PUMPING MARVELLOUS HEART FAILURE CHARTER

Pumping Marvellous
for heart failure patients

Help us make Heart Failure clearer for everyone
+44 (0) 1772 796542
hearts@pumpingmarvellous.org
www.pumpingmarvellous.org

LET'S
B.E.A.T
HEART FAILURE
TOGETHER

People interacting with healthcare services must be treated with respect. They must have equal, timely and appropriate access to optimal treatments and care, as outlined by national and international guidelines. Equally, that respect must be reciprocated to healthcare professionals.

People must understand all communication at the point of discussion, explained clearly and in an understandable format. Healthcare professionals should validate patient understanding to foster a relationship where the patient should always feel at ease to ask any questions about their situation.

It is also vital that patients feel engaged with their various health teams. This leads to patients and their families having optimal confidence in their treatment and care.

Our "Patient Charter" is for both Patients and their Families, Doctors, Nurses and Allied Health Professionals, Government, Politicians, Academics and providers of goods and services to the UK health economy. We have provided you with a glossary which will help you navigate some of the terminology, even though we have tried to reduce the jargon and acronyms.

All medical terminology is written down in understandable language on the next page. It is highlighted in the charter with the terminology being asterisked.

Nick Hartshorne-Evans
CEO and Founder
The Pumping Marvellous Foundation

TOP TIP

Throughout the charter there are QR codes that are linked to resources which can help you live better with heart failure. Use your mobile device (e.g. your phone or tablet) to scan the code.

Glossary

Ablation
Ablation is a keyhole procedure to treat certain heart rhythm problems caused by short-circuits or extra heartbeats, targeting these short-circuits using targeted burns, radiofrequency, laser or freezing temperatures.

Angiogram
Investigation that uses a special dye (contrast) and X-ray imaging to look at the blood flow of the heart.

Congenital
An existing malformation (of the heart) at birth.

ECG – Electrocardiogram
An ECG measures the electrical activity of the heart.

ECHO – Echocardiogram
A scan to observe the function of the heart and its valves.

Ejection Fraction
Ejection fraction (expressed as a %) is a measurement of the blood pumped out of the left ventricle with each contraction.

Electrolytes
Salts or minerals in the blood, such as sodium and potassium. A blood test abnormality in electrolytes can detect a fluid/acid-base imbalance or problems with kidney function.

Ferritin
A blood protein that contains iron (a ferritin test helps to show how much iron your body stores).

Guidelines
Guidelines means talk to healthcare professionals about good medical practice.

Idiopathic
Idiopathic is where the Heart Failure has no identifiable cause.

Iron Deficiency Anaemia
Iron deficiency anaemia is caused by a lack of iron in the body.

MDT - Multidisciplinary Team
A team of healthcare professionals who have different skills and job roles.

MRI - Magnetic Resonance Imaging
A scan that produces detailed 3D images.

NICE
National Institute for Health and Care Excellence.

NT-proBNP – Natriuretic Peptide Blood Test
An NT-proBNP blood test can be taken to rule out Heart Failure.

Palliative Care
Support, treatments and care for people living with a life-limiting condition. This also includes support for their family and friends.

Prevalent
Prevalent means how commonplace Heart Failure is in society. It is the number of people diagnosed with Heart Failure divided by the total population.

Prognosis
The likely course of a medical condition.

SMC
Scottish Medicines Consortium.

Syndrome
A syndrome is a set of medical signs and symptoms and together they are associated with a certain condition, for example Heart Failure.

Thyroid
A gland in the neck that produces hormones. Hormones are the body's chemicals that carry messages.

Urea
Urea is a chemical and the main constituent of human urine.

X-Ray
A scan that produces images of the inside of the body.

A Patient and Family-Developed Charter for People Living with Heart Failure

The charter outlines what you should expect from your care and treatment after a diagnosis of Heart Failure in the UK. This must consist of the best available optimised care and treatments provided by the UK health and social care system.

This charter reinforces the expectations of patients and families concerning access to treatments, support services and overarching care, wherever they are in the UK.

Who is this for?

UK CITIZENS
We need to talk more and raise awareness of Heart Failure to ensure an optimised and invested health system, capable of managing an increasingly prevalent* condition.

PATIENTS AND THEIR FAMILIES AND CARERS
The charter defines what patients and families should expect from the UK health and social care system.

HEALTHCARE PROFESSIONALS
To gain insight as what it's like to live with Heart Failure, along with the patient and family expectations. It can also be used as an adjunct to aid and assist local business plans and national strategy.

GOVERNMENT AND POLITICIANS
To educate policymakers as to the impact of Heart Failure at an individual and societal level, so that those insights and citizen expectations are at the front and centre of decision making and policy.

PROVIDERS OF GOODS AND SERVICES TO THE UK HEALTHCARE ECONOMY
To understand the needs of the beneficiaries of their goods and services and deliver insight around patient needs.

WHAT ARE WE TRYING TO ACHIEVE?

Our patient community want to live well with Heart Failure; to have an improved quality of life and live longer through:

- Clear communication of what should be expected by patients and their families living with Heart Failure.
- Ensuring the UK health and social care system has the informational resources to confirm or refute a diagnosis of Heart Failure accurately.
- An improvement in people's quality of life, length of life and a reduction in hospital admissions and readmissions, thereby allowing people to live better with Heart Failure irrespective of where they live in the UK.
- Laying the foundations to achieve a sustainable approach to supporting self-management and self-care with Heart Failure, contributing to an improved quality of life.
- Help recognise and amplify the need to support people living with Heart Failure, enabling the system to support them.
- Emphasising the importance of timely and effective communication between patients, family or carer and their healthcare teams.
- Providing clear insights to governments, politicians and policymakers into the severity, chronicity and healthcare impact of Heart Failure, underpinned by a call to action: we can beat Heart Failure if all stakeholders collaborate.

What is Heart Failure?

Heart Failure is a syndrome*, meaning that your heart cannot pump enough blood to your body; either your heart has a problem filling up, or it doesn't pump enough blood out. There is always a reason why you have heart failure.

THERE ARE THREE TYPES OF HEART FAILURE

HFrEF	HFmrEF	HFpEF
Heart Failure with reduced Ejection Fraction*	**Heart Failure with mildly reduced Ejection Fraction***	**Heart Failure with preserved Ejection Fraction***

THIS CHARTER ADVOCATES TO ENSURE THAT PEOPLE WITH ALL TYPES OF HEART FAILURE HAVE ACCESS TO SPECIALIST SERVICES.

What causes Heart Failure?

HEART FAILURE ALWAYS HAS A CAUSE.

LEADING CAUSES INCLUDE:

HYPERTENSION
high blood pressure

DIABETES

VALVE DISEASE
problems with the valves

MYOCARDIAL INFARCTION
heart attack

ARRHYTHMIAS
heart rhythm problems, like atrial fibrillation

CONGENITAL* HEART DISEASE
disabilities that affect the function of the heart

CARDIOMYOPATHY
conditions affecting the heart muscle, some are due to genetic mutations

OTHER CAUSES CAN INCLUDE

- Viral Myocarditis – a viral infection
- Anaemia* – lacking enough red blood cells to carry oxygen to the body
- Alcohol-induced – too much alcohol
- Recreational drug-induced
- Overactive thyroid*
- Pregnancy related
- Pulmonary Hypertension – high pressure in the lungs
- Obesity

Sometimes the exact cause of Heart Failure cannot be established. The term used to describe this is "idiopathic*".

Symptoms of Heart Failure

THE MOST COMMON SYMPTOMS OF HEART FAILURE INCLUDE

BREATHLESSNESS
may occur at rest or when lying down

EXHAUSTION
tiredness all the time, especially after any exercise

ANKLE SWELLING
may include legs and tummy swelling due to fluid retention

LET'S
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HEART FAILURE TOGETHER

TYPICAL SYMPTOMS INCLUDE

- **B** BREATHLESS
- **E** EXHAUSTION
- **A** ANKLE SWELLING
- **T** TELL YOUR GP OR NURSE

OTHER SYMPTOMS MAY INCLUDE

- Persistent cough
- Wheezing
- Bloated tummy
- Loss of appetite
- Rapid weight gain or loss
- Dizziness and/or fainting
- Confusion
- Fast heart rate
- Heart palpitations

PEOPLE WITH HEART FAILURE ALSO SUFFER FROM DEPRESSION AND ANXIETY DUE TO THE CONSEQUENCES OF THEIR ILL HEALTH.

How do I find out if I have Heart Failure?

Heart Failure is diagnosed through a series of simple tests that your GP can do; depending on the results, follow-on tests/examinations at the hospital may take place.

TESTS THAT CAN BE PERFORMED BY YOUR GP

SIGNS AND SYMPTOMS + **MEDICAL HISTORY** + **NT-proBNP BLOOD TEST*** =

TESTS THAT CAN BE REQUESTED BY YOUR GP OR HOSPITAL

ECG* + **ECHOCARDIOGRAM* AND POSSIBLY MRI*** + **CHEST X-RAY***

Only once you have had a heart scan (echocardiogram* or MRI* scan of the heart) can a definitive diagnosis of Heart Failure be confirmed.

What to Expect Following a Diagnosis of Heart Failure

TESTS FOR HEART FAILURE

Tests are important to investigate the cause of Heart Failure and also guide management. Below are some of the common tests.

Tests to investigate the underlying cause of Heart Failure

Several investigations may be undertaken to try and establish the underlying cause of your Heart Failure. Common first-line investigations must include blood tests inclusive of an NT-proBNP test* (a widely available blood test that can help diagnose if a patient may have Heart Failure), Echocardiogram*, ECG*, Cardiac MRI* scan, Angiogram* (if appropriate).

Monitoring your Heart Failure: blood tests at least every 6 months

- Routine blood testing is performed to monitor your kidney function and blood count at least 6-monthly, more frequently for those with impaired kidney function, and after a change in certain medications
- Commonly requested blood tests include: urea*, creatinine and electrolytes* (test of kidney function), thyroid* disease (test to measure thyroid* function), full blood count (test to ensure you do not have anaemia*) or ferritin* levels to check you don't have iron deficiency* that remains common in people with Heart Failure.

MULTIDISCIPLINARY TEAM (MDT)*

A Multidisciplinary Team (MDT)* is your team of healthcare professionals that all have different skills to collectively help manage your Heart Failure.

Your Multidisciplinary Team (MDT)* should include:

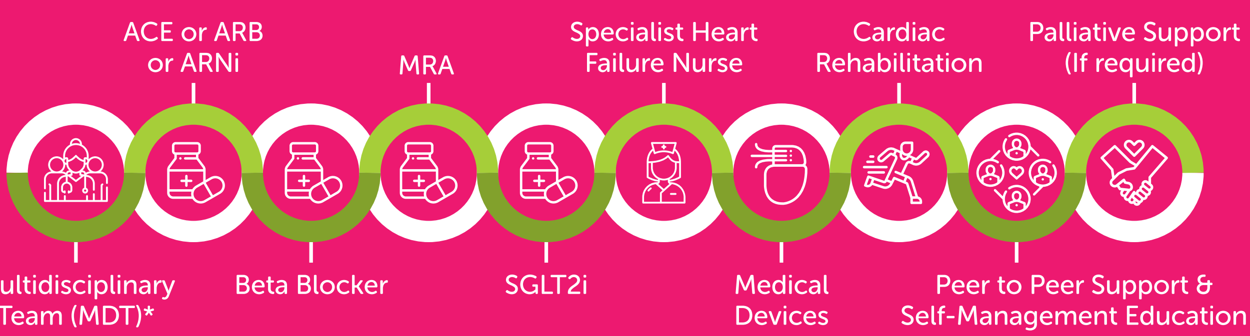
- Consultant Cardiologist (subspecialty in Heart Failure)
- Heart Failure Specialist Nurse (HFSN)
- GP based at your GP surgery

Additionally, this may include:

- Pharmacist (perhaps a Heart Failure specialist)
- Cardiac Rehabilitation Practitioner
- Palliative team
- Specialist in the care of older people/mental health support

Once you are discharged to your GP surgery, if your symptoms get worse your GP can always refer you back into the MDT*.

THE 10 PILLARS OF SUPPORT FOR PEOPLE WITH HEART FAILURE



ACE or ARB or ARNi

MRA

Specialist Heart Failure Nurse

Cardiac Rehabilitation

Palliative Support (If required)

Multidisciplinary Team (MDT)*

Beta Blocker

SGLT2i

Medical Devices

Peer to Peer Support & Self-Management Education

UNDERPINNED BY A PATIENT-FRIENDLY CARE PLAN AND EDUCATION ENABLING SELF-MANAGEMENT

NB - Not all pillars are appropriate for all types of Heart Failure.

What to Expect Following a Diagnosis of Heart Failure

TREATMENTS

Treatments can be in the form of tablets, cardiac rehabilitation, pacemakers, internal cardiac defibrillators (ICDs), valve treatment and if suitable a heart transplant. For the latest treatments go to www.pumpingmarvellous.org or scan the QR code.

CARDIAC REHABILITATION

It is important to eat the right food and keep moving. Cardiac rehabilitation helps you to self-manage your symptoms better and should be the start of you thinking about how you can manage your Heart Failure better. You should be offered cardiac rehabilitation by your Heart Failure Specialist Nurse or GP once you are stable.

Visit the Pumping Marvellous Foundation's FREE Cardiac Rehabilitation Hybrid Platform:
www.pumpingmarvellous.org/heart-failure-guide/heart-failure-rehabilitation/

MENTAL HEALTH SUPPORT

Sometimes people can suffer from anxiety and depression due to their diagnosis of Heart Failure and the ensuing symptoms that they will need to manage. If you are struggling with your mental health, then make sure you tell your Heart Failure Specialist Nurse or GP.

OPERATIONS

This may include procedures like valve replacement or repair, angioplasty, bypass, ablation* or advanced Heart Failure operations like transplant.

PALLIATIVE SUPPORT*

For those patients who remain markedly symptomatic despite optimal treatment, or whose condition is deteriorating, your Heart Failure Team may discuss the role of palliative and supportive services to help you live better with your symptoms.

LEARN MORE

Welcome to our Marvellous podcasts, powered by AI and driven by the voices of patients!

We're thrilled to have you join us on this incredible journey of discovery, learning, and connection. And guess what? We've got something extra special you — please give a warm welcome to our brand-new presenters, Fred and Daphne!

Fred and Daphne are here to guide you through captivating stories, insightful discussions, and expert advice that's both empowering and inspiring.

SCAN ME

If you have HFrEF (Heart Failure with reduced Ejection Fraction*) pop on your headphones, get a cup of coffee or tea and scan the QR code or visit www.qr.pumpingmarvellous.org/Podcast_Listen

If you have HFpEF (Heart Failure with preserved Ejection Fraction*) pop on your headphones, get a cup of coffee or tea and scan the QR code or visit www.qr.pumpingmarvellous.org/PodcastHFpEF

SCAN ME

How Can Patients and Their Families Help Themselves?

- MANAGE YOUR SYMPTOMS AND KNOW WHAT TO DO WHEN THEY GET WORSE
- TAKE YOUR PRESCRIBED MEDICATION AS PER THE PRESCRIPTION
- SELF-MANAGEMENT AND SELF-CARE, LEARN TO LOOK AFTER YOURSELF
- TALK, ENGAGE AND BUILD A RELATIONSHIP WITH YOUR HEALTH TEAMS
- IF YOU NEED HELP, DO NOT BE AFRAID TO ASK
- EXERCISE AND KEEP MOVING
- FOLLOW INSTRUCTIONS FROM YOUR HEALTH TEAM
- JOIN OUR PATIENT AND FAMILY COMMUNITY

Here are some valuable resources to help you live better with Heart Failure.

Scan this QR code to access your patient information.

SCAN ME

What does it look like going forward?

Heart Failure is a serious condition. However, for most people, with an early diagnosis and treatment, in many instances, it can be managed effectively. Treatments can help to keep symptoms under control for many years. Although Heart Failure is not a positive term, we can tell you that by working with your health team and self-managing well, many people go on to live well with Heart Failure. Remember: you are not on your own.

A Charter Written by Patients for Patients

WHAT YOU SHOULD EXPECT:

1. RECOGNITION OF POTENTIAL HEART FAILURE SYMPTOMS
2. AN ACCURATE AND TIMELY DIAGNOSIS
3. IF DIAGNOSED, AN INITIAL CONSULTATION WITH A CONSULTANT CARDIOLOGIST WITH SUBSPECIALTY IN HEART FAILURE
4. TO BE OFFERED THE BEST STANDARDS OF TREATMENT AND CARE AS OUTLINED BY NATIONAL AND INTERNATIONAL GUIDELINES*
5. ACCESS TO A SPECIALIST HEART FAILURE MULTIDISCIPLINARY TEAM INCLUDING A CONSULTANT CARDIOLOGIST WITH SUBSPECIALITY IN HEART FAILURE, HEART FAILURE SPECIALIST NURSE, GP, PHARMACIST, MENTAL HEALTH SUPPORT, CARDIAC REHABILITATION AND PALLIATIVE CARE* SERVICES
6. A CARE PLAN THAT IS SHARED WITH YOU, THE PATIENT, YOUR CARER OR FAMILY MEMBER, IF NECESSARY, AND ALL MEMBERS OF YOUR HEALTH TEAM ABOUT THE TREATMENTS AND CARE NEEDED
7. TO BE OFFERED UNDERSTANDABLE EDUCATIONAL INFORMATION, THAT CAN BE LEARNT AND USED TO SELF-MANAGE AND SELF-CARE EFFECTIVELY
8. A SMOOTH, COMMUNICATIVE DISCHARGE PROCESS FROM A MULTIDISCIPLINARY TEAM TO A GP PRACTICE WITH PIFU PRINCIPLES
9. AN OPEN DOOR BACK INTO A HEART FAILURE NURSE TEAM, WHO ARE PART OF AN MDT*, FOR FURTHER ASSESSMENT IF SYMPTOMS GET WORSE
10. ONCE UNDER THE CARE OF A GP, CONTINUING ACCESS TO EXTRA CARE WHEN NEEDED. ACCESS TO THE LATEST APPROVED TREATMENTS AVAILABLE TO PEOPLE LIVING WITH HEART FAILURE, WHETHER UNDER A MULTIDISCIPLINARY TEAM OR NOT

Your Role and Commitment to Your Care

Helping you to live as well as you can when you have Heart Failure is a two-way street. Although we have expectations from our healthcare teams, many of the things we can manage are down to ourselves and the decisions and choices we make. Therefore, it's more like a contract. Healthcare teams look after you through optimised care; you agree to do your best to self-manage and self-care.

MONITORING MY HEART FAILURE SYMPTOMS

- I am responsible for my condition
- I will understand what my symptoms are and when they get worse
- Any worsening of my symptoms from normal or side-effects from medications, I will inform my health team as soon as I recognise they are getting worse

SEEK HELP FROM MY MEDICAL TEAM IF MY SYMPTOMS ARE GETTING WORSE

- I monitor my symptoms regularly, and if I feel a worsening in my symptoms, I will contact my health team.
- I am aware that my Heart Failure may get worse and may lead to hospitalisation by not doing this

BUILD A RELATIONSHIP WITH MY HEALTH TEAM

- The interactions and education inform the choices I make and receive from my healthcare team. Building an open and honest relationship with my healthcare team is essential because it enables me to manage my condition better and receive optimised care and treatment

I AM TRYING TO MAINTAIN A HEALTHY LIFESTYLE

- Every choice I make has an impact on my health
- I will try to follow a healthy lifestyle, including regular exercise when I can, along with a balanced healthy diet
- Stop smoking
- Reduce my alcohol consumption, or stop (with support) when advised to do so

ASK QUESTIONS WHEN I DON'T UNDERSTAND

- To help get better at self-managing my condition, I will ask questions to help me know what I can do to help myself
- If I have any questions, I will ask them to the appropriate member of my healthcare team and seek an answer

FOLLOW THE ADVICE FROM MY HEALTH TEAM

- I will follow the advice from my healthcare team
- I have the right to question and understand what I am being asked to do
- I understand my healthcare team are providing me with their best advice, supporting my wellbeing and therefore, I must attend all appointments as requested

TAKING MY MEDICINES AS PRESCRIBED

- I will take all medication as prescribed
- I will discuss with my healthcare team any side effects I may experience
- I will not adjust my medication unless told to do so by my healthcare team
- Some of the medications may take time to get used to, but I realise that the benefits of the medicines outweigh the downsides
- I will discuss and agree on what treatments are best for me

EMBRACING CHANGE

- I will embrace change if it works for me
- I will discuss the difference with my healthcare team, determining whether it is beneficial for me

FIRST PRECEDENT

Recognition of Symptoms and Early Diagnosis

The recognition of Heart Failure symptoms, along with observation of a person's medical record, should prompt the timely use of a simple blood test called an NT-proBNP*. This is now widely available across primary care. If the NT-proBNP* is elevated, this raises suspicion of Heart Failure and patients should be referred in a timely manner (as per guidelines* for an echocardiogram* and face-to-face diagnosis).

1.1. On presentation of common symptoms[1.1.1.], a clinical examination and blood test, including an NT-proBNP* test to rule our Heart Failure, should be taken.

1.2. NT-proBNP*>2000nG/L indicates that the patient should be referred urgently for an echocardiogram* and be seen within 2 weeks. NTproBNP*400-2000nG/L indicates that the patient should be referred for an echocardiogram* and be seen within 6 weeks. [1.2. 1.2.1.]

1.3. If a diagnosis of Heart Failure is confirmed, then the patient should be referred to a specialist multidisciplinary team, including the following members:[1.3.]

- **1.3.1.** Consultant Cardiologist with a subspecialty interest in Heart Failure
- **1.3.2.** Heart Failure Specialist Nurse
- **1.3.3.** GP
- **1.3.4.** Access to a Pharmacist

Following a diagnosis of Heart Failure all patients must have a follow-up review within 2 weeks.

1.4. Diagnosis of Heart Failure should be made face-to-face by a lead physician with subspecialty training in heart failure (usually a consultant cardiologist) who is responsible for making the clinical diagnosis. The patient should expect a full and honest appraisal of the diagnosis and prognosis*. Patients should also be informed of any test results, initial and planned treatments, and what happens next.
At this meeting a patient should expect an explanation of frailty and the potential impact this can have upon managing Heart Failure:

- **1.4.1.** What is Heart Failure?
- **1.4.2.** What type of Heart Failure do they have? HFrEF, HFmrEF or HFpEF (see page 5 for explanations)
- **1.4.3.** Why they have Heart Failure
- **1.4.4.** Heart Failure treatments
- **1.4.5.** What do the treatments do?
- **1.4.6.** Any potential side effects
- **1.4.7.** The impact of other conditions on Heart Failure and their treatment
- **1.4.8.** Points of contact to answer further queries or if feeling unwell
- **1.4.9.** Personalised care plan

SECOND PRECEDENT

Consultation and Treatment

Patients must be offered the best standard of treatment and care as outlined by national and international guidelines*, whilst under the care of the multidisciplinary* team. Patients must have a care plan that is shared with them and, if applicable, their family. The first appointment after diagnosis must be an extended consultation of no less than 30 minutes face-to-face. During this first appointment, the patient's care plan must be shared with them. They must be offered patient education about Heart Failure, offered advice on how to self-manage and self-care, offered support for their mental health, if required, and informed what the next steps look like regarding their care and advised about the impact, if any, on their other conditions. If applicable, an assessment of frailty, a comprehensive geriatric evaluation, and discussions regarding advanced care planning for individuals considered to be in their final year of life, where appropriate, must be reviewed.

2.1. Diagnosis of Heart Failure should be made face-to-face by a lead physician with subspecialty training in Heart Failure (usually a consultant cardiologist) who is responsible for making the clinical diagnosis. The patient should expect a full and honest appraisal of the diagnosis and prognosis*. Patients should also be informed of any test results, initial and planned treatments, and what happens next.

2.2. On discharge from hospital, if applicable, patients must be offered a discharge plan which must include details of care, treatment, next steps, education and understandable self-management plans to follow.[2.2.]

2.3. Patients diagnosed with Heart Failure should be seen by a member of the multidisciplinary team within 2 weeks of an official diagnosis. This should be an extended appointment of no less than 30 mins.[2.3.]

2.4. During the first appointment, every patient should be given a clear, understandable care plan that is shared with the patient and accessible to the carer or family if necessary. This should reflect the diagnosing Consultant Cardiologist's conversation.[2.4.]

2.5. People with Heart Failure must be offered education to support self-management and self-care. [2.5.]

2.6. The multidisciplinary team should ensure the patient has understood the information given [2.6.]. This is to ensure understanding around:

  2.6.1. Self-management
  2.6.2. Recognising Heart Failure symptoms
  2.6.3. What to do if symptoms get worse
  2.6.4. Who to call and when, if symptoms get worse
  2.6.5. The 'whys?' and 'whats' of medication

2.7. Self-Care

  2.7.1. People with Heart Failure need help in self-managing and self-caring. Heart Failure is a long-term condition that needs managing not only by the healthcare team, but also by the person with it, and those around them.

2.8. The patient must have access to the multidisciplinary team until their Heart Failure is stable and treatments are optimised for them. There is no set time attributed to this; it is personal and depends on the requirements of the individual patient.[2.8.]

2.9. Patients must have access to national and international guideline driven treatment, irrespective of cost.[2.9.1.] This must include adjuncts to national guidelines* or any technology appraisal, whether medication, device or pathway, that are authorised by NICE* or the SMC* or appropriate authorising body.

2.10. Mental health is particularly important to people with Heart Failure. Access should be offered to a mental health specialist if required. This referral should take place if the patient is either under a multidisciplinary team or by primary care. People with Heart Failure can suffer disproportionately with anxiety and depression. This affects their quality of life.

2.11. People with Heart Failure generally have multiple conditions to manage. It is important they are informed about all their conditions, so that they understand their care and treatment plan. [2.11.] It is important to treat the whole person and it is recommended that the Heart Failure multidisciplinary team should also seek the advice of other specialists for the management of other conditions (such as diabetes or kidney specialist, care of the elderly physician, chest physician).

THIRD PRECEDENT

Discharge from Multidisciplinary Team

During and following discharge from the multidisciplinary team, patients must continue to use and have access to their care plan and understand that if their Heart Failure deteriorates they can self-refer back into their Heart Failure Nurse Team. Any changes in medication must be communicated to the patient's GP practice within 5 days of a specialist appointment.

3.1 Where the patient is being discharged from the multidisciplinary team back into primary care, there should be an understandable transferrable written plan shared with the patient and family if necessary. This matters to patients and family members so that they know what is going to happen next.[3.1.]

3.2. Once a patient is back under the care of their GP practice and if symptoms deteriorate, the patient can self-refer into their Heart Failure Nurse Team by communicating directly with that team.[3.2.]

3.3. Changes in medication must be communicated to GP practices within 5 working days of the appointment where the change has happened.

3.4. All patients must be included in primary care records and coded correctly to ensure they benefit from at least annual reviews, tests and investigations and inclusion in prevalence data. If this has happened at the point of diagnosis, it must on the point of discharge to primary care.

CONTINUUM OF CARE

FOURTH PRECEDENT

Heart Failure Specialist Nurse Access and Referral

Heart Failure nurses are the most important member of the multidisciplinary team and act as the patient advocate. After an initial diagnosis of any Heart Failure, the patient must be assigned to a Heart Failure Nurse who works within an MDT* environment, either in the community or hospital.

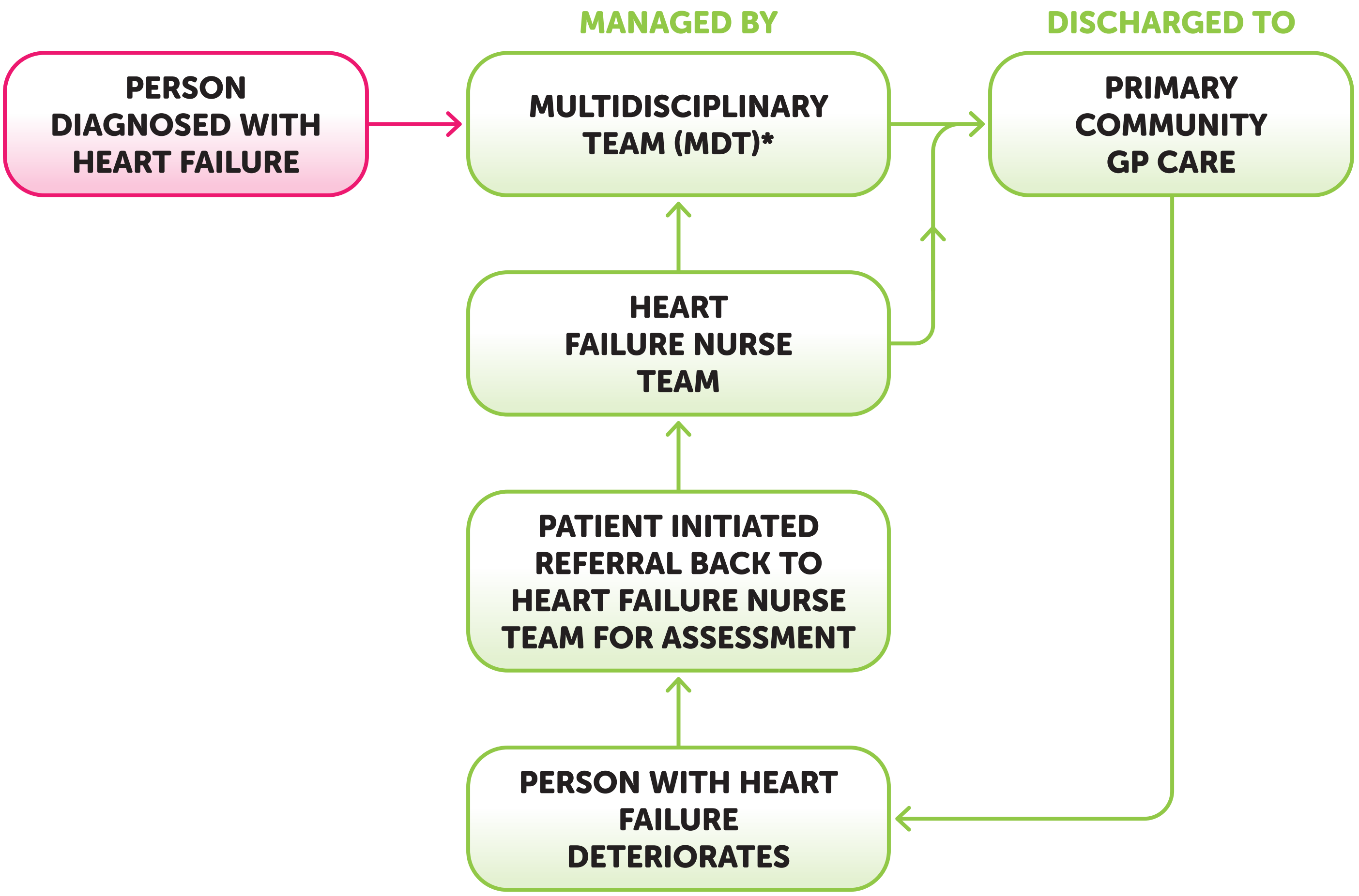
4.1. **People who are diagnosed with Heart Failure, whether:**
  - **4.1.1.** Heart Failure with reduced Ejection Fraction* (HFrEF)
  - **4.1.2.** Heart Failure with preserved Ejection Fraction* (HFpEF)

4.2. Should be referred to a Multidisciplinary Team (MDT)* including a Consultant Cardiologist with a subspeciality in Heart Failure, Heart Failure Specialist Nurse, pharmacist and a GP.[4.2.]

4.3. Patients should be managed by the MDT* until they are stable and optimised on treatment.[4.3.]

4.4. Patients should be able to self-refer back into their Heart Failure Specialist Team

4.5. Patients should have access to a Heart Failure Specialist Nurse operating out of the hospital or community setting.



Support

Living with Heart Failure is important. Heart Failure is a long-term condition that needs lifelong management. Heart Failure management is not just a point in time. Ensuring the patient has access to appropriate support, to ensure their quality of life is maximised, is important. Every person, at the appropriate time, should be offered cardiac rehabilitation, palliative care* support, mental health support, benefit and income support, along with signposting to organisations like the Pumping Marvellous Foundation for peer-to-peer support and Heart Failure education.

These are the support mechanisms needed to ensure people live well with Heart Failure.

5.1. Ensure that this support is tailored according to patient's cultural background, educational and language capabilities.[5.1.]

5.2. When needed, every patient should be offered services provided by a palliative care* team.[5.2.]

- **5.2.1.** The patient's GP and/or Heart Failure Nurse Team should work seamlessly with the palliative care* team to transfer care.
- **5.2.2.** Equality of access to palliative care services (whether in the patient's home or in a hospice) should be made readily available to people with advanced Heart Failure, just like to those people living with cancer.

5.3. When needed, a patient can request a referral for mental health support. It is the responsibility of their GP to enable this, being responsible for their overall care, but other members of the MDT* can also enable this if the patient seeks their support.

5.4. When needed, a patient can request benefit and income support. Access to benefit and income support is important to many people with Heart Failure. Not being able to access this type of support creates huge levels of anxiety and may lead to depression.

5.5. Every patient should be directed to local and national patient support groups, like the Pumping Marvellous Foundation, and be offered or signposted to other support that may be needed by a person living with Heart Failure.

5.6. Patients expect good communication between all their healthcare teams, joining up their needs to offer comprehensive care that is understood by them.

It is important to understand that clinical treatments and care are all part of the conversation to help people live as well as they can with Heart Failure. Treatments and care should form the basis and foundations by which people can start to live with Heart Failure. This will allow the other components, that make up what patients need, to be more achievable. People can then live their life and contribute to their family and the greater society as this is what the vast majority of patients tell us they want.

References

1.1.1 https://www.nhs.uk/conditions/heart-failure/symptoms/

1.2. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#diagnosing-heart-failure

1.2.1. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#diagnosing-heart-failure

1.3. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#diagnosing-heart-failure

2.2. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#team-working-in-the-management-of-heart-failure

2.3. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#giving-information-to-people-with-heart-failure

2.4. https://www.nice.org.uk/guidance/ng106/chapter/Recommendations#team-working-in-the-management-of-heart-failure

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https://www.england.nhs.uk/long-read/heart-failure-with-preserved-ejection-fraction-pathway-support-tool/

How Do You Know What We're Saying is Correct?

This charter has been authored by the many thousands of patients in our Community. All the ideas and points in this charter are taken directly from the feedback of patients and carers with Heart Failure detailing what they would want.

We have consulted our expert Patient Educators across the UK throughout the process and implemented their recommendations.

We have consulted our team at our head office in Preston in the UK and implemented their recommendations.

We have consulted our Clinical Advisory Board of world-leading Heart Failure specialists to ensure clinical accuracy.

Our charity, the Pumping Marvellous Foundation, was developed by our Founder and CEO, Nick. Since his diagnosis of Heart Failure in 2010, Nick has spent his life understanding Heart Failure from the patient perspective. He works across the NHS, NICE* and the SMC* in Scotland as a patient expert. He also advocates for Heart Failure patients and their families on a global stage.

Why do we do what we do?

What we do, is driven by you and your needs as a person or a family member who is impacted by Heart Failure. We know what these needs are, as we are patients and carers ourselves.

THE PUMPING MARVELLOUS FOUNDATION

The Pumping Marvellous Foundation is the UK's patient-led Heart Failure charity. Everything we do is driven by the needs of the patients and families impacted by Heart Failure. We help people live better with Heart Failure and advocate for them at the highest level within the NHS.

Pumping Marvellous
for heart failure patients

Help us make Heart Failure clearer for everyone
+44 (0) 1772 796542
hearts@pumpingmarvellous.org
www.pumpingmarvellous.org

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