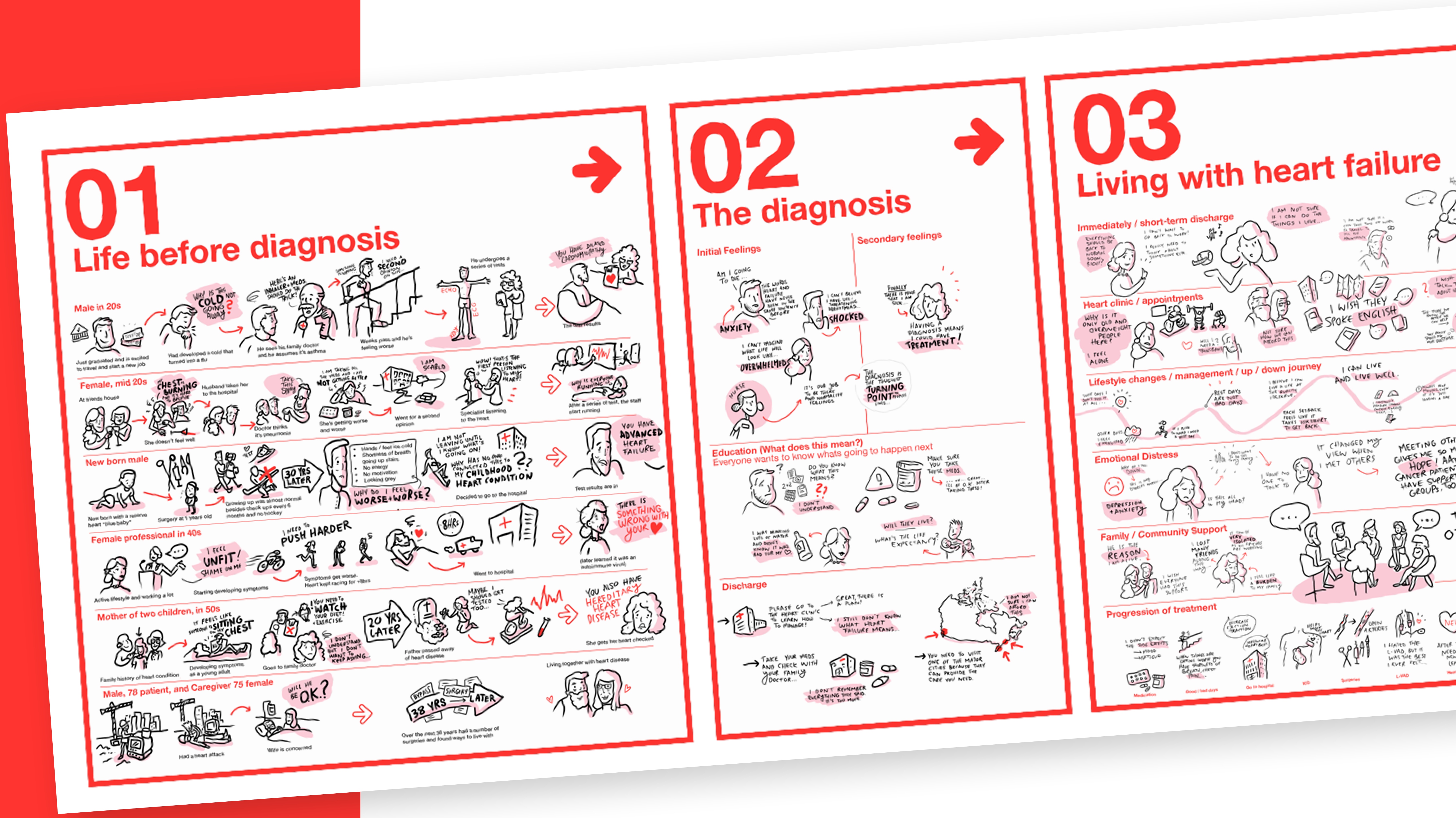
Patient Journey Map



Capturing real experiences to empower a global community living with and caring for heart failure.

HeartLife
FOUNDATION

It’s about life, not failure.

Opening Words

The HeartLife Foundation is on a mission to transform the quality of life for people living with heart failure by engaging, educating, and empowering a global community to create lasting solutions and build healthier lives.

The patient journey map initiative was undertaken to fully understand the burden of heart failure and develop real-world solutions based on the lived experiences of heart failure patients and their family caregivers. The patient journey map will be used to improve the understanding of heart failure across the care continuum, facilitate discussions with various stakeholders to drive change, and develop real-world solutions for those living with heart failure.

Although we don't yet have a cure for heart failure, medical therapies, lifestyle changes, and support can help people manage their condition well and live the high-quality life they deserve.

Our vision is to create a better everyday life for people living with heart failure, because it's about life, not failure.

This initiative is dedicated to Canadians living with heart failure, healthcare professionals who dedicate their lives to caring for others, our amazing support network of family and friends, and the entire HeartLife community.

Jillianne Code, Ph.D
Co-Founder

Marc Bains
Co-Founder

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Overview:

Developing the first patient journey map for Canadians living with and caring for people with heart failure.

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Purpose:

The purpose of a patient journey map is to visualize the experiences of people living with and caring for people with heart failure face. The patient journey map captures and summarizes real stories, emotions, questions, and lifestyle challenges heart failure patients experience in their care continuum. The patient journey map serves as a tool to build common understanding for the unique life journeys of heart failure patients and family caregivers charting the path from early signs and symptoms, the moment of diagnosis, and discharge, to on-going treatment and continual lifestyle management.

By truly empathizing with and learning about what heart failure patients experience today, we can highlight their current needs, pain points, and wishes on how to improve care. As a next step forward, we believe bringing people together can stimulate conversations and actions to design solutions which could improve quality of life.

We're taking the first step to ensure the patient's voice is heard.

This is for:

- ➔ **Patients** who want to learn about the possible life journey ahead and to feel empowered to take ownership of their health.
- ➔ **Caregivers** and family members who want to understand possible challenges, opportunities, and options available and to know they are not alone in the journey.
- ➔ **Healthcare professionals** who want to empathize with the lived experience of patients and recognize opportunities to support them within their responsibility of care.
- ➔ **Policy makers and private and public institutions** who want to identify opportunities and support the development of solutions to improve quality of life.
- ➔ **And everyone who is interested in heart health and heart failure.**

HeartLife FOUNDATION

The HeartLife Foundation is a patient-driven charity whose mission is to transform the quality of life for people living with heart failure by engaging, educating, and empowering a global community to create lasting solutions and build healthier lives.

Our vision is to create a better everyday life for people living with heart failure. It's about life, not failure.

Visit our website: www.heartlife.ca

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Kreatives is a design strategy company on the mission to push the world forward. Located in Munich, we help leaders and organizations use design to improve the world.

Check us out at www.kreatives.co

And the incredible patients, caregivers, and healthcare providers who participated in the project.

Thank you!

The Approach:

We took a design thinking approach to conduct 10 in-depth (virtual) interviews with a range of people who have a relationship with heart failure — including patients, caregivers/family members, and healthcare professionals. Each interview lasted between 60–90 minutes. Once all the interviews were conducted, our team mapped and visualized the unique experience of each heart failure patient — highlighting similarities and differences in their journey, interactions with healthcare professionals, pain points, wishes, questions, and opportunities to create real impact.

We explored the following themes in our interviews:

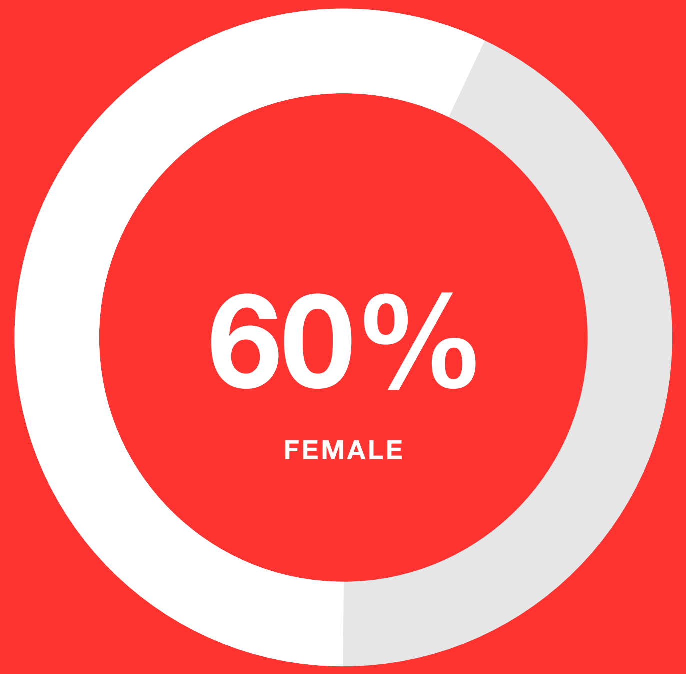
- The first signs and symptoms
- The journey and experiences leading to a diagnosis
- The diagnostic experience
- Living and managing life with heart failure
- Mental health and community support
- Needs and wishes to improve quality of life
- Education, empowerment, and engagement
- Improved access to care

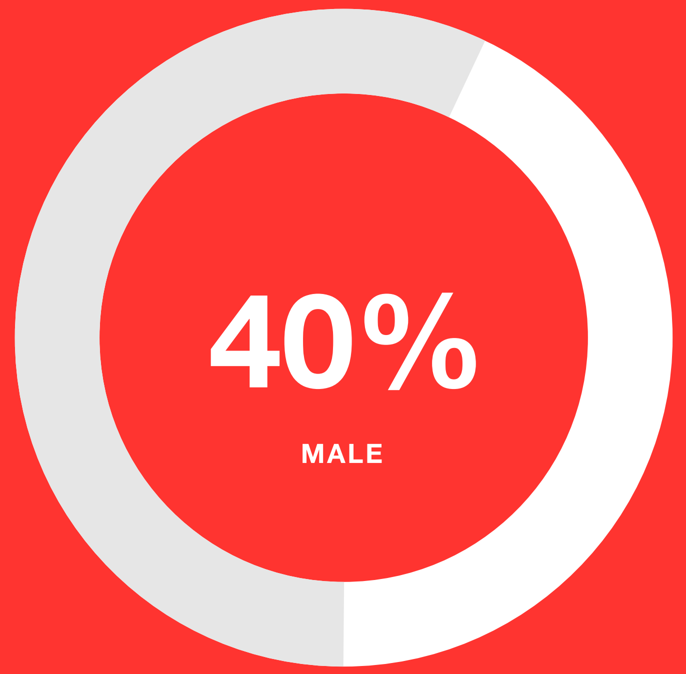
We interviewed:

HEART FAILURE PATIENTS

HEALTHCARE PROFESSIONALS
(DOCTORS AND NURSES)

CAREGIVERS/FAMILY MEMBERS





Aged from **30s** → **70s**

Patients ranged from newly diagnosed heart failure patients to people who have been living strong with heart failure for over 40 years.

Some individuals are currently living with an implantable cardioverter-defibrillator (ICD), others have a left ventricular assist device (LVAD), others had 1 or more transplants; all are taking medication.

Everyone's relationship or entry into heart failure is unique and individualized, whether they had a known heart disease from birth or a sudden onset in their 30s.

All patients we spoke to had some form of family/caregiver support.

Everyone we spoke with are either members of or are connected to the HeartLife Foundation.

Everyone we spoke with resides in Canada.

Why Journey Mapping?

The patient journey map is a visual tool which summarizes the experience and interactions a heart failure patient goes through over time. Unlike traditional process or flow charts, a journey map captures the feelings, emotions, and thoughts highlighting pain points, needs, and wishes in their life journey.

In the report, we define the terms as follows:

- **A patient is someone who has heart failure, whether unknowingly or diagnosed with.**
- **A caregiver is a family member or spouse supporting the patient in their life journey.**
- **A healthcare professional is a doctor, nurse, cardiac specialist, psychologist, dietician, exercise professional, and general practitioner.**

The patient journey map can serve as a foundation to:

01 Document the current experiences people living with or caring for heart failure go through.

02 Raise awareness for heart failure in an effort to educate, empower, engage, and connect people who are living with, recently diagnosed with, caring for someone with, or generally interested in heart failure and heart health.

03 Ensure the patient's needs, voice, experiences, and outcomes are heard — the first steps toward patient-centred care.

04 Stimulate new solutions/resources to improve quality of life (from quick wins to cultural transformation in healthcare).

05 To create change in how we see, view, and treat heart failure in Canada.

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"Everyone has a unique story and experience leading to diagnosis and living with heart failure.”

Patient Journey Map: From the early signs and symptoms to living a full life with heart failure

Each individual's life story and journey is unique.

We divided the patient journey map into three major stages:

01 Life before diagnosis
02 The diagnosis
03 Living with heart failure

Patient Journey Map

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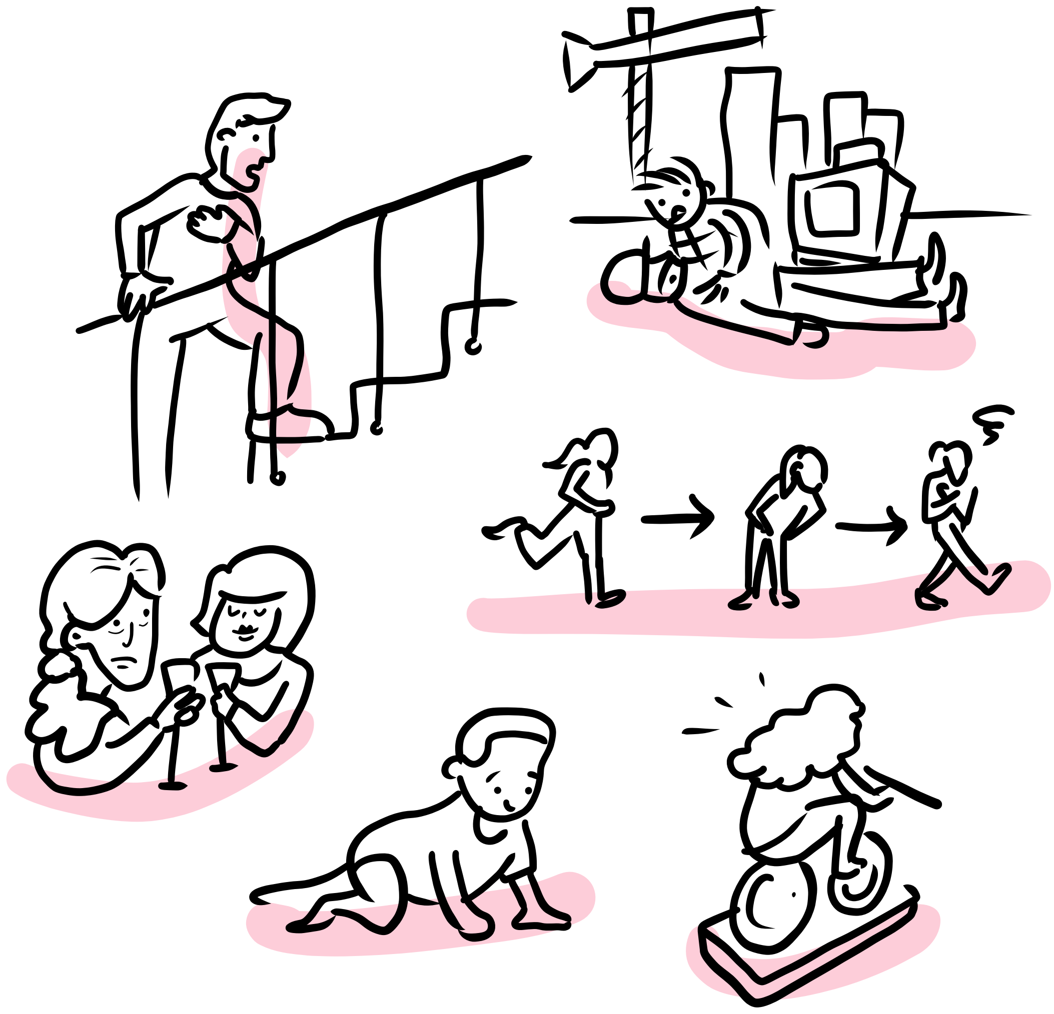
01
Life before diagnosis



02
The diagnosis

03
Living with heart failure

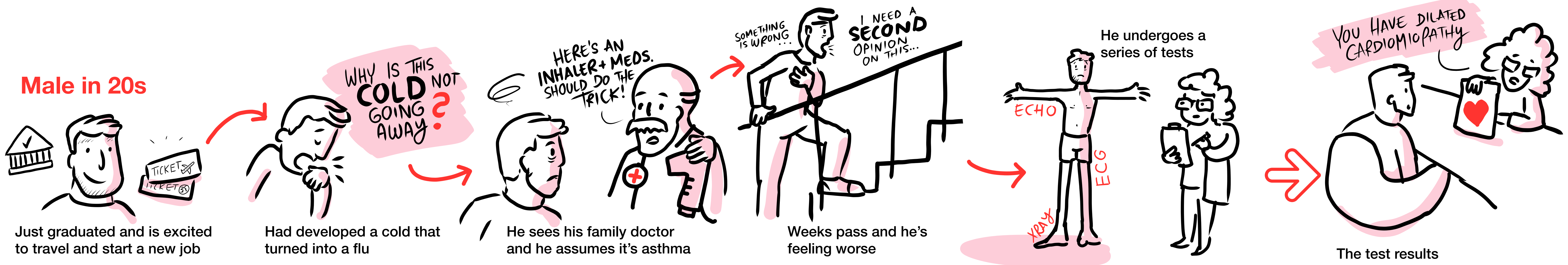
Life Before Diagnosis

Everyone has a unique life and journey leading into the first signs and symptoms of heart failure. Some people are born with a congenital challenge in the heart, some have an auto-immune or heredity predisposition, some developed symptoms after a cold/flu, and some have a dramatic onset. It doesn't matter who you are — anyone can eventually be diagnosed with heart failure.

The following journeys show many different life paths leading to a heart failure diagnosis. It is quite common for patients who experience early signs and symptoms to be misdiagnosed until their condition progresses to a stage where they feel they need a second medical opinion or go to the hospital. It is common for patients to feel unsure when:

- ➔ it's hard to breathe
- ➔ it's hard to walk or go up the stairs
- ➔ they feel burning in the chest
- ➔ they have swollen ankles or bloating
- ➔ they have low energy
- ➔ they have cold feet and hands

Male in 20s



Just graduated and is excited to travel and start a new job

Had developed a cold that turned into a flu

He sees his family doctor and he assumes it's asthma

Weeks pass and he's feeling worse

He undergoes a series of tests

The test results

Female, mid 20s

At friends house

She doesn't feel well

Husband takes her to the hospital

Doctor thinks it's pneumonia

She's getting worse and worse

Went for a second opinion

Specialist listening to the heart

After a series of tests, the staff start running

New born male

New born with a reverse heart "blue baby"

Surgery at 1 years old

Growing up was almost normal besides check ups every 6 months and no hockey

- Hands / feet ice cold
- Shortness of breath going up stairs
- No energy
- No motivation
- Looking grey

Decided to go to the hospital

Test results are in

Female professional in 40s

Active lifestyle and working a lot

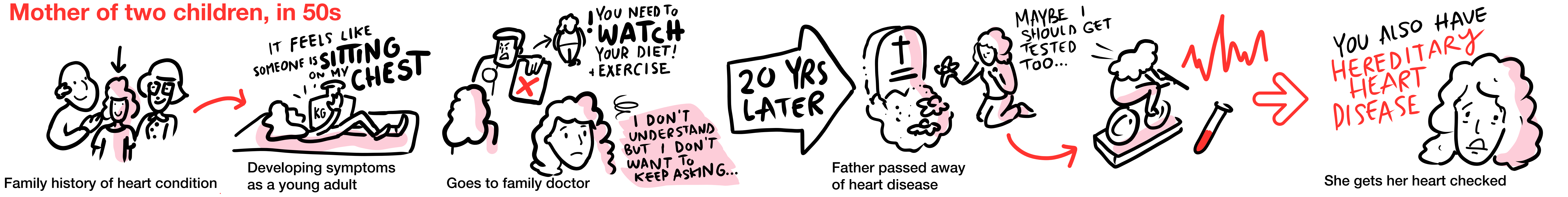
Starts developing symptoms

Symptoms get worse.
Heart kept racing for +8hrs

Went to hospital

(later learned it was an autoimmune virus)

Mother of two children, in 50s



Family history of heart condition

Developing symptoms as a young adult

Goes to family doctor

Father passed away of heart disease

She gets her heart checked

Male, 78 patient, and Caregiver 75 female

Had a heart attack

Wife is concerned

Over the next 38 years had a number of surgeries and found ways to live with

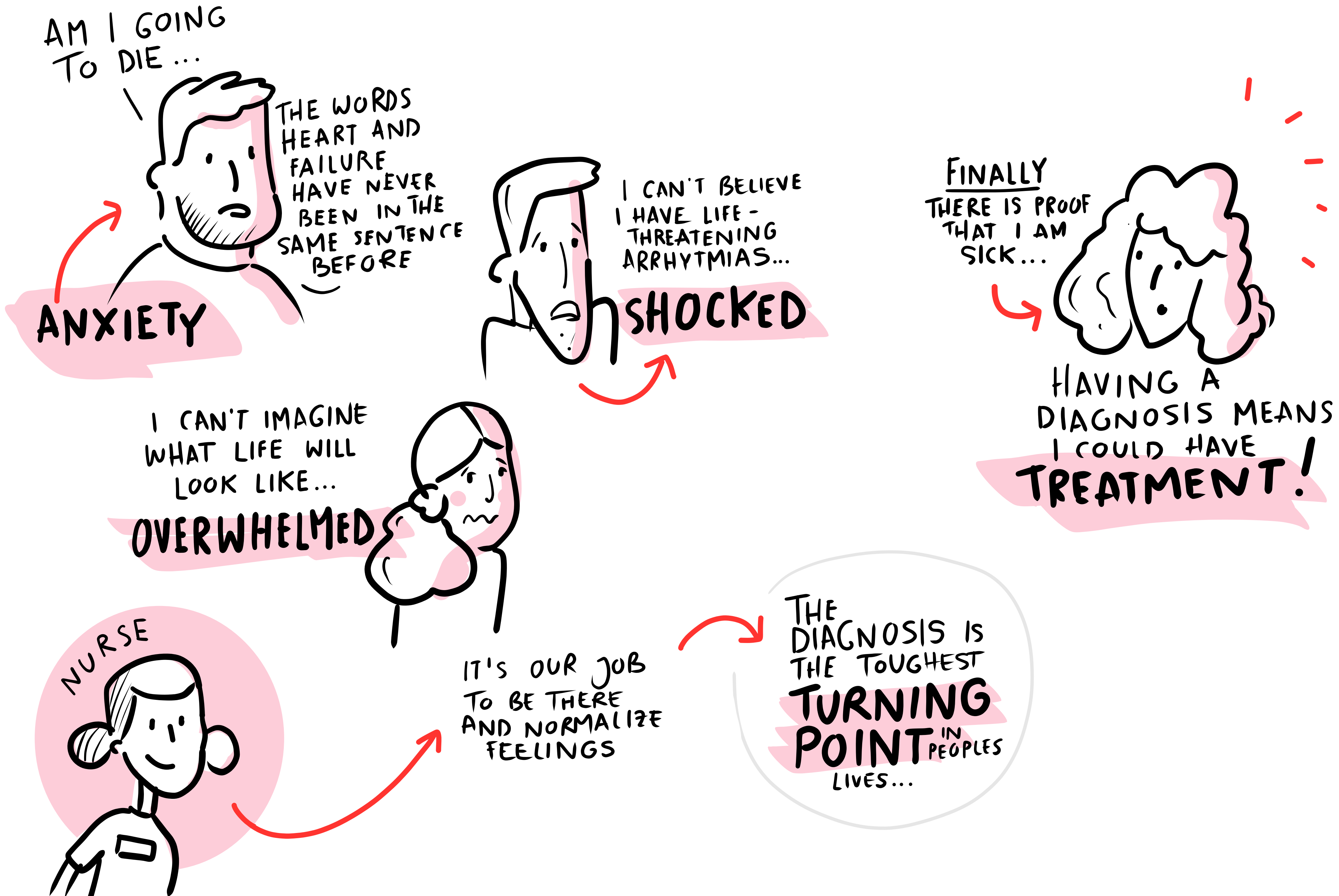
Living together with heart disease

During Diagnosis

Everyone's experience is so individualized with one exception: The initial feeling of receiving a diagnosis is shock, no matter how prepared someone may be. The diagnosis is the toughest turning point in someone's life. Once the feelings of shock or anxiety have settled, some patients may feel that having a diagnosis finally means they are able to receive the proper treatment and care.

Initial Feelings

Secondary feelings



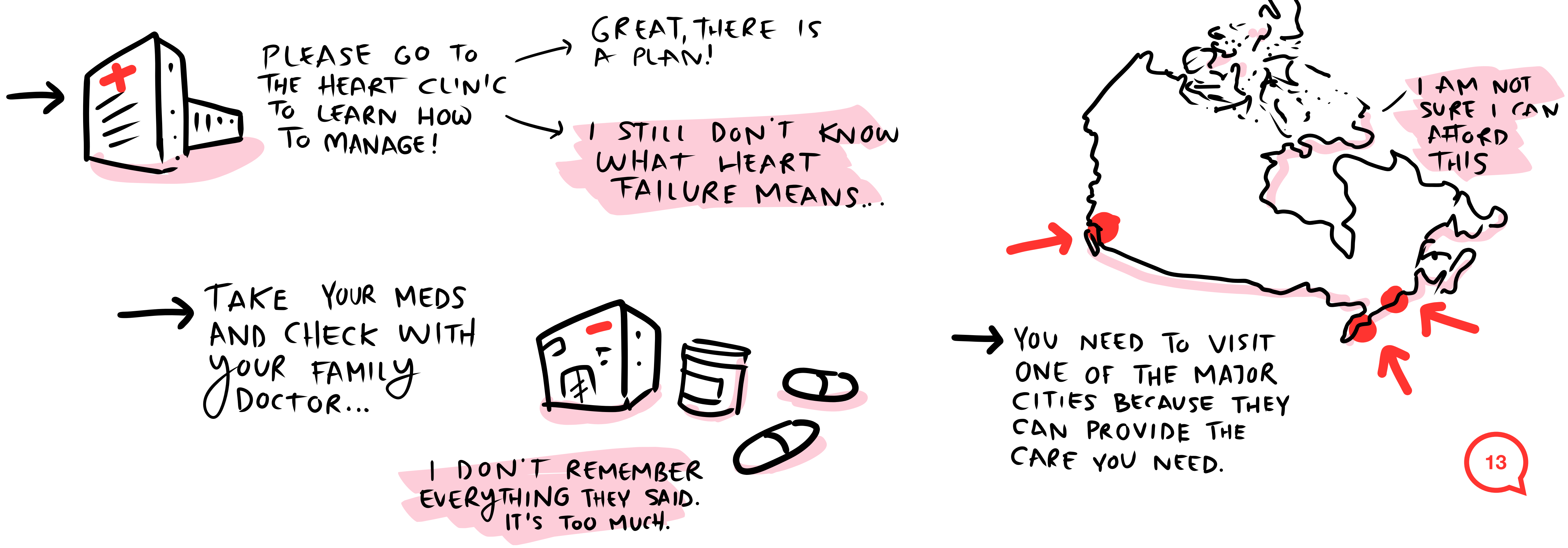
Education (What does this mean?)

Everyone wants to know whats going to happen next

Patients begin to learn about what it means to have heart failure and how to self-manage it. Their reflection of their early signs and symptoms may begin to make sense. Others, they may still be unsure and confused about what it really means to have heart failure.

Discharge

During the discharge from hospital, heart failure patients have very mixed experiences. Some patients feel much more informed or confident that there is a care plan ahead for them. Others feel they are left with limited information or cannot remember or understand everything that has been shared. Patients sometimes experience denial, feeling that "this cannot be happening to me."

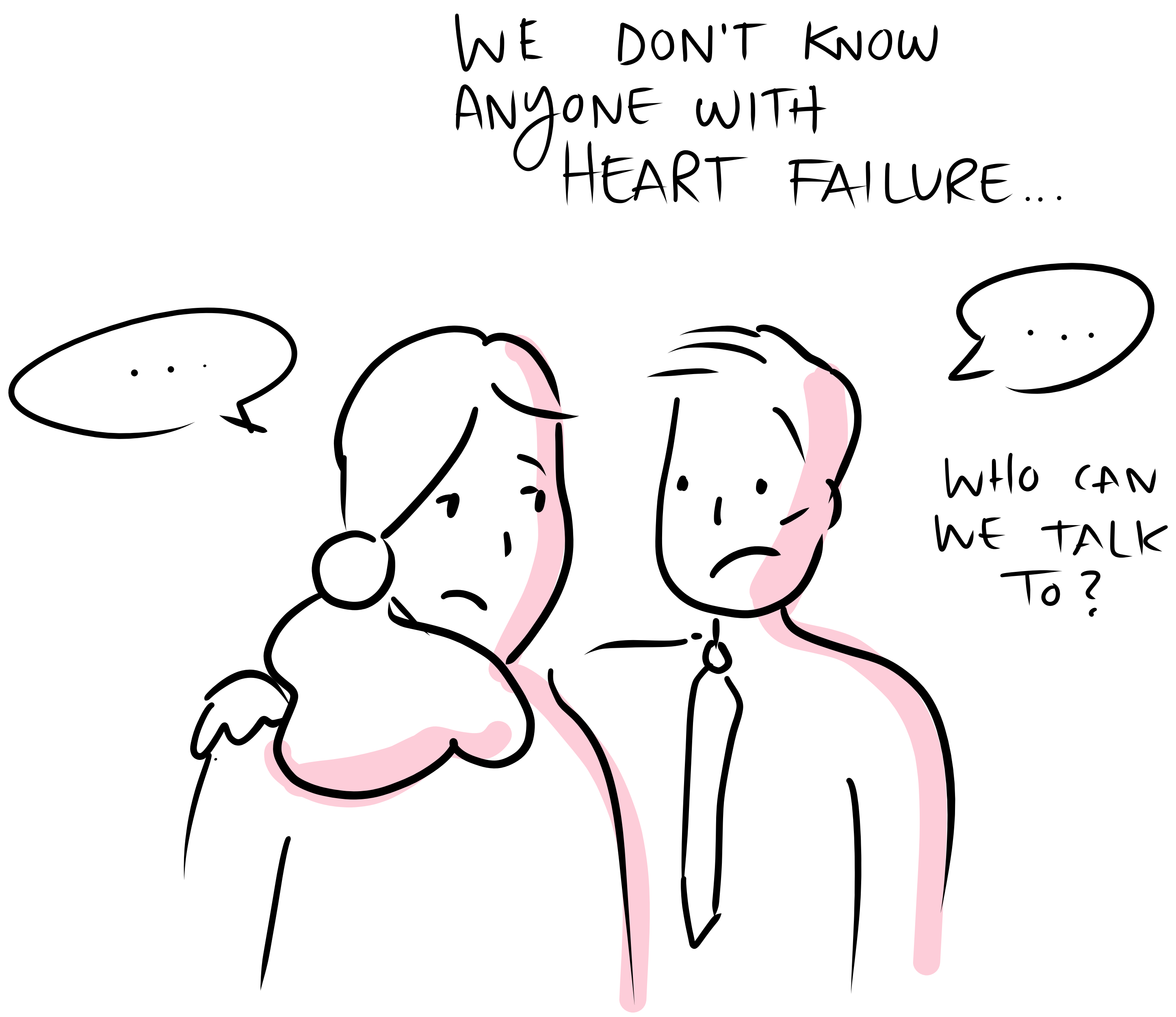


Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

Immediately After Discharge (Short-Term)

Right after discharge, heart failure patients may have mixed feelings and emotions in the next steps of their life. Some may assume life will return to normal and feel ready to contribute at work or go back to school. Others may have a feeling of uncertainty or fear that they will not be able to return to their activities they love. Newly diagnosed patients may also feel overwhelmed with the number of appointments or the need to travel to see specialists; they may fear the financial burden of taking time off of work or the extra costs incurred. It is also normal for families and caregivers to feel alone in the journey as they may not have been directed to any resources or communities for support.



Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

Heart Clinics/Appointments

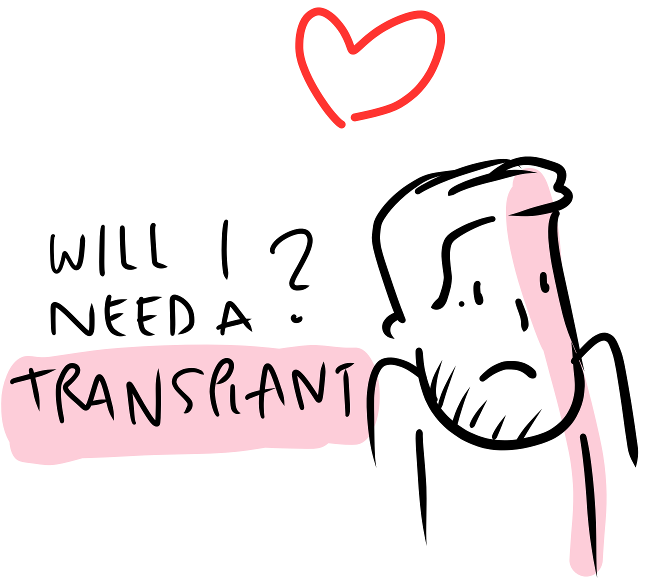
Heart failure patients who are referred or have access to their local heart clinic typically learn more about how they can monitor and manage their health.

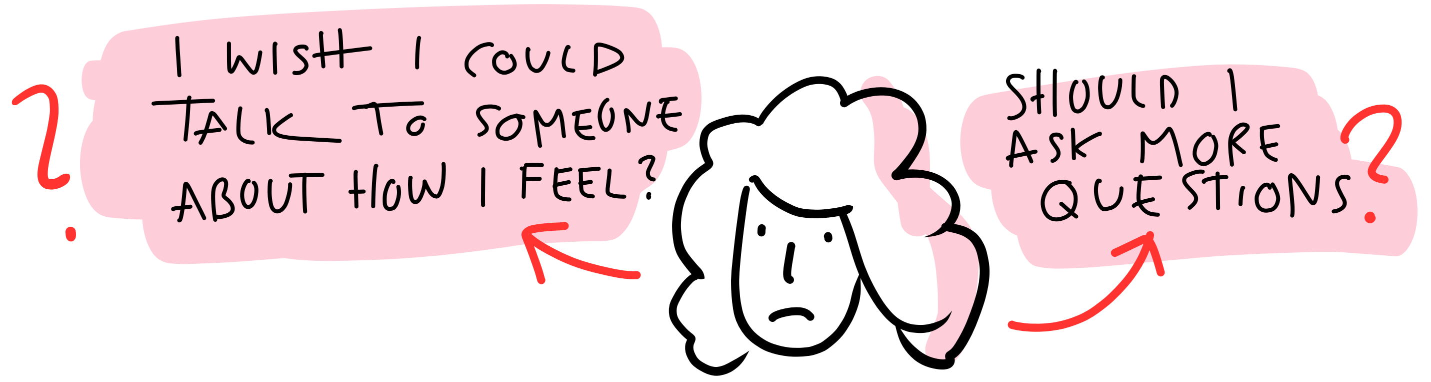
They usually learn about the importance of:

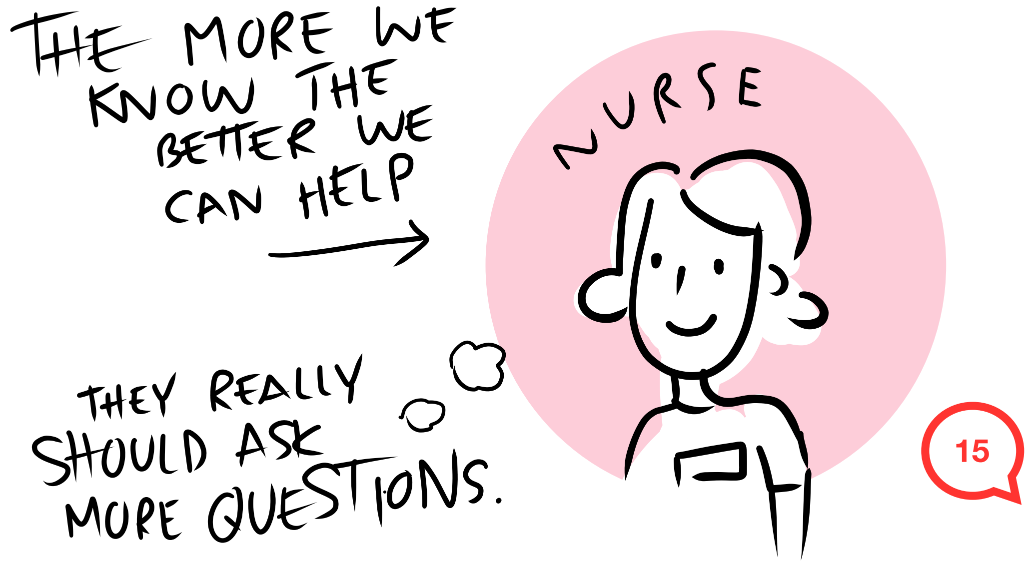
- fluid balance
- having a low sodium diet
- exercise
- monitoring blood pressure and heart rate
- medication

Heart failure patients who need to travel to attend clinics or appointments often face extra financial stress and burden. They tend to be unaware of potential government aid or financial services. Younger patients often feel they are the only young people at the heart clinics and this can lead to a sense of loneliness.

During regular doctor checkups, many heart failure patients wish their doctors would speak to them in a way they could understand, rather than medical jargon. Patients may feel uncomfortable communicating, causing them to shy away from asking questions when they don't understand. In contrast, nurses we spoke with wish patients would ask more questions as they believe the more they know how a patient feels, the better they can support them.







Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

Lifestyle Changes

Being diagnosed with heart failure doesn't mean life is over. It means an adaptation to daily activities and monitoring one's body. It is very common for heart failure patients to share the emotional and physical up-and-down journey. Some days, patients don't even feel any signs or symptoms; other days they may feel more exhausted. We learned it is important for patients to distinguish and monitor when they have a "good day," a "bad day," or a "rest day – and that "rest days are not bad days."

Heart failure patients feel they can still live a high-quality life with slight adaptations. For example, when travelling, they may need to research where the closest hospital is or make healthy, low-sodium meal choices.

Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

Emotional Distress

An important and overlooked challenge heart failure patients face is emotional distress, including depression, and anxiety. The feelings and emotions felt are not physically shown; as a result, there is limited mental health support. It is common for patients to feel lonely or not want to be a burden to their family or healthcare providers. It is very important to validate and acknowledge any emotions and feelings patients face.

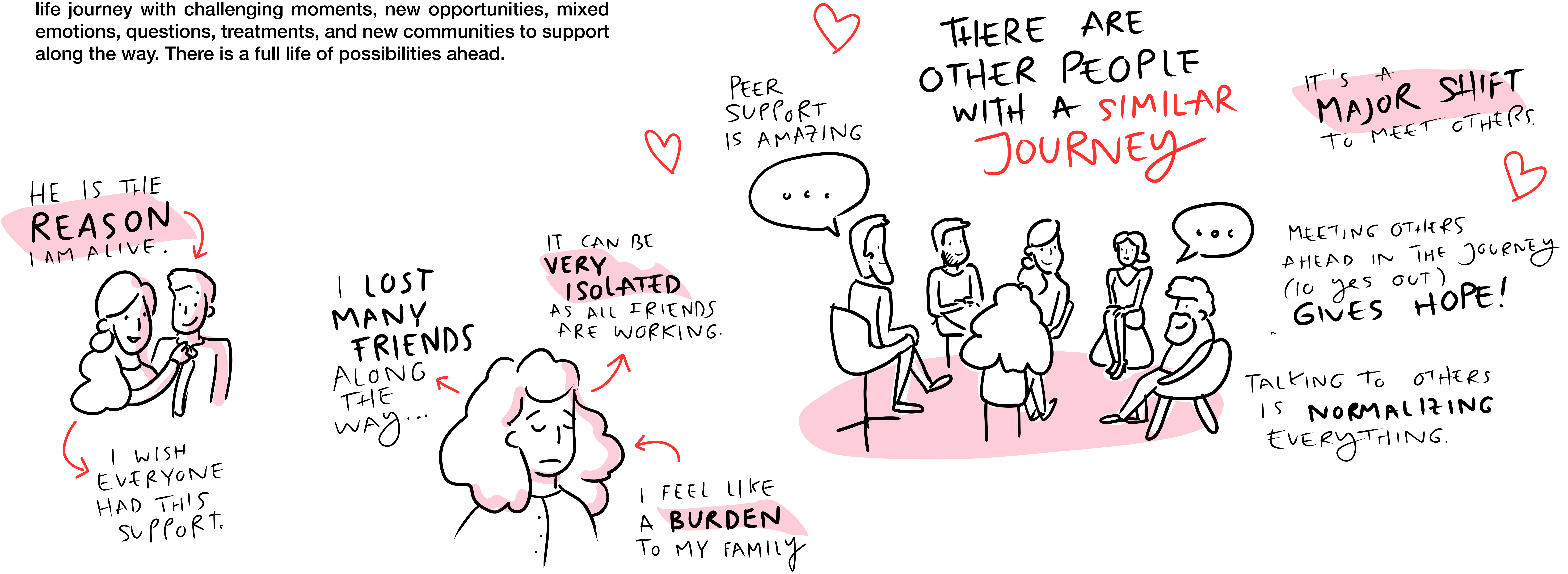
Meeting other heart failure patients and communities gives patients hope — hope they are not alone and can live a quality life. Heart failure patients often wish they would have the same access to communities, support, and care as for cancer or diabetes patients.

Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

Family and Community Support

Heart failure patients have expressed the importance of having support from friends, family, and caregivers. In the journey, it is normal to feel isolated or alone when other friends are working or going to school; we've even heard stories about losing some friends along the way. However, meeting others who are going through a similar journey normalizes the emotions and provides hope. Having peer and community support is one way of providing mental health and social support to heart failure patients.



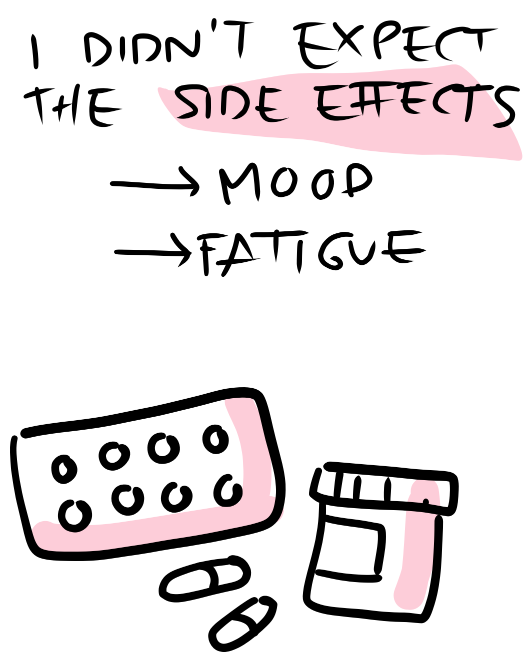
Living with Heart Failure

After discharge, heart failure patients need to adapt to a new life journey with challenging moments, new opportunities, mixed emotions, questions, treatments, and new communities to support along the way. There is a full life of possibilities ahead.

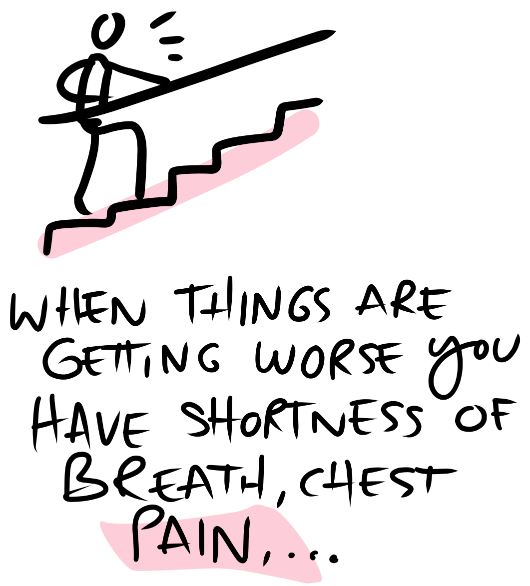
Progression of Treatment

All heart failure patients we spoke to left the hospital with medication. Many shared the unexpected or unexplained side effects, such as mood changes or fatigue. As heart failure continues to progress over time, patients may feel an increased intensity of shortness of breath, chest pain, etc. Typically, patients go to the hospital to get an assessment of why their symptoms have progressed; sometimes it's due to a decreased ejection fraction or irregular heartbeats.

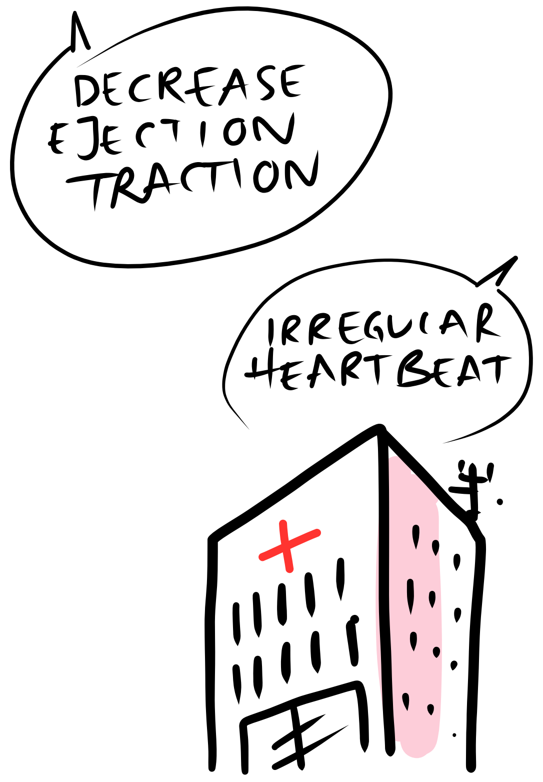
Living with heart failure is lifelong and the frequency or intensity of treatment can vary at different points during the heart failure journey. The progression of treatment typically moves from medication to having an ICD implanted. Sometimes, patients may require surgery, such as having stents implanted in order to open the arteries to reduce the workload on their hearts. If the condition progresses, patients may get an LVAD to mechanically pump the heart or be placed on the heart transplant list.



Medication

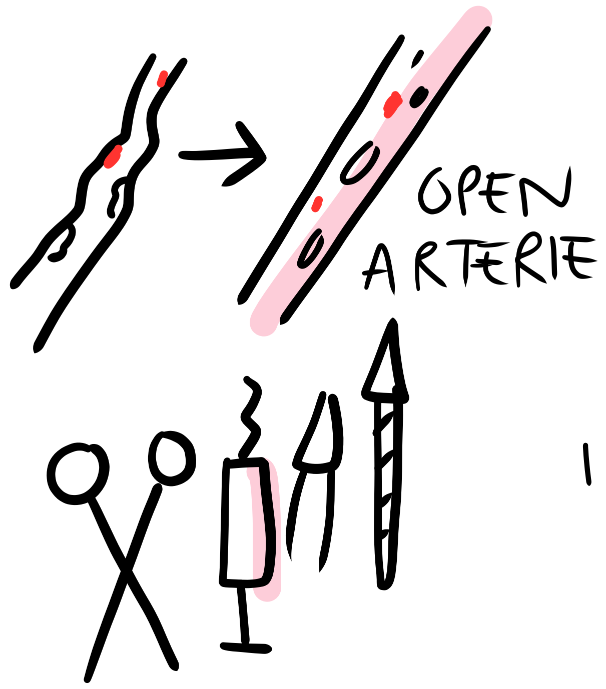


Good / bad days



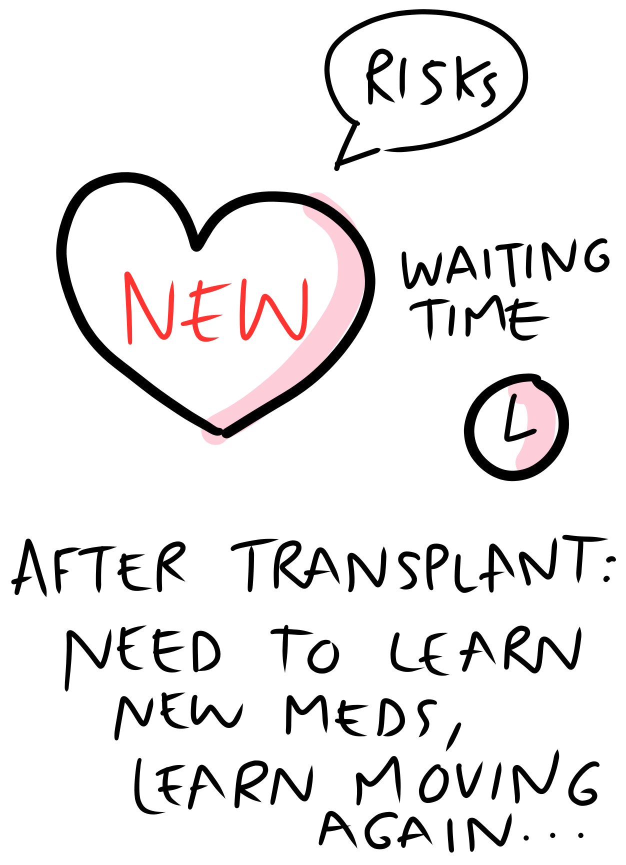
Go to hospital

ICD



Surgeries

LVAD



Heart Transplant

End of Life

Patient Journey Map

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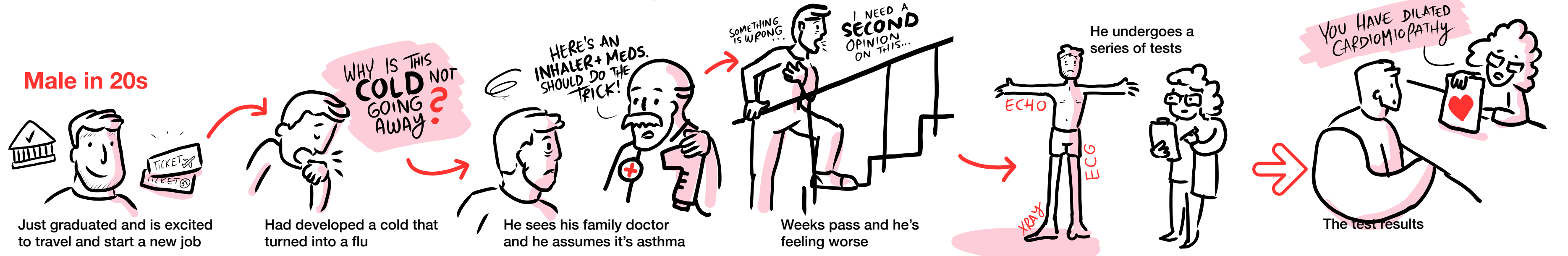
01 Life before diagnosis

Male in 20s



Just graduated and is excited to travel and start a new job

Had developed a cold that turned into a flu

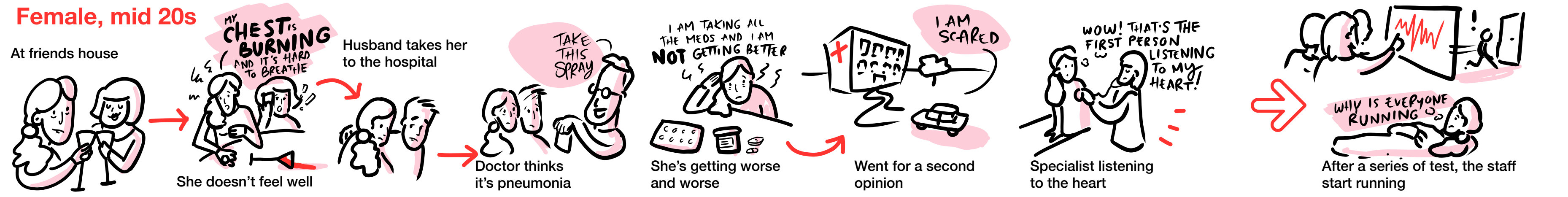
He sees his family doctor and he assumes it's asthma

Weeks pass and he's feeling worse

He undergoes a series of tests

The test results

Female, mid 20s



At friends house

She doesn't feel well

Husband takes her to the hospital

Doctor thinks it's pneumonia

She's getting worse and worse

Went for a second opinion

Specialist listening to the heart

After a series of test, the staff start running

New born male

- Hands / feet ice cold
- Shortness of breath going up stairs
- No energy
- No motivation
- Looking grey

New born with a reserve heart "blue baby"

Surgery at 1 years old

Growing up was almost normal besides check ups every 6 months and no hockey

Decided to go to the hospital

Test results are in

Female professional in 40s

Active lifestyle and working a lot

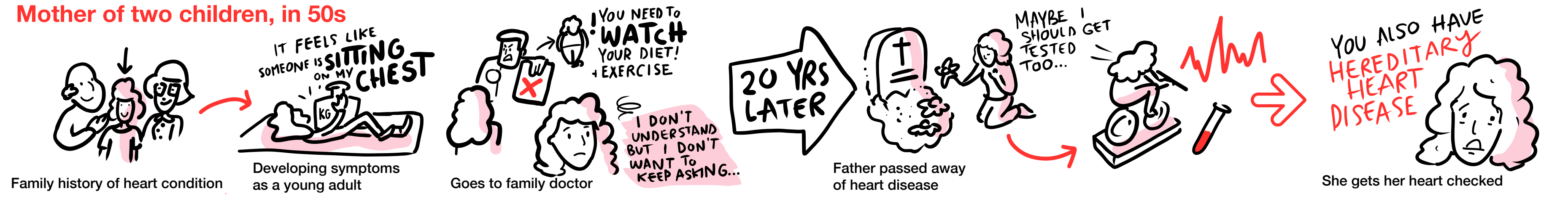
Starting developing symptoms

Symptoms get worse.
Heart kept racing for +8hrs

Went to hospital

(later learned it was an autoimmune virus)

Mother of two children, in 50s



Family history of heart condition

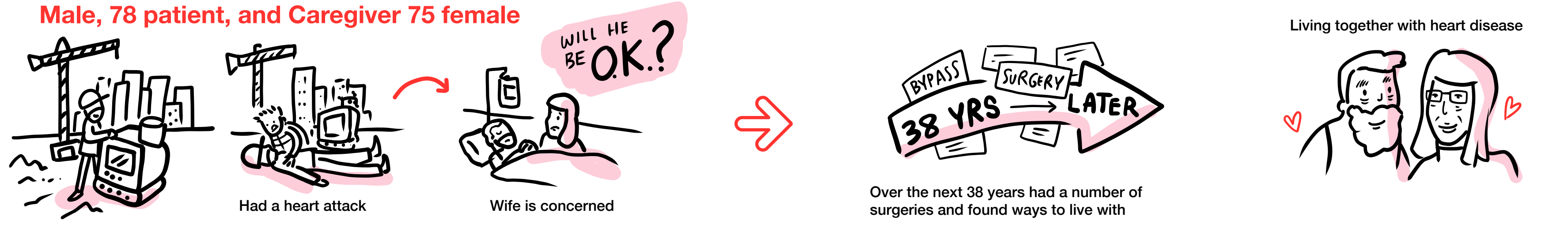
Developing symptoms as a young adult

Goes to family doctor

Father passed away of heart disease

She gets her heart checked

Male, 78 patient, and Caregiver 75 female



Had a heart attack

Wife is concerned

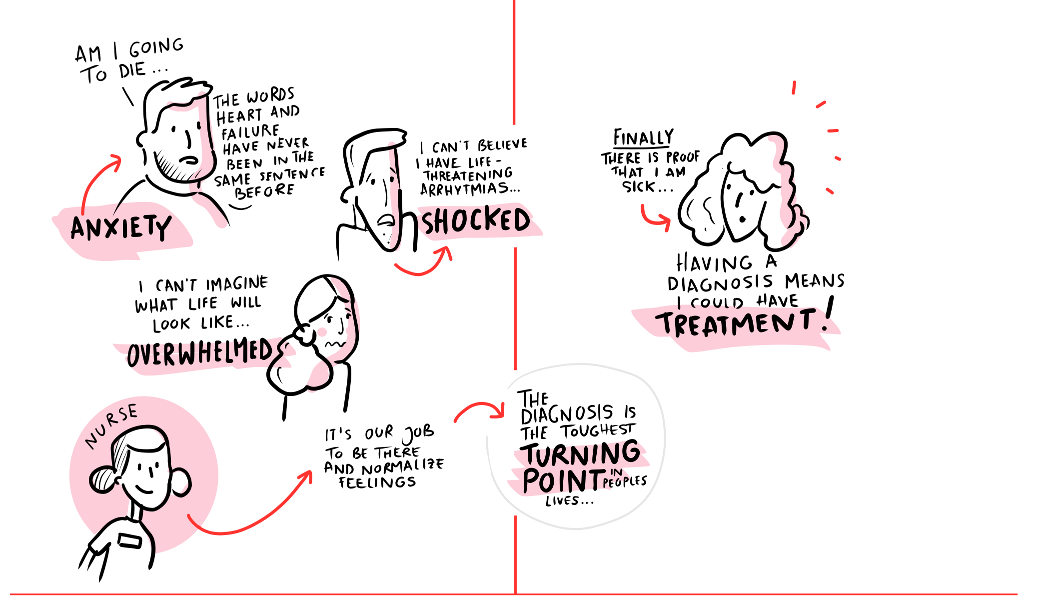
Over the next 38 years had a number of surgeries and found ways to live with

Living together with heart disease

02 The diagnosis

Initial Feelings

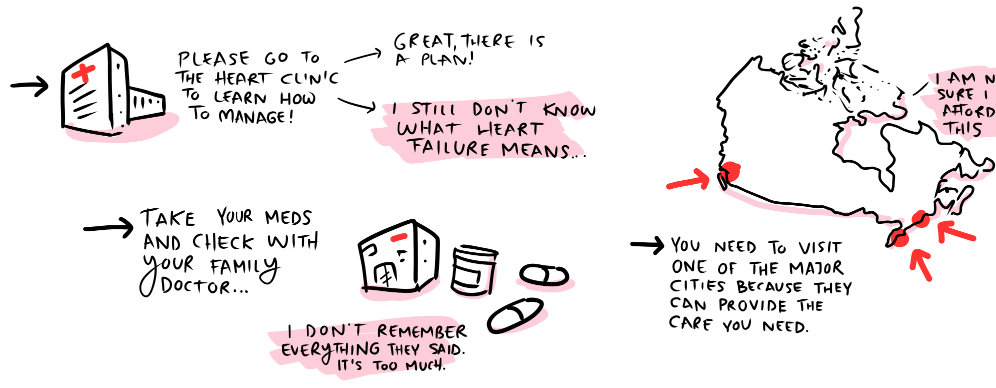
Secondary feelings



Education (What does this mean?)

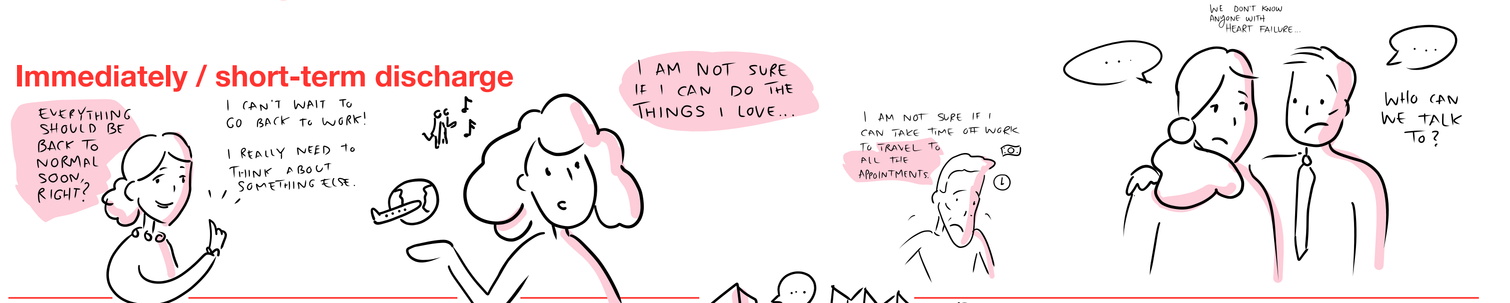
Everyone wants to know whats going to happen next

Discharge



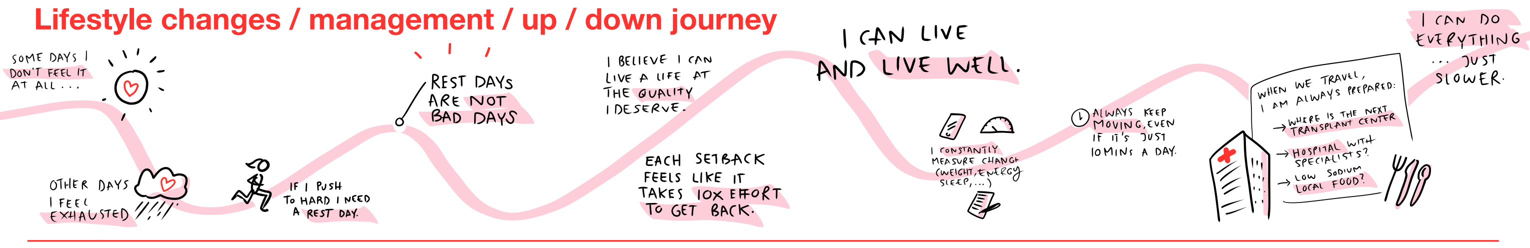
03 Living with heart failure

Immediately / short-term discharge

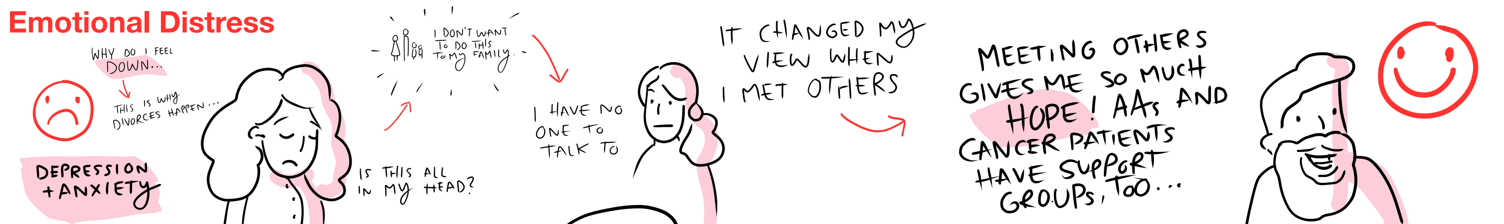


Heart clinic / appointments

Lifestyle changes / management / up / down journey

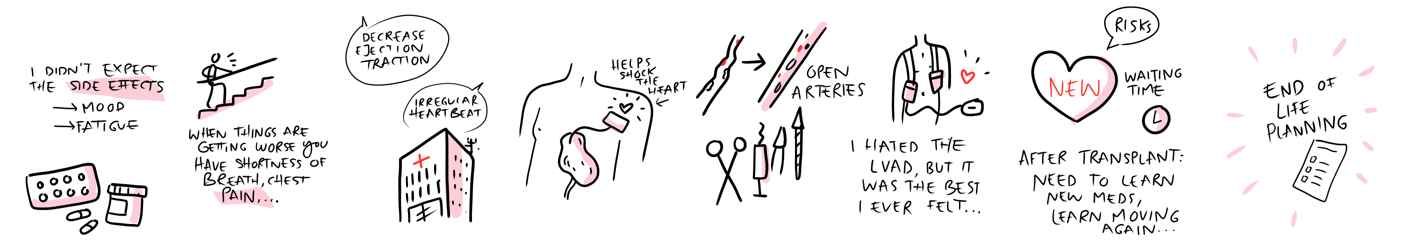


Emotional Distress



Family / Community Support

Progression of treatment



Medication

Good / bad days

Go to hospital

ICD

Surgeries

LVAD

Heart Transplant

End of Life

Opportunities Ahead: Emerging themes for positive change

Opportunities Overview

Exploring ways to educate, transform, and empower people living with and caring for people with heart failure.

While conducting the interviews with patients, caregivers, and healthcare professionals, seven themes for positive change emerged. **The themes include:**

01 Raising awareness for heart failure

02 Importance of mental health support throughout the journey

03 Helping people live the life they want after diagnosis

04 A more empathetic, informed, and empowered discharge experience

05 Improved access to care

06 Building communities around heart health

07 Transforming healthcare culture in Canada

Within each of the seven themes for change, we crafted a series of “How might we…?” statements to spark the conversation for bringing people together to tackle these challenges, ideate solutions, and design the desired experiences to improve quality of life.

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> “People assume it’s only for the elderly. Anybody could get it, no matter who you are.”
>
> HEART FAILURE PATIENT

01 Raising awareness for heart failure

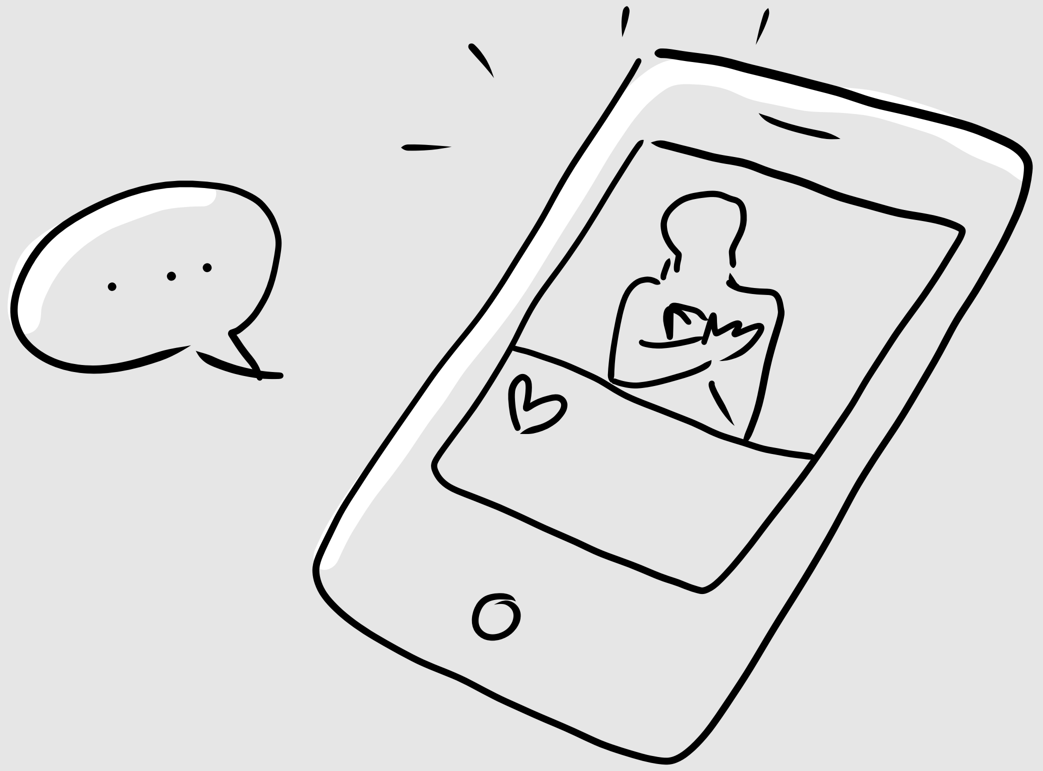
Heart failure is an invisible disease

All patients, caregivers, and healthcare professionals we spoke to agreed that heart failure is an invisible and silent disease that can affect anyone, from a two-year-old child all the way to an eighty-year-old woman. Even people diagnosed with later-stage heart failure can look fine and ‘normal’ in the eyes of the public; onlookers may even wonder why “someone so young is walking so slowly.”

Tendency for misdiagnosis or delayed diagnosis

Since heart disease and heart failure can present as invisible, we heard many similar stories of patients who felt they had been misdiagnosed or had a delay in their diagnosis when showing early signs and symptoms. It was very common to hear of patients searching for a second medical opinion when their initial treatments weren’t working or their symptoms were getting worse. Some patients even admitted themselves to the hospital and refused to leave until there was an answer to why they were experiencing early signs and symptoms. Some patients felt their care might have been delayed because their doctors weren’t able to diagnosis early enough.

“My care was delayed for 20 years because I wasn’t diagnosed at the beginning.”
HEART FAILURE PATIENT



Opportunities:

- How might we increase the public’s awareness of heart health and heart failure —as it can affect anyone, young and old?
- How might we increase awareness for the signs and symptoms of heart failure?
- How might we get testing for heart disease earlier on?
- How might we detect the signs and symptoms earlier for those more susceptible to heart failure?
- How might we increase the conversations about heart failure?

02 Importance of mental health support throughout the journey

Raising awareness for mental health

We heard over and over again from patients and caregivers about the importance of and the need to raise awareness for mental health support and services. Often, the physical signs and symptoms related to heart failure are given attention, but not the mental and emotional challenges. Caregivers have also shared how the emotional challenges and depression can create a lot of despair for patients.

“The number-one need is mental health support.”
CAREGIVER

Validating the emotional feelings

In moments where patients feel “low,” we need to acknowledge that their feelings, thoughts, and experiences are real. Some patients wished for healthcare professionals to validate their feelings and emotions so they could feel safe and heard.

“I wish they treated us like it’s not all in our head. We need to feel safe.”
HEART FAILURE PATIENT

Improving access to mental health support

When asked, 90 percent of heart failure patients said they would use mental health support/services if it was offered and available. Healthcare professionals also agreed that mental health support is an amazing but scarce resource for patients, and that is non-existent for caregivers and family members.

Opportunities:

- How might we raise the awareness and conversation about mental health?
- How might we normalize the feelings patients have?
- How might we recognize the signs for mental support earlier?
- How might we improve access to mental health care?
- How might we empower patients or caregivers with the tools for emotional and mental self-care?

03 Helping people live the life they want after diagnosis

Increasing education around the journey ahead

We heard strongly from patients and caregivers that there is a life living with heart failure – you can live and live well. Often, the uncertainty of the journey can cause distress, trauma, and a feeling of limitation, as patients may feel they can no longer participate in the activities they love.

“The goal has to be to empower patients to take action for their care.”
CAREGIVER

Lifestyle management education

Patients have found different ways to self-manage their lifestyle (exercise, diet, medication, work, and fun) and there is an opportunity to share and try different management strategies. Patients also believe it’s important to understand and monitor the difference between how they feel on a good day, rest day, or bad day. There is also a wish to learn more about medication and the potential side effects.

“There is lots we can do to improve life; it just needs to be explained.”
HEART FAILURE PATIENT

Patient-driven resources

We learned that patients have already collected a wealth of knowledge, such as ways to improve lifestyle management, recommendations for accommodations for hospital appointments, or even marking down the closest hospital or heart specialist when travelling. There is also a need and a wish for all these resources to be created, shared, and communicated in a way that is easy to understand.

Opportunities:

- How might we help patients ‘see’ a quality of life ahead?
- How might we empower patients with tools and resources to take ownership of, track, and monitor their health?
- How might we share best practices for lifestyle management (e.g., medication, exercise, diet, etc.)?
- How might we enable patients to design patient-led resources?
- How might we empower patients to believe in the possibilities and have hope they can live the life they desire?

04 A more empathetic, informed, and empowered discharge experience

Feeling informed on what to do next at discharge

Patients felt they had mixed experiences during their discharge from the hospital. Some patients shared how hard it was for them to understand 'medical jargon' and wished the language used was more for laypeople. Also, when different doctors or other healthcare professionals shared different or competing advice, this led to a feeling of panic or uncertainty. In addition, we heard that there is limited to no information shared with caregivers — even if there were resources or services out there to support them in the journey, they were unaware.

The healthcare professionals we spoke to believed patients need to be educated and informed about their care options, services, and resources available. Healthcare professionals believe the patient's ability to engage in their own healthcare will help them understand how to self-care, which will lead to better outcomes.

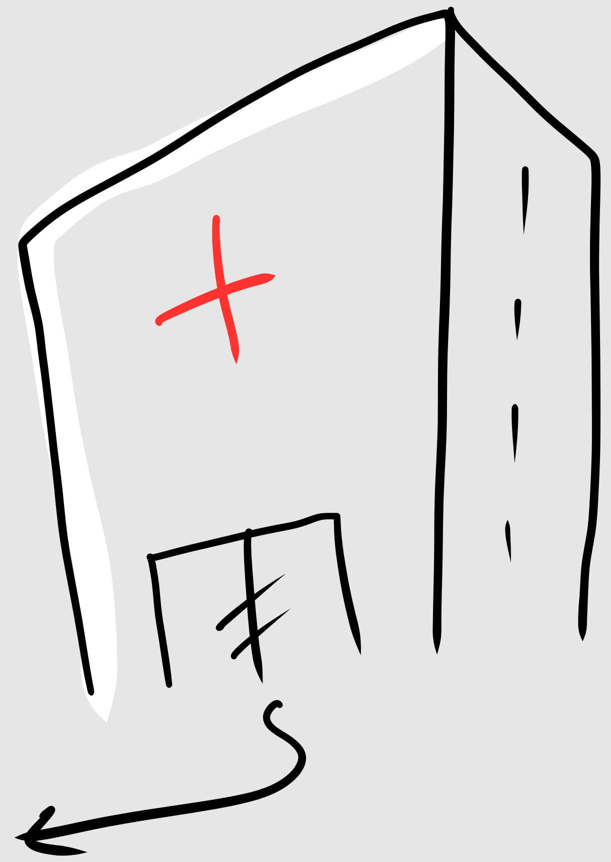
The possibility to have a more customized discharge plan

Patients voiced that they would like to have a more customized discharge plan that works for their unique health and lifestyle. A discharge plan for someone who is younger and more physically fit may include treatment or advice which is different from that given to someone who may be older or sedentary. There is a wide range of experiences, and care should be more individualized.

Both patients and healthcare professionals shared how providing access to patient medical records could empower the ownership of care. When patients can see how their actions and behaviours (such as taking medication or exercising) can improve their health status (such as the ejection fraction), this combination could lead to positive reinforcement.

More empathy and openness to asking questions

Both patients and healthcare professionals felt patients should ask more questions and be their own advocate for the care they need. Healthcare professionals wished patients would not be afraid to call the doctor or nurse when they don't feel well. Yet, patients felt they didn't want to ask more questions because they felt they were being a nuisance.



Opportunities:

- How might we help patients understand all the resources that are available once they are discharged?
- How might we help patients understand and translate their discharge plan to daily activities?
- How might we help patients monitor, track, and act according to their individual goals and lifestyle?
- How might we give patients the feeling that they can ask questions when they don't understand?
- How might we help patients take ownership of their care?

05 Improved access to care

Access to a multi-disciplinary team

Heart failure encompasses a variety of treatments and therapies including medications, devices, mental health, cardiac rehab, and nutrition. As such, patients, their caregivers, and healthcare professionals all expressed the need for a holistic approach to heart failure. Successful care requires a coordinated approach and plan that includes real-time access to services, information, and support.

Reduce the need to travel long distances for care

It is not uncommon for patients who live in smaller cities or rural areas in Canada to commute to the bigger cities (such as Vancouver, Toronto, Montreal, or Ottawa) to receive the care they need. The frequent commute can create additional financial stress, as patients may need to take time off work and spend money on travel and accommodation. One healthcare professional even shared her concern that some patients have to drive four to six hours to see a specialist for only one hour. There is a need and wish to explore digital offerings to offload the stress of long commutes.

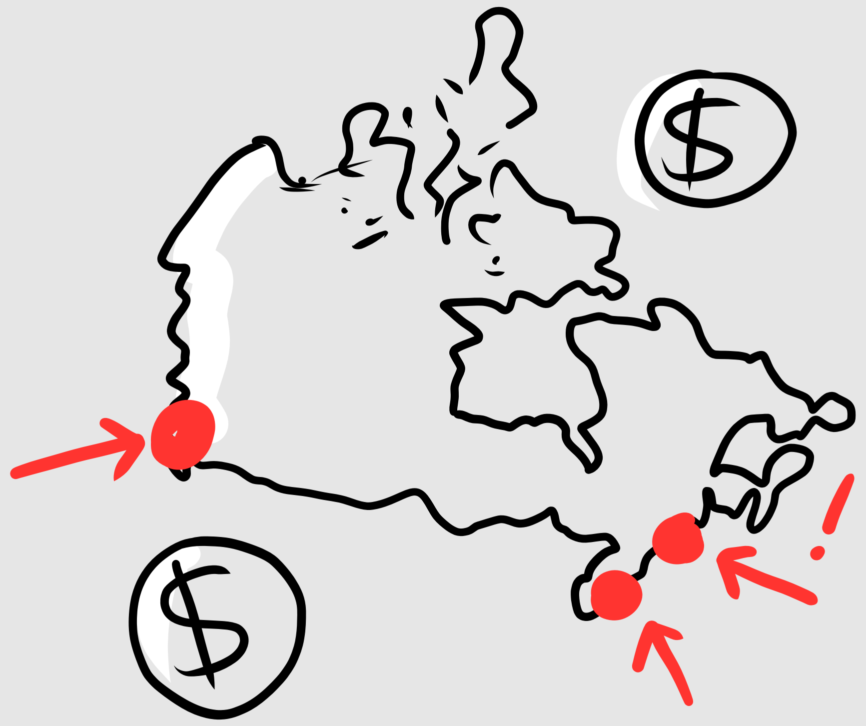
Access to supporting services

Beyond reducing the need for long commutes, we also learned having supporting services such as ride-sharing services could make it easier for patients to travel to the appointments, since not everyone can drive, owns a vehicle, or has access to public transportation. Even services which provide or offload the costs for accommodation when seeing a specialist could benefit. Patients and family members shared openly how decreasing the financial burden would improve their quality of life.

Easier communication channels to healthcare professionals

The healthcare professionals we interviewed encouraged patients to have more frequent touch points or communication. These healthcare professionals felt they could ‘jump in’ and help when things don’t feel normal. Yet, some patients felt they were not empowered to reach out. Sometimes the waitlist to see the specialist created a barrier to access.

> “Some patients die before they get to see the doctor because the waitlist is so long.”
> HEART FAILURE PATIENT



Opportunities:

- How might we use technology to provide care which doesn’t require being physically present?
- How might we find ways to provide supporting services for people to reach their appointments?
- How might we decrease financial burden or provide aid for those in need?
- How might reduce the barrier to contact healthcare professionals?
- How might we build a team of professionals around patients?

Bring communities together for patients and caregivers

We learned patients and caregivers are seeking ways to learn, share, and connect with each other, due to the limited resources offered within the Canadian healthcare system. Healthcare professionals have even voiced the need to have patient-to-patient support, perhaps in the form of mentor/mentee scenarios — as long as there is a shared place for patients and caregivers to talk to each other.

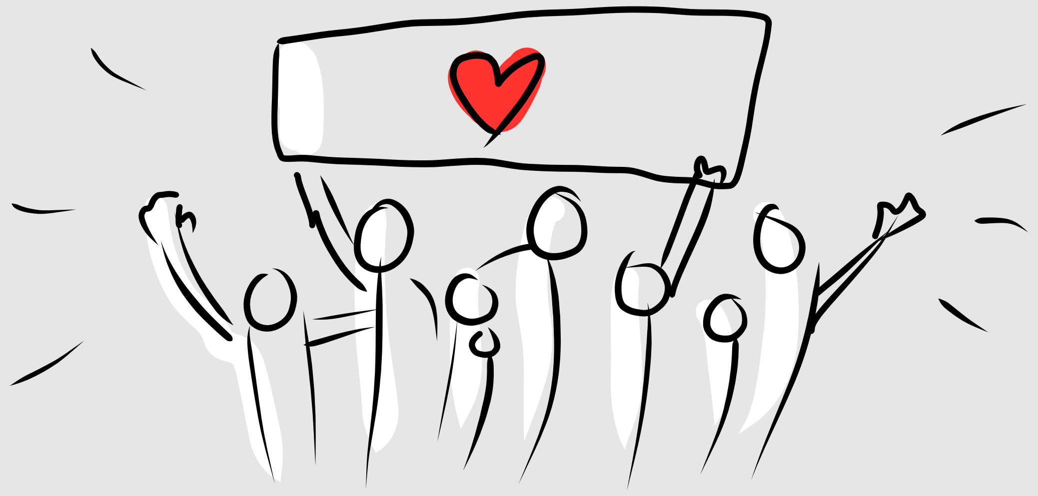
After being diagnosed with heart failure, families have voiced that they didn't know anyone with heart failure and there was no caregiver or family support, even after a transplant. It was also hard for caregivers to ask for support, as their loved ones were already dealing with so much stress and anxiety.

"I wished someone had checked on me. My husband was dealing with a lot and I didn't want to add to the stress."
CAREGIVER

Design more events to share and converse around heart health

One family we talked to shared how going to a heart health convention dramatically improved their quality of life. Attending events helped them learn about the latest treatments and therapies. They even saw their doctor at the event, which empowered the family to ask questions and try the new treatments they learned at the conference.

"They need to invite caregivers and patients to more conferences. If we didn't go, we would not have learned about the medications."
CAREGIVER



Opportunities:

- How might we find more ways to connect patients with each other?
- How might we find more ways to connect caregivers to each other and available resources?
- How might we design more events/gatherings for the community to come together?
- How might we involve all parties in important conversations?
- How might we make it easy for the community to find and connect with each other?

Enabling a listening culture

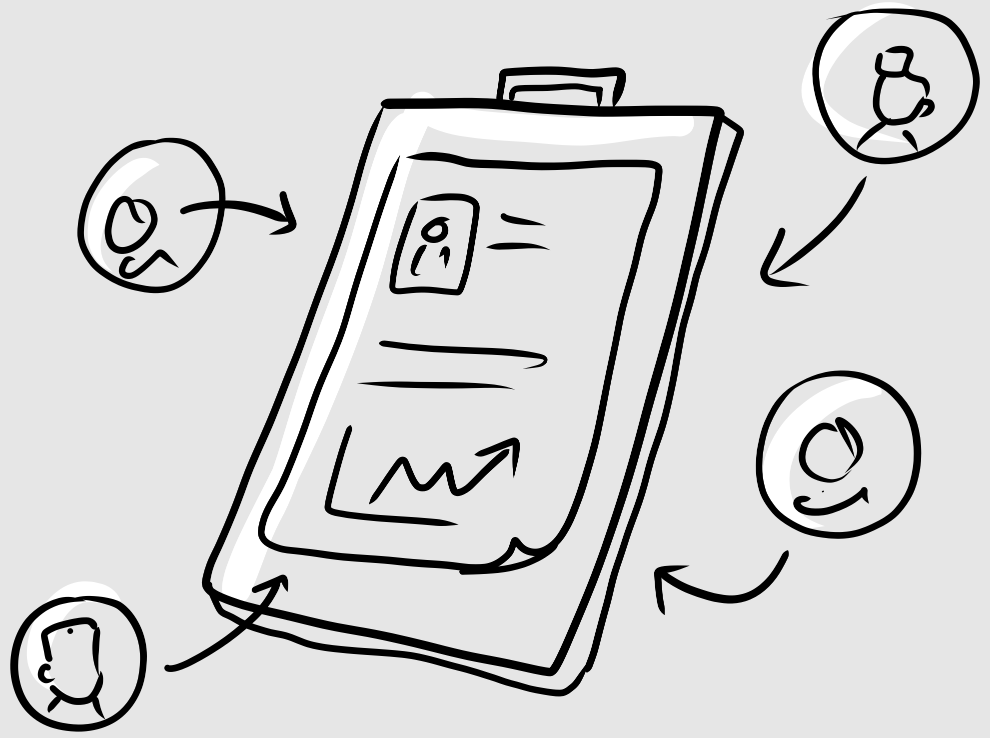
When heart failure patients shared their stories and the experiences they had with going to the doctor, some patients felt their treatment was delayed because health professionals didn't 'really' listen to how they felt. The patients also felt they didn't want to keep asking questions to the doctors because they didn't want to be a nuisance. Having a heart failure diagnosis was a positive moment for them, justifying the way they felt. Patients wished for more empathy, for doctors to ask questions, and relationship-building skills.

"For so long, no one was listening. Having a diagnosis justifies the way I feel."
HEART FAILURE PATIENT

Patient-centred care is not a one-size-fits-all approach

The healthcare professionals we spoke to believe we need to transform the culture of care around the patient's goals — meaning the patient defines what's important to them, and the role of healthcare is to make sure patients make informed decisions, and own their mortality. We learned that the healthcare system in Canada is still operating in a historical model of value in which professionals are incentivized by time — keeping patients out of the hospital or alive.

"If you are paid by the number of people you see, there is little incentive to spend more time to talk."
HEALTHCARE PROFESSIONAL



Opportunities:

- How might we begin conversations around patient goals?
- How might we show that empathetic care can improve the patient care experience?
- How might we move to patient-centred care vs provider-centered?
- How might we design new ways to incentivize healthcare professionals?
- How might we normalize relationship-building with healthcare professionals?

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