

My Marvellous Guide to Heart Failure

Be a 'marvellous' heart failure patient

Me & My Heart Failure

“The end to *those* questions”

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



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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THINGS I CAN DO

3.1

Our patient community believe that taking control of your condition is the most influential way to manage your heart failure on a daily basis.

Before we move on, a crucial question you need to ask yourself is, "do I want to self-manage?"

If you're still reading then you are curious or you've said yes to the previous question.

As a large patient community, this aspect of care is something we have discussed long and hard and whilst not always based on evidence, it is based on patients' everyday life experiences of managing their heart failure and then finding out what works for them.

What follows is the result of our community's thought processes and experiences in their management of heart failure.

Insights from patients

"Learn your limits and find the new you!"

Deborah

"Rest when you need to but you still need to live your life. Rule it, don't let it rule you!"

Jacqui

"Take control of your own recovery."

Lorna

"Recognise the symptoms and act accordingly."

Victoria

"Be honest with yourself and listen to what your body is telling you."

Lorna

"Trust your instincts - if you feel something is not quite right, get it checked out."

Tracey

"Don't be afraid to seek advice."

Dawn

"Self-management means knowing your own body on both good days and bad."

Susan

MY APPOINTMENT DIARY

3.2

Your Appointments

Appointments with your Cardiologist, Heart Failure Nurse and GP are very important. It is an opportunity for you to have a conversation about how you feel. Below is a list of reasons why the appointment is important for you and your team.

- **It's your time to discuss your condition and any challenges you may be experiencing.**
- **It can also be reassuring to know that things are under control, both with you and with your Clinician.**
- **It's also a time when you get feedback after previous tests and investigations and what that next step looks like for you.**
- **It's an opportunity for the next step in your treatment plan.**
- **Surprisingly enough, it's a good opportunity to find out about new members of your team e.g. cardiac rehabilitation.**
- **It's time for your Clinician to find out how you are feeling. At this point you can use the NYHA scale which you will see when you read on.**
- **It's a time for you to ask questions and get the answers you may have been storing up since the last appointment. In your 'My Appointment Diary' tool you will find a section to write down any questions before your appointment.**

Questions to ask

"What will these tablets do for me?"

Donna

"What can I do to improve my quality of life?"

Sam

"Can I still exercise?"

Liana

"What over the counter medicines can I not take now?"

Nick

"How do I know if my heart failure is getting worse... What signs or symptoms should I look out for?"

Bronnach

THE NYHA SCALE - A USEFUL TOOL

3.3.1

What is it?

The NYHA scale is usually used by Clinicians to assess you. However, as you are the only one who knows how you feel, it's a great tool to help you explain to Clinicians what's been going on whilst they aren't there.

Conserving your energy

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 your battery generally depends on how your 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 you have and to try and plan out how you will use it throughout the day to prioritise the activities that are most important to you.

What you need to consider

Depending on your NYHA level, things that you may need to think about are:

- Your work
- Driving
- Your social activities
- Your sex life

Talk to your healthcare professional about any changes you may need to make to your day-to-day life to make sure you can manage your energy levels and get the most out of each day.

USING THE NYHA SCALE

3.3.2

How to use the NYHA Scale

Carefully read through the different classes on the NYHA Scale, and determine where you feel you are. You can then discuss this with your Clinician.

The NYHA Scale

NYHA Class	Symptoms
NYHA Class 1	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations, or shortness of breath.
NYHA Class 2	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in tiredness, palpitations, or shortness of breath.
NYHA Class 3	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
NYHA Class 4	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 increases.

So where are you 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 this condition based on the symptoms you are experiencing.

So where are you on this scale today? We should let you know that you may move around on the scale as your condition and treatments change.

Where are you on the scale?

CLASS 1

"I can perform all physical activity without getting overly short of breath, tired, or having palpitations".

CLASS 2

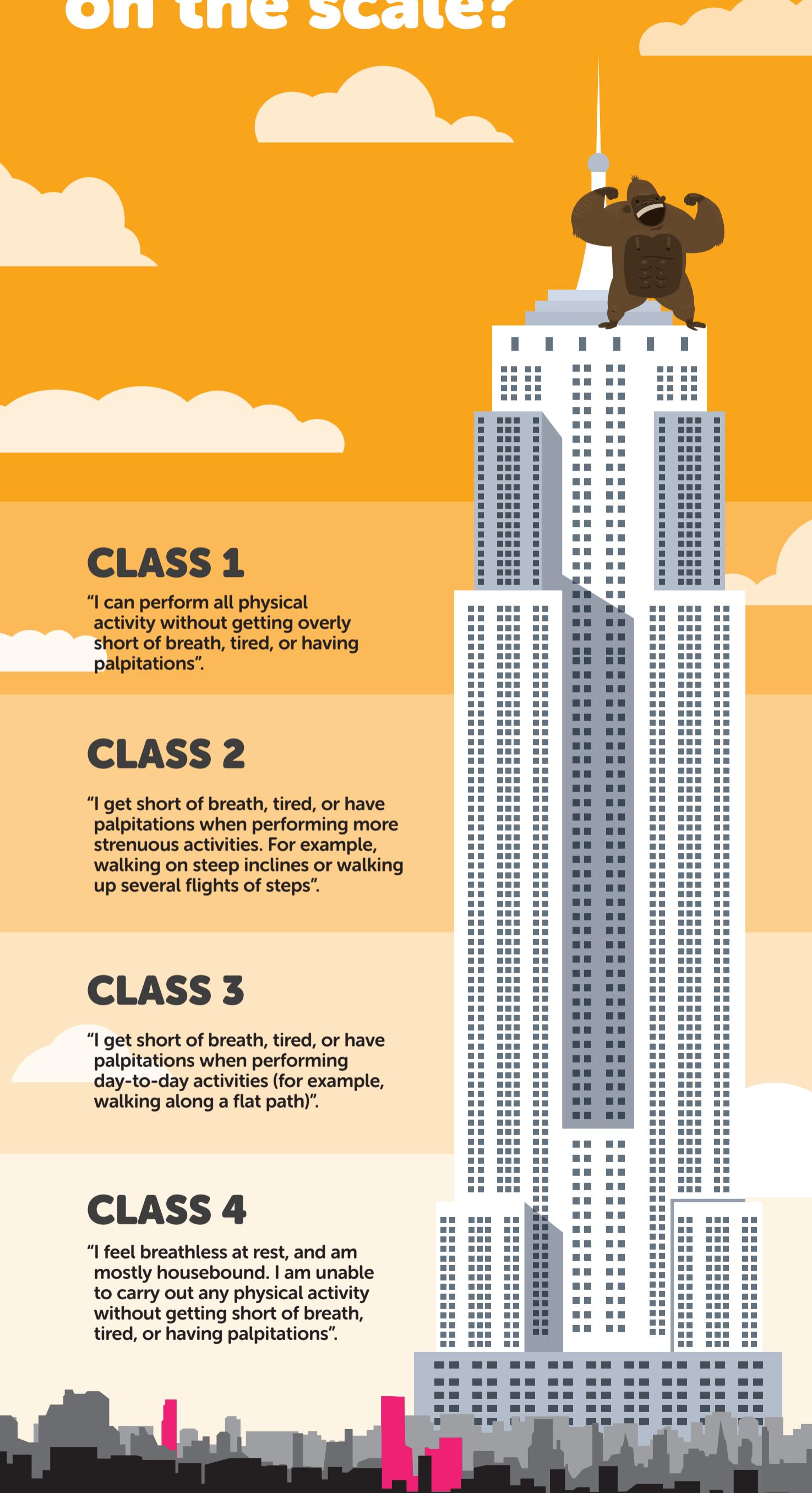
"I get short of breath, tired, or have palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps".

CLASS 3

"I get short of breath, tired, or have palpitations when performing day-to-day activities (for example, walking along a flat path)".

CLASS 4

"I feel breathless at rest, and am mostly housebound. I am unable to carry out any physical activity without getting short of breath, tired, or having palpitations".



DEALING WITH NYHA LEVEL 4

3.4

Quality of life

Many heart failure patients have an excellent quality of life and their life expectancy is very good. We have discussed how the NYHA is a good tool to reflect how you are feeling. For some people with heart failure, despite all the very best of therapies and care, their overall condition may deteriorate. Their NYHA may remain at NYHA III/IV and, if desired, an open conversation with a healthcare professional on life expectancy and a palliative approach to care can occur.

In many areas of the country, palliative and hospice care is now provided for long-term conditions such as heart failure. Organisations such as Macmillan, Marie Curie and the hospice movement now look to support heart failure patients.

No matter what your NYHA status is, if you or your carer have any concerns, feelings or desires to discuss or explore either your condition or end of life care, do not be afraid to raise the issue with your healthcare professional. They will also be able to provide you with a list of services in your area.

If you require any further information, please contact the Pumping Marvellous Foundation where we can help signpost you to local help.

LOOKING AFTER MY UPS AND DOWNS

3.5

Using the Heart Failure Lights

Keeping an eye on your symptoms in heart failure is a key skill for you to be able to help yourself. It gives you and your carer an easy way to spot either improving or worsening symptoms.

Your Daily Routine

Make sure you **take the prescribed tablets for your heart**.

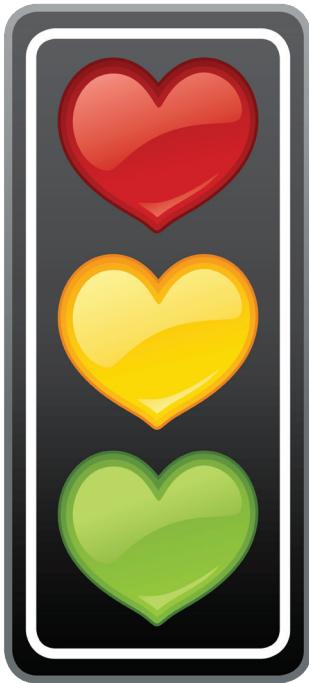
When you get up in the morning, **weigh yourself** after going to the toilet for the first time. Write this down and **compare it to yesterday's weight**. If there is a **change, look at the traffic lights**.

Eat a balanced diet and don't add salt. Don't use low salt alternatives - see **section 3.10**.

Check for either reduced or increased swelling in your feet, ankles, legs and stomach.

Ask yourself if your **breathing pattern is the same as normal**.

Balance exercise and rest; **know your limits**.



IMPORTANT NUMBERS

Community Heart Failure Team

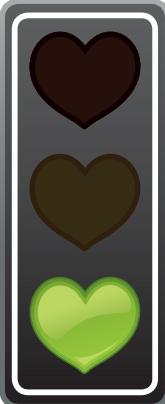
Monday - Friday
0300 123 0 979
Ext.4183

UHNM Heart Failure Team

Monday - Friday **01782 672800**
or page via switch **01782 715444**
(pager number **07623611301**)

Out of Hours

111
or
0300 123 0 989



GREEN - KEEP WATCH

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



You are no more breathless than usual.



Your ankles are no more swollen than usual.



All of your other medical conditions are OK.



You are as active and mobile as you normally are.



Your main carer's health is unchanged.

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.



AMBER - STAY ALERT

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



You are feeling more breathless than usual.



Your legs are more swollen than before.



You are breathless at night or need more pillows to sleep on.



You are unable to be as active as usual/you are a bit more muddled than usual.



Any of your other conditions are worsening.



Your main carer is becoming more ill and unable to help look after you as much as before.

HOW ARE YOU?

Your weight has increased or your weight has increased by 4lb/2kg over 3 days **and/or** 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 a sooner appointment with the heart failure specialist team/GP/Practice Nurse if you feel it is necessary.



RED - TAKE ACTION

If your symptoms continue to worsen over 3 days, or you have any of the problems below;



You have had diarrhoea or vomiting for more than 24 hours.



Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.



You have worsening or new angina.



You have worsening breathlessness or leg swelling or are unable to be as active as usual.



Your medication has been reduced but not by your heart failure team.



You have symptoms of an infection and/or you feel very unwell.



Any of your other medical conditions are continuing to worsen.



You have blacked out.



You have become confused about your medications.

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?

Consider urgent advice from GP, or heart failure service. If you feel very unwell, call **999**.

MY MEDICAL TEAM

3.6

When patients were asked, "who is the most important person in supporting you in the management of your heart failure?", they told us it was their carer and family. So first, a big thank you to all those carers out there fulfilling such an important role. Please pass on the carer booklet that you will have been given with the 'Marvellous Guide'. You will no doubt build your own team around you and every team is different; it depends on who you think is your best team from your squad and who you are going to play at certain times. Having the right team to tap into is something that Pumping Marvellous feels is vital in helping you self-care. See **section 3.7** for how to form your team.

So who are the people who can support you? Number two in the list is the Heart Failure Specialist Nurse. Our patients and carers felt that having access to one enabled a connection to all the other members of the team.

Heart Failure Specialist Nurse

In the UK, we are lucky to have Heart Failure Specialist Nurses. Unfortunately, not every patient will have a Specialist Nurse and it does depend on where you live and the type of services offered. Heart Failure Specialist Nurses will be found in both the hospital and community setting. The Nurses will generally have a strong background in cardiology. They are often Nurses who can prescribe, so they can review and prescribe your tablets ensuring you are on the best of drugs and at the right dose. They can also arrange for tests and investigations and interpret the results so they can tell you what they say. The Heart Failure Specialist Nurse is also a good link for the patient to have access to both your Consultant Cardiologist and GP. They can act as an advocate, the go-between that enables patients and their carers to link the different services provided. This is useful as the health system can be quite complicated when looking from the outside in; your Heart Failure Specialist Nurse can help to 'join the dots'.

They are also able to give physical, social, and psychological support and can bring in any additional professionals and agencies to support you in managing both your heart failure and other conditions or issues you may have.

Your GP Practice

Having a good rapport with your GP is vital. Having a regular GP who knows and understands you and your condition is valuable as they tend to be more accessible than Cardiologists in hospitals. Your GP is often your first point of call; although your GP may not specialise in your condition, they will identify and send their findings to a specialist service if needed.

Practice Nurse

Your Practice Nurse is often someone with whom you may already have a strong relationship. The Practice Nurse role is to support, monitor and treat you for any long term conditions that you may have. If your heart failure treatment has been optimised and your condition is stable, then you may be discharged to the care of your Practice Nurse. They are an important cog in your team and are generally more accessible than your GP.

Cardiologist

Cardiologists are highly qualified and experienced Doctors in cardiology. Recently, Cardiologists have begun to specialise in specific areas of cardiology, e.g. heart failure. You are usually under one Cardiologist who will manage your care and it will depend on your clinical picture both when and how often you will be reviewed by them.

Pharmacist

Your Pharmacist is a great place to go to ask questions about the medications you take and find help with what you can take when you have other issues (like a cold or other common conditions). They generally complete a medicine review with you periodically. They are definitely a friendly face in a world where appointments are a norm as generally you don't need an appointment. Ask them some questions next time you go and collect your prescription medicines.

Patient Groups

We know the power of talking to somebody in a similar situation is a powerful and valuable way to learn about your condition. At the end of the day, that's how the Pumping Marvellous Foundation helps by providing appropriate support when needed by patients and their carers through peer to peer support. Ask a member of your team to put you in touch with your local support group or, if you haven't got one, then please feel free to engage with us. We have a national patient community and are constantly helping people like you and your carer live better with heart failure. There are various ways to talk to us, please see below:

 **0800 9 788133**

 **hearts@pumpingmarvellous.org**

 **heartfailureaware (open)**

 **helpforhearts (closed)**

 **@pumpinghearts**

 **www.pumpingmarvellous.org**

Other Team Players

We would say the above players are the essential team members everybody should have access to, but there are others that you can select or may find it useful to engage with. These could include the following which your main team players could refer or signpost you to:

- **Heart Failure Rehabilitation Practitioner**
- **Hospice**
- **Psychological Support**
- **Dietetics**

WHO IS MY TEAM?

3.7

Identify your core team

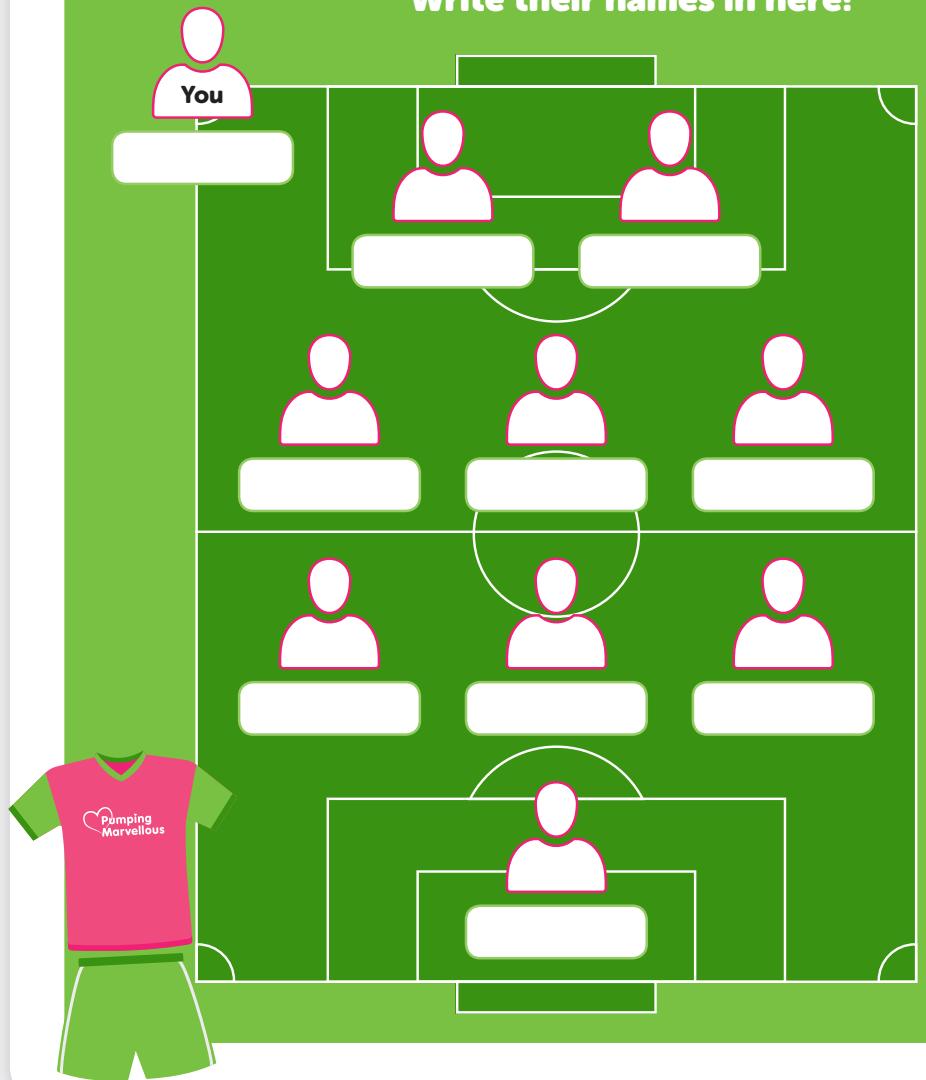
Our patient community tells us that there a number of key players who you need to support you. It is important to realise that these key players help you to form your squad. By engaging and building a relationship with them you will quickly form an idea of who you need in your squad.

Spend some time filling out who is in your team. Remember, you can have substitutes.



Who is my team?

Write their names in here!



GETTING THE MOST FROM YOUR GENERAL PRACTICE

Forming a relationship

We have a number of patients who are willing to support both the charity and other patients. We call these experts Patient Educators. Pierre is one of our Patient Educators; read his advice on forming a good relationship with your GP.

"I feel that where heart failure is concerned, it is key to have the right GP. This is vital as he/she is the main day-to-day contact any heart failure patient has.

Strike up a good relationship with the receptionists as they can help you a lot with prescriptions, appointments, etc.

Be an educated patient i.e. know about the condition and how it affects you. Know your medication and what it does for you and how it works to improve your condition.

Try not to come across with an attitude of 'there's nothing they could tell me about heart failure'. Remember, they are part of your team and are trying to help you.

Choose the right Doctor for you within the practice. This is a bit like an interview process, but really you know who the good ones are from, well, the not so good ones. The one you feel best about, I don't mean the one who you know, the one you can get to agree with whatever you are saying, but the one who will work to do their best to maintain and improve your condition and at times push and encourage you.

If you are lucky enough to have a Heart Failure Nurse, point this out to them, as the Doctors do not know everything about your condition. This will help your Doctor as they will know that the Nurse is in partnership with them. If there are any issues, there is a good source of information and advice a patient can access. Here is an example: my kidney function was abnormally high and my Doctor said that they would stop one of my tablets, Spironolactone. I said I would give the Heart Failure Nurse a ring just to get their thoughts on it, which he had no objection to as he felt more informed and valued advice from a specialised Heart Failure Nurse would be great. I fed back the information and didn't stop Spironolactone. My Doctor was very pleased as he recognised that, as a team, the correct decision was made for the patient."

Pierre's Key Tips

- 1. Explain to your Doctor/practice that due to your condition you would like to see the same Doctor at all times.**
- 2. This may be difficult in emergencies, but if it is an emergency for a heart failure patient, in reality the GP would not be the first port of call.**
- 3. Discuss your current symptoms with your doctor and how together you can both work to improve your health. Discuss access with your Doctors as seeing the same Doctor enables you to build up a good relationship. If you feel you need to see your Doctor, ask if they wouldn't mind you ringing to get a telephone appointment. Quick access can make a big difference in heart failure. It is very reassuring knowing you have that facility available to you.**
- 4. Where heart failure is concerned, it is key to have the right GP, which in turn helps the self-management process.**
- 5. Work with your Doctor if they have suggestions e.g. on healthy lifestyle options, different medications. Do not dismiss this as they may offer a good solution to help improve your condition.**
- 6. Heart failure patients are just normal people and normal people have normal problems. A good relationship with your Doctor and GP practice will no doubt be better for you.**

GETTING THE MOST OUT OF YOUR CARDIOLOGIST

Your Cardiologist is your heart doctor and you may rarely see them or see them only once. Other members of your heart team such as your GP or your Specialist Heart Failure Nurses may be in contact with them on your behalf at other times.

It is important that you get the most out of your consultation and ask all of the questions you want or need to know.

The Heart Failure Checklist

This is your chance to ask the Doctor about your diagnosis.

- **What the impact of this condition is on your life**
- **Whether it will impact on your life expectancy**
- **Whether it will improve**

What part of your heart isn't working?

The question is, have I got HeFREF or HePPEF? This is because , depending on which one you have, your Doctor needs to consider different medications and potentially special devices (see **section 2.5.1**).

What has led to you having heart failure?

This may be one or many things, but this is your chance to ask your Doctor.

- **It is important in your case to know what actually caused the heart to fail. Whether there is something more specific that can and should be done to improve your heart function.**
- **What are the risks and benefits of these more specific treatment?**

TECHNOLOGY: AN ALTERNATIVE TEAM MEMBER

3.10

There are now various technology solutions to assist patients and carers in the management of their condition. Some areas may have invested in telemonitoring, this may involve patients downloading readings of their blood pressure, pulse and weight for example. You may find some health apps that will help you with your goals e.g. Apple Watch, NIKI, and Fitbit. However, before embarking on a purchase we suggest you check with your health professional if this would be a suitable investment for yourself.

Pumping Marvellous have a very active and successful Facebook community, where peer to peer support is offered in a safe environment. NHS Heart Failure Nurses refer patients and their carers to this facility to help with some of those issues that are faced on daily basis by patients and their carers.

For regular news information around heart failure we also run the world's largest patient led information page, you can find all that latest developments and research that our patient community find positive and hopeful.



[heartfailureaware \(open\)](#)



[helpforhearts \(closed support group\)](#)



[@pumpinghearts](#)

What are the treatment options for my heart failure?

Remember the treatment can be:

- **Lifestyle changes**
- **Medications**
- **Non-tablet treatments like cardiac devices.**

This is your opportunity to discuss all of these with your Cardiologist.

What is the aim of treatment for my heart?

The aim of all medical treatment is either:

- **To keep you living for as long as possible**
- **Keeping you symptom free**
- **A combination of both of the above**

However sometimes you can only treat the symptoms. When treatment options are aimed at symptoms only the medical term is 'palliation' or palliative care. This can be confused sometimes with care right at the end of life.

Although palliative care specialists are involved with end of life care, they also have a big role to play, for some people to help alleviate symptoms such as:

- **Pain**
- **Breathlessness**
- **Worry and stress**
- **Fear**

The whole concept of discussing life expectancy can be a difficult thing to think about for some people. Your Doctor will always have a full and frank discussion about this if this is what you want them to do. If it is, make sure:

- **You are happy for them to discuss these issues with you in the clinic - if not choose another location or time where you will be more receptive to this discussion**
- **You take whoever you want in with you if you are discussing serious issues**
- **You take notes if you need to**
- **Arrange another time to see your Cardiologist or Specialist Nurse again if this is too much to take in one go and you need to mull it over and discuss it at another time.**

Other conditions and your heart failure

Your Cardiologist may not be able to help improve the other medical conditions you suffer with, but they may be able to suggest who to see to investigate or improve some of these conditions over and above your GP.

Giving you the information you need to manage your condition and what to expect in the short, medium and sometimes the long-term.

This is an area that has been identified as one that is poorly addressed between heart failure sufferers and their Cardiologists. It is difficult because you can see from this checklist the potential amount of information that is involved in just one consultation.

Your Doctor should tell you:

- **What tests are coming next - if any**
- **What they entail and what the risks and benefits are of each**
- **When they will see you next - if at all**
- **What the warning signs are for you to see them sooner or to contact your Heart Failure Nurse sooner (see heart failure in lights)**
- **Who else from the heart failure team will be seeing you (this is often the cardiac rehabilitation and Heart Failure Nurse teams)**
- **What treatments are likely to be started today and at other times in the community for your heart failure**

Make sure you are happy you have all the information that you need at the end of your consultation. However if this is all too much to take in remember:

- **A letter with all of this in should go to your GP - so you can chat it through with them (see Pierre's tips)**
- **Heart Failure Nurses will have access to these letters and can chat any concerns through with you**
- **You can always arrange to see your Cardiologist again if there were things you feel were not clear when you left the clinic or once you got home**

STAYING ACTIVE

3.11

Our patients tell us of the marvellous benefits of heart failure rehabilitation. There are structured programmes available which have a variety of activities to suit all ages, capabilities, tastes and community localities. Remember, physical activity isn't just about the gym.

Ask your Heart Failure Nurse, GP or other Healthcare Professional for the services that are available to you and the ones that meet your capabilities and needs. Attending a formal exercise class may be something that you have never done before, but visit your team and consider giving it a try. Some heart failure patients feel that undertaking a planned exercise programme changes and enhances their life.

There are many benefits to your health and well-being from being physically active (this is when you move your body and utilise more energy than you would at rest) or participating in a structured exercise session (where you perform planned movements aiming to specifically improve your level of cardiovascular fitness or muscular strength/endurance).

Benefits

- Improved breathing
- Weight loss
- Blood pressure and diabetes control
- Improved general well-being

Examples of physical activity include leisurely activities such as walking, cycling, gardening and dancing when performed at a low to moderate intensity.

Examples of exercise can include the physical activities previously mentioned but carried out at a higher intensity. Other activities comprise of organised sport, circuit training or the use of cardiovascular and resistance equipment commonly found in fitness studios.

Taking Part

Prior to participation in an exercise programme you will need to ensure that your medical professional has agreed with your choice of exercise. This may initially involve participating in physical activities in and around the home prior to your progression into structured exercise. Regardless of your choice and stage of progression, remember that your body is designed to move and should be encouraged to do so, preferably in a fun and enjoyable manner.

It is important to begin slowly; as you continue your physical activity, you can increase the size and speed of your movements progressing gradually.

Intensity Whilst Participating

Whenever you are participating in your physical activity, it is important that you monitor how hard you are working or your 'intensity' which will be specific to you. You will become aware of changes taking place: your breathing will get deeper and quicker, you may feel your heart start to beat faster and you will feel your body become warmer. All these changes are perfectly normal reactions to exercise. When exercising, you should always be able to hold a conversation so if you start beginning to gasp, you need to slow down a little until you are no longer gasping for air.

Remember if you feel that what you are doing is too hard, then it probably is so slow down!

Frequency/Duration/Programmes of Activity

The NHS Choices web site has a variety of information for the recommended levels and duration of activity. You will also find a variety of programmes with regard to activity programmes that meets all ages and levels.

www.nhs.uk/livewell/fitness/pages/physical-activity-guidelines-for-adults.aspx

If you are someone that experiences angina and have pain when exercising, do not attempt to work through the pain. See **section 2.6** on chest pain management in 'Medical Stuff'.

Ask your Healthcare Professional on the services and programmes that are available for you in your area.

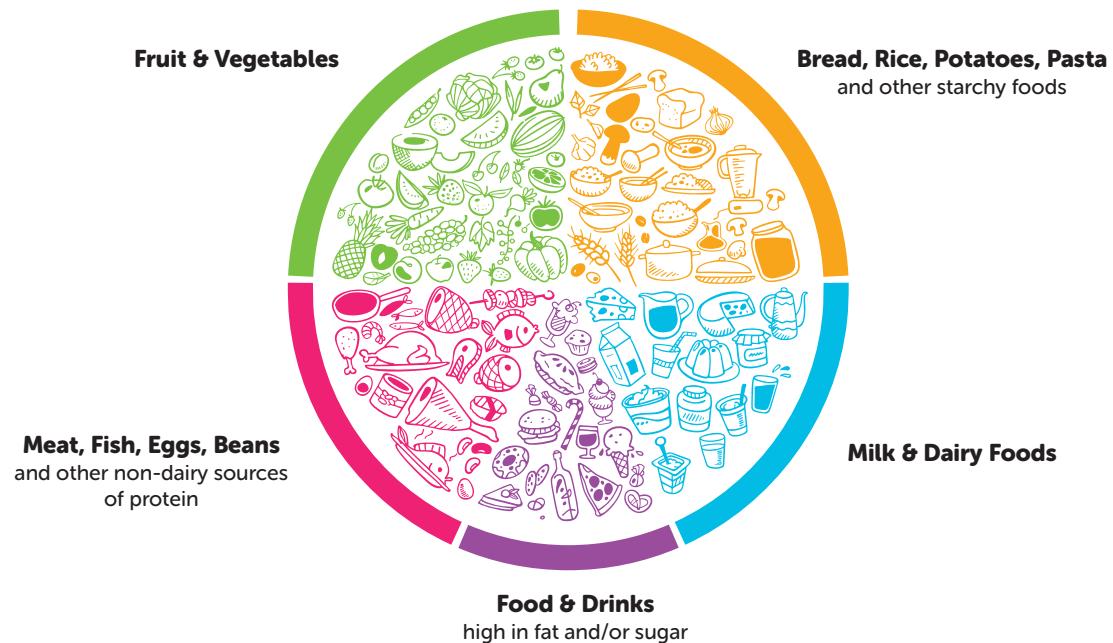
Top Tips

- Set yourself a goal which will provide something for you to work towards and when you reach that goal, reward yourself for your achievement.
- Choose an activity that you enjoy and have fun doing. Try out new physical activities as you never know what you may be missing.
- Do you know someone that may be interested in taking part with you? You will be able to encourage and support each other.
- Be sure to wear appropriate clothing which is loose fitting and comfortable. For outdoor activities, consider how the weather impacts upon you as you perform your physical activities.
- When possible, try to reduce the amount of time you spend sitting and try to move more often (even if it's getting up to change the TV channel).

WHAT IS HEALTHY EATING FOR ME?

3.12

All foods can be included in a healthy diet. You just need to make sure you get the right balance.



The Eatwell plate shows the proportions of how much of what you eat should come from each food group. This includes everything you eat during the day, including snacks. So, try to eat:

- **Plenty of fruit and vegetables**
- **Plenty of bread, rice, potatoes, pasta and other starchy foods - choose wholegrain varieties whenever you can**
- **Include some milk and dairy foods**
- **Include meat, fish, eggs, beans and other non-dairy sources of protein**
- **Just a small amount of foods and drinks high in fat and/or sugar**

Why should I focus on healthy eating?

It's the old saying "you are what you eat" and it's true; how else does your body grow, replenish and maintain itself?

Healthy eating can help protect your heart from further heart disease and can also help you to maintain a healthy weight and reduce your risk of:

- **Diabetes**
- **High Blood Pressure**
- **High Cholesterol**

The Main Dietary Messages

Eat less saturated fats

Cut down on full fat dairy products, butter, lard, ghee, pies, pastry, biscuits, cakes and processed meats, e.g. sausages, burgers. Vegetable oils such as coconut oil and palm oil are also high in saturated fat and should be limited.

Choose low fat dairy foods, e.g. low fat milk, low fat yoghurt and trim visible fat from red meats and remove skin from poultry.

Swap to olive oil or rapeseed oil. Avoid frying foods: grill, steam or oven bake instead.

Eat more oily fish (Omega-3 fats)

Omega-3 fats help the heart to beat more regularly and reduce the stickiness of the blood, making it less likely to clot.

For comprehensive advice and information on a healthy diet (including how you can reduce weight safely and successfully), visit the following link:

www.nhs.uk/livewell/goodfood/pages/goodfoodhome.aspx

How much fluid should I take?

Your healthcare professional may advise you to monitor your fluid intake. The heart does not like extra fluid in the system as it results in it having to work harder. Indeed if the heart is struggling, you may find that extra fluid builds up in your body in the form of swelling, either to the legs or stomach for example, or even in your lungs which causes breathlessness. That is why you may be prescribed water tablets in order to get rid of it.

Your healthcare professional may recommend that in order to help your heart, you restrict how much fluid you take in. They will discuss the amount they recommend reducing your fluid intake to e.g. 2 litres a day is just over 4 pints. If you do have to restrict your fluid intake, and you experience a dry mouth or feel very thirsty, the following tips may help.

Top Tips

- Try using a smaller cup or mug for your hot drinks.
- Chewing gum or sucking a sugar free sweet may also help.
- Freeze grapes or wedges of orange or lemons to suck on. Slices of pineapple or watermelon are also thirst relieving.
- An ice lolly is also a good way of keeping your mouth moist and relieving thirst without cutting into your fluid allowance.

If your skin becomes dry, try using a moisturiser cream. It does not have to be an expensive one, but applied regularly will stop your skin becoming dry and itchy.

How much salt should I have?

We know that excessive salt/sodium is not good for your heart. It helps to retain fluid in your body and increases blood pressure. We need no more than 2-3 grams of salt a day in our diet, and yet the average adult in Britain consumes more than 9 grams. Many food products are now colour-coded, so avoid those products that list salt as red, and watch out for the amber products too, as these will indicate high amounts of salt in the product, processed foods are particularly high in salt. Try and avoid adding salt at the table, and cooking vegetables in salt. It is a matter of getting used to this so do it gradually, and swapping salt for herbs, spices or lemon juice on your food may be an alternative.

Do not use LoSalt as this is high in potassium which can interfere in the function of your kidneys, and the rhythm of your heart.

Smoking Cessation

Stopping smoking is the single most important thing that you can do to help your heart. Smoking means your heart has to work harder than a smoke free heart. It has to be faster using more energy that could be put to better use. If you stop smoking your circulation will improve within a few weeks, your lungs will gradually start to work better. The cells in your body will receive more oxygen, which in turn should help you to feel more energised and healthier.

For help, and support in regards to stopping smoking, than do visit the following NHS website:

quitnow.smokefree.nhs.uk

Discuss with your GP, Practice Nurse or any other healthcare professional who will be happy to direct you to your local services.

There is now considerable information with regard to the potential risks of drinking of alcohol and its detrimental effect on the heart and the circulatory system. To put this into context, heart and circulatory diseases are the UK's biggest killers with an annual death rate in excess of 191,000 men and women. Evidence shows that excessive drinking has a direct effect on the heart.

Potential risks of drinking

Long-term drinking and heavy alcohol consumption are linked with weakness of the heart muscle. This is known as alcohol induced cardiomyopathy. It results in the heart not pumping efficiently (in other words, heart failure).

Sporadic heavy drinking (binge drinking) increases the risk of developing coronary heart disease, which is the most common form of heart disease. Department of Health figures show that men nearly double their chances of developing coronary heart disease by drinking more than eight alcohol units a day. Women have 1.3 times greater risk of developing coronary heart disease when they drink more than six units a day.

In January 2016, the government issued new guidance on drinking safely, for all the details please visit;

www.drinkaware.co.uk/check-the-facts/what-is-alcohol/new-government-alcohol-unit-guidelines

Any Benefits?

There is evidence to suggest that a regular pattern of drinking relatively small amounts of alcohol (one or two drinks a few times a week) reduces the risk of heart disease in men over the age of 40 and post-menopausal women.

For any additional information please visit:

www.drinkaware.co.uk

How does drinking too much alcohol affect my heart?

'Holiday Heart' Syndrome

Binge drinking or a period of heavy alcohol consumption can cause a sudden, irregular rhythm of the heart in otherwise apparently healthy people. The result is shortness of breath, changes in blood pressure, an increase in the risk of heart attack and even sudden death.

An increased risk of high blood pressure

According to the Department of Health, men who regularly consume more than eight alcohol units a day are four times more likely to develop high blood pressure. Women who regularly consume more than six alcohol units a day double their risk of developing high blood pressure. People who have had a heart attack may be at greater risk of developing high blood pressure or further damaging the heart muscle as a result of drinking alcohol.

An increased risk of thrombosis (blood clotting)

Alcohol can affect levels of a substance in the blood called homocysteine. High homocysteine levels increase the risk of blood vessel blockages.

Alcohol Induced Cardiomyopathy

Regular heavy drinking may lead to an enlargement or damage of the heart muscle, resulting in the heart failing to pump efficiently (heart failure).

WHAT ABOUT TRAVELLING?

3.16.1

As you know, holidays are an important time to rest and relax. Many of us look forward to our annual holiday and over the last few decades, taking a holiday abroad has become a reality for many of us. If you have retired or are planning to retire, travelling is perhaps something that you have planned and saved for. The question is, how will being diagnosed with heart failure affect your ability to travel?

Firstly, it's important to discuss the holiday you have planned with your GP, Cardiologist and or Heart Failure Nurse to ensure that you are fit to travel. It could be that previous holidays may now not be suitable for you. Don't worry; there will still be holidays that you will be able to take.

Having been diagnosed with and living with heart failure, you may find your confidence has been knocked and you are a little apprehensive about what you can and cannot do when going on holiday or travelling. We know that it may take time to build our confidence up and, by doing this gradually, you will learn what you feel comfortable doing. You could start with a weekend away and see how you get on. You'll learn a lot about yourself and then you can work out what will work for you going forward. This is an important element of self-management and will give you the confidence to do the things you are capable of doing.

Altitude

If you intend to travel to high altitudes, please check with your Doctor to make sure you will be able to cope. Altitude forces the heart to work harder. Where a healthy heart can respond to the demands of high altitude, someone with a heart condition may therefore struggle.

Depth

If you are contemplating diving, it is essential that you have a thorough check-up with your healthcare professional and discuss if you are fit to dive. Diving courses require you to have a medical statement to state if you are fit to dive.

Increasing your fluids

High temperatures will obviously make you perspire more, leading to a loss of body fluid. This results in your heart having to pump harder to get the smaller amount of fluid to your working muscles, skin and other parts of your body. Therefore, you will need to increase your fluid consumption (choose water). Mention to your Heart Failure Nurse that you are going to a hot country and he/she will help you with adjusting your fluid intake.

Although it's not easy when you are on holiday, try to avoid caffeinated drinks and alcohol which exacerbates the problem. Wear light clothing and keep in the shade with a hat and sunglasses. If you look cool, you'll be cool!

Tips for travelling

- Prepare for your trip well in advance and choose a destination where you are confident in medical facilities and access to medical treatment.
- Check that your accommodation and the local facilities are suitable. Avoid staying at a hotel situated at the top of a steep hill, miles away from the nearest town.
- It is generally not advisable to use the spa facilities (e.g. baths, saunas, Jacuzzis or steam rooms) if you have high blood pressure, a heart condition, angina or have had a heart attack.
- Do not use facilities that involve a sudden change of temperature (e.g. a sauna) followed by plunging into cold water. If you are planning to use such facilities, please ask your Doctor first.
- Do not overexert yourself. When travelling, use lightweight luggage (preferably on wheels) and make use of porters.
- Plan your journeys carefully, allowing plenty of time. Don't rush!
- Take out adequate travel insurance to cover your condition (see section 3.16.2 for advice on travel insurance).
- Take sufficient medication for your entire trip (and a little more!)
- Take a list of your medications and their dosages. If you can, depending on your relationship with your GP or Cardiologist, ask them to provide a letter explaining the simple facts around your condition. You could give this to a local healthcare provider along with your list of medications.
- Avoid hectic itineraries and don't exert yourself.

Remember, if you have any concerns then do discuss your plans with your team.

For advice on travelling, visit the following website which provides good and specific advice on travelling to various climates and destinations:

www.fitfortravel.nhs.uk/advice/general-travel-health-advice/air-travel.aspx

TRAVEL INSURANCE

3.16.2

Travel insurance is an important part of going on holiday. Sometimes, heart failure is assumed as a barrier to going on a holiday abroad as there is generally a lack of signposting to those insurers who can help.

Firstly, there is distinct difference between travelling in Europe and outside of Europe. We recommend you get travel insurance wherever you are going and get signed off by your GP or Cardiologist, preferably in a letter you can keep.

If you are travelling in the EEA (European Economic Area) or Switzerland, you can obtain reduced healthcare costs, or sometimes free healthcare, if you have a European Health Insurance Card. Visit the following web site to apply:

www.gov.uk/european-health-insurance-card

If you are travelling outside the EEA, we highly recommend you get travel insurance. In some areas of the world, if you need treatment of any kind, this can become extremely expensive where the cost may have consequences outside of your control. As an example, this is evident in North America.

We realise one of the biggest obstacles for both heart patients and all patients with long-term conditions is to get back to normality. In terms of travel, this is achieved by acquiring excellent insurance when you go on holiday. One of the most frequently asked questions we hear is 'where can I get good travel insurance'? Believe us; you don't want to travel abroad without it.

**For further information please visit our website
www.pumpingmarvellous.org.**

Please note with the UK leaving the EU this may affect the way healthcare works across the EU for UK citizens.

MY SUMMER GUIDE

3.16.3

Fluid

Your Clinician may have advised you to restrict your fluid to two litres a day. However, there is a move away from this due to a lack of evidence. Take advice from your Clinician; however, in summer it will be necessary to increase your fluid intake (especially water) and avoid excess alcohol intake.

Medication

If you are taking the drug Amiodarone, stay out of the sun as much as possible. If you have to go in the sun, cover up as it will make your skin photosensitive, which means it will burn no matter what you do. GPs will often provide a high factor sun block for you to use.

If you are taking Beta Blockers such as Bisoprolol or Carvedilol, you will generally be more susceptible to changes in the heat. Therefore, stay out of the heat where you can.

Sunburn

To avoid sunburn, the most important thing you can do is protect your skin. You can enjoy the sun safely by using a minimum sun protection factor of SPF 15. Spend some time in the shade and wear a t-shirt and hat. Apply plenty of sun cream around your shoulders, neck and arms and then move onto your body and legs. Always follow the instructions on the back of the product and, if you swim, reapply regularly. Don't forget your eyes so always wear 100% UVA protection sunglasses.

MY WINTER GUIDE

3.16.4

Your heart failure will no doubt be affected by the weather. If it is cold, your heart has to work harder to keep you warm and if the weather is hot, your heart works harder in order to keep you cool. Here is some general advice to help support you in with the extremes of the weather.

Winter

Winter seasons will bring cooler temperature and, for some, ice and snow. It's important to know how cold weather can affect you as a heart failure patient. In cold weather, you should avoid sudden exertion, like lifting a heavy shovel full of snow. Even walking through heavy, wet snow or snow drifts can strain a person's heart.

Many people aren't conditioned to the physical stress of outdoor activities and don't know the dangers of being outdoors in cold weather. Winter sports enthusiasts who don't take certain precautions can suffer accidental hypothermia.

Hypothermia

Hypothermia means the body temperature has fallen below 35°C. It occurs when your body can't produce enough energy to keep the internal body temperature warm enough. Heart failure causes most deaths in hypothermia. Symptoms include lack of co-ordination, mental confusion, slowed reactions, shivering and sleepiness.

Children, the elderly and those with heart disease are at special risks. As people age, their ability to maintain a normal internal body temperature often decreases. Because elderly people seem to be relatively insensitive to moderately cold conditions, they can suffer hypothermia without knowing they are in danger.

Angina

People with coronary heart disease often suffer angina (chest pain or discomfort) when they are in cold weather. Some studies suggest that harsh winter weather may increase a person's risk of heart attack due to overexertion.

High Winds

Besides cold temperatures and high winds, snow and rain can also steal body heat. Wind can be especially dangerous, because it removes the layer of heated air from around your body. At -1°C in a 30 mile per hour wind, the cooling effect is equal to -9°C. Similarly, dampness causes the body to lose heat faster than it would at the same temperature in drier conditions.

Alcohol

Don't drink alcoholic beverages before going outdoors or when outside. Alcohol gives an initial feeling of warmth, because blood vessels in the skin expand. Heat is then drawn away from the body's vital organs.

Top Tip

To keep warm, wear layers of clothing. This traps air between layers, forming a protective insulation. Also, wear a hat or a head scarf. Heat can be lost through your head. Your ears are especially prone to frostbite. Keep your hands and feet warm too, as they tend to lose heat rapidly.

The heart failure patient's winter survival kit

As you may be aware, cold weather is not good news for heart failure patients. We thought you may find the “toolkit” useful as it is important to look after yourself during the cold weather and winter months. Firstly, before we give you advice, you have to realise that you are more vulnerable than others. Understand and accept it. When you have done this, carry on.

- **Make sure you have had your regular seasonal flu jab at the doctors; you should also ensure that you have had a pneumonia vaccination as well.**
- **Hat, scarf, and gloves - always carry these as they prevent you losing heat but also, if you are on Beta Blockers, you can be more susceptible to the cold.**
- **Always have a fully charged mobile phone with you when you go out. If you don't have one, then tell your carer or perhaps inform a friend of where you are going and what time you expect to be back.**
- **If bad weather is expected and you have to make a car journey, make sure you take your tablets with you and a bottle of water to take them with.**
- **Consider investing in equipment for car journeys in the snow (e.g. a snow shovel, body warming packs, snow socks for car tyres) in case you get into any difficulties.**
- **Have a list of your medications and your diagnosis just in case.**
- **Make sure if you are going out in the car that you take your coat, hat and gloves (no matter how short your journey).**
- **If you are susceptible to the cold air and get breathless, wrap a scarf around your face.**

- If there is bad weather forecasted, make sure that you have a sufficient supply of medicines in case you cannot get to your GP's or pharmacy.
- Make sure your car is prepared for the winter months. Visit the RAC, AA or similar bodies for general advice.
- We know this is a tough one to explain but if you are worrying about the cost of heating your house due to the ever rising fuel bills, go somewhere where you can keep warm. This could involve simply going to a pub, bar, café or supermarket for a mug of coffee or tea. We know that it is not always easy, but it does make sense. If this is not possible, don't heat the whole of the house/flat; just heat the rooms you need.
- Wrap up warm in your house. Fashion doesn't make sense in the house; nobody can see you so wear thick jumpers, a double layer of socks and thermal underwear. A lot of the discount clothing retailers are touting for your business at the moment and there are some really good deals on clothing. Stores include Asda George, Primark, Matalan, Tesco, Sainsbury's and TK Maxx.

Keep a good store cupboard

Make sure you have some of the basics in your kitchen cupboard. Here are the Pumping Marvellous Top 10 essential items to have in:

- Long life milk
- Low salt baked beans
- Low salt tinned soup
- Tinned tomatoes
- Eggs
- Part baked bread rolls
- Tinned fruit, in juice not syrup
- Frozen vegetables or tinned vegetables in water
- 10 litres of drinking water if your pipes freeze
- Packets of rice or pasta with a good selection of spices

Getting a common cold

Having a cold can make you feel pretty lousy, even for people without heart failure. It can really set you back and recovering from it may take a little longer. Prevention is better than cure, so if you can avoid people or situations which may leave you vulnerable to catching a cold then do so; basic hand hygiene also goes a long way. Other factors which help are a healthy diet and physical activity to keep the body's immune system at its best.

The prevention of flu and pneumonia is vital and we strongly recommend that you have the seasonal flu vaccination. The pneumonia vaccination should last you for a number of years.

So what should you do if you have a cold?

- Take plenty of rest; it helps the body to recover.
- Avoid taking an anti-inflammatory (such as Ibuprofen and Diclofenac) as they can make your heart failure worse by causing your body to retain fluid.
- Avoid decongestants as they can have a detrimental effect on your blood pressure.
- If you have a sore throat, try gargling with warm water.
- A drink of lemon juice and a small amount of honey can bring some relief.
- If you wish to take a pain relief, Paracetamol as prescribed on the packet will help and not interfere with any of your medication.
- Antibiotics will not help your cold, however, if you are concerned then do consult your healthcare professional.

END OF SECTION CHECKLIST

3.18

Question 1

Which city helps me know where I am with my heart failure?

- A Paris
- B Sydney
- C New York

Question 2

Can you name three things you can do to help manage your heart failure?

- 1
- 2
- 3

Question 3

Which traffic light colour are you at the moment and why?

Question 4

Can you name three of your team?

- 1
- 2
- 3

Question 5

How does Pierre suggest you work with your GP?

- A In partnership with you.
- B Just listen to what he or she says.
- C Just tell them what he or she wants to hear.

Get your Heart Failure Nurse to help your check your answers with you.

Question 6

Can you name three benefits to you of staying active?

- 1
- 2
- 3

Question 7

How many food groups are there?

- A 4
- B 5
- C 6

Question 8

What can excessive alcohol intake produce?

- A Irregular heart rhythms
- B High blood pressure
- C Both of the above

Question 9

Can you name three ways you should go about preparing for a holiday in the sun?

- 1
- 2
- 3

Question 10

Can you name three ways you should go about preparing for a trip out in winter?

- 1
- 2
- 3

**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



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helpforhearts (closed support group)