

A Marvellous Guide to Caring for Heart Failure Patients

A Carer's Story...



WELCOME TO THE PUMPING MARVELLOUS FOUNDATION



So what is a carer? Do you recognise yourself as a carer? If you are reading this then you are someone who has a significant role in supporting someone with heart failure.

You may live 24 hours or 240 miles away, or share a 24 hour day with someone who has heart failure. To them you are their significant other, someone that they recognise as being instrumental in successfully living with heart failure. This 'Marvellous Guide' has been written by fellow carers and patients with heart failure as a result of their day-to-day experiences of caring and living with heart failure, their joys and tribulations, their coping strategies, their emotional journey.

The level of care required by the person you are supporting will vary considerably according to your circumstances and the measure of heart failure they are experiencing, however, this guide contains a variety of information which you may find useful and which relates to your specific needs.

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.

What is heart failure?

The heart consists of muscles that pump blood around the body. With heart failure, the heart is not pumping correctly and is often enlarged because it is having to work extra hard.

Generally there is a reason why the heart is not pumping correctly. The vast majority of the time this is due to the heart muscle being damaged because it is getting a poor blood supply. This can happen after a heart attack, or when someone's had high blood pressure, which has affected the heart.

Other causes include:

- A virus has affected the efficiency of the heart
- The heart's rhythm isn't normal
- Genetically the heart is not structured as well as it should be
- The valves in the heart are damaged
- Excessive alcohol intake
- Recreational drugs
- Some chemotherapy medication
- In rarer cases, there is a form of heart failure associated with pregnancy

Sometimes, we just don't know what the cause is.

So how bad are things?

We are aware that heart failure is a serious condition, however the important thing to remember is that there is now a good understanding of it and that there are a number of treatment options available, from medication to cardiac devices, to help manage it. Like many other conditions the relentless challenge of discovering newer treatments is always on the horizon.

So where are they in New York?

A strange question perhaps, but patients and Healthcare Professionals often find the New York Heart Association (NYHA) classification scale useful in assessing the severity of this condition based on the symptoms they are experiencing.

So where is the person you are supporting on this scale today?

NYHA Class	Symptoms
NYHA Class I	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations, or shortness of breath.
NYHA Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations, or shortness of breath.
NYHA Class III	Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
NYHA Class IV	Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort is increased.

People with this condition often find they have a certain amount of energy – like a battery – to get them through each day. How much energy is in the battery generally depends on how the condition is assessed on the NYHA scale. Just as you would think about how to get the most out of a battery, it's good to think about the amount of energy the person you are supporting has. Try and plan out how they will use it throughout the day and prioritise the activities that are most important to them.

What does this mean for me?

Where the person you are supporting is in New York and what your own circumstances are will determine how much of an impact the heart condition has on your day-to-day life.

One of your most important roles is to help the person you are supporting to try to stay positive and have a can-do attitude – this can really help them to play an active role in their own condition. Research by the European Journal for Cardiovascular Nursing (EJCN) shows that those who can adapt to their illness and take control of it are happier and have a better quality of life.

Although it will probably change aspects of your own life, it does not need to take over your life completely. Your first instinct might be to try and do everything for the person you are supporting, but you need to take a step back every now and then and live your own life. We have seen time and time again that focusing on yourself and giving yourself some time away from 'caregiving' makes you a better carer.

Practical Support

One way that you can help the person you are supporting to take control of their condition is to encourage them to keep an eye on the factors on the next page in order to identify if they are getting into difficulties. They may also help you to identify when medical advice is required for the person you are supporting.



Symptom Checker

HOW ARE YOU?

Your weight has not increased or your weight had increased by 4lb/2kg over 3 days but you agree with the statements below;

1. You are no more breathless than usual.
2. Your ankles are no more swollen than usual.
3. You are as active and mobile as you normally are.
4. Your main carer's health is unchanged.

WHAT SHOULD YOU DO?

There is no need for a review by the heart failure specialist team/GP/Practice Nurse apart from your regular reviews. However, you should be reviewed at least twice a year.

HOW ARE YOU?

Your weight has increased/has increased by 4lb/2kg over 3 days and/or and one of the statements below is true;

1. You are feeling more breathless than usual.
2. Your legs are more swollen than before.
3. You are breathless at night or need more pillows to sleep on.
4. You are unable to be as active as usual/ you are a bit more muddled than usual.
5. Any of your other conditions are worsening.
6. Your main carer is becoming more ill and unable to help look after you as much as before.

WHAT SHOULD YOU DO?

Try simple measures to improve your symptoms **and/or** consider an earlier appointment with the heart failure specialist team/GP/Practice Nurse if you feel it necessary.

HOW ARE YOU?

If over 3 days your symptoms continue to worsen, **or** if you have other symptoms below consider phoning your GP or the urgent contact numbers below.

1. You have had diarrhoea or vomiting for more than 24 hours.
2. Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.
3. You have worsening or new angina.
4. You have worsening breathlessness or leg swelling or are unable to be as active as usual.
5. If your medication has been reduced but not by the heart failure team.
6. You have symptoms of an infection and/or you feel very unwell.
7. Any of your other medical conditions are continuing to worsen.
8. You have blacked out.
9. You have become confused about your medications.

WHAT SHOULD YOU DO?

Contact your heart failure team or GP as soon as possible, or consider calling 999 if you feel very unwell.

So how should I feel?

If it feels rather daunting, don't panic. Fellow carers have described some of the emotions that you may be feeling right now. Perhaps at some time in the future you may experience similar thoughts and feelings.

Some of the fears and strains:

- The weight of responsibility
- A feeling of isolation
- Having to learn on the job
- Have I missed an important sign/deterioration?
- Being afraid
- Being angry
- Being frustrated
- A sense of loss
- When I am away from them I can never relax due to worrying about them
- What would happen if something happens to me?
- What does this mean for the other family members to whom I give care and support?
(e.g. caring for grandchildren, looking after an older relative)
- Constant anxiety
- What about me?

If you feel any of the above, it is *perfectly normal*.



So how should I feel?

So let's take them in turn. Fellow carers talk of occasions when they can feel very isolated and the weight of responsibility of supporting someone with heart failure appears daunting. We will discuss this further when we talk of developing your team. This is natural and we hope that this guide will help you to cope better with those understandable feelings.

There is a certain element of learning on the job as you and the person you are supporting develop your own routine, however, don't let the condition define you. If you have any concerns, do discuss them with your Healthcare Professional, it is a team effort at the end of the day.

On occasions, you may experience a feeling of loss, anger and frustration at the changes to your life and your plans for the future necessitated by the condition of the person you are supporting. This can mean re-evaluating what you feel is most important to you. You can, however, see this as a positive and discover that an adaption to those plans or a different direction altogether may be just as rewarding. You have permission to have all those feelings. Social and financial implications of finding yourself as a carer may be of great concern to you, see our section on supportive services.

Carers also talk of the overriding concern of knowing that the person they are supporting is 'okay'. It is a constant question that carers ask, "Are you ok? How are you feeling?", and many carers say that they cannot relax when they are away from the ones they are caring for due to the anxiety of not knowing if they are okay. Being overprotective is perfectly understandable. This is often a confidence issue which does come with time and often improves. Develop an open dialogue with the person you are supporting and have a stand by plan so that if an issue arises when you are away, for example out shopping, then an effective strategy is in place. That is also true should you take ill and are unable to undertake your usual tasks. It is really important to have a standby plan in case you have to be away and a crisis occurs. This could mean thinking about getting a careline installed and always wearing the pendant, accepting offers from friends or neighbours to be on standby or thinking about using a local carer or sitting service. It can be very difficult for someone needing care to accept such support for the first time but it is essential to think about extra support just in case you need it. Carers themselves can get ill and other family members may need urgent support from time to time!

But what about me? That's the important issue for this guide, so let's discuss this in more detail.

My Golden Rules

It is so important that you take care of yourself in order to effectively undertake the role of carer to the person you are supporting. We have discussed that this condition should not define you and the following considerations may help you in this process. Discuss them with the person you are supporting, your family and friends. It will help you all to understand the impact that being a carer can have on you as an individual.

- You are doing a great job, take pride in that.
- Try and have time for you - ensure that you still undertake any hobbies or events that you find most enjoyable to you.
- Take care of yourself, that is important. It is not being selfish but sensible, you need to be well to undertake your role.
- Ask for support, everyone has their limits, recognise yours and call on those who can support you. Friends and neighbours do like to help but in most cases they will wait for you to make the first move and ask them!
- It is perfectly normal to have a range of difficult emotions, to feel angry or down, to have good days and bad days, but on those days do not feel guilty.
- It is important that your commitment to the individual you are supporting is recognised and that family and friends also understand the significance of your role. Keep in touch with friends and family – even if you are temporarily exchanging meeting up face-to-face with phone calls, text messages, Skype and e-mails!

You can add your own golden rules, identify to yourself what is important to maintain your personal well-being as ultimately this will make you a more effective carer.



Tapping Into the Wider Team

Developing a team around you makes sense. You don't have to do this all on your own. There are other people who can be in your wider support team and you can have a big say on who they are, including Healthcare Professionals, family members, friends and others. Try and share it about among others and talk about it with them.

Most carers supporting someone with heart failure become a carer without any previous knowledge of what support may be out there to help them. Make sure that you know the full range of people who might help you. Your local carers centre, organisations like Pumping Marvellous, Age UK, the British Heart Foundation and your local hospital should have information available, but check! In addition to your regular visits to the hospital team, there may be good people in your local community services, for example Specialist Community Nurses.

Don't forget that many local health services now run expert patient programmes and other peer support groups. They are wonderful sources of information, advice and friendship. Check with your GP surgery, your hospital team or with your local carers centre for further information.

Remember, the person you are supporting may not see the need for support in the same way that you do. They are receiving support from you - the caregiver. You need to make sure that there is someone to look after you as well and that there are enough people on the team to make sure you do not feel isolated and overburdened.

The heart failure of the person you are supporting may have an impact on areas of your life which may mean you need to consider seeking some help and guidance.

Financial Support

The condition of the person you are supporting may have a bearing on your financial income. This could be as a result of their or your inability to work, or additional financial resources that you require in order to care for them.

The UK system is subject to change and financial support and benefits which are available to you will be subject to current legislation and your personal circumstances. The following website will provide you with the various benefits that may be open to you.

www.gov.uk/browse/benefits

Citizen's Advice may also be able to help you to steer through the maze of the benefit system. Their website will point you to your local organisation.

www.citizensadvice.org.uk

Your local town hall will also be able to direct you to any local Welfare Rights Team that will be available within your locality.

Carers UK publish a wide range of fact sheets and information booklets on applying for benefits and allowances. These are available online or can be ordered as paper copies. Don't forget that the Personal Independence Payment and the Attendance Allowance (for older people) are not means-tested. Your local carers centre will be able to advise you if you are unsure about applying or worried about filling in very long forms.

www.carersuk.org

If you do not have access to the internet ask a member of the family who may be able to do this for you. If that is not possible then contact your local town hall who will be able to direct you to your local social services department.

You may also wish to discuss this with your GP or Heart Failure Specialist Nurse who will be able to request an assessment for you.

Hands-on Support

It is hoped that the person you are supporting has a key Professional Healthcare Worker involved in their care. Our patients and carers highly value the Heart Failure Specialist Nurse, therefore, if you do not have a Heart Failure Nurse then ask your GP if there is a service available for you to be referred to. Your Healthcare Worker or GP should ensure that you have the additional healthcare support that the person you are supporting may require, e.g. District Nursing Team. Suggest a referral to your local cardiac rehabilitation team to the person you are supporting. This team deal with many aspects of successfully managing heart failure symptoms including physical activity, lifestyle issues, education on heart failure, stress and anxiety. Cardiac rehabilitation is known to greatly reduce symptoms and prevent any further hospital admissions.

There may arise a time when the person you are supporting needs additional physical carer support. Depending where you are and your financial circumstances may determine the amount of support that you are offered. The important thing is to get in contact with your local social services in order to have an assessment undertaken.

If you do not have a heart failure team then visit www.justheartfailure.org
There you will be able to find the nearest teams to where you live and how to access their services.



Under the Care Act 2014 and Scotland Carers Act 2018, it is suggested that carers have a right to request an assessment in their own right and separate to any entitlement of the person they care for. Support available will vary according to where you live, but it is likely to include a wide variety of options, ranging from short breaks to providing a computer or practical help in the home. The Care Act requires all councils to provide free information and advice to carers and those they support. Many councils will provide some support for carers without charge (recognising the value of their contribution). Your council's website will have information on what is available and how to request an assessment. Your local carers centre will also be able to provide information and advice. If the council considers that you and/or the person you care for are eligible for support, they may offer you a personal budget or direct payment. The personal budget tells you how much money the council is willing to pay for your care or support. You can take this money as a direct payment (which means that you spend it on the support agreed at your assessment). However, you do not have to accept a direct payment and the council, a relative or another organisation can handle the money for you if you prefer.

From April 2015, you can also request a personal health budget. The assessment for personal health budgets will be carried out by your local clinical commissioning group and/or your hospital team and can be used for a wide range of support to improve health and well-being.

It is difficult to keep up-to-date with the various services that are offered as these change on a frequent basis. For England and Wales the following website will point you towards the services offered in your area by entering the relevant post code.

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

Emotional Support

The person you are supporting will have good and bad days, both physically and emotionally. Not surprisingly, living with heart failure can cause anxiety and depression. Although you will always try to be as supportive as possible, you too will have good and bad days and sometimes you may find it gets too much. At times like these you need to talk to someone else, whether that is a Healthcare Professional, a member of the family or a friend. Remember that there are counselling and other services which can help you – and the person you care for - but you may need to ask for the referral.

Remember your golden rules

You need to take care of yourself, recognise your own limits and seek help from others when necessary. You need to maintain elements of your own life, including ones that do not necessarily include the person you are supporting. None of this is selfish, it is essential to help you be a better carer. If you find that your feelings are becoming too great, you are struggling with your emotions and feeling anxious and depressed, do see your GP, again don't struggle but seek support.

Useful Organisations

The Pumping Marvellous Foundation offers a range of support and information on day-to-day life in relation to living with heart failure, particularly in regard to successful self-management. Please visit:

www.pumpingmarvellous.org

The Foundation also runs a closed Facebook group where other patients and carers can share their experiences and offer support in the successful management of heart failure. You can find this information on the back cover of the Marvellous Guide.

Many national and community organisations offer a variety of support services and your local town hall should be able to point you towards the groups in your area. These may include Age UK, Carers UK, the Carers Trust, the Lions, the Rotary Club, the British Heart Foundation and Cardiomyopathy UK. If the person you are supporting is seriously ill discuss with your GP what palliative care services are available in your area.

Providing Care from a Distance

It is not always possible to live with or nearby someone with heart failure who you are helping to care for due to work, family or other commitments. Some particular points to think about when caring for someone from a distance are:

- Try to develop a routine for keeping in touch. Find a time of day for regular telephone or Skype calls. This means that both you and the person you are supporting know when to expect a call and ensures you can feel confident and comfortable that the person you are supporting is okay.
- For help on how to install and use Skype on your computer or smart device, go to the following website: www.support.Skype.com.
- Don't forget the value of new technology, for example carelines and telecare enable you to keep in touch regularly and feel confident that the person you are caring for is safe. Many councils provide careline and telecare services – look on your council website and ask your local carers centre for information.
- Ensure that the person you are supporting has a plan of action should they experience any problems and that they have a list of people to contact if necessary.
- Have the Healthcare Professional's name and contact details to hand. If you are at all worried, or if a regular call has been missed, contact the Healthcare Professional or someone local to them (such as a neighbour) who can go around to check on them if needed.
- Consider if an assessment is needed. If you are worried about how they are coping, either physically or emotionally, consider organising an assessment by your local social services, but make sure you discuss this with them first.



It's Good to Talk

A significant part of caring for someone with a heart problem is helping them to get on with their life and have as much independence as possible, within the limits of the symptoms they experience.

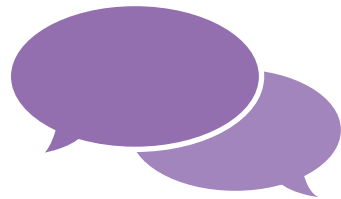
That's why it's good to talk regularly about the help you are giving and to find out what is important to them. It may be they would like to try to do a little more for themselves and don't need some of the help you have been giving, or that there are particular tasks – like taking a shower or getting dressed in the morning - that with your help would become less daunting.

During these 'heart to heart' discussions you may also find that the person you support opens up about how they feel about being diagnosed with heart failure (angry, confused, fearful, relieved they are alive, frustrated). This can also help you make decisions together about the support you give. For example, if the person you support feels depressed or frustrated and these feelings don't go away, it might be a good idea to encourage them to speak to their family Doctor or the Cardiac Nurse or (if they are willing) to a local community group where they may find peer support. GPs and other Healthcare Professionals will refuse to talk to the partner/carer without the patient being present due to confidentiality. Talk to the person you care for and get their permission to discuss their care with their health team if you are worried.

Talk to us

At Pumping Marvellous, we're always happy to listen to you and support you as best we can.

Give us a call on **01772 796 542**.



Talking to the person you support about what is important to you is also essential. It can help them understand why you are, for example overprotective (you don't like to see them struggle) or why you sometimes try to persuade them to do more (you want them to be as independent as possible) or get a bit irritated with them (it's maybe because you are worried about how you are doing as their caregiver). It can also help to ensure that the person you are supporting understands that whilst you want to support and help them, you also need time to look after yourself too.

Patients also talk of the guilt that they may experience on account of the support that they require. They may talk about themselves as being a 'burden' and they may worry about other family members, for example older relatives or children and grandchildren who they can no longer support in the same way. They can feel as though they have somehow failed and there is an initial sense of sadness, loss and frustration as they can see the impact of the support they require.

So it's very important to talk openly and honestly with each other and share the emotions that you are both going through. It's also important to remember that you are still a husband, wife, partner, friend or neighbour and much more than a patient and a carer! Try and keep the friendship, candlelight and romance in your relationship. Physical contact is good for a relationship, choose a quiet and intimate moment for you to talk and discuss that aspect of your relationship. If either of you have any concerns or issues, then do discuss them with your Healthcare Professional. Don't forget that heart failure affects the whole family and talk to children, other relatives and close friends. They may want to help and understand but may be very hesitant about voicing their own fears and concerns and offering support.

It is also necessary to state that the individual with heart failure is a person in their own right. The carer may not always love them. They may feel trapped in a situation that they resent and hate and it would be wrong to assume that all relationships are necessarily close and loving. Remember your golden rules and draw on the support and experience of a wider team.

The positives of being a carer

Many carers express the positive aspect of finding themselves in the role of the carer. Indeed carers often say that this has brought them closer together. It can be an opportunity to reset mutual goals, take on and develop new roles and tasks within their relationship. The role of the carer is rewarding and a different way of expressing mutual respect.

Top Tips from Patients and Carers

Here are our top tips from our patients that you may find useful.

Be persistent, whether about supporting self-management or engaging with your Healthcare Professional, don't be frightened to assertively discuss your case.

Know what to do in case of an emergency, make sure you have the relevant telephone numbers.

Establish a good rapport with your GP.

Ask for support if you feel that you need it, it's no good struggling on, that can make matters worse. It makes sense to make arrangements for support before there is a crisis!

Cardiac rehabilitation is a great partner for you, ask about local services.

Gain knowledge, that way you can better support the person self-manage their condition – join a local Carer Support Group so that you can exchange ideas; learn more about local services and make new friendships.

Think about peer support for the person you care for – having heart failure can be a lonely business and there are groups to offer practical advice and friendship.

Patient Quotes

Here are a few quotes from our patients and carers, you may find them helpful and even amusing!

'Are you sure that you have taken your tablets?'

'You feel guilty because you can do it and they can't.'

'He now does as he is told.'

'The reassurance of a positive answer to the question, "are you okay?"'

'Will you slow down and give yourself a rest.'

'The carer is on the same journey as the patient.'

'KISS! Keep it simple, stupid.'

So Begins Your Journey

We do HOPE that this guide has provided you with information, support, empathy and hope as you start on your journey in the role of carer, whatever that may be for you.

A most important message is now is to say **THANK YOU**. The role of the informal carer saves the health and social care system of the UK a huge amount in terms of finance and support services. Thank you from patients, Healthcare Professionals and the wider society for reading this booklet and helping in the way that you do.

A big thank you goes to all the patients who are members of the Pumping Marvellous Family for sharing their experiences and acquired knowledge, in order to produce this guide.

We HOPE that you find it useful and supportive.



NOTES:

Other 'Marvellous Guides' available in the series

You can find other resources written by patients like you, for patients like you on our website, plus many more publications designed to help you out with managing your heart failure.

Hope

Designed for newly diagnosed people with heart failure

PPCM awareness

Designed for pregnant mums

PPCM toolkit

Designed for mums diagnosed with PPCM

CRT and ICD pre-implant toolkit

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

Heart Failure in Lights

A great tool to help you manage your symptoms

Toolkit for Carers

A marvellous guide to help people who care for people managing heart failure

Heart Failure and Holidays

Ideal for people wanting some help with going on holiday with heart failure

Walking a day in my shoes

Marvellous guide for people wishing to inform their families about heart failure

Guide to GTN

A simple guide to helping you take GTN spray or tablets

A Marvellous Guide to Medicines for Heart Failure

Learn about your marvellous medicines, how they work and handy tips from patients

My Appointment Diary

A handy guide to help you manage your heart failure

If you are looking for support why not join our Facebook Group where you'll find great peer to peer support. Search for "Help for Hearts" on Facebook.

Pumping Marvellous Help for Hearts



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/heart-failure-patient-academy/heart-failure-toolkit

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



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

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We dedicate this 'Marvellous Guide' to Jane and Michael Howell who were with us from the start, through the thick and the thin

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heart failure aware



PMTVLive



help for hearts (closed support group)



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