

My Marvellous Guide to Heart Failure

*Be a 'marvellous'
heart failure patient*

More Help

The end to those questions

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

**Pumping
Marvellous**
The heart failure charity

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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WELFARE & BENEFITS

4.1

We want you to know that we understand this can be a tricky part of managing your life going forward. We know through our own experiences that you can get what you deserve and that being comfortable and knowledgeable about the system is significantly beneficial.

You will also be aware that the benefit landscape is changing all the time, therefore we will keep this page light on information whilst pointing you to the correct websites.

There are a range of benefits heart failure patients may be entitled to claim. These include ESA (employment support allowance), DLA (disability living allowance) for under 16s, PIP (personal independence payment) for working age adults aged between 16 and 64 years old and AA (attendance allowance) for over 65s.

For further information, please visit the government website:

www.gov.uk/browse/benefits

The Citizens Advice Bureau may also provide advice:

www.citizensadvice.org.uk/benefits/

If you or your carer require additional input, support or equipment to enable you to manage, please visit the following website where you will be directed to social services in your area for a free assessment:

www.gov.uk/apply-needs-assessment-social-services

When making a claim for any benefit, it's important you give as much detail as possible as to how your ill health/disability impacts your daily life. This includes the help and support you need to complete basic daily tasks (even if you do not get that help). You should also provide examples where you can; this should ensure the decision maker gets a clear picture of the impact your health has upon you on a daily basis.

Please contact the Pumping Marvellous Foundation if you require any further advice.

PENSIONS

4.2

Being diagnosed with heart failure may cause you to think about reviewing your pension arrangements. Recently, there have been significant changes to pension regulation. Information appears to be changing regularly in this field, so have a look at the following links for information on the topic.

For advice and information on your state pension entitlements, visit the following website:

www.gov.uk/pensions-advisory-service

The Citizens Advice Bureau also covers the subject:

www.citizensadvice.org.uk/debt-and-money/pensions/

The Pensions Advisory Service provides independent advice on the pension system:

www.pensionsadvisoryservice.org.uk/

RELATIONSHIPS & ROMANCE

4.3

Relationship Communication

An old TV advert said 'it's good to talk' and indeed it is. All relationships will come under pressure at some time or other, for a variety of reasons. Keeping an open channel of communication is vital. When you are diagnosed with a condition such as heart failure, you and your partner's world may be turned upside down. It is good for both of you to discuss and share your concerns and feelings. You may find that the social, financial and physical implications of your condition puts your relationship with your partner under considerable pressure. Relate provides invaluable information, support and counselling for individuals and couples of any sex or orientation.

www.relate.org.uk/relationship-help/help-relationships

You may find that talking to another person with heart failure (or another carer of a heart failure patient) helps considerably. There may be a local group which can help you. If not, we run a closed Facebook group where you can become a member.

www.facebook.com/groups/helpforhearts/

This group has many patients who help each other on a daily basis with living with heart failure. Patients talk about their conditions and how they have overcome their challenges. It is a safe place to talk and is highly moderated just for this reason.

Fifty shades of pink and green

Having a physical relationship is important to many people, and having heart failure should not prevent you having one. Indeed many would say that whatever form a physical relationship takes, it can bring pleasure, closeness and a feeling of normality. When first diagnosed with heart failure you may feel too unwell for a physical relationship, but once your symptoms are under control then your heart failure should not prevent you from enjoying a healthy sex life.

- **If you have any concerns, discuss these with your partner, it is important to talk about any fears or limits you may feel you have.**
- **Discuss with your GP, Doctor or Nurse any issues or difficulties you may be having. They will not be embarrassed, it's part of their job, and neither should you be.**
- **Avoid sex for the time being if you are feeling unwell, or having any pain or chest discomfort.**
- **Don't expect too much of yourself, as with any long-term condition, you may feel anxious or depressed which may be having a bearing on you wanting to having a physical relationship. Discuss with your partner or healthcare team member if this is the case.**
- **Choose a time and environment that is right for you, where you feel relaxed and comfortable.**
- **Many people feel that just holding each other, hugging and kissing is rewarding and reassuring for both partners.**

For further information, visit the European Cardiology Heart Failure Association website at www.heartfailurematters.org.

EMPLOYMENT & HEART FAILURE

4.4

Being Employed

Being diagnosed with heart failure may have an impact on your occupation. You may be forced to have a period of time off work. Although you may find the conversation difficult, it is important to maintain contact with your employer and have an open and frank conversation and relationship on the impact of your condition. This is an area where you can really help yourself so instead of waiting for your employer to contact you, make them set up a regular schedule of telephone calls so you remain in control. If you think about it, the more you are seen to be wanting to communicate, the more your employer understands the challenges and can therefore help you when you return to work. If you haven't been referred to your occupational health department, ask for a referral. If you haven't got an occupational health department, contact your union or other professional body for information and support if you find yourself on long-term sickness.

Many people do not understand the term 'heart failure' and that applies to employers as well. You may find the following information helpful in explaining to your employer what heart failure is.

For many individuals, continuing to work is not just about the financial need. Many people actually enjoy their job, have great work colleagues and appreciate the social interaction that work provides. It is therefore important to have a frank conversation with your employer of how your symptoms will affect your capacity to work. It may require some adjustment from both you and the employer, particularly if you work a long shift pattern, or your role requires a good deal of physical activity.

We also appreciate that for some individuals there will be little support from their employers, especially in terms of sick pay. Please see **section 4.1** for further information.

Discussing heart failure with your employer

I have an inefficient heart which results in my heart not being able to pump blood efficiently around my body. It is called heart failure; it doesn't mean 'I am failing'.

I may experience the following symptoms:

- **Breathlessness**
- **Fatigue**
- **Swelling of my legs and ankles**
- **Restriction in my physical activity**

I am managing my symptoms. I take regular medication, monitor my symptoms, lead a healthy lifestyle and attend regular check-ups with my health team. If you have any further questions please ask me or visit the **Pumping Marvellous Foundation** website which provides information on heart failure.

www.pumpingmarvellous.org

Further Reading

The following government website provides information on employees and employers' entitlements and responsibilities:

www.gov.uk/taking-sick-leave

The government's health and safety executive website provides information on any legal issues with regard to employment law:

www.hse.gov.uk/sicknessabsence/legalguidance.htm

ACAS promotes excellence in employment and human resources and can act as a mediation service:

www.acas.org.uk/index.aspx?articleid=1461

The benefits system is frequently under review. The following link provides the latest government information of disability and sickness benefits:

www.gov.uk/financial-help-disabled/disability-and-sickness-benefits

The Citizens Advice Bureau also provides independent information on a range of benefits and services that may be available to you:

www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/benefits-for-people-who-are-sick-or-disabled/

For general advice on a range of benefits, you can visit the following government website:

www.gov.uk/browse/benefits

DRIVING WITH MY CONDITION

4.5

For information with regard to any driving restrictions as a result of your cardiac condition, please visit the following government website:

www.gov.uk/browse/driving/disability-health-condition

As regulations change, please visit the website for the latest information.

Making the decision to stop driving can be difficult, but if you feel that your health is affecting your ability to drive safely then you may have to make the decision to stop. You do not want to put yourself, your passengers or other road users at any sort of risk.

If your partner, family or friends are suggesting that you should stop driving, discuss the issue with them openly and listen to their concerns. It may be a difficult conversation, but they will no doubt be thinking of your well-being. The blue badge scheme allows concessions for parking your car. Please visit the following site for information regarding qualification and application for the scheme:

www.gov.uk/apply-blue-badge

You can ask for a referral to a mobility centre who will assess you and provide information into what vehicle or aids may assist you driving with any disability. You can ask for a referral from your GP:

www.mobility-centres.org.uk/

Depending on your age and circumstances, you may qualify for a Motability allowance. This is now part of the personal independent payment. Please visit the following government website for further information:

www.gov.uk/pip/overview

MARVELLOUS GUIDE IN SUMMARY

4.6

To summarise what you have read so far our patient community identifies the most important points that will help you with managing your condition on a day to day basis.

Before we identify these with you we hope you've found some real golden nuggets of information which you can take away and use. We all know this isn't easy but from experience, if you learn how to achieve something difficult you can apply the way you solved one problem with solving the next.

So see these points as the starting point of your new "marvellous" journey. They are not the only skills you will need to acquire but they will give you a good foundation.

First look at the module your Nurse has given you. Knowing why you have heart failure will help you put it all into context and enable you to understand what you need to do next.

Section 2 - Medical Stuff

The '**Medical Stuff**' section tells you in 'patient speak,' in step by step format what the investigations and therapies are for people like you with heart failure.

Section 2.3 - Symptoms of Heart Failure

Know your symptoms. By knowing your symptoms this will help you to apply your own fixes.

Section 2.5 - Core Medication

Know what your medicines do, know why you are taking them and know what the side effects if any look like for you. This will help you maintain their importance in your care, take them as prescribed and try not to miss them.

Section 3 - Me & My Heart Failure

The **'Me & My Heart Failure'** section gives you tools on how you can help manage your condition. It gives you tools that whilst not under the care of Healthcare Professionals will enable you to get to grips with your condition and help you manage it more effectively. It's amazing what a little bit of knowledge and the right attitude to self-care can do.

Section 3.2 - My Appointment Diary

Your appointment is one of the most important times for you and your Healthcare Professional to get to know how you are doing. Preparation, preparation and preparation are the three key words. As the Healthcare Professional has prepared for your appointment, make sure that if you have questions that you ask them now.

Section 3.3.1 - The NYHA Scale - A Useful Tool

Where are you in New York? Use this as a method of telling your Healthcare Professionals where you are, they will understand you and will value your feedback.

Section 3.5 - Looking After My Ups and Downs

Understanding your heart failure and how this relates to your symptoms will help you make decisions that will help you manage your condition.

Section 3.6 - My Medical Team

Knowing who your team are and how they are part of your team are really important. They are referred to as your 'Multi Disciplinary Team'. Also, if you haven't got one of these team members you should ask why not.

Section 3.8 - Getting The Most Out of Your GP

Do not underestimate the value of relationships. A good relationship will get you a lot more than if you didn't have that relationship.

Section 3.9 - Staying Active

Exercise is one of the best self-prescribed therapies, make sure you have been signed off for this by a Healthcare Professional and do it at your own pace and most importantly feel the benefit.

Section 3.10 - What Is Healthy Eating For Me?

Remember, you are what you eat, so eat healthily.

Section 4 - More Help

The **'More Help'** section covers the little extras that may not be essential to every individual but do play a part in our lives.

Section 4.3.1 - Relationships & Romance

Remember your family are part of your team, they need you as you need them. Make sure they have an opportunity to recharge their batteries as well.

**We hope that you
have found this
Marvellous Guide to
Heart Failure useful.**

*If you'd like any further information, please
visit us at www.pumpingmarvellous.org.*

MY MARVELLOUS GUIDE TO HEART FAILURE



Contact Pumping Marvellous



0800 9 788133



hearts@pumpingmarvellous.org



heartfailureaware (open)



www.pumpingmarvellous.org



@pumpinghearts



helpforhearts (closed support group)