

# Supportive Palliative Care in Heart Failure - what may matter to you.



**Authored by Patients  
and Specialist Nurses**

HELPING PEOPLE LIVE BETTER WITH HEART FAILURE



# WELCOME TO THE PUMPING MARVELLOUS FOUNDATION

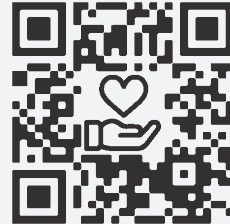


We would like to start off and thank our team of Patient Educators who have helped create this guide. They have given their insights into a positive life they have achieved because of the care they have been given. Also many thanks to the Specialist Heart Failure Nurses who have given their time to help create this valuable resource. Thank you also to the wider patient community who, on a daily basis, give peer to peer support and share their experiences of what it is like to live with heart failure. If you search "Help for Hearts" on Facebook you too can join the community, or just scan the code below.

**Nick Hartshorne-Evans** - CEO, Pumping Marvellous Foundation

**Angela Graves** - Chair, Pumping Marvellous Foundation, Consultant Nurse in Heart Failure

**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.



# Your Journey

From the moment you're diagnosed with Heart Failure you're opened up to a whole new world. Changes seem to come at you all at once. You will experience new terminology, tests, scans, lifestyle changes and a bewildering array of medication. You'll also hear many people's opinions on what you should be doing, so as you can see there's a lot to take on board and it's easy to feel overwhelmed. At the Pumping Marvellous Foundation we believe that everyone needs a helping hand, wherever they are in their journey.

Our Patient Educators have shared their thoughts on Palliative Care in this guide. Some received little or no information about their condition or how it was to be treated. Others say they just couldn't take in what was being said, due to shock or because they were so unwell. You may wish to know everything, right from the beginning, or for others the bare minimum of information is all they feel they can cope with.

At the Pumping Marvellous Foundation we appreciate everyone approaches their diagnosis and management of their condition differently. This guide is here to support you in understanding what Palliative Care in Heart Failure may mean to you. Use the guide as an initial introduction to your Palliative Care, or an ongoing resource to support you with managing your Heart Failure. Managing your Heart Failure is important and our "Marvellous Big Pocket Guide to Heart Failure" is a great way of grasping some ways you can live well with Heart Failure. Ask your Heart Failure Nurse for a copy if you don't have one.



# SUPPORTIVE PALLIATIVE CARE



This Pumping Marvellous guide is designed to raise awareness, change existing perceptions and encourage the inclusion of Palliative Care to the overall management of Heart Failure.

## What is Supportive Palliative Care?

Palliative Care is a multi-professional approach that aims to enable people to live well following a lifelong diagnosis such as a Heart Failure. It should be considered alongside the very effective treatments we now have for Heart Failure, to support minimising any ongoing unmet physical, psychological, psychosocial and/or carer needs.

Contrary to existing beliefs, Palliative Care can be considered at any time following a diagnosis of Heart Failure, and may include end-of-life care as appropriate. It is important to know that Palliative Care has much more to offer throughout. Your Heart Failure and Primary Care Teams will address most of your Palliative Care needs.

Care for people who are approaching the end of their life is only one component of Palliative Care. Being offered Palliative Care does not mean end-of-life is approaching soon; rather, Palliative Care is something much broader and can last years.

## Let us think about Heart Failure and when Palliative Care is needed

Heart Failure is a syndrome, i.e., a collection of symptoms characterising an illness. With Heart Failure, these symptoms might include your body retaining fluid in your legs or abdomen (swelling), shortness of breath, or fatigue. These symptoms occur when your heart is struggling to pump or relax as it should to ensure enough blood, oxygen and nutrients are circulated around your body. Our Marvellous Pocket Guide to Heart Failure outlines reasons why you may be in Heart Failure and treatments for it.

Palliative Care may be considered alongside active Heart Failure treatments: as Heart Failure is a lifelong chronic condition, you will require medications and other treatments throughout. As with all long-term conditions, you are likely to experience periods where you feel as if nothing has changed, and at other times you may have periods where you feel less well. Most people are likely to need adjustments to their treatment plan in response to changes in their condition. This may include Palliative Care therapies to support any changing unmet needs. Palliative Care may also be considered alongside more advanced treatments such as mechanical support or cardiac transplant.

Supportive Palliative Care may be considered appropriate at diagnosis for some people to support initial unmet needs and/or complex decision-making, or it may be considered at any time during someone's illness, either because of Heart Failure or other co-existing conditions. You may feel uncertain about some treatments and care choices that you may need to think about along the way. The teams looking after you will help explain and support you, and your family, with decision-making throughout.

The key message here is that Palliative Care can be considered appropriate at different times during a person's lifetime, following a lifelong diagnosis such as Heart Failure. It might be helpful to think about Palliative Care as a cardigan that you wear when you are feeling less well and remove when you are feeling better. For some, this may happen several times throughout their lifetime, and for others, it may not be needed. You are unique, therefore your experiences will differ from others.

# What can Supportive Palliative Care offer me?

A goal of Palliative Care is to prevent/relieve suffering through early identification and assessment of physical, psychological, social, occupational, carer and unmet spiritual needs. Looking after the 'whole person' and those important to them in this way is known as a holistic approach. Practicing holistic Palliative Care ensures that problems and needs are assessed as they arise.

Palliative Care aims to support patients and families to live as well as possible, from diagnosis to end-of-life. It should be considered alongside all other therapies intended to improve and prolong life. The World Health Organisation suggest the provision of Palliative Care is a human right; therefore, it should be available to us all when needed.

## Managing expectations in preparation of change is part of Supportive Palliative Care

We plan and prepare for so much change in our life: marriage, birth, moving house, divorce, holidays; the list is endless. Yet we very rarely invest the same amount of time or effort in thinking ahead and making plans for the physical, psychological and general wellbeing changes that will inevitably happen to everyone during their lifetime.

Many of us will already be experiencing some physical, mental and general wellbeing changes due to illness, symptoms, ageing, slowing down and caring responsibilities. But how many of us can honestly say we were prepared for this change happening to us, or those around us?

This booklet has been designed to encourage you **to think more about what this change** would mean to you. It may be helpful to think about this using a 'What matters to me?' 'Who matters to me?' 'Why does it matter to me?' and 'When will it matter to me?' approach.

Everyone is unique. Therefore, this approach will vary from person to person. For example, some people want to read, know and discuss everything – whilst for others, being able to refer to the information at a time when it has more relevance to them will be more appropriate.

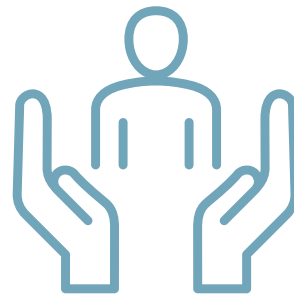
Heart Failure is a lifelong condition, which for many people can mean living well for many years. For others, however, uncertainty and prolonged periods of instability may result in poorer health and wellbeing.

Thinking about what matters to you, and more importantly, talking about this may help you establish your values and care preferences with your family and healthcare professionals. For some, this may include discussing what should and shouldn't happen to you when you become more unwell.

Any of the healthcare professionals managing your care are part of the team involved in providing Palliative Care. For most people, these teams are familiar to you and will support you in your needs as they occur. For many, this is your Heart Failure and Primary Care Team.

On occasion, it can be necessary for Specialist Palliative Care Teams to provide additional support to your Heart Failure and Primary Care professionals. Your team (either the heart or primary/community doctors/nurses) may suggest this, or you can ask them if you think you might benefit from this. Your local area may also have specialist services that you can self-refer to.

Hospices and Specialist Palliative Care Teams have expert knowledge about therapies and treatments that may bolster your primary medication to help with intractable symptoms (for example, breathlessness/fatigue). Some services offer access to complementary therapies or day services, respite or admission for symptom management. Provision of this varies across the UK as most of these services are charitably funded. Hospices offer Palliative Care as well as end-of-life care that can take place over years – therefore your team may suggest this option as a means of addressing ongoing unmet needs and to enhance your quality of life.





## Advanced Care Planning (ACP)

ACP is a part of Palliative Care that involves thinking ahead about your health choices if you were to become more unwell. ACP is for everybody, irrespective of having illnesses like Heart Failure, and covers a breadth of topics such as: resuscitation preferences; advanced decisions to refuse treatment; setting up a power of attorney to manage health/financial needs if incapacitated; planning funerals; making wills; and thinking about where we want to be cared for if we are either sick, approaching end-of-life, or when we die. This informs our families, carers and healthcare professionals about our wishes – moreover, ACP is flexible and you can change it in line with your views (referring to the ‘What matters to me?’ approach is effective here).

Healthcare professionals note that many people don’t consider these important topics while they are well. This means decisions are having to be made in a period of crisis which can cause distress. Sadly this can sometimes mean patients and families don’t get the choice of care and support they want. Discussing care choices when you are well and more able can help to inform important decision-making for you and your family, whether at a time of need or at end-of-life.



# Patient Quotes

"I think the main point for me when producing a Palliative Care booklet is to get the point across that it doesn't mean you are literally about to die. Sorry sounds harsh but I think that's what a lot of people think." - Julia

**"Being referred to Palliative Care, understanding why I was being referred, and whether it means death is approaching quickly, or how being palliative could affect any future treatment?" - Michelle**

"What matters to me is that I know exactly what being referred to Palliative Care means for me and my family. Palliative Care means to me that I need extra support." - Donna

**"Palliative Care if and when, planned in advance, so it happens as soon as you need it — no fighting, no shouting, no getting knocked back when you're already down and sinking. A smooth transition." - Gary**

# Patient Quotes

“My quality of life continued as much as possible in this final chapter of my life. I would want to know that my wife and family understood what was happening and that we had quality time together. I would hate it to be a predominately sad time, I would want to create happy memories.” - Stephen

**“Sometimes the choice between painful, unguaranteed success, invasive treatment, or as good a quality of life as possible for an undetermined time is difficult to choose. However, I hope Palliative Care, just like my Heart Failure Team will be there for me, if further treatment isn’t an option or choice. This is what matters to me.” - Dan**



## Useful Contacts - Patient Organisations and Related Services

### [www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)

The UK patient-led Heart Failure charity, the go-to site for both patients with Heart Failure and carers looking after them.

### [www.cardiomyopathy.org](http://www.cardiomyopathy.org)

Website to support patients with heart muscle disease.

### [www.ageuk.org.uk](http://www.ageuk.org.uk)

Website with a range of information and services for the older person.

### [www.carersuk.org](http://www.carersuk.org)

Website of organisation for carers.

### [www.macmillan.org.uk](http://www.macmillan.org.uk)

Organisation website that supports not just those with cancer but for those requiring Palliative Care services.

### [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Information on a wide range of issues and details of local branches for appointments.

### [www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)

Details as to how to apply for a blue badge enabling free parking.

### [www.relate.org.uk](http://www.relate.org.uk)

Organisation that provides information and counselling services for couples.

### [www.nhs.uk/Pages/HomePage.aspx](http://www.nhs.uk/Pages/HomePage.aspx)

Link to various NHS services.

### [www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11](http://www.nhs.uk/Service-Search/Care-providers-and-care-at-home/LocationSearch/11)

Information for carers.

### [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

Information in regards to current information benefits.

### [www.acas.org.uk](http://www.acas.org.uk)

Information of both employers and employees for training and mediation.

### [www.gov.uk/pensions-advisory-service](http://www.gov.uk/pensions-advisory-service)

Pension advice, both state and private.

### [www.gov.uk/contact-jobcentre-plus](http://www.gov.uk/contact-jobcentre-plus)

Employment advice and opportunities.

### [www.samaritans.org](http://www.samaritans.org)

Agency providing immediate support and crisis management.

### [www.moneyadvice.service.org.uk/en](http://www.moneyadvice.service.org.uk/en)

This is an independent body set up the Government to provide information and support on a range of financial matters.

### [www.gov.uk/guidance/cardiovascular-disorders-assessing-fitness-to-drive](http://www.gov.uk/guidance/cardiovascular-disorders-assessing-fitness-to-drive)

Driving information from the DVLA.

## Useful Contacts - Medical Organisations and Further Information

[www.bhf.org.uk](http://www.bhf.org.uk)

Website to support those with a range of conditions in relation to heart disease.

[www.bsh.org.uk](http://www.bsh.org.uk)

The Clinicians' organisation for those who specialise in Heart Failure.

[www.nice.org.uk](http://www.nice.org.uk)

NICE (National Institute for Health and Care Excellence)

NICE's role is to improve outcomes for people using the NHS and other public services.

NICE Chronic Heart Failure Guidelines (under review) - [www.nice.org.uk/guidance/cg108](http://www.nice.org.uk/guidance/cg108)

NICE Acute Heart Failure Guidelines - [www.nice.org.uk/guidance/cg187](http://www.nice.org.uk/guidance/cg187)

[www.scottishmedicines.org.uk](http://www.scottishmedicines.org.uk)

SMC - Scottish Medicines Consortium.

The national source of advice on the clinical and cost-effectiveness of all new medicines for NHS Scotland. Our aim is to ensure that people in Scotland have timely access to medicines that provide most benefit based on best available evidence.

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)

Health Improvement Scotland is to enable the people of Scotland to experience the best quality of health and social care.

[www.heartfailurematters.org](http://www.heartfailurematters.org)

European Society of Cardiology website, Clinician organisation but does have patient information.

## Useful contacts - Other Charities and Non-Profit Groups

Here at Pumping Marvellous we are enthusiastic about working with other charities who, like us, are aiming to help individuals and their carers by providing information and support to manage their health and general wellbeing. Please find the list below:

### Atrial Fibrillation Association

[www.atrialfibrillation.org.uk](http://www.atrialfibrillation.org.uk)

### Cardiomyopathy UK

[www.cardiomyopathy.org](http://www.cardiomyopathy.org)

### Hospice UK

[www.hospiceuk.org](http://www.hospiceuk.org)

### British Cardiovascular Society

[www.bcs.com](http://www.bcs.com)

### Heart Failure Matters (European Society for Cardiology)

[www.heartfailurematters.org](http://www.heartfailurematters.org)

### British Heart Foundation

[www.bhf.org.uk](http://www.bhf.org.uk)

### Heart Valve Voice

[www.heartvalvevoice.com](http://www.heartvalvevoice.com)

### British Society for Heart Failure

[www.bsh.org.uk](http://www.bsh.org.uk)

### Marie Curie Charity

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

# Other Useful Contacts

## Government

**NHS Choices**

[www.nhs.uk](http://www.nhs.uk)

**NICE**

[www.nice.org.uk](http://www.nice.org.uk)

**SMC**

[www.scottishmedicines.org.uk](http://www.scottishmedicines.org.uk)

## Mental Health Charities

**Mind**

[www.mind.org.uk](http://www.mind.org.uk)

**Rethink**

[www.rethink.org](http://www.rethink.org)

## General Information

**Patient**

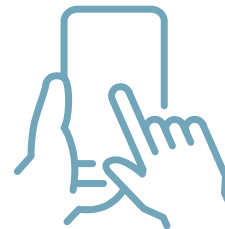
[www.patient.info](http://www.patient.info)

**Travel insurance for people with Heart Failure**

[www.pumpingmarvellous.org/what-we-do/heart-failure-travel-insurance/](http://www.pumpingmarvellous.org/what-we-do/heart-failure-travel-insurance/)

**Driving with a medical condition**

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/491028/aagv1.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/491028/aagv1.pdf)



## Other “Marvellous Guides” available in the series:

### **HOPE - A Patient's Guide to Being Told You Have Heart Failure**

Designed for people newly diagnosed with Heart Failure

### **My Marvellous Big Pocket Guide to Heart Failure**

A key guide to help you manage your Heart Failure

### **My Marvellous Guide to Caring for Heart Failure Patients**

A marvellous guide to help people who care for people managing Heart Failure

### **My Marvellous Guide to Having a Cardiac Device Fitted**

To enable people to make an informed decision about having a cardiac device.

### **My Marvellous Guide to Having an Echo**

Everything you need to know about having an echo scan on your heart

### **My Marvellous Guide to Medicines for Heart Failure**

Our guide that explains how the various medicines work that you are likely to be prescribed for Heart Failure

All guides are written by patients and clinically validated for accuracy by leading UK Heart Failure Specialists. To access go to this link;

**[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)**

### **My Marvellous Guide to PPCM (Peripartum Cardiomyopathy)**

Designed for mums diagnosed with PPCM

### **My Marvellous Guide to Travelling with Heart Failure**

Ideal for people wanting some help with going on holiday with Heart Failure

### **My Marvellous Guide to Using GTN**

A simple guide to helping you take GTN spray or tablets

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

Marvellous guide for people wishing to inform their families about Heart Failure

### **Heart Failure in Lights**

A great tool to help you manage your symptoms

### **My Appointment Diary**

Help in managing your Heart Failure



# Palliative Care Team

Your Carer's Name:

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Your GP's Name:

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Your Cardiologist's Name:

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Your Heart Failure Nurse's Name:

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Your Practice Nurse's Name:

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Your Pharmacy's Name:

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Your Hospice's Name:

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Your Palliative Care Team Name:

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Your Palliative Care Nurse's Name:

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Your Carer's Telephone Number:

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Your GP's Telephone Number:

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Your Cardiologist's Telephone Number:

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Your Heart Failure Nurse's Telephone Number:

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Your Practice Nurse's Telephone Number:

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Your Pharmacy's Telephone Number:

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Your Hospice's Telephone Number:

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Your Palliative Care Team Telephone Number:

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# CardioTrials

Interested in Medical Research in Heart Failure - **CardioTrials**, the charity's innovative platform, matches you with medical research and trials that best suit your needs and requirements.



# CardioTrials.org



Scan the code or go to [www.cardiotrials.org](http://www.cardiotrials.org)

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



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

*Acknowledgements and thank yous*

**Patient Educators across the UK from the Pumping Marvellous Foundation**

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# Contact Us



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@pumpinghearts



[www.pumpingmarvellous.org](http://www.pumpingmarvellous.org)



heart failure aware



[hearts@pumpingmarvellous.org](mailto:hearts@pumpingmarvellous.org)



help for hearts (closed support group)



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