

My Marvellous Guide to 'Walking a Day in My Shoes'

A Patient's Story



Authored by patients like you



HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



The Pumping Marvellous Foundation would like to again thank our Patient Educators who not only suggested this marvellous guide, but also shared their journey of being diagnosed with heart failure and the challenges that they face.

Relationships with family and friends can be frustrating and even damaging as a result of not being able to fully understand the challenges of living with heart failure. This guide, therefore, seeks to explain what living with heart failure is like for the patient, seen through their eyes, in their shoes.

People with heart failure tell us they experience a variety of symptoms, problems and issues whilst living with heart failure. These can take the form of a physical or psychological nature. Not every patient with heart failure feels all of these and some may experience them constantly or occasionally. However, if you know someone with heart failure, then reading on may give you an invaluable insight into what it's like living with heart failure, from diagnosis to living each day.

PLEASE NOTE: this booklet should not replace and/or substitute the interactions with and advice you are given from your Healthcare Professional. If you have any concerns about your condition then do discuss them with your Healthcare Professional at the earliest opportunity.

What is heart failure?

The heart consists of muscles that pump blood around the body. With heart failure, the heart is not pumping correctly and is often enlarged because it is having to work extra hard.

Generally there is a reason why the heart is not pumping correctly. The vast majority of the time this is due to the heart muscle being damaged because it is getting a poor blood supply. This can happen after a heart attack, or when someone's had high blood pressure, which has affected the heart.

Other causes include:

- A virus has affected the efficiency of the heart
- The heart's rhythm isn't normal
- Genetically, the heart is not structured as well as it should be
- The valves in the heart are damaged
- Excessive alcohol intake
- Recreational drugs
- Some chemotherapy medication
- In rarer cases, there is a form of heart failure associated with pregnancy

Sometimes, we just don't know what the cause is. This is called idiopathic.

So how bad are things?

We are aware that heart failure is a serious condition, however, the important thing to remember is that there is now a good understanding of it and there are a number of treatment options available to help manage it, from medication to cardiac devices. Like many other conditions, the relentless challenge of discovering newer treatments is always on the horizon.

Emotions of being diagnosed with heart failure

Heart failure patients tell of the range of emotions they experience when first being diagnosed with heart failure and the impact that can have with life going forward.

It messes with your head.

It robs you of your confidence, you withdraw into yourself.

It changes your values.

It means you can no longer plan even simple things, like trips or holidays.

It forces you to re-evaluate your goals and ambitions.

You can become obsessed with the condition.

You worry so much you forget to live.

You become scared of the unknown.

You avoid making memories.

You grieve for your former life, career and relationships.

You realise you are now different, you are no longer seen as or feel normal.

Coming to terms with it

Our Patient Educators tell us that these feelings and experiences are a means of coming to terms with your condition. So how did they move forward and turn negative emotions to positive solutions? Understanding and sharing with the person who has heart failure may help you both.

Dealing with a diagnosis of heart failure manifests itself in many ways with many different people. People deal with aspects of their life in different ways, some more acceptable than others.

This may be the first time a person may have had to deal with a real change to their life. Here are some of the comments from the authors.

“Deal with the frustration, you haven’t failed, you need to readjust.”

“Acceptance is the stage before you can move forward.”

“Don’t look back in anger, see this as an opportunity, a second chance to form a different and even a better life.”

“You may freeze, or even hit rock bottom, before you begin to come back up, but you will arise again.”

“A positive attitude helps you to heal.”

“A certain amount of anxiety is normal, it is when that anxiety overwhelms you that there is a problem. Talk and share, consider counselling, investigate it and see if it is for you.”

“Don’t worry about the things that you cannot change, but change the things that you can.”

Nick's Story

Nick explains how he came to terms with his diagnosis and how he moved forward.

"For me, there were two ways of dealing with heart failure and I must emphasise that the better the team of people you have around you, the better. The team of people should also have an appreciation of your condition."

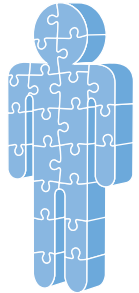
The first way

"Look at life as being one big jigsaw. Before my diagnosis of heart failure my jigsaw was complete. I don't mean that things couldn't have been better but there was a level of contentment, there was definitely room for improvement, believe me. When I received my diagnosis my jigsaw was shattered, blown into its constituent pieces. So how did I go about building the new me?

After the initial diagnosis, I set about using my life skills to carefully locate the corners, edges and then working with the colours to start to construct my new jigsaw. You can relate the corners to things like:

- **Survival – I wanted to live, nothing more.**
- **Belief – I believed in myself.**
- **Attitude – With the right attitude I could do anything.**
- **Knowledge – Use my life knowledge to help.**

I created a new me. With a big scoop of HOPE I became the Jigsaw Man. My new me was set and although I occasionally needed to add new pieces, my new normal was created."

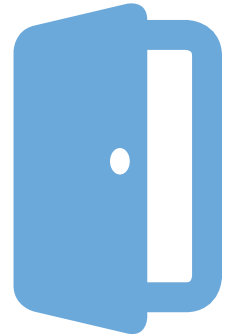


The second way

"Have you ever seen *Monsters Inc*, you know the famous Disney Pixar film about children and their dreams? If you haven't, then watch it, it's brilliant.

Relate this to the film. In my mind I had a special key, it was my key and nobody else's key. All the bad things that affected me because of my diagnosis with heart failure were locked away gradually over time behind this door. My key keeps this door shut and keeps all the bad things at bay. Occasionally, when things happen in my life, my symptoms get worse, my jeans get tighter, I get more tired, I know how to keep this door locked. It's not just having the key, but it's knowing how to turn it; and knowing how to keep it shut. However, the funny thing is that when I ask my team to help me keep this door shut, they don't know they are doing it and that's the power of teamwork.

I am the leader of my condition, my team help me lead."



Common Challenges

Heart failure patients may also experience many physical challenges, many of you will see them just as everyday activities that we undertake effortlessly and we take our ability to do so for granted. For people with heart failure, some of these activities are impossible to do or they result in breathlessness, fatigue or extreme weariness.

- Showering, washing your hair, shaving, getting dressed.
- Standing and cooking a meal, often resulting in destroying your appetite. Eating a meal can leave you exhausted.
- General household tasks, particularly vacuuming, bending down.
- General gardening, especially mowing and weeding.
- Walking, occasionally only short distances, particularly on an incline, especially stairs.
- Extremes of weather, either too hot or too cold.
- Medication for heart failure may result in side effects leading to additional weariness, dizziness and frequent visits to the toilet.
- It can affect your sex drive, due to lack of confidence or physical incapacity.
- For women who are menstruating, it results in additional weariness.

Many heart failure patients will attempt to manage these symptoms by adopting techniques to reduce their impact.

- They will undertake these activities, but slowly pacing themselves through them.
- Sometimes people can deal with them, other days they struggle or can't. It's the roller coaster of heart failure.
- Patients will develop keen organisation skills to achieve their goals.
- They may see their condition as a positive opportunity to reassess their goals, opportunities, general health and life ambitions.

Family dynamics may have a bearing on how heart failure impacts on both an individual and their role within the family. For further support for carers, please see our "Marvellous Guide to Caring for Heart Failure Patients" which you will find on our website in the patient academy section.

Our Patient Educators wanted to bring this out into the open because they themselves feel it and the community also feels it.

A person's ability to self-care relies on many aspects, however, we know that being positive and having positive people around you is a crucial element to managing this condition, not only from the patient's point of view but also their family, friends and acquaintance's point of view.

People with heart failure as well as their family and carers see great value in talking to each other. Come and join our Facebook group where your conversation will be in private and only with people with heart failure or those helping them live better lives.

Just search "Help for Hearts" on Facebook.

Understanding

It is often difficult to understand the emotions that people with heart failure feel, what you see, as a family member or friend, may not reflect what the patient is experiencing. Sometimes you may never see it as they have learnt to hide or disguise it from you.

You're so tired, I get tired...

...but this is a different form of tiredness.

I offer sympathy...

...what I need is empathy.

Why is it that some days you are worse than others?

I have good days but also bad days and I may be better in the morning and worse in the afternoon.

You look OK...

...what I look like on the outside doesn't reflect what I feel on the inside.

You are still you...

...yes I am but I am not the old me I used to be.

Why do you sometimes want to be alone?

Because I sometimes need space.

If you have any concerns or questions, get in touch with
Pumping Marvellous.



*Another Mini Toolkit by The Pumping Marvellous Foundation
Crowdsourced information from REAL patients.*

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heart failure aware



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help for hearts (closed support group)



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