

My Marvellous Guide to Heart Failure due to Valvular Heart Disease

A Patient's Story

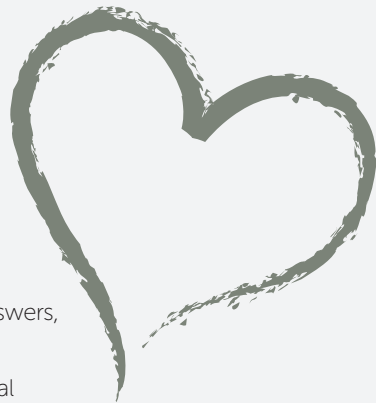


**Authored by a Specialist Nurse in Structural
Heart Disease, Consultant Cardiologist,
and patients like you**



HELPING PEOPLE LIVE BETTER WITH HEART FAILURE

WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



Our Guide to Heart Failure due to Valvular Heart Disease will provide you with some initial information, answers, support, and give examples of how to treat problems with heart valves. This guide has been developed in conjunction with Lauren Connolly, who is a leading Specialist Nurse in Structural Heart Disease at the Royal Brompton and Harefield Hospitals.

We recommend that you visit our website for further support at www.pumpingmarvellous.org where you will find other Marvellous Guides, or gain invaluable support from fellow patients and carers in our closed support group on Facebook; just tap into the search bar on Facebook 'Help for Hearts' where you can apply to enter. If you prefer, you can always give the team a ring on **01772 796542**.

Nick Hartshorne-Evans Heart Failure Patient, Founder and CEO of The Pumping Marvellous Foundation

Angela Graves Chair of The Pumping Marvellous Foundation



Scan this QR
code to access
our Patient
Charter.

Valvular Heart Failure – Treatments

There are many treatments available for Heart Failure due to Valvular Heart Disease; these range from medication, to keyhole procedures and open-heart surgery. Open-heart surgery often requires a heart-lung bypass machine, where your heart is briefly stopped for the surgery to take place, whereas keyhole procedures (sometimes called minimally invasive or 'transcatheter' procedures) can be performed on a beating heart, and are therefore generally considered lower risk.

Additionally, minimally invasive procedures can be performed from the groin or neck, avoiding the need for any incisions in the chest. Should you require heart valve surgery, your heart care team (heart specialist and surgeon) will be able to advise which type of procedure is best for you.

Unless you are deemed as needing an urgent procedure, it is recommended that your medication is reviewed by a specialist and is optimised and stable prior to having any invasive procedures. It is important to remember that you will continue on your medication (perhaps at lower dosage) after these procedures as they will continue to support your heart function once your valve has been repaired.

The type of treatment you are referred for will very much depend on a number of factors, such as:

- The valve that is diseased
- The type of disease
- The size and shape of your heart and valve can also affect what device or treatment is suitable (in some cases the devices available simply do not fit!)
- Other medical conditions

Standard of Care

The gold standard treatment for repairing or replacing a diseased valve is open-heart surgery. However, if you are not suitable for open-heart surgery, then a less invasive keyhole procedure with less recovery time may be more suitable for you. You may be turned down for open-heart surgery if you are too frail or have other medical conditions (comorbidities) that may impact the procedure and your recovery. To be offered open-heart surgery, you must be well enough to tolerate the surgery, as well as make a full recovery. Recovery from open-heart surgery can take up to six months; however, most people return to normal activities in 12 weeks.

Should you be offered one of the keyhole techniques, you will be referred to a specialist centre where you will be reviewed by an expert at a clinic appointment. Many of these keyhole procedures, such as MitraClip, or 'TAVI' (transcatheter aortic valve intervention) procedures, are now widely accepted as a safe and effective for the right patient. As most of these treatments are only delivered in a small number of specialist centres in the UK, there may be a waiting list. However, it is important to remember that your Doctor or Nurse will be able to bring the treatment date forward should you become unwell, experience worsening symptoms, or they are worried about you.

The following section will cover the different transcatheter (keyhole) procedures available, by valve type (mitral, tricuspid or aortic). Remember that all patients will be considered for everything, from medical treatment to keyhole surgery and open-heart surgery; the specialist team will offer you the most suitable treatment in your best interests. You are welcome to ask questions and you do not have to accept any treatment offered to you.

Risks

Every medical treatment, whether it is medication or a procedure, may carry some risk. If your doctors think you are at high risk of complications from open-heart surgery to repair or replace your valve, and that a less invasive (keyhole) procedure may be safer for you, you may be offered one of the treatments outlined below. In some cases, no surgical or keyhole procedure is safe or suitable; in this case you would be closely monitored by your specialist heart care team.

Alternatives to a Keyhole Procedure

The risks set out above need to be balanced against the risk of not having the procedure at all. If your valve is not repaired or replaced, you are likely to continue to have symptoms such as breathlessness, fatigue, dizziness and fluid overload and these symptoms may worsen over time. Medication can help to relieve your symptoms, but your valve disease will continue to deteriorate. In addition, other areas of your heart may change size and this may make you more symptomatic or unwell.

It is important to talk to your Doctor about the effects of not having any treatment.

Finding Out What Treatment is Right for You

Prior to any treatment, a number of tests must be completed to see if your valve disease has reached the stage where it requires fixing, and if you are suitable for the procedure. These tests will allow your specialist team to safely plan for all eventualities and to ensure your procedure and the recovery runs as smoothly as possible. You may need some or all the tests below:

Blood Tests

We will need some up-to-date blood test results to look at your kidney function, blood levels and heart strain.

Electrocardiogram (ECG)

For an ECG, electrodes (small sticky patches with leads) are put on your arms, legs and chest. The electrodes are connected to a monitor that records the rhythm and electrical activity of your heart. The test takes about 10 minutes.

Echocardiogram (Echo)

An echocardiogram uses sound waves (ultrasound) to build up a moving picture of your heart. This helps doctors learn more about the structure and function of your heart valves and heart chambers. An echocardiogram takes around 30 minutes. Scan the QR code below to view our Marvellous Guide to having an Echo.



Transesophageal Echo (TOE)

A TOE is another way of carrying out an echo that allows your Doctor to look more closely at your heart. A flexible tube (probe) is passed down your throat to send sound waves to your heart, and collect echoes that bounce back. A TOE takes approximately 15–30 minutes.

Coronary Angiogram

A coronary angiogram uses a series of X-rays to allow doctors to look at the coronary arteries. The coronary arteries are the main arteries that supply blood to your heart muscle. A thin plastic tube (catheter) is guided through an artery in your groin or wrist, to your heart. Then a special dye is injected through the catheter so your arteries clearly show the dye and the doctor can examine whether there are any narrowing or blockages of your heart arteries. A coronary angiogram takes about 30 minutes.

Computed Tomography (CT) Scans

A CT scan is an X-ray that produces three-dimensional images of your body. A radiographer will give you an injection containing a special dye so that your blood vessels and heart show clearly on the scan. A CT scan can also be used to look at the arteries that supply your heart muscle (coronary arteries) – a test called a CT coronary angiogram.

Your Doctor will discuss with you which of these tests they think is best to look at your coronary arteries. A CT scan takes approximately an hour.



Treatment for the Mitral Valve

The mitral valve can be diseased in two ways; mitral stenosis (stiff valve) or mitral regurgitation (leaky valve).

Treatment for Mitral Regurgitation

Transcatheter Edge-to-Edge Repair (TEER)

Transcatheter edge-to-edge repair is performed using either the Abbott MitraClip or Edwards PASCAL implant. These devices can be used to repair a leaking mitral valve and relieve symptoms of Heart Failure associated with mitral regurgitation.

The TEER Procedure

A TEER procedure involves repairing the mitral valve through the skin via the groin, using a thin flexible tube, called a catheter. It does not involve open-heart surgery or cutting the breastbone.

The TEER device holds the leaflets together in a specific area of the valve, leaving holes (orifices) on either side for the blood to flow into the left ventricle (heart pump). Your specialist team will decide how many clips should be implanted during the procedure; on average, most patients will have two. You will be able to get out of bed and walk around a few hours after your procedure.

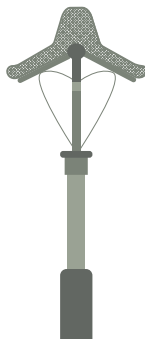


Figure 1. MitraClip

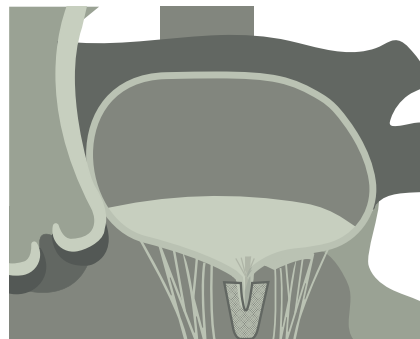


Figure 2. MitraClip implanted on the mitral valve

Procedure time: 1-3 hours.

Anaesthetic: General anaesthetic (you will be asleep).

Risks: 1-2% risk of death, stroke or major complication. 2% risk of bleeding or bruising. In addition, your specialist team will discuss the chances of converting to open heart surgery and abnormal heart rhythms.

Time in hospital: 2-3 days (depending on your condition prior to coming into hospital).

Medication: As well as your usual medication, you will need to take an anti-platelet drug for three months after your procedure as well as, or in addition to your usual blood thinners (anti-coagulants). Your Doctor or Nurse will assess this at the time.

Benefits: Symptomatic relief: improvement in shortness of breath, walking distance and less/no swelling in the ankles/feet.

Prevention of admission to hospital, overtime Heart Failure can lead to admissions to hospital for a drip to offload the fluid your heart is unable to pump off. Having treatment to repair your mitral valve may prevent this.

Improved quality of life, with less or no symptoms you could continue your life as you did prior to having Heart Failure.

Alternatives: If you are unsuitable for this treatment or decide not to go ahead, it is important that you discuss this with your Doctor or Nurse. In general, the alternatives offered may be medication or open-heart surgery.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Mitral Valve Replacement (Keyhole)

Transcatheter Mitral Valve Replacement

Tendyne Transcatheter Mitral Valve Replacement

Mitral valve replacement has conventionally been performed using open-heart surgery, requiring use of a bypass machine. As an alternative and less invasive procedure, a Tendyne transcatheter valve replacement may be offered. This treatment for mitral regurgitation (leaky valve) is performed by replacing the leaky valve with a surgical valve, placed on top of and replacing the old, diseased valve.

The Tendyne Procedure

The Tendyne valve is inserted through a small cut (approximately 5cm) on the left side of your chest, in between your ribs. This is less invasive than open-heart surgery which requires cutting the breastbone and it does not require bypass (meaning that your heart will beat throughout the procedure).

A small tube (catheter) is inserted into the incision between your ribs and the Tendyne valve is passed within this, through to the bottom of your heart (called the apex) and implanted into the valve position.

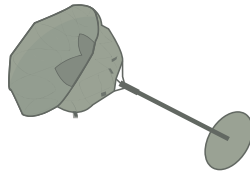


Figure 3. Tendyne Valve (Abbott)

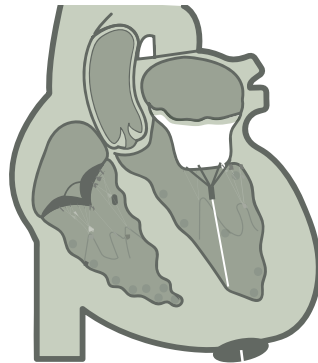


Figure 4. Tendyne valve implanted in the mitral valve position

Procedure time: 2-4 hours

Anaesthetic: General anaesthetic (you will be asleep).

Risks: As this is a relatively new treatment, you will be quoted risk on an individual basis. As with any medical procedure this carries a small risk of death, stroke, bleeding and bruising. In addition, you would discuss the risks of reoperation and conversion to open-heart surgery should your team feel it is the safest thing to do at the time.

Time in hospital: 5-7 days (depending on your condition prior to coming into hospital).

Medication: As well as your usual medication, you will need to take aspirin for the rest of your life.

Benefits: Symptomatic relief: improvement in shortness of breath, walking distance and less/no swelling in the ankles/feet.

Prevention of admission to hospital, overtime Heart Failure can lead to admissions to hospital for a drip to offload the fluid your heart is unable to pump off. Having treatment may prevent this.

Improved quality of life, with less or no symptoms you could continue your life as you did prior to having Heart Failure.

Alternatives: If you are unsuitable for this treatment or decide not to go ahead, it is important that you discuss this with your Doctor or Nurse. In general, the alternatives offered may be medication or open-heart surgery.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Open-heart surgery may be offered if you are well enough to tolerate not only the surgery but the recovery, which can take up to six months, although most people return to normal activities in around 12 weeks.

Mitral Balloon Valvuloplasty

A mitral balloon valvotomy, or valvuloplasty, is a procedure to repair the mitral valve that has been narrowed due to excessive calcium on the valve (mitral stenosis). In a narrowed heart valve, the valve flaps (leaflets) may become thick or stiff and fuse together (stenosis). This reduces blood flow through the valve. This treatment may improve blood flow through the heart valve and improve your symptoms; however, this is usually a temporary solution to delay surgery or improve symptoms in the short-term. Mitral balloon valvuloplasty is considered a low-risk treatment that can be used to delay open-heart surgery for some patients.

Procedure time: 45 min – 1.5 hours

Anaesthetic: Local anaesthetic (you will be awake for this procedure).

Risks: 1% risk of death or stroke, 5-10% risk of causing significant mitral regurgitation.

Time in hospital: 1 day

Benefits: Symptomatic relief: improvement in shortness of breath, walking distance and less/no swelling in the ankles/feet.

Prevention of admission to hospital, overtime Heart Failure can lead to admissions to hospital for a drip to offload the fluid your heart is unable to pump off. Having treatment may prevent this.

Improved quality of life, with less or no symptoms you could continue your life as you did prior to having Heart Failure.

Alternatives: If you are unsuitable for this treatment or you decide not to go ahead, it is important that you discuss this with your Doctor or Nurse. In general, the alternatives offered may be medication or open-heart surgery.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Open-heart surgery may be offered if you are well enough to tolerate not only the surgery but the recovery, which can take up to six months, although most people return to normal activities in around 12 weeks.

Treatments for the Tricuspid valve

Transcatheter (keyhole) treatment for the tricuspid valve can be done in two ways; it can be repaired by clipping the leaflets together, or a new valve can be implanted on top of the old, damaged one. The type of procedure you could be offered will depend on the anatomy of your valve and the way your valve is diseased. Any other health concerns will also be considered, and your specialist team will decide based on what they feel is best for you.

TEER

Similar to the mitral valve, the tricuspid valve also has a transcatheter edge-to-edge (TEER) option. The procedure is a treatment to repair your leaking tricuspid valve and relieve symptoms of Heart Failure. It involves repairing the tricuspid valve by clipping the leaflets together at the point they are not functioning.

The TEER Procedure

A TEER procedure involves repairing the mitral valve through the skin via the groin, using a thin flexible tube, called a catheter. It does not involve open-heart surgery or cutting the breastbone. You can have more than one TEER implanted, and they can be implanted in different areas of the valve. Your specialist team will assess during the procedure how many clips you may need.

You will be able to get out of bed a few hours after your procedure.

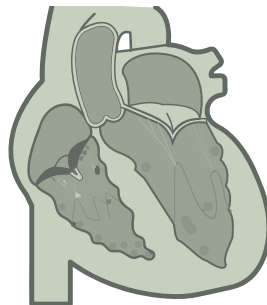


Figure 5. implanted TriClip

Procedure time: 2-4 hours

Anaesthetic: General anaesthetic (you will be asleep).

Risks: 1% risk of death, stroke or major complication. 1% risk of bleeding or bruising.

Time in hospital: 1-3 days (depending on your condition prior to coming into hospital).

Medication: As well as your usual medication, you may be asked to take anti platelet medication or your usual blood thinning medication (anti-coagulants). Your Doctor or Nurse will tell you what to take and how long for.

Benefits: Symptomatic relief: improvement in shortness of breath, walking distance and less/no swelling in the ankles/feet.

Prevention of admission to hospital, overtime Heart Failure can lead to admissions to hospital for a drip to offload the fluid your heart is unable to pump off. Having treatment may prevent this.

Improved quality of life, with less or no symptoms you could continue your life as you did prior to having Heart Failure.

Alternatives: If you are unsuitable for this treatment or decide not to have treatment, it is important that you discuss this with your Doctor or Nurse.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Open-heart surgery may be offered if you are well enough to tolerate not only the surgery but the recovery, which can take up to six months, although most people return to normal activities in around 12 weeks.

Transcatheter (Keyhole) Tricuspid Valve Replacement (TViV)

The transcatheter tricuspid valve replacement is used to replace the leaking tricuspid valve without open-heart surgery or bypass. It is considered a low-risk procedure for the right patient. This can be implanted into an old, damaged valve.

The Transcatheter Tricuspid Valve Replacement Procedure

A thin tube is passed from the groin into the vein. The new replacement valve is passed through this tube and into the right side of the heart. At this point the specialist team will check the position with X-ray and once the correct position is found, the new valve will be deployed, pushing the old, damaged valve out of the way.

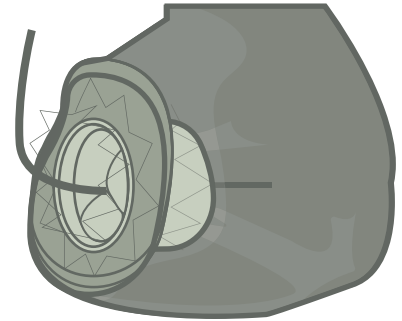


Figure 6. Tricuspid valve in valve

Procedure time: 45min – 2 hours

Anesthetic: General anesthetic (you will be asleep for this procedure).

Risks: 2-3% death, stroke or major complication. 3% risk of the valve moving after implantation. 1% risk of perforating the heart. 1% risk of bleeding.

Time in hospital: 1-2 days. (Please be aware this will vary depending on your condition prior to the treatment).

Medication: As well as your usual medication, you will be asked to take blood thinning medication (anti-coagulants) following this procedure. Your doctor or nurse will prescribe the appropriate medication for you.

Benefits: Symptomatic relief from Heart Failure symptoms: improvement in shortness of breath, improved exercise tolerance/walking distance and less or no swelling in the ankles/feet.

Prevention of admission to hospital, overtime Heart Failure can lead to admissions to hospital for a drip to offload the fluid your heart is unable to pump off. Having treatment may prevent this.

Improved quality of life, with little or no symptoms you could continue your life as you did prior to having Heart Failure.

Alternatives: If you are unsuitable for this treatment or you decide not to go ahead, it is important that you discuss this with your doctor or nurse.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Open heart surgery may be offered if you are well enough to tolerate not only the surgery but the recovery, which can take up to six months, although most people return to normal activities in around 12 weeks.

The Aortic Valve TAVR (Formally TAVI)

Transcatheter aortic valve implantation (TAVI) is a common procedure performed in many hospitals across the UK. It is used to treat a type of aortic valve disease called aortic stenosis (narrowing of the aortic valve). The procedure will implant a new valve on top of the aortic valve to allow the blood to flow through more easily.

A small cut will be made in your groin or by your shoulder. The new valve will be passed through a thin flexible tube called a catheter. Once the new valve is in place it will be inflated and move the old, damaged valve out of the way.

Procedure time: 45min – 2 hours.

Anesthetic: General anesthetic or local anesthetic. Most commonly patients are awake for this procedure, allowing for a faster recovery and discharge home. In some cases, where it is deemed higher risk, the patient will be under general anesthetic (asleep) for the procedure.

Risks: 2-3% death or major complication. 3% risk of stroke. 2% risk of bleeding. 10-20% risk of needing a permanent pacemaker following the procedure. The risk is usually higher as this patient group tends to be elderly and frail.

Time in hospital: 2-3 days. (Please be aware this will vary depending on your condition prior to the treatment).

Medication: As well as your usual medication, you will be asked to take one or two additional blood thinning medications (anti-coagulants). Your Doctor or Nurse will tell you what to take and for how long.

Benefits: Symptomatic relief; improved fatigue and energy levels, improvement in shortness of breath, reduced or no dizziness and chest pain, possible increase in exercise tolerance (depending on your previous abilities).

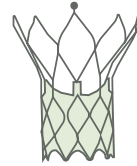


Figure 7. TAVI valve (Abbott portico)

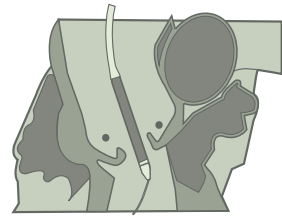


Figure 8. catheter across aortic valve.



Figure 9. TAVI valve implanted in aortic valve

Prevention of admission to hospital with Heart Failure related symptoms. Improved quality of life.

Alternatives: If you are unsuitable for this treatment or you decide not to go ahead, it is important that you discuss this with your Doctor or Nurse.

Your medication can be adjusted by a Heart Failure specialist and monitored by your Heart Failure Nurse. Your valve will continue to deteriorate but medication can help to manage the symptoms.

Specialist Centres

A small number of specialist centres offer these treatments and you can be referred by your GP or local hospital from anywhere in the UK to these hospitals, regardless of your home location.

Useful Contacts - Charities, Organisations and Services

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

Website to support patients with heart muscle disease.

www.ageuk.org.uk

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

www.carersuk.org

Website of organisation for carers.

www.citizensadvice.org.uk

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

www.gov.uk/browse/benefits

Information in regards to current information benefits.

www.bhf.org.uk

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

www.bsh.org.uk

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

www.nice.org.uk

NICE (National Institute for Health and Care Excellence): improving outcomes for people using the NHS and other public services. NICE Chronic Heart Failure Guidelines (under review) www.nice.org.uk/guidance/cg108

NICE Acute Heart Failure Guidelines - www.nice.org.uk/guidance/cg187

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

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

www.heartfailurematters.org

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

Useful Contacts - Charities, Organisations and Services

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

British Cardiovascular Society

www.bcs.com

British Heart Foundation

www.bhf.org.uk

British Society for Heart Failure

www.bsh.org.uk

Cardiomyopathy UK

www.cardiomyopathy.org

Heart Valve Voice

www.heartvalvevoice.com

Government

NHS Choices

www.nhs.uk

NICE

www.nice.org.uk

SMC

www.scottishmedicines.org.uk

Mental Health Charities

Mind

www.mind.org.uk

Rethink

www.rethink.org

One Step at a Time

We hope that our Marvellous Guide to Heart Failure due to Valvular disease has triggered thoughts around some of the questions you may have. We know this is not a position you want to be in but it's about taking small steps, which is a good thing. You may never have had to deal with something like this but if you want to then self-management can be the key to a better life and enable you to find your normal again. This may be the start of your journey so if you need help do seek out further advice from your Healthcare Professional or visit our website www.pumpingmarvellous.org

Other 'Marvellous Guides' in the Series

All guides are written by patients and clinically validated for accuracy by leading UK Heart Failure specialists.

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Or visit pumpingmarvellous.org

My Team:

Your Carer's Name:

Your GP's Name:

Your Cardiologist's Name:

Your Heart Failure Nurse's Name:

Your Practice Nurse's Name:

Your Pharmacy's Name:

Your Carer's Telephone Number:

Your GP's Telephone Number:

Your Cardiologist's Telephone Number:

Your Heart Failure Nurse's Telephone Number:

Your Practice Nurse's Telephone Number:

Your Pharmacy's Telephone Number:

Other Team Details:

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



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

Acknowledgements and thank yous

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Nick Hartshorne-Evans Founder and CEO the Pumping Marvellous Foundation - Reviewer

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