coat or hide anything from me. Give me the facts and give me your advice and opinion in a timely fashion in a form I can understand."***
>
> \- Patient Partner

LIVING WITH ADVANCED HEART FAILURE

In the early stages of your heart failure, your care provider's goal was to improve your heart function and help you lead a high quality life. Over time, you may have had the return of some heart failure symptoms, but with treatment changes, your heart function and symptoms improved again.

Unfortunately, heart failure is a progressive illness that worsens over time. In its progression, your ability to do daily activities decreases and your symptoms return more often and become more challenging to treat despite everyone's best efforts and medicines.

How does heart failure progress?

The progression of heart failure is unpredictable and it is hard to know how long new and added therapies will keep your heart failure symptoms well controlled.

Heart failure symptoms fluctuate from periods of time when they feel controlled or managed, to periods when symptoms are severe and require more treatments to help control them.

This diagram is a picture of the unpredictable, but progressive course of heart failure, sometimes referred to as the "disease trajectory".

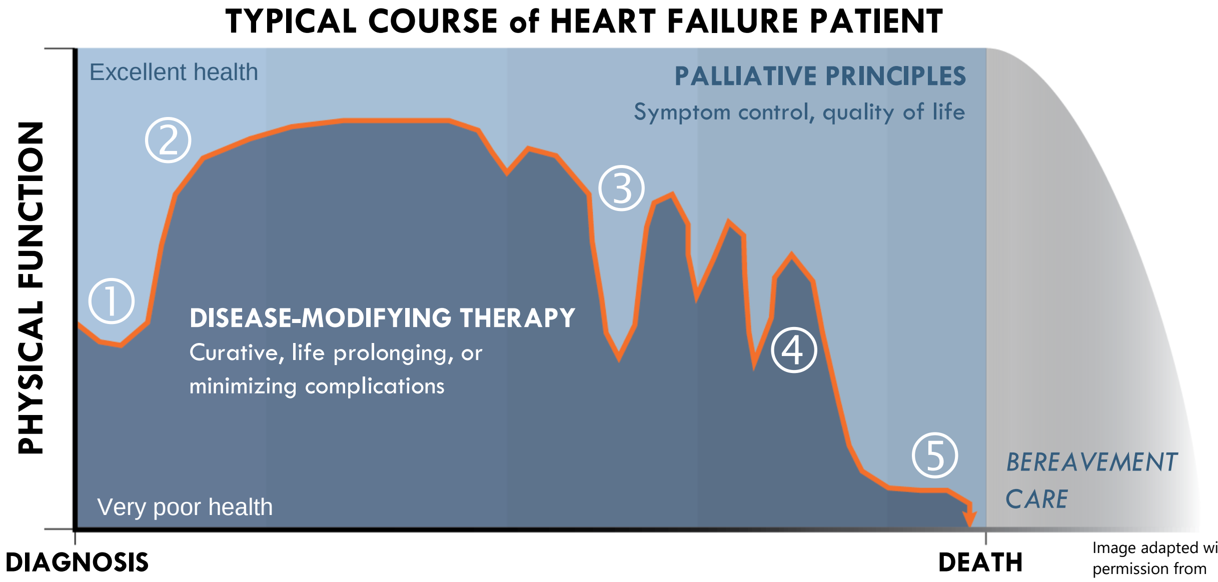


Image adapted with permission from Goodlin, SJ. JACC 2009;54: 386-96.

SYMBOL ON GRAPH	DESCRIPTION	HF /AHF
①	Initial symptoms and diagnosis of heart failure. Treatment begins.	HEART FAILURE
②	Heart failure is stable. Treatments work well and symptoms are controlled. This stability can occur for an extended period and is different for each person.	
③	Return of heart failure symptoms while on treatment. Treatment is increased and symptoms are controlled, but each flare of symptoms requires further changes. Over time, even with increased treatments, the previous level of health cannot be restored. Increased emphasis is placed on symptom management or supportive care (also known as palliative care).	ADVANCED HEART FAILURE
④	Worsening of heart failure symptoms, even with maximum treatment. The focus of care turns to managing symptoms.	
⑤	Entering into the final stage of life.	

What signs indicate my heart failure is progressing?

Advancing heart failure means heart failure therapies are not working as well as before. Your symptoms will return more often and are harder to control. You may find you visit your care provider or hospital more often. These are warning signs that your condition is changing. If you refer back to the Heart Failure Zones, you may find you are now remaining in the Yellow Zone most days.

SYMPTOM	WHAT CHRONIC HEART FAILURE FEELS LIKE	WHAT ADVANCED HEART FAILURE FEELS LIKE
SHORTNESS OF BREATH	Breathlessness during activity (most commonly) or while resting Sometimes may have difficulty breathing while lying flat Waking up tired or feeling anxious and restless	Breathlessness with very little activity, and often at rest Waking up tired or feeling anxious and restless
PERSISTENT COUGH	Coughing that worsens with lying flat or with activity	Coughing that occurs at rest and worsens with lying flat Coughing can produce white or pink-tinged mucus
RETAINING FLUID OR "EDEMA"	Swelling in the feet, ankles, legs or abdomen, fingers Weight gain of 4 pounds in 2 days or 5 pounds in a week Shoes feel tight or your clothes fit differently from one day to the next Water pills or "diuretics" help to control the fluid retention	Leg swelling is constant, some days are worse than others Appetite decreases, nausea is frequent Fluid retention is difficult to improve even with medication
TIREDNESS/ FATIGUE	A tired feeling all the time Difficulty with activities like climbing the stairs, carrying groceries or walking	A tired feeling all of the time, some days worse than others Difficulty with activities like showering, getting dressed, making simple meals
POOR APPETITE/ NAUSEA	A feeling of being full or bloated even though you have not eaten much	Poor appetite and bloating that occurs most of the time
CONFUSION OR IMPAIRED THINKING	Difficulty problem-solving, remembering details, feeling disoriented A caregiver or relative may notice this first	Difficulty thinking things through, more forgetfulness
FAST HEART RATE	Heart is racing or pounding with activity; for some, heart may race or pound even when at rest	Heart races more often
DEPRESSION/ ANXIETY	Feelings of sadness and loss related to changes in ability to do usual activities Sometimes results in an anxiety or depression	Feelings of sadness may become ever-present, and more often result in sense of loss, depression, anxiety

What comes next for me?

At this time, given that your heart function cannot be improved, the focus shifts to addressing the symptoms you feel. This type of care is called *supportive or palliative care*. Palliative or supportive care focuses on maximizing quality of life in the setting of serious illness, like heart failure. This is the time to create (or confirm) a plan to support shared decision-making about your health care choices. A range of strategies and practical supports are available to help you as your condition progresses.

This is an important time to have conversations with your healthcare provider to ensure treatments offered are likely to be helpful to you, based on what is most important to you and your quality of life.

> ***"I don't know about you but I would rather have clear bad news than be somewhere I didn't know… I didn't have enough information…"***
>
> - Patient Partner

Progression to advanced heart failure also brings changes in emotions. Receiving information that is surprising and unwelcome may bring uncomfortable emotions. For some, this may lead to ineffective coping strategies such as avoidance or denial. Gaining a good understanding about your changing heart and what those changes mean, will help you fully participate in treatment planning. You are also less likely to be surprised by changes as your condition progresses.

This is also the time to enlarge and inform your circle of support to include family and/or other key support people. Bring a support person to medical appointments to help them better understand your condition and hear about treatment plans.

A common understanding and open communication will help you, your loved ones, and your care team cope and work effectively together.

How can I manage better now?

As you progress into a time of more unstable symptoms, some of the most important things to consider include ways for you to better manage life each day. Your energy levels will be lower, breathing may become more difficult, and you may experience "brain fog" or memory loss. You may also not be used to focusing on your own needs before those of others. Now is the time to begin to do just that. As your energy levels change and decrease, conserving or managing the energy you do have is vital. People around you want to help you manage, but often do not know what you need.

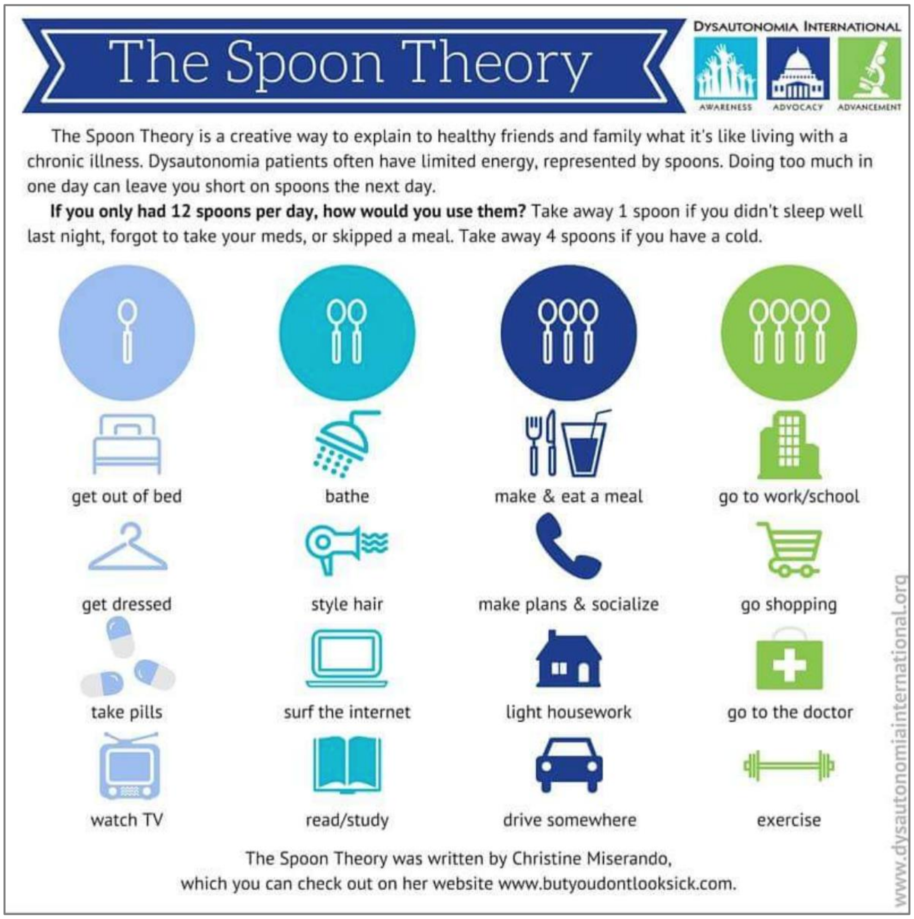
DAILY COPING

Symptoms can change each day and even throughout the day. Some days will be better than others. It is helpful to be able to adapt as your symptoms change. Planning for an activity to look forward to is very helpful and hopeful. Communicate to those around you that plans are tentative, depending on how your day is going. Adapting your plans based on how you are feeling will reduce stress and conserve energy.

PACING

Pacing activities is key. Assuming you only have 12 or fewer spoonfuls on energy in the day, consider how you might use it.

> *"I pace myself…I do pretty well at the laundry…I don't try to walk up the stairs…I have someone to vacuum. She's actually a friend."*
>
> - Patient Partner



The Spoon Theory

The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

If you only had 12 spoons per day, how would you use them? Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.

The Spoon Theory was written by Christine Miserando, which you can check out on her website www.butyoudontlooksick.com.

ACCEPTING HELP

It is good to ask for help with things before they become overwhelming. This is not a weakness but a strength as you learn your new limitations before they exhaust you. Everyone's path is different and yours is unique to you.

Friends or family can check and see if there is something they can do to assist. They can help you sort things out in your mind and be reminders if you are experiencing brain fog or memory issues.

You are not alone. There are many people who care about you and are willing and able to assist you through these changes. Making lists of needs or activities you could use help with can be useful. A prepared list or “job jar” allows people who offer help to pick something they are comfortable doing. You know your specific needs and can personalize a list that reflects what will help you best.

> *“I have several friends that live in the neighbourhood that I would call. There’s a police officer next door who’s given me his home number”.*
>
> \- Patient Partner

Many neighbourhoods have community volunteers who have time and desire to help their neighbours. Letting them help you builds mutual connection and goodwill. University students are another source of help through low cost student employment or volunteer programs.

SUGGESTIONS FOR HOW OTHERS CAN BEST ASSIST YOU INCLUDE:

☐ Housecleaning
☐ Grocery shopping
☐ Meal preparation: create easy-to-prepare foods, freezer items or bringing in take-out meals
☐ Taking out the garbage/recycling/newspapers
☐ Doing laundry
☐ Making/changing the bed
☐ Offer reminders/ assistance for taking, ordering, picking up or arranging delivery of medications
☐ Help open or loosen bottles
☐ Chauffeuring you to appointments or for the enjoyment of a car ride
☐ Joining you on your walks - even around the house or the block
☐ Making or changing your appointments, organizing your calendar
☐ Banking - including paying bills
☐ Getting and returning books from the library
☐ Cutting the grass, working in the garden
☐ Cleaning sidewalks and driveways after inclement weather
☐ Arranging for and supervising home maintenance or home repair workers
☐ Helping with car maintenance: fill-ups, oil changes, starting and driving the car regularly
☐ Coordinating their help with caregivers in your home
☐ Helping you fill in forms
☐ Assisting with pet care

RESOURCES

BC Senior's Guide	BC Ministry of Health
https://pathwaysbc.ca/ci/6482	

Heart Failure Zones	Heart and Stroke
https://fraser-northwest.pathwaysbc.ca/content_items/1709	

Self-Check Plan for Heart Failure Management	American Heart Association
https://pathwaysbc.ca/ci/6240	

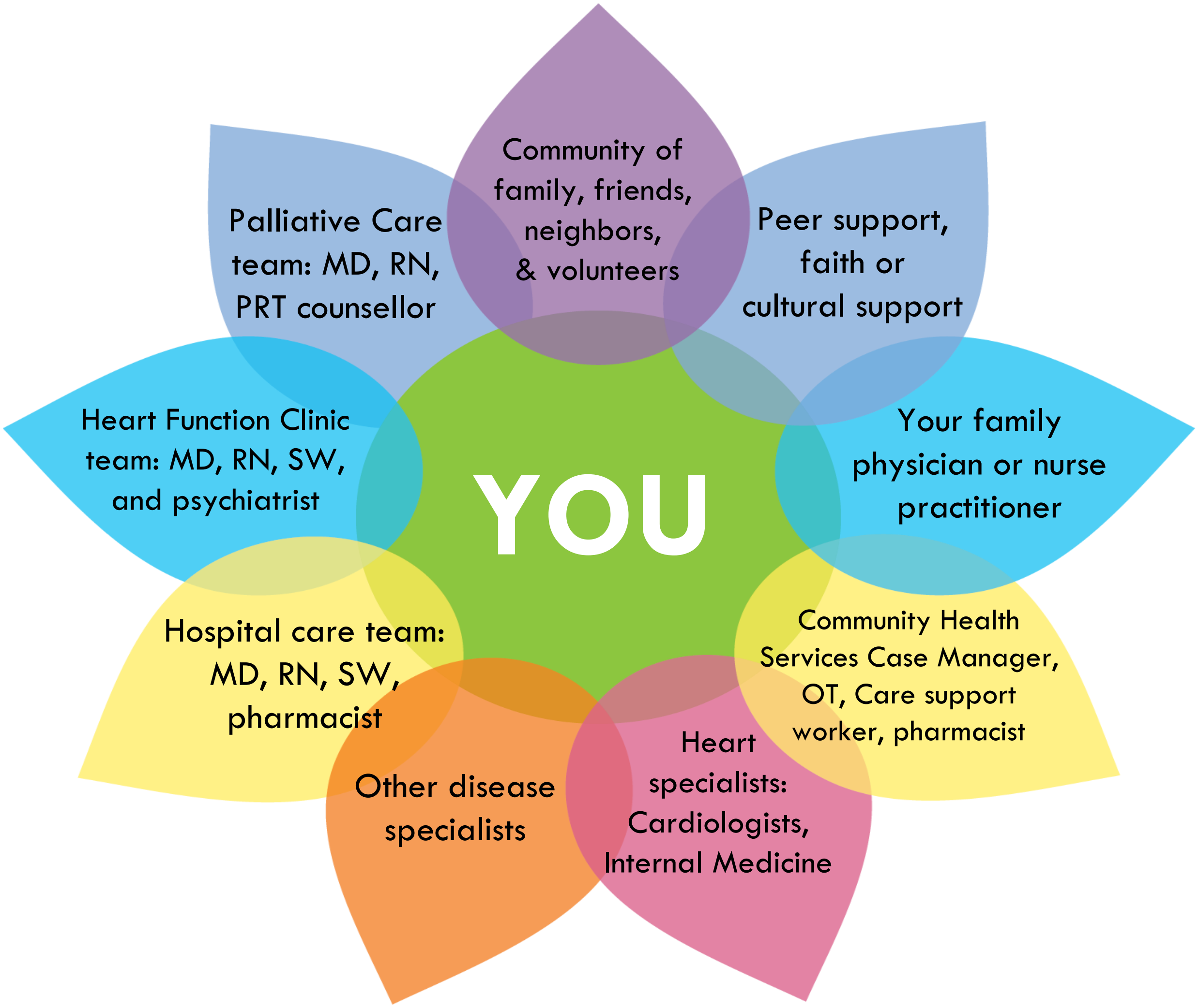
Seniors Services	
Fraser Health	Chilliwack and Fraser Health Rural
	Maple Ridge – Pitt Meadows
	New Westminster - Tri-Cities
	Surrey - North Delta
	White Rock / South Surrey
Interior Health	Ashcroft - Clearwater - Lillooet - Lytton - Merritt
	Kelowna - West Kelowna - Lake Country - Peachland
	Kootenay Boundary
Island Health	Comox Valley
	Cowichan Valley
	Gabriola Island
	Parksville - Qualicum Beach - Port Alberni
	Victoria - South Island
	Capital Region – Senior Services Directory
Vancouver Coastal	North Shore
	Sea to Sky
	Vancouver

SHARED DECISION MAKING WITH YOUR HEALTHCARE TEAM

You and your family are at the center of all care. Your thoughts, questions and feedback are key to establishing good teamwork. Good teamwork and strong support may improve your quality of life.

Team members will come and go as your needs shift. This diagram illustrates the many potential sources of help and assistance as your heart failure advances through the stages to end of life. Links are provided in the Tools and Resources section.

CIRCLES OF SUPPORT



Design by Curtis Bilson

Communication is so important in the circle that surrounds you. Consider requesting that updated care plans and decisions are shared widely. This will provide improved support and lessen the burden on you and your family.

COMMUNITY CONNECTIONS

Community connections of extended family, friends, neighbours and, for some, local volunteers, cultural or faith groups can also play key to your overall well- being throughout your illness.

Who is involved in my treatment and care decisions as my heart failure progresses?

Your medical team may include:

- **Primary care:** Your primary care provider is typically a physician or nurse practitioner who is guiding the treatment and treatment planning for your care. Your primary care provider may be a family doctor or nurse practitioner. Primary care acts as your “quarterback" if you have multiple illnesses and specialists.

- **Specialists in heart failure:** Your primary care provider may work in partnership with an Internal Medicine specialist, Cardiologist or Heart Function Clinic cardiologist.

- **Hospital care providers:** If you are in hospital, a doctor known as a Hospitalist (who is a family doctor) may be directing your care throughout your admission. Your Hospitalist may also be working with specialist physicians to support your care.

- **Specialists for other conditions:** You may have physicians caring for other health problems on your team such as a diabetes doctor (Endocrinologist) or kidney specialist (Nephrologist).

- **Specialists in palliative care:** As your heart failure progresses, specialists in symptom management may work with your care team to ensure symptoms like increasing shortness of breath are effectively treated. Their goal is to maximize quality of life in the setting of serious illness. Symptom management specialists are also known as Palliative Care physicians. These specialists work to help you live as comfortably as possible through to the end of life.

> ***“All of a sudden we’ve got this team who are going to help us and are going to be there if we need them.”***
>
> \- Patient Partner

As my needs change, where can I find support?

Your primary care provider is able to connect you with community care services which may include these team members:

- **Home Care Case Manager:** Assesses needs and arranges for help from Community Health Services (CHS). Your case manager can guide you on arranging respite support if needed.
- **Home Care Nurse:** Monitors your changing symptoms and communicates with primary or symptom management team members. Often acts as your gateway to the rest of the health care system.
- **Occupational Therapist:** Assesses your home set up and suggests practical ways to help you preserve energy and improve your quality of life.
- **Personal Support Worker:** Helps you with bathing or other activities of daily living.
- **Social Worker:** Provides emotional support and planning assistance as you adapt to the changes in your life.
- **Pastoral Care/Spiritual Support:** You may have your own faith community that provides comfort as your health changes.
- **Pharmacist:** Can provide information about changing medications and help set up systems for medication management to ease the work of organizing and tracking medications.

SHARED DECISION MAKING

As your heart failure advances, you may face difficult conversations and decisions. Your primary care provider may invite you to a serious discussion with you about your illness. You may be sent a letter ahead of the appointment to help you prepare. You are encouraged to include a support person or family member in this appointment.

You may also lead in asking your primary care provider for an appointment to discuss the seriousness of your advancing heart failure. Serious illness discussions are always important and they are essential when your condition is changing. Honest discussions, early and often, are key to building strong relationships of care. Your care providers will share the facts about your condition – you bring your personal goals and preferences to the conversation. This communication flow promotes shared decision-making.

Remember, you don’t have to make decisions on your own. If you are also being treated for other medical conditions and have many specialists caring for you, your primary care provider (family doctor, medical clinic or nurse practitioner) will sort what might be, at times, confusing information and direction.

Clear, open communication with input from informed family or friends will allow you and your care provider to build a care plan that is realistic, supportive and specific to your health possibilities and preferences. Establishing a good care plan may enable you to focus your energy on people and things important to you, rather than worry about things that cannot be known or predicted.

What supports effective, open communication?

- **Being prepared**
  Organize and bring with you a list of your current medications, symptoms and any changes you have noted. Prepare a list of questions prior to meeting your team member.
- **Asking questions**
  To make decisions that are right for you, you need to have information that is specific to you. This starts with asking questions so you fully understand the information provided.

You are encouraged to bring a support person to appointments but if no-one is available, even just taking notes may help you remember important information. With your provider's permission, recording your conversation may be another useful approach so you and family can review the discussion later.

Some questions you may want to ask:

- Is my heart failure progressing slowly or rapidly?
- Are there things I can be doing to improve the quality and length of my life?
- What can I expect in the future in terms of my symptoms – will they improve?
- How can get better sleep?
- How can I tell whether my symptoms are from my heart failure or one of my other medical conditions?
- Are there any decisions about my care that I need to make today?
- What decisions do I need to make about future therapies or interventions and when do I need to make them?
- What are the benefits and drawbacks of any treatment options?
- Are there any medications that aren't helping me feel better that I can STOP taking?
- Why does my brain feel foggy?
- Can we set up a regular time to review my goals and treatment decisions?

Clarify what you hear

When the information you receive is unclear, ask for it to be explained again in a different way or with simpler words. Repeat back what you hear in your own words. This will confirm you have understood correctly or help the care providers to realize they need to clarify further.

Making your thoughts and wishes clearly known helps ensure care plans meet your needs as much as possible. This includes advising your primary care provider of the need to understand what is important to you, including speaking with each other with openness and honesty.

COMMUNICATING WELL: FROM BARRIERS TO SOLUTIONS

Challenges to establishing good decision-making partnerships with your health care providers occasionally occur. Some common barriers, and potential solutions, are outlined below:

BARRIERS	POTENTIAL SOLUTIONS
FEAR, ANGER, STRESS OR OTHER EMOTIONS	Strong emotions can interfere with your ability to process information and make good decisions. Acknowledge and share your feelings so you and your team can identify the cause of the emotion and some ways to manage it.
DEPRESSION AND ANXIETY	Depression and anxiety are common in people with advanced heart failure. It's normal to feel sad or worried after finding out your heart failure is worsening. Talking about your emotions with a family member, friend or healthcare provider may help. If you find either anxiety or deep sadness interferes with your daily life, you may benefit from counselling and/or medication
DIFFICULTY UNDERSTANDING COMPLEX HEALTH INFORMATION	You don't have to be a medical expert to actively participate in your care. Asking questions and repeating back what you hear can help members of your medical team to clarify. Having a support person present to hear or review the information provided can be extremely helpful, especially for decision-making.
FAMILY DYNAMICS	Some families prefer not to talk about worsening health or care decisions. However, preparing your family and alerting them to your changing health status, preferences and goals for future care is important. Your care team may be a resource to help your family understand the importance of conversations and planning in advance of health crises.
CULTURAL AND RELIGIOUS DIFFERENCES	Culture and religion can influence what care you choose and how you choose to receive it. Share with your care team how your beliefs influence your care and treatment decisions. Ask for help if issues arise. Depending upon your background and affiliations, an Indigenous liaison nurse, spiritual care counsellor or clinical counsellor may provide help to both you and your family.
LANGUAGE DIFFERENCES	Professional medical interpreters are recommended to facilitate important conversations where language differences present a barrier to understanding. These interpreters can be accessed by your health care team through the provincial translation service. Advance scheduling is required. Some families ask a family or community member who works in health care to assist with translation if they prefer that person's involvement. However, this may be less effective if this informal translator feels uncomfortable with what is being discussed. In hospital, available staff who speak your language may be called to translate.

BARRIERS	POTENTIAL SOLUTIONS
NOT ENOUGH TIME WITH YOUR PRIMARY CARE PROVIDER	Ask your primary care provider how best to book appointments for serious illness discussions and decision-making. Doing so reduces time pressure when you bring questions to your appointment. Your provider may be able to book a longer appointment or a series of meetings to ensure there is enough time. Coming prepared can make best use of your time. If you feel that you and your family need more support for these important conversations and complex decisions, a palliative care specialist or social worker may also be helpful during this process.
DISAGREEING WITH YOUR DOCTOR	In shared decision-making, you and your doctor are partners. Sometimes partners disagree. If a disagreement occurs, continued communication is critical to understanding each point of view and for finding options that work for both. Your care provider may bring in additional team members to support you both.

RESOURCES

Talking About the Future – Patient Letter	Province Wide
https://fraser-northwest.pathwaysbc.ca/content_items/5803	

ADVANCE CARE PLANNING AND DIFFICULT CONVERSATIONS

Health changes bring opportunities for self- reflection. Your goals and wishes for care may change over time. Knowing and describing your values and what is most important to you will help your family and care providers during conversations about what is now possible.

Advance care planning is the process of thinking, talking and writing about your preferences for future health care treatment. It helps you identify a substitute decision maker who would make health decisions and speak for you only if you are unable to do so.

Planning includes organizing legal documents (like a Power of Attorney, Will, and Health Care Representation Agreement) to provide support for you and your family. Preparing helps to ensure that your substitute decision maker and care provider know all your care decisions and will reflect your values and wishes. Documentation of your wishes is known as your Advance Directive.

RESOURCES

Advance Care Planning	
First Nation Health Authority	https://pathwaysbc.ca/ci/5881
Fraser Health	https://pathwaysbc.ca/ci/5374
Interior Health	https://pathwaysbc.ca/ci/5195
Island Health	https://pathwaysbc.ca/ci/6353
Northern Health	https://pathwaysbc.ca/ci/6354
Vancouver Coastal Health	https://pathwaysbc.ca/ci/6355

Advance Care Planning in Canada	Speak Up Canada
https://pathwaysbc.ca/ci/6352	

BC Guidelines.ca Advance Care Planning: Resource Guide for Patients and Caregivers	BC Ministry of Health
https://pathwaysbc.ca/ci/2566	

Representation Agreement Explained	NIDUS
https://pathwaysbc.ca/ci/1628	

ADVANCE CARE PLANNING: Considerations for Daily Living

TRANSPORTATION

Advancing heart failure has practical planning implications for your daily life. For example, an unstable heart may impact your ability to drive and lead to a driving restriction. Your care provider will let you know if you are too ill to qualify for licensing. No longer driving can be a difficult loss. Think ahead and identify transportation options: family, friends or volunteer drivers, public transit and taxi services.

PARKING

If you are able to continue to drive, yet shortness of breath or increased frailty becomes challenging, you may benefit from a *Disability Parking pass* to help you park closer to your destination.

PET CARE

If you are a pet owner, planning ahead for your pet's care when you are no longer able to manage, ensures you will not find yourself making arrangements during a crisis. Volunteers to walk and help with dog care can be arranged through *Elderdog Canada*.

RESOURCES

Transportation and HandyDART	BC Seniors Guide (BC Ministry of Health)
https://pathwaysbc.ca/ci/6482 **Click on "Transportation" link on right hand side to navigate to numerous resources in BC*	

Dog Care Support for Seniors	Elder Dog
https://fraser-northwest.pathwaysbc.ca/programs/2818	

Parking Permits for People with Disabilities	SPARC BC
https://fraser-northwest.pathwaysbc.ca/programs/556	

ADVANCE CARE PLANNING: Difficult Choices

As your heart failure advances and your symptom burden increases, you and your care provider may review the usefulness of current therapies and options for the direction of care.

There will come a time when even a shock from an *Implantable Cardioverter Defibrillator* (ICD) is unlikely to extend your life if your heart stops, or you may decide that you would not wish to receive a shock to prevent sudden cardiac death. It is important to communicate this decision to your care providers so they can take steps to ensure your wishes are respected and to prevent unwanted ICD firing.

> ***"Clarity is helpful. Quantification is helpful. Even a ballpark like…because something that we can make our own decisions about rather than just let the world roll over us like a steamroller and not knowing what part we could play in making our own appropriate adaptations."***
>
> - Patient Partner

Kidney failure may be triggered as the heart function worsens. Conversations regarding kidney replacement therapy (i.e. dialysis) may also take place as you and your care provider recognize your changing condition.

During each hospitalization, you will be asked to indicate how aggressively you wished to be treated to prolong your life. This information is then translated into a *Medical Orders for the Scope of Treatment* known as a "MOST" score. In the community, your care provider will periodically address this issue as well and can provide you with a copy of a form which will state your preferences.

Your care provider may discuss the pros and cons of resuscitation if you were to suffer a cardiac arrest out of hospital, for example. If you do not wish to be resuscitated, there are forms your care provider can give you to have on hand at home.

As your heart failure approaches the later stages, your care provider can apply for benefits on your behalf to help cover the cost of symptom relieving medications and special equipment to support you at home, like a hospital bed or commode. These benefits are provided through the *BC Palliative Benefits Program* which is a Pharmacare program.

Medical Assistance in Dying, known as MAiD, has been legal in Canada since 2016. You may wonder if it is an option for you. Information about MAiD is available on Island Health's public website and on the BC Government website. If you wish to explore this further, please discuss it with your primary care provider.

RESOURCES

When to consider Implantable Cardioverter Defibrillator (ICD) deactivation, A Guide for Patients and family	Heart and Stroke
https://pathwaysbc.ca/ci/6241	

Medical Orders for Scope of Treatment - MOST	
Fraser Health	https://fraser-northwest.pathwaysbc.ca/content_items/5375
Interior Health and Northern Health	https://pathwaysbc.ca/ci/6361
Island Health	https://pathwaysbc.ca/ci/1964 https://pathwaysbc.ca/ci/4717
Vancouver Coastal	https://pathwaysbc.ca/ci/6362

Medical Assistance in Dying - MAiD	
Fraser Health	https://pathwaysbc.ca/ci/1889
Interior Health	https://pathwaysbc.ca/ci/6358
Island Health	https://pathwaysbc.ca/ci/6359
Northern Health	https://pathwaysbc.ca/ci/6274
Vancouver Coastal	https://pathwaysbc.ca/ci/6360

ADVANCE CARE PLANNING: Considerations for Care at the End of Life

Individual preferences and circumstances determine options for care as you approach the final stages of your life. You and your family may have discussed being cared for at home through to the very end. You may have decided this is not possible or is not your choice. Your care provider will connect you to a *Community Health Services* (CHS) Case manager who will outline possible options for you.

A family member who is able to leave work temporarily in order to provide care may be eligible for the *Employment Insurance Caregiver Benefit*.

Discussing your wishes for care after death with your family is helpful and can lessen their challenges during your final days. These conversations are not always easy and if not possible, leaving written instructions may provide support. If you pre-plan funeral arrangements, you can focus on the present moments you share and enjoy together.

RESOURCES

Home Support Services	
Fraser Health	https://www.fraserhealth.ca/Service-Directory/Services/home-and-community-care/home-support-services#.YkNmlyjMK01
Interior Health	https://www.interiorhealth.ca/health-and-wellness/child-community-and-home-care/help-with-living-at-home#home-support-services-available
Island Health	https://www.islandhealth.ca/our-services/home-care-services/accessing-community-health-services
Northern Health	https://www.northernhealth.ca/services/home-community-care
Vancouver Coastal	http://www.vch.ca/your-care/home-community-care/care-options/home-support

Compassionate Care Employment Insurance (Caregiver)	Government of Canada
https://pathwaysbc.ca/ci/268	

Employment Insurance Sickness Benefits and Leave (Patient)	Government of Canada
https://pathwaysbc.ca/ci/6363	

Expected / Planned Home Deaths	BC Ministry of Health
https://pathwaysbc.ca/ci/2174	

Plan a Funeral or Memorial	BC Ministry of Health
https://pathwaysbc.ca/ci/6244	

Hospice Care	
Fraser Health	https://pathwaysbc.ca/ci/6364
Interior Health	https://pathwaysbc.ca/ci/6365
Island Health	https://pathwaysbc.ca/ci/6366
Northern Health	https://pathwaysbc.ca/ci/6367
Vancouver Coastal	https://pathwaysbc.ca/ci/6369

Hospice and Palliative Care	Canadian Virtual Hospice
https://pathwaysbc.ca/ci/5256	

BC Palliative Care Benefits	BC Ministry of Health
https://pathwaysbc.ca/ci/6370	

Palliative Care - Honoring Culture, Spirituality and Traditions	Living My Culture
https://pathwaysbc.ca/ci/6372	

MAINTAINING MENTAL HEALTH AND QUALITY OF LIFE

Experiencing sadness, anger, stress, regret, fear, depression and anxiety is common when your heart weakens and symptoms increase. Changes in your day-to-day function and focus are taking place within a time of increased uncertainty. This also makes coping more challenging.

Your body feelings and range of emotions are natural reflections of this time of your life. Even so, finding support and ways to address your experiences are key to ensuring you achieve the best quality of life each day.

> *"The biggest thing is the emotional side of it. I'm getting better, but at times it's kind of overwhelming when I think about the future, or lack of the future…that part's the hardest part."*
>
> \- Patient Partner

Your journey is a personal one. The following suggestions offer a wide range of ideas, from patients living with advanced heart failure. In the hopes that some will resonate with you, focus your energy on activities that provide the most enjoyment:

- Celebrate letting go of energy draining activities that you have done as a matter of habit
- Let others help by creating lists of what you are prepared to release to their care
- Consider a regular gratitude practice
- Choose a day you can become device-free to create time for spontaneous, relaxing/fun opportunities
- Finding something in nature that brings you joy - touching flowers, being in nature, watching a sunrise, listening to the rain, or stroking a pet

> *"I don't have any energy. That parts frustrating. And yet, like I am saying, when it's nice out I say, hey great, I can get out today."*
>
> \- Patient Partner

Explore practical, everyday living adjustments such as:

- Using blister packs to eliminate pill sorting
- Reducing your use of stairs
- Moving the bedroom to the main floor
- Installing safety features in your home (grab bars, stair glide, bath/shower seat)
- Reduce household chores by engaging regular cleaning help

Access Community Health Services Occupational Therapists and/or mental health, spiritual support professionals, including peer support through Heart Life.

> *"The important thing is to rest and organize your life so that it's manageable and not insurmountable."*
>
> \- Patient Partner

HONOURING CULTURE, SPIRITUALITY AND TRADITIONS

Finding meaning during this time in your life, whether through connection to others or affirming your spiritual beliefs, can ease our heart failure process. It may ease any emotional struggle that you and your caregivers may experience. Acknowledging this 'being alive every day' process, even to yourself, can make it easier to avoid being stuck in trying to maintain how your life had been before your illness. It will enable you to better accept what is currently possible. You may find your focus shifts, enabling you to find joy, and appreciation for the spirit in what matters to you in the present moment.

We are all spiritual beings. When faced with serious health challenges, many people go on a kind of spiritual journey, seeking meaning, comfort and peace. The course of this spiritual journey will be different for everyone.

For some it is a central aspect of their being, for others not so much. This may be something you want to discuss with others or reflect upon privately. Honouring the spiritual side of your life is as important as your everyday living and health care practices.

Ceremonial practices, cultural beliefs and traditions may provide relief and comfort as you face challenges brought with your declining health. Revisiting your cultural traditions may provide a source of valuable renewal as your energy is challenged by illness.

RESOURCES

Counselling – Free or Low Cost	
Fraser Health	Chilliwack and Fraser Health Rural
	Maple Ridge – Pitt Meadows
	New Westminster - Tri-Cities
	Surrey - North Delta
	White Rock / South Surrey
Interior Health	Ashcroft - Clearwater - Lillooet - Lytton - Merritt
	Kelowna - West Kelowna - Lake Country - Peachland
	Kootenay Boundary
Island Health	Comox Valley
	Cowichan Valley
	Gabriola Island
	Parksville - Qualicum Beach - Port Alberni
	Victoria - South Island
Northern Health	https://www.northernhealth.ca/services/end-life-care-palliative-care#services
Vancouver Coastal	North Shore
	Sea to Sky
	Vancouver

BC Seniors Guide	BC Ministry of Health
https://pathwaysbc.ca/ci/6482	

Bereavement Helpline	BC Bereavement Helpline
www.bcbh.ca/contact.php 1-877-779-2223	

Caring for Someone with Heart Failure and Taking Care of Yourself	Cardiac Services BC
https://pathwaysbc.ca/ci/5647	

Community Resources for Family Caregivers in BC	Doctors of BC
https://pathwaysbc.ca/ci/1464	

Heart Life Foundation	Province Wide
https://heartlife.ca/	

Spiritual Health	Canadian Virtual Hospice
https://pathwaysbc.ca/ci/6373	

Community Services	
Fraser Health	Chilliwack and Fraser Health Rural
	Maple Ridge – Pitt Meadows
	New Westminster - Tri-Cities
	Surrey - North Delta
	White Rock / South Surrey
Interior Health	Ashcroft - Clearwater - Lillooet - Lytton - Merritt
	Kelowna - West Kelowna - Lake Country - Peachland
	Kootenay Boundary
Island Health	Comox Valley
	Cowichan Valley
	Gabriola Island
	Parksville - Qualicum Beach - Port Alberni
	Victoria - South Island
Northern Health	https://www.northernhealth.ca/our-communities
Vancouver Coastal	North Shore
	Sea to Sky
	Vancouver

Seniors Services	
Fraser Health	Chilliwack and Fraser Health Rural
	Maple Ridge – Pitt Meadows
	New Westminster - Tri-Cities
	Surrey - North Delta
	White Rock / South Surrey
Interior Health	Ashcroft - Clearwater - Lillooet - Lytton - Merritt
	Kelowna - West Kelowna - Lake Country - Peachland
	Kootenay Boundary
Island Health	Comox Valley
	Cowichan Valley
	Gabriola Island
	Parksville - Qualicum Beach - Port Alberni
	Victoria - South Island
	Capital Region – Senior Services Directory
Vancouver Coastal	North Shore
	Sea to Sky
	Vancouver

CHAPTER 2: Information for Carers

While it's recommended that family and carers read all of this guide, this section has been prepared to assist members of a patient's support community.

Where can I turn for support and ideas?

As the needs of your loved one increase, self-care is key for all who provide care and support. Familiar sayings such as "you have to put on your own oxygen mask before you can help others" or "you can't reach your destination without gas in the tank" capture the importance for family and other supporters to pay attention to themselves, too.

> ***"I try to walk the line between hovering and getting out of the way and not interfering and doing what only I can do."***
>
> - Patient Partner

Someone living with advanced illness may worry about becoming a "burden" on you, despite your reassurances otherwise. Caring during a time of serious illness is a long term commitment of time and energy. Good communication and a self-care plan for carers are important.

Suggestions:

- Check in regularly with the person you are supporting
- Adjust as you go. Discuss how you will both know when additional help or a new strategy is needed. This will help avoid care team exhaustion.
- Learn about community resources and think through scenarios and support strategies ahead of time.
- Connect to others who share your experience, for support and good ideas.

Support through the end of life is available. Assistance with planning and care and support for bereavement is available through your community health services (CHS care teams). Check with your local hospice to access counsellors who can assist you and your family through this process.

Caring for Someone with Heart Failure and Caring for Yourself (Cardiac Services BC) offers a useful summary for recognizing signs of stress and offers tips on how to avoid it. You will find that caring well for yourself is the best way of ensuring you can provide the best care for others.

Community Resources for Family Caregivers in BC (Doctors of BC) provides a comprehensive list for one to one supports and resources. (This publication provides a summary of financial benefits for caregivers with eligibility criteria and links to the forms.

RESOURCES

Caring for Someone with Heart Failure and Taking Care of Yourself	Cardiac Services BC
https://pathwaysbc.ca/ci/5647	

Community Resources for Family Caregivers in BC	Doctors of BC
https://pathwaysbc.ca/ci/1464	

Compassionate Care Employment Insurance (Caregiver)	Government of Canada
https://pathwaysbc.ca/ci/268	

Expected / Planned Home Deaths	BC Ministry of Health
https://pathwaysbc.ca/ci/2174	

Family Caregivers of BC	Family Caregivers of BC
https://pathwaysbc.ca/ci/696	

Hospice Care	
Fraser Health	https://pathwaysbc.ca/ci/6364
Interior Health	https://pathwaysbc.ca/ci/6365
Island Health	https://pathwaysbc.ca/ci/6366
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	Victoria - South Island
	Capital Region – Senior Services Directory
Vancouver Coastal	North Shore
	Sea to Sky
	Vancouver

Funeral / Memorial information	
BC Ministry of Health	https://pathwaysbc.ca/ci/6244
Memorial Society of BC	https://fraser-northwest.pathwaysbc.ca/programs/2932

WORKS CITED

1. Cover Page. Heart Hands Photo. Stock Snap. Accessed April 14, 2021. https://stocksnap.io/photo/heart-hands-3DD567FCA3

2. Page 4. Image adapted with permission from Goodlin, SJ. JACC 2009; 54: 386-96

3. Page 9. Job Jar. Adapted from https://commasandampersandsblog.wordpress.com/2014/08/27/book-jar-six-months/

4. Page 13-16. Shared Decision Making and Communicating Well sections adapted from the American Heart Association (https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/overcoming-barriers-to-shared-decision-making) and Heart Failure Society of America Patient Information modules (https://hfsa.org/heart-failure-educational-modules).

5. Page 14. Cartoon Doctor and Patient. Clipartkey. Accessed May 8, 2021. https://www.clipartkey.com/view/owoxJi_clip-art-cartoon-picture-of-doctor-and-patient/

6. Page 18. Driving and transportation for seniors. Fraser Health. Accessed on March 14, 2021. Driving and transportation for seniors - Fraser Health Authority

7. Page 18. Accessible Parking Spots: Are They All the Same? National Mobitlity Equipment Dealers Association. Accessed on May 24, 2021. https://nmeda.org/accessible-parking/

8. Page 18. Seniors and Pets. Aging In Place. Published on December 13, 2011. Accessed on March 14, 2021. Seniors and Pets | Updated for 2021 | AgingInPlace.org

9. Page 23. Earth, Teach Me by Nick Kenrick. Creative Commons. https://search.creativecommons.org/photos/21473fb0-c6ed-45fd-be79-db0881f7f975

Version Number	Date	Notes
Version 1.0	June 2021	
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