

My Marvellous Guide to Heart Failure

*Be a 'marvellous'
heart failure patient*

My Marvellous Guide

“The end to *those* questions”

Endorsed by the the patient board of the
Pumping Marvellous Foundation.



Welcome to your Marvellous Guide to Heart Failure.

*We hope that it helps to answer some of
the questions you have about heart failure.*

In memory of Les Simmons

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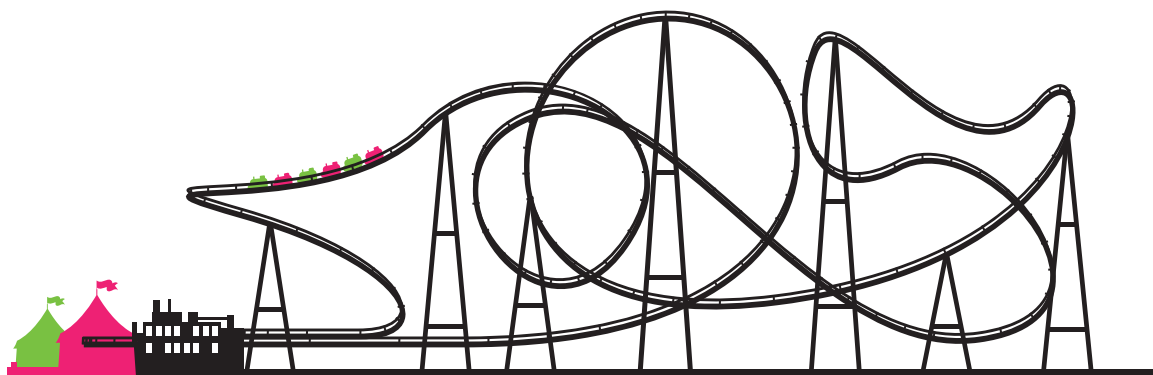
HOW TO BE A MARVELLOUS HEART FAILURE PATIENT

1.1

The End To All Those Questions

Wouldn't it be great to find an end to all those questions about how to have a better life whilst living with heart failure? To discover how to be a 'marvellous' heart failure patient whilst knowing why and how to get to grips with your condition?

As authors of this publication, we believe we have put together a comprehensive guide that will help you to become a 'marvellous manager of your heart failure'.



The Marvellous Guide is designed to smooth out the ups and downs of managing your heart failure.

AN INTRODUCTION

1.2

Welcome

This 'Marvellous Guide' to heart failure (don't you just hate that word failure?) has been created by our patient community both locally to the University Hospitals of North Midlands, nationally by our patient community in the UK and internationally by our wider community all over the globe. They believe that if they had had a resource like this, it would have been a lot easier to manage their condition.

The way the guide is constructed and the information it contains has all been at the direction of the people who know about living well with heart failure, the patients and their carers.

You may wish to work your way through the whole guide or read the parts that you want to learn about. Not everything in the 'Marvellous Guide' will relate to everybody, however, we are willing to bet that there will be parts for everyone.

Please note: This booklet should not replace and/or substitute the interactions with and advice you get from your healthcare professional, and if you have any concerns about your condition you should discuss these with your healthcare professional at the earliest opportunity.

ACKNOWLEDGEMENTS

1.3

Our Acknowledgements

We would especially like to thank those patients and carers, wherever they are, for their input into what sometimes can be a real roller coaster of an experience. We would like to specifically thank the patients and carers of Stoke and the surrounding area who helped us design and pioneer how heart failure patients and their families live a better life with their condition.

Our thanks also go to the marvellous team led by Dr Dargoi Satchi, Ash Patwala and Diane Barke from the Royal Stoke University Hospital who have been open-minded enough and marvellously passionate about improving the quality of life of heart failure patients and those affected by heart failure. As soon as we met Dr Satchi, we knew he would be up for it!

We would also like to thank Novartis for their support in supplying us with a philanthropic grant to enable us to produce this guide.

WHO ARE PUMPING MARVELLOUS?

1.4

Pumping Marvellous

The Pumping Marvellous Foundation (PMF) is the UK's heart failure charity. It was founded by a heart failure patient whose experiences whilst rehabilitating have shaped the Foundation's goals and principles of a patient-centric charity focused on improving patients' lives.

The beneficiaries are all people who suffer from heart failure together with their family and friends. The Pumping Marvellous Foundation's goal is to deliver HOPE to its beneficiaries through the facilitation of better outcomes by cross-working and advocating the beneficiaries at a local, regional, national and international level; working hand in hand with commissioners and clinicians to deliver better pathways and be the patient voice of progression. Our services include patient driven solutions, created by patients, guided but not policed by the Foundation, available in printed and online format. The Pumping Marvellous Foundation is funded through donations and fundraising by individuals, support from the NHS and charitable organisations together with corporate sponsorship.

All of the nearly 900,000 heart failure sufferers, their families and carers in the UK qualify for assistance. The Foundation has no bias towards specific sub groups. Heart failure is an umbrella of individual conditions and spans across all socio-economic groups therefore our support is varied and tailored to the specific needs and requests. The Foundation is headquartered in Lancashire and has a network of regional volunteers across the country who deliver the core messages and actively participate in campaigns, publications, distribution of literature and local relationship building. We have a strong online presence which enables the Foundation to reach out and catalyse progression in heart failure care with stronger engagement with clinicians and sufferers and their families.

The Four Objectives

- ♥ Help heart failure patients, their carers and families to manage their condition on a daily basis. If you know what you are supposed to be doing then doing it doesn't seem to be so challenging.
- ♥ Raise awareness to the general public and primary care functions like A&E and GPs to the symptoms of heart failure. The quicker the diagnosis, the better.
- ♥ Optimise the team of people who surround the patient's care (Multi Disciplinary Team).
- ♥ Conduct innovative and engaging methods to get people to think about heart failure differently.

WHAT WE GET INVOLVED IN

1.5

♥ Awareness

Drive awareness of heart failure through the general public, healthcare professionals, politicians, policymakers, commissioners and academia.

♥ Support

We offer support to sufferers of heart failure, their carers and family.

♥ Advocacy

We represent the opinions and needs of heart failure patients across the UK. We give the patient a voice where representation is needed, at the top table.

♥ Self-management

We offer patients and families the help to self-manage their condition through coaching and developing them through the peaks and troughs of managing heart failure.

♥ Partnership

We work with clinicians and decision makers as to how the patient voice can improve care to people suffering with heart failure.

♥ Access

We work with all stakeholders in heart failure to ensure that the patient's need to access the latest therapies is heard.

GET IN TOUCH

1.6



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www.pumpingmarvellous.org



[heartfailureaware](https://www.facebook.com/heartfailureaware) (open)



[helpforhearts](https://www.facebook.com/helpforhearts) (closed support group)



[@pumpinghearts](https://twitter.com/pumpinghearts)



www.travelinsuranceforhearts.org.uk

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helpforhearts (closed support group)