



A QUICK GUIDE TO
**CARING FOR
SOMEONE**
WITH HEART FAILURE



You may be a husband, wife, son, daughter, friend or a neighbour. You may live 24 hours a day with the person you are caring for, or you may live a 24 hour journey away.

But you are the one who is recognised as significant in helping someone with heart failure live with their condition.

This booklet – which has been co-developed with substantial input and support from the Pumping Marvellous Foundation, the UK’s patient-led Heart Failure Group – has been developed based on people’s experience of supporting those living with heart failure. It has been developed as an easy reference guide to enable you to begin to understand the condition and how you can help your loved one to self-manage it.

We would like to thank Nick Hartshorne-Evans, Founder, CEO and heart failure patient and Angela Graves, Clinical Lead and heart failure specialist nurse, from the Pumping Marvellous Foundation, for their close collaboration in writing the guide.

We would also like to thank you – on behalf of patients, healthcare professionals and wider society – for reading this booklet and helping in the way you do.

Please note: This booklet should not replace and/or substitute the interactions with and advice you and your loved one get from a healthcare professional, and if you have any concerns about their condition you should discuss these with their healthcare professional at the earliest opportunity.



2) CARER'S CHARTER

At the heart of your commitment to your loved one or friend with heart failure, can be a set of principles that helps you to take care of yourself, as well as him or her. Caring for someone with heart failure means understanding the condition and its impact on life as well as you can, but should not mean that you are defined by the condition.

Try to always remember the following and talk these through with your loved one.

- Remember you are doing a great job, take pride in that.
- Try and have time for yourself, ensure that you still undertake hobbies or events that you most enjoy.
- Take care of yourself - it is important to remember this is not being selfish but sensible, you need to be well in order to be able to help your loved one be well.
- Don't be afraid to ask for support - everyone has their limits, recognise yours and call on those who can support you.
- It is perfectly normal to have a range of difficult emotions, to feel angry or down, to have good days and bad days; on those days do not feel guilty.
- It is important that your commitment to your loved one is recognised and that family and friends also understand the significance of your role, so talk about your role and any difficulties that you may be having.



UNDERSTANDING HEART FAILURE

The heart consists of muscle that pumps blood around the body. With heart failure, the heart is not pumping correctly and is often enlarged because it is having to work extra hard¹.

It is different to a heart attack – which involves a lack of blood to the heart usually caused by a clot to the arteries that supply it².

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^{1,3}. This can happen after a heart attack, or when someone has high blood pressure, which has affected the heart. Other causes include^{1,3}:

- 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.

There's no question that this heart condition is serious. But the good news is that there is a lot of understanding about the condition, a number of effective treatments available and in development, and several things you and your loved one or friend can do to play an active role in the management of their heart condition.

Heart failure symptoms can sometimes get rapidly worse. This is called an acute episode or acute heart failure³. This may be due to a temporary event and not last for long, but acute heart failure will require some form of intervention from health care professionals³.



3)

SO WHERE IS YOUR LOVED ONE 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 stage of this condition based on how much your loved one is limited during physical activity.³

So where is your loved one on this scale today?

NYHA CLASS	SYMPTOMS ⁴
I	Your loved one can perform all physical activity without getting short of breath or tired, or having palpitations.
II	Your loved one gets short of breath or tired, or has palpitations when performing more strenuous activities. For example, walking on steep inclines or walking up several flights of steps.
III	Your loved one gets short of breath or tired, or has palpitations when performing day-to-day activities (for example, walking along a flat path).
IV	Your loved one feels breathless at rest, and is mostly housebound. He/she is unable to carry out any physical activity without getting short of breath or tired, or having palpitations.

“I am always saying to him ‘will you slow down and give yourself a rest’”

Caregiver

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 your loved one or friend has and to try and plan out how they will use it throughout the day and to prioritise the activities that are most important to them.



4)

WHAT DOES THIS MEAN FOR ME?

Where your loved one or friend is on the New York Heart Association (NYHA) classification scale 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 your loved one 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 shows that those who can adapt to their illness and take control of it have a better quality of life.⁵

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 your loved one, but you need to take a step back every now and then and live your own life. We have seen time and again that focussing on yourself and giving yourself some time away from ‘caregiving’ makes you a better carer.

Your loved one’s heart failure may impact areas of your life for which you may need to consider seeking some help and guidance, whether that is related to:

- Finances
- Work
- Intimacy of your relationship

Do contact your healthcare professional or social support if you feel you need help.

PRACTICAL SUPPORT

One way that you can help your loved one or friend to take control of their condition is to encourage them to keep an eye on the following factors day-to-day, and there may be ways you can help along the way.



KEEP AN EYE ON...^{3,6}**Sudden weight increase.**

If they suddenly gain weight, it may be because fluid is building up in the body because their heart failure is getting worse.

Swelling.

You may notice swelling in their lower legs, abdomen or feet, which happens when the body retains fluid.

Breathing.

They may have difficulties breathing, especially with exertion or when lying flat in bed.

Fatigue.

Many people with this condition will feel very lethargic - remember that your loved one has a daily energy battery.

Dizziness/light headedness.

They may sometimes feel dizzy or light headed due to the condition and the medication that they are taking.

Medications.

They may be on a lot of tablets – they've all got a role to play. For a full list of medications, see the guidance in this booklet.

WHAT YOU CAN DO TO HELP

CONTACT A HEALTHCARE PROFESSIONAL IF...

Encourage them to weigh themselves at the same time every day.
Remind them to watch how much fluid they are taking in and that they don't exceed the amount suggested by their healthcare professional.

They gain about 4-5 pounds (about 1.8-2.3 kilogrammes) in the space of 2-3 days.⁷

Encourage them to take frequent rests during the day.
If there is swelling, they should keep their legs elevated on a stool.

The swelling becomes significantly worse.

Encourage your loved one to not to over-exert themselves. If breathing is worse at night, give them plenty of pillows to prop them up in bed to help them breathe.

The breathing or coughing becomes significantly worse.

Encourage them to have breaks every day. Make sure they pace themselves and don't overdo things.

The level of fatigue worsens and begins to affect day-to-day activities.

Encourage your loved one to take their time to get out of bed and steady themselves before they begin to walk.

It is causing them to stumble or fall.

Encourage them to take control of their medication. They should know exactly what they are taking how often and why. A daily tablet organiser could help keep track day-to-day.

They have any concerns about the medication such as side effects, or if they feel the medication is not having the desired effect.

4)

EMOTIONAL SUPPORT

Your loved one will have good and bad days, both physically and emotionally. 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 the caregiver charter at the beginning of this booklet. 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 your loved one. None of this is selfish, it is essential to help you be a better carer.

In addition, if you find that you and your loved one are finding it challenging to manage the physical symptoms of the condition, then contact your loved one's healthcare professional and make an appointment as soon as possible. Get help when you need it - you do not have to do it all on your own.

CARER STRESS

Caring for someone can have a big impact on your own mental and physical wellbeing and so it is important to try and recognise if you are beginning to get into difficulties. Some things you may experience along the way may include:

- Feelings of anxiety, irritability and depression
- Being unable to sleep
- Failing to eat properly
- Increasing alcohol intake, or excessive smoking
- A decline in your physical health
- Having difficulties concentrating
- Tiredness and lethargy
- Neglecting responsibilities

If you begin to experience these symptoms, remember the caregiver charter, ask for help so that you can share out the load and don't be reluctant to accept offers of help. Give yourself a short time in the day that is just for you e.g. take a long hot bath. Investigate if there are any carer support groups in your area. If you are concerned about your physical or mental health then do see your healthcare professional.

“The carer is on the same journey as the patient”

Caregiver

MEDICATIONS AND INTERVENTIONS

How was your loved one's heart failure diagnosed⁸?

They may have had a number of blood tests, tracings and scans of their heart, as well as a thorough examination by their healthcare professional to determine they have heart failure.

- **Blood Tests**

These are routine tests to check how effectively the kidneys and liver are working. Also, if your loved one has anaemia (where they have fewer red blood cells than normal or they have less haemoglobin than normal in each red blood cell) or problems with their thyroid (a large gland in the neck), blood tests will have been conducted, to see if they have been affected by or caused heart failure.

A specific blood test may have been taken which measures something called natriuretic peptides (a type of hormone produced by the heart), levels of which indicate that they may have heart failure.

- **Electrocardiogram (ECG)**

This gives healthcare professionals a tracing of the heart and is very informative. It lets the healthcare professionals know if the heart is going too fast, too slow, and if there are problems with the heart that may have occurred in the past.

- **Echocardiogram**

This is vital in diagnosing heart failure. It gives a scan of the heart that shows how efficiently it is pumping, its size and the condition of the valves.

Other, more complex scans may also be undertaken which can help healthcare professionals understand what has happened to the heart.

MEDICATIONS

Following a diagnosis of heart failure, your loved one may have been given different medications to take. You can read about them on the following pages along with some tips on taking them.

A good place to start, however, is to understand why it is very important for them to take their medications as instructed by their healthcare professional. We understand that taking lots of pills can sometimes feel like a burden, along with some of the symptoms your loved one may incur along the way.

We also know, however, that if people take their medications regularly as instructed by healthcare professionals, then this may have a positive effect on health and wellbeing.

Your loved one may find some of the medications take a little time to get used to but it is important to persevere and they generally will adapt to them in no time. If they continue to find they are struggling, do urge them to speak with their healthcare professional.

“Get the reassurance that you need by frequently asking your loved one if they are ok”

Caregiver

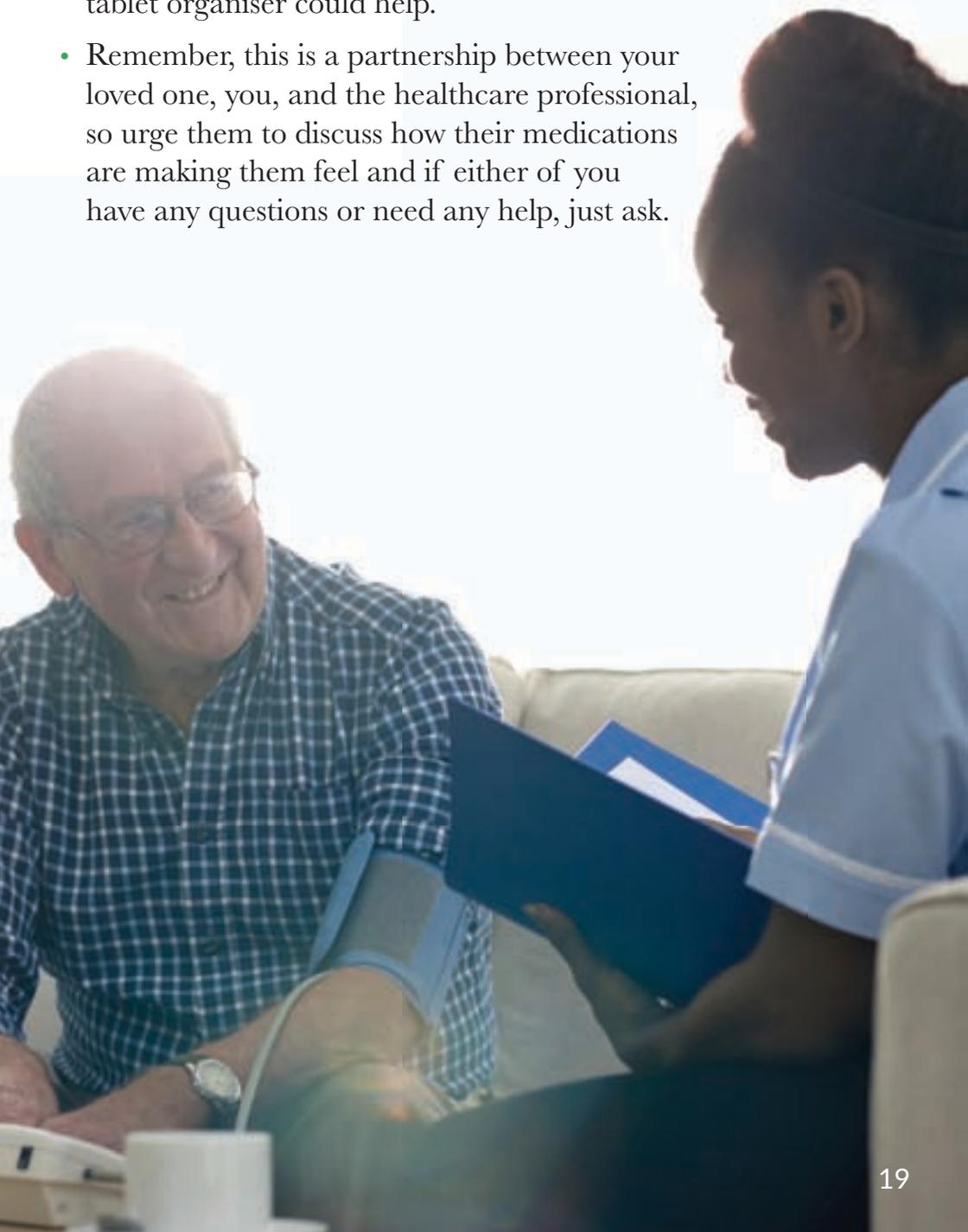
5)

Some general tips on taking medication:

- Patients should be in charge of their own medication. They should know exactly what they are taking and how often, and understand why they are taking it.
- Medication can sometimes make people feel worse before it makes them feel better, so it is important they don't give up or suddenly stop taking medication without first discussing it with a healthcare professional.
- It can be a slow process to get to the dose of a medication that works best for each individual. Sometimes some tablets have to be started at low doses and gradually increased, so make sure your loved one does not get discouraged – they will get there in the end.
- They may need to take a lot of tablets – they've all got a role to play.



- They should try not to miss taking their medication and make sure they take each one on time and as recommended. A daily tablet organiser could help.
- Remember, this is a partnership between your loved one, you, and the healthcare professional, so urge them to discuss how their medications are making them feel and if either of you have any questions or need any help, just ask.



These are some of the medicines your loved one may be advised to take for their condition. The below provides a guide, but you and your loved one should always check the prescribing information of any medicines they are taking.

Beta blockers⁹.

The names of these medicines will often end in ‘-olol’.

WHAT THEY DO

Make the heart beat slower and ease the workload of the heart, relaxing blood vessels around the body.

POTENTIAL SIDE EFFECTS

Most people taking beta blockers have either no or very mild side effects. More commonly reported side effects include:

- *Dizziness*
- *Tiredness*
- *Blurred Vision*
- *Cold hands and feet*
- *Slow heartbeat*
- *Diarrhoea and nausea*

These tablets are started at low doses and slowly increased because they may lower the heart rate too much.

ACE (Angiotensin Converting Enzyme) inhibitors^{10,11}.

The names of these tablets will often end in ‘-pril’.

WHAT THEY DO

Ease the workload of the heart by relaxing the blood vessels around the body, which reduces the strain on the heart.

POTENTIAL SIDE EFFECTS

Side effects do not appear very often and some may go away if the medicine is continued. More common side effects include:

- *Dizziness*
- *Headache*
- *Drowsiness*
- *Diarrhoea*
- *Low blood pressure*
- *Weakness*
- *Cough*
- *Rash*

A common side effect is a dry, irritable cough which often settles. However, if this proves troublesome, the healthcare professional may use an alternative medication, which is an ARB (see next page).

The patient should expect to be monitored with blood pressure checks and tests.

ARB (Angiotensin receptor blockers)¹² - for patients who cannot tolerate ACE inhibitors, these make it easier for the heart to pump by widening the blood vessels. The names of these medications often end in ‘-sartan’.

WHAT THEY DO

These work in a similar way to ACE inhibitors.

These medicines also increase the release of water and salt (sodium) to the urine, which in turn may lower blood pressure as well.

POTENTIAL SIDE EFFECTS

Side effects do not appear very often and some may go away if the medicine is continued. More common side effects include:

- *Dizziness*
- *Headache*
- *Drowsiness*
- *Weakness*
- *Rash*
- *Fever or chills*
- *Back pain*

The patient should expect to be monitored with blood pressure checks and tests.

Diuretics^{13,14} - or “water pills” (e.g. furosemide, bumetanide, spironolactone, eplerenone). The patient may be on more than one type of water tablet because they work in different ways on the kidneys.

WHAT THEY DO

Help the body get rid of extra fluid, so there is less fluid for the heart to pump.

POTENTIAL SIDE EFFECTS

The following can occur in some people:

- *Nausea*
- *Dizziness*
- *Rash*
- *Muscle cramps*

Some may find it inconvenient as they may need to visit the toilet more frequently than normal.

People may need to plan their day around their water tablets – for example, staying at home for a while after they have taken them.

Regular blood tests are required to ensure the kidneys are not affected by the number of water tablets taken.

5)

IMPLANTABLE DEVICES / PACEMAKERS

- **Cardiac Resynchronisation Therapy (CRT) / biventricular device**⁸

A CRT / biventricular device may be suitable for some people with heart failure. These devices send tiny electrical signals to the heart to help it beat in a more synchronised way and ultimately help the heart to pump more efficiently. However, these devices may not be suitable for everyone with heart failure.

- **Implantable Cardiac Defibrillator (ICD)**⁸

Not only does the heart have a beat, but also a rhythm. Sometimes there is a problem with the rhythm which may have serious consequences. In these cases an ICD may be recommended. This requires implantation of a small box under the skin in the top of the chest – wires are attached to the muscle of the heart on one end and the box at the other end. This provides a means of dealing with any would-be fatal heart rhythm problems.

Occasionally a CRT and an ICD may be combined together into one device.



PROVIDING CARE FROM A DISTANCE

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

- Try to develop a routine for keeping in touch. Find a time of day for regular telephone calls or calls via your computer using (often free) software such as Skype or Viber. This means that both you and your loved one or friend know when to expect a call and ensures you can feel confident and comfortable that your loved one is OK.
- Make sure your loved one knows exactly what to do if they get into problems. Ensure they have a list of people to contact. Have a plan in place.
- Have your loved one's healthcare professional name and contact details to hand. If you are at all worried, or if your loved one has missed a regular call, contact the healthcare professional or someone local to your loved one (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 your loved one is coping, either physically or emotionally, consider organising an assessment by your local social services, but make sure you discuss this with your loved one first.



A REGULAR TEAM 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 to be able to do.

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 'team talks' you may also find that the person you care for opens up about how they feel about being diagnosed with heart failure (angry, confused, fearful, relieved they are alive, frustrated) which can also help you make decisions together about the support you give. For example if the person you care for 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.

Talking to the person you care for about what is important to you is also essential. It can help them understand why you are, for example, over protective (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 caring for understands that whilst you want to support and help them, you also need time to look after yourself too.

TAPPING INTO A WIDER TEAM

Remember, you don't need to try and do it 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 is in your support team, including healthcare professionals, family members, friends and others. Try and share it out among others, and talk about it with them.

Remember, your loved one 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.

For more information on heart failure, visit:

WWW.KEEPITPUMPING.COM

REFERENCES

- 1** Harrison's 'Principles of Internal Medicine', Seventeenth Edition pages 1442 - 1455
- 2** American Heart Association, What is a heart attack.
Available at http://www.heart.org/HEARTORG/Conditions/HeartAttack/AboutHeartAttacks/About-Heart-Attacks_UCM_002038_Article.jsp
Last assessed: April 2015
- 3** Mosterd A, Hoes A, et al. Clinical epidemiology of heart failure, *Heart* 2007;93:1137-1146
- 4** Holland R, Rechel B et al. Patients' Self-Assessed Functional Status in Heart Failure by New York Heart Association Class: A Prognostic Predictor of Hospitalizations, Quality of Life and Death. *Journal of Cardiac Failure* 16:2:2010
- 5** Obieglo A, Uchmanowicz I, et al. The effect of acceptance of illness on the quality of life in patients with chronic heart failure, *European Journal of Cardiovascular Nursing*; 1:7:2015
- 6** American Heart Association, Warning signs for heart failure.
Available at: http://www.heart.org/HEARTORG/Conditions/HeartFailure/WarningSignsforHeartFailure/Warning-Signs-for-Heart-Failure_UCM_002045_Article.jsp
Last assessed: April 2015
- 7** Chaudhry A, Wang Y, et al. Patterns of weight change preceding hospitalization for heart failure, *Circulation*. 2007;116:1549- 1554
- 8** McMurray J, Adamopoulos S, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012, *European Heart Journal* (2012) 33, 1787–1847
- 9** Erdmann E, Safety and tolerability of beta-blockers: prejudices and reality, *European Heart Journal Supplements* (2009) 11 (Supplement A), A21–A25
- 10** Brown N, Vaughan D, Angiotensin-Converting Enzyme Inhibitors, *Circulation* 1998; 97: 1411-1420
- 11** Sweitzer N, What is an angiotensin converting enzyme inhibitor?, *Circulation* 2003; 108: e16-e18
- 12** Terra S, Angiotensin Receptor blockers, *Circulation* 2003; 107: e215-e216
- 13** BHF, Drug Cabinet: Diuretics.
Available at <https://www.bhf.org.uk/heart-matters-magazine/medical/drug-cabinet/diuretics>
Last assessed: April 2015
- 14** BHS, Thiazine and Thiazide-like Diuretics,
Available at
<http://www.bhsoc.org/pdfs/therapeutics/Thiazide%20and%20Thiazide-like%20Diuretics.pdf>
Last assessed: April 2015





