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Sussex ICB_Primary Care HF Diagnostic & Treatment Pathway

Primary Care Heart Failure Patient Advice Sheet

Follow up: you may be referred by your GP to be seen in the cardiology outpatient clinic or remain under your GP for ongoing management of heart failure. Some patients may also be referred to a heart failure specialist service. You will be told by your GP what follow up to expect.

Monitoring your blood pressure and pulse: you should obtain a home **blood pressure monitor** (HBPM), take regular readings and keep a record of your blood pressure, pulse rate, and if your pulse feels regular or irregular so you can share them with your doctor or nurse when you have a review.

Monitoring your weight: weigh yourself every morning. If your weight goes up suddenly by 2 – 4 pounds (about 1 kilo) in 2 days you could be retaining fluid.

Worsening of symptoms and self management of diuretics: if you notice a worsening of your breathlessness, have more ankle swelling, or notice a sudden weight gain, you may need a change to your diuretic treatment. If your doctor or nurse has advised you then self manage by taking an extra diuretic for **3 days** (for example: Furosemide 20mg – 40mg tablet **OR** Bumetanide 0.5mg – 1mg tablet), or telephone your doctor or nurse to discuss.

If you do self-manage for 3 days and your symptoms have not improved after 3 days then telephone your doctor or nurse for a review.

Activity: try to be as active as your condition allows. Walking is good and can be built into your daily regime. If you get breathless during exercise, you should slow down or stop.

Rest: if you have oedema (swelling) in your legs it will help when resting to elevate your legs on a footstool. If your breathing feels more difficult lying flat in bed try increasing the amount of pillows you use.

Diet: it is important to reduce the amount of salt in your diet as it can make you retain water. Do not add salt at the table and avoid cooking with it. Avoid salty foods such as Marmite, Bovril and crisps. Convenience foods are also particularly high in salt. In addition we recommend a 'healthy diet': reduce the amount of saturated fat, aim to eat at least five portions of fruit and vegetables a day, and eat fish twice a week.

Alcohol: drinking too much can sometimes make your heart failure worse so drink no more than 1 or 2 units of alcohol a day. Some patients will be advised to have none.

Medication: you will be started on a number of medicines that will improve your symptoms and are a key part of your treatment. It is important to continue taking the medication unless instructed differently by your doctor or nurse. If you have any problems taking your medicines or getting supplies please speak to your doctor, nurse or pharmacist.

Smoking: if you smoke, stop smoking. If you would like a referral to a smoking cessation service who can support you though this process please talk to your doctor or nurse.

Vaccines: make sure you have an annual flu vaccine, Covid booster and a one-off vaccine for pneumonia.

Support: If you have any questions please ask your doctor or nurse. Further information can also be found in the **resource page** where the **British Heart Foundation Heart Failure hub** and the **Pumping Marvellous Foundation** hold all their resources for patients and families.

Benefits: You may be eligible to claim for Attendance Allowance which is for people over State Pension age who need help due to illness or disability. It is a non-means-tested tax-free weekly payment. **Find out more and apply here:**

Driving & transport: **check your eligibility and apply for a blue badge here.**

Heart Failure Patient – Self Management

Contact your heart failure nurse/GP if you are concerned.

If you are no longer seeing a heart failure specialist team/nurse but were discharged on the patient-initiated follow-up pathway (PIFU) you my be able to self-refer back to the service.

The symptom checker is a useful guide on what to look out for and what to do: http://qr.pumpingmarvellous.org/SymptomSM

This guide is also available in Welsh, Bengali, Polish, Punjab and Urdu.

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.

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.

JOIN OUR PATIENT AND CARER COMMUNITY - SCAN WITH YOUR DEVICE HERE

AMBER - STAY ALERT

Your weight has increased/had 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.

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 symptoms of an infection and/or you feel very unwell.
- You have blacked out.
- Any of your other medical conditions are continuing to worsen.
- You have become confused about your medications.
- My medication has been reduced/stopped and I am not sure why/my heart failure team are unaware.
- You have worsening breathlessness or leg swelling or are unable to be as active as usual.
- You have worsening or new angina.
- Your carer becomes very ill/has been admitted to hospital and is unable to take care of you.
- You have had diarrhoea or vomiting for more than 24 hours.

WHAT SHOULD YOU DO?

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

This Marvellous Symptom Checker has been put together by the Pumping Marvellous Foundation and developed with NHS heart failure teams and patients from Staffordshire. For details of any terms you don't understand please visit the patient academy on the Pumping Marvellous website.

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Pumping Marvellous
for heart failure patients

Resources for Clinicians and Patients

British Heart Foundation

For patients:

- BHF patient support information
- British Heart Foundation: Living with heart failure booklet
- Heart Failure Matters patient information

Plus BHF helpline info:

Call* **0300 330 3311** open weekdays 9am – 5pm, Saturdays 10am – 4pm. Or email at hearthelpline@bhf.org.uk and BHF nurse will get back to you as soon as possible. **costs are the same as calling a home or business landline.*

For healthcare professionals:

- BHF professional information (Not HF specific)

Pumping Marvellous Foundation

For patients:

- Resources for people living with heart failure

Contact **01772 796542** or email hearts@pumpingmarvellous.org

For healthcare professionals:

- NHS Teams patient information order form

Cardiomyopathy UK

- http://www.cardiomyopathy.org

Arrythmia Alliance

- https://heartrhythmalliance.org

AF Association

- https://heartrhythmalliance.org/afa/uk

NICE Guidelines

- NICE Chronic Heart Failure Guideline – 2018 (ng106)

UCLPartners Proactive Care Frameworks

- UCLPartners CVD resources

Provide a platform for optimising clinical care and self-care for people with these high-risk conditions, supporting primary care teams to do things differently and at scale. They are free and can be downloaded directly into a practices clinical system and help identify the individuals who would benefit from a review and possible referral.

The following slide packs include pathways and resources to support clinicians treating patients with single or multiple cardiovascular conditions.

- Atrial Fibrillation
- Heart Failure
- Hypertension
- Lipid management including Familial Hypercholesterolaemia
- Type 2 Diabetes

Primary Care Cardiovascular Society (PCCS) CVD Academy

- About the academy

For clinicians:

The Academy provides PCCS members with a variety of different educational resources in cardiovascular disease. Each module is CPD accredited and you can download a certificate directly from the Academy.