



Te Whatu Ora
Health New Zealand
Waitematā

Advanced Heart Failure

Information to help support decision making for residents in Residential Aged Care and their families/ whānau

*Manaaki mana kaumatua
All-encompassing care, respect and dignity of caring for our elders*

Acknowledgments

This information booklet was updated in 2021 and has been provided by the Residential Aged Care Integration Programme Work Group and Waitematā District Health Board. We acknowledge everyone who supported the development of the original version; staff in residential aged care, experts in the field and consumers.

Our aim is to write about the issues we have noticed that can cause concern for people with advanced heart failure and their families/whānau.

Registered nurses are available to further discuss the topics in this booklet, and guide you to think about preferences for your care. We have also suggested some practical ways families/whānau or other companions can provide support.

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Introduction

This booklet is written for a person with advanced heart failure living in residential aged care and also for their family/whānau, and friends. It has been developed to provide advice on what to expect during the final stages of heart failure. Please ask for an interpreter if this is needed. You can also discuss any of the information with a healthcare provider.

Heart failure is a progressive disease. There may come a time when a person with heart failure becomes totally dependent on others for the necessities of life. As the disease progresses, the person's goals of care change. Clear communication and information is very important.

Your healthcare providers (e.g. nurse or doctor) are able to provide support and discuss this information with you and your family/whānau. Having knowledge of the likely course of heart failure gives you, and the health care team, the opportunity to plan care. You and your family/whānau may have preferences about end of life care. Discussing this with the team gives the opportunity for these preferences to be honoured.

There are many health problems that cause damage to the heart (e.g. high blood pressure, diabetes or heart attacks). These conditions make it more difficult for the heart to pump blood around the body. This can cause many different symptoms, but the most common ones are tiredness, shortness of breath, and fluid retention (swelling). This can make it harder to manage personal care and reduce quality of life; this may cause stress for a person and their family/whānau.

More important than the diagnosis, is the impact it has on a person, their family/whānau and friends. Disease progression will be different for each person and depends on the type of heart disease and past medical history. The way people cope also varies, and is influenced by personal skills and life experiences. There is a lot of information about heart diseases, including heart failure, on the internet and from organisations such as the Heart Foundation NZ (see section Support for Family/ Whānau on page 20).

Although progression of heart failure is unique for each person there are usually several common stages. The information on the next page will assist you and your family/whānau or friend to understand which stage you are in. People can move back and forth between the stages, but over time there is a general trend of decline. Identifying which stage you are at can be useful, as it supports you and the health care team when planning the goals of your care.

Typical Progression of Heart Failure

New York Heart Association Functional Classification System for Congestive Heart Failure
Severity: People may move between the stages, but the general trend is towards deterioration.

		Goals of Care	Setting
Mild	No limitation of physical activity. Ordinary physical activity does not cause symptoms of heart failure.	<ul style="list-style-type: none"> – Assessment and diagnosis – Education of person and family/whānau – Symptom management 	Community, outpatient and home based services
Moderate	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity causes symptoms of heart failure (e.g. breathlessness and fatigue). <i>Examples:</i> Difficulty showering or walking any distance.	<ul style="list-style-type: none"> – Monitoring to reduce exacerbations¹ and prevent deterioration – Management of exacerbations 	Increasing need for home support for care giver and person with heart disease as ability to manage physical activities
Severe	Marked limitation of physical activity. Comfortable at rest but less than ordinary activity causes symptoms of heart failure (breathlessness and fatigue). <i>Examples:</i> Difficulty walking to another room, dressing and undressing.	<ul style="list-style-type: none"> – Support and education of person and family/whānau – Planning ahead: Advance Care Plan, Enduring Power of Attorney – Symptom management – Monitoring to reduce exacerbations¹ and prevent deterioration – Management of exacerbations which may be more frequent 	Increasing likelihood of residential aged care
Very Severe	Unable to carry out any physical activity without symptoms of heart failure or symptoms of heart failure at rest. <i>Examples:</i> Difficulty getting out of bed or moving in bed.	<ul style="list-style-type: none"> – Symptom management – Monitoring to reduce exacerbations¹ and prevent deterioration – Management of exacerbations (may not survive) – End of life care/ palliative care – Follow Advance Care Plan 	Collaborative care with Hospice

Bereavement care for the family/whānau

1. Exacerbation: increase in severity due to infection or other causes

Principles of care

Providing care with dignity is a priority. A care plan which includes the cultural, spiritual, religious values and beliefs of the person will help to provide individualised nursing care. The person, their family/whānau and staff may plan this care together.

When someone is dying from heart failure it is especially important to consider quality of life and plan for any problems that may arise. Some of the most common areas of care to consider are discussed below, and on the following pages. The person, family/ whānau and the team can talk about these areas when planning care.

Fluid in lower legs, feet, hands, bottom, abdomen and lungs

This happens because the heart is not pumping blood normally. Fluid leaks from the bloodstream into the body tissues. Fluid naturally flows to the lowest place so legs, bottom and abdomen are the areas that swell the most. The lowest places in the body change when a person lies down. The extra fluid can cause weight gain, breathlessness, increased tiredness and strain on an already tired heart.

Strategies

Raising/ elevating the legs can help fluid circulate and be removed from the body by the kidneys:

- Compression stockings or bandages can also assist with circulating the fluid.
- Wearing loose and comfortable clothing and socks reduces discomfort.
- Promote comfort when sleeping by raising the head and upper body using pillows, a hospital bed or La-Z-Boy chair.
- The doctor/nurse practitioner (NP) or nurse may:
 - Review to see if medication may be helpful
 - Advise a low salt diet
 - Advise to monitor and/ or restrict fluid intake (the amount can vary)
 - Request regular checking of weight.

Moist cough

When the heart is not pumping normally, fluid can leak from the blood into the lungs. This causes a moist cough, with sputum that is usually white and frothy. Oxygen is not helpful for relieving this cough.

Strategies

- Sitting in a more upright position, or leaning slightly forward can help.
- Breathing exercises may help.
- Relaxation techniques may be helpful.
- Tell staff if the cough is getting worse.
- The doctor/ nurse practitioner may be able to prescribe medication that helps.

Breathlessness

When fluid increases in the lungs, the breathing rate increases, and the heart has to work harder. Lying down can cause more breathlessness and disturb sleep. Oxygen is not usually helpful because it cannot change the cause of the breathlessness.

Strategies

- The doctor/ nurse practitioner will review medications – these can often help with breathlessness and the anxiety that being breathless can cause.
- Plan for activities and minimise effort (e.g. it may not be necessary to shower every day).
- Avoid rushing and allow more time.
- Allow for a rest between activities.
- Ask staff for assistance and advice.
- Tell staff if breathlessness is getting worse.
- If breathless when lying down, try sleeping more upright with pillows.
- A room with good ventilation or a personal fan that moves air may ease symptoms of breathlessness.
- Let staff know what works best.

Fast or irregular heart beat

As heart failure progresses the heart becomes larger, and the heart rate can become more irregular. Feeling tired is a common symptom.

Strategies

- Planning activities to minimise effort.
- More rest may be needed, especially before meals or activity.
- The doctor/ nurse practitioner can see if medication may be needed.

Dizziness

Blood pressure can be very low in heart failure. This can cause dizziness and feeling faint. Dizziness can also be caused by a sudden drop in blood pressure when there is a position change (e.g. standing after sitting).

Strategies

- Change position slowly, and allow time for the feeling of dizziness to reduce or stop before moving further.
- The doctor/ nurse practitioner can see if a change or reduction in medication may be helpful.



Tiredness

Extreme tiredness is common with heart failure. The body tissues (e.g. muscles) are not getting the oxygen and energy they need, and this can cause feelings of tiredness.

Strategies

- Plan for activities to minimise effort and save energy (e.g. it may not be necessary to shower every day).
- More rest may be helpful especially before meals or activity.
- Discourage rushing, and allow more time.

Medicines

In the last days or weeks of life, some medications may no longer be helpful and others may need to be added. The doctor/ nurse practitioner will consult with Hospice or hospital specialists for advice when required. Medications will be discussed with residents and their family/ whānau when adjustments might be helpful to ease symptoms or reduce harm.

Strategies

- The doctor/ nurse practitioner and nurse will assist with symptom management and answer questions about whether specific medicines might be helpful.
- Hospice can be called on for complex symptom management, for example pain, breathlessness or restlessness.
- There may be other health professionals called upon for advice (e.g. physiotherapist, pharmacist).
- Spiritual and/ or cultural advisors can offer support and advice.



Common medicines used in heart failure

Diuretics (e.g. furosemide, bumetanide or metolazone)	Stimulates the kidneys to get rid of fluid. Can cause dizziness due to a decrease in blood pressure or dehydration. Can cause low levels of potassium in the blood, which can be helped with supplements.
ACE inhibitors (e.g. pills that end in “pril” such as lisinopril, perindopril or quinapril)	Widens blood vessels to reduce the amount of pressure the heart has to pump against. In some people the ACE inhibitors cause a dry cough. If this happens, you will be changed to a different medicine.
Angiotensin II receptor blockers (ARBs) (e.g. pills that end in “artan” such as losartan or candesartan)	These work in a similar way to ACE inhibitors (above).
Beta blockers (e.g. pills that end in “lol” such as metoprolol, carvedilol, bisoprolol)	Slows the heart rate so the heart doesn’t have to work so hard and allows time for the heart to fill and pump blood more efficiently. Can make people feel cold and “slowed down.” Can cause fatigue and weakness after dose increases, but as your body adjusts these symptoms usually go away – tell your nurse or doctor if these symptoms don’t improve.
Aldosterone antagonists (e.g., spironolactone, eplerenone)	Prevents scarring of the heart muscle, lowers blood pressure and decreases salt and fluid retention.
Angiotensin receptor blocker combined with neprilysin inhibitor (e.g. sacubitril and valsartan (entresto))	Alternative treatment to ACE inhibitors or ARB’s alone. Also can decrease fluid retention.
Digoxin	Slows down the heart rate and makes the heart beat stronger. May require blood tests to monitor medication levels in the body.
Morphine	Improves symptoms of breathlessness. This is usually added when other medicines are not effective at controlling shortness of breath, usually at the end stages of heart failure. It is not addictive when used for this reason.

These medicines can all cause dizziness, due to lowering blood pressure. Please tell your nurse and doctor if you feel dizzy.

Pacemakers and Implantable Cardioverter Defibrillators (ICD's)

Some people with heart failure have a pacemaker inserted to improve the heart rate and rhythm of the heart pump. This also allows the doctors/ nurse practitioners to be able to increase some medications that improve the heart pump, without slowing the heart rate too much.

Some pacemakers are fitted with a defibrillator, which can give the heart a small electric shock to prevent sudden death from cardiac arrest.

Pacemakers cannot stop the natural decline of heart function in people with heart failure. However, it can improve symptoms and provide the ability to give more beneficial doses of medication that can improve heart function and slow progression. As heart failure progresses, there will come a time to plan to have the defibrillator function turned off, but the pacemaker function can continue.

When is admission to hospital appropriate?

Unexpected events such as falls, fractures, stroke or infection can occur in anyone's life. The decision to go to hospital will depend on the nature of the event, whether it will be of benefit for the person's overall well-being and whether the person wants to go.

The way that unexpected events are managed depends on the goal of care for the person. Sometimes going to hospital is necessary to get treatment which maintains function, or relieves suffering. For example, a fall may cause a broken bone which may need a cast; or a serious cut may need stitches.

However, in some cases it may not be helpful to go to hospital. Moving a person from their familiar surroundings can cause anxiety, disorientation and further decline of their physical function.

An Advance Care Plan may help everyone's thinking about when going to hospital is appropriate, and when it would not be helpful or beneficial. The clinical team can advise and guide you about Advance Care Plans.

Hospital level residential aged care facilities provide skilled medical and nursing care. Staff are familiar with their residents' needs and choices, and in many cases are able to provide ongoing care in the facility (e.g. for chest infections, wound

infections and urinary tract infections). When necessary, your doctor/ nurse practitioner or nurse will get advice from Hospice/hospital specialists.

Making decisions about whether to go to hospital or stay in the facility depends on where the most appropriate care can be provided.

Resuscitation

Resuscitation is also known as cardiopulmonary resuscitation (CPR). It is used when a person collapses because their heart stops beating. The heart is manually pumped by someone pressing firmly on the chest at the rate of a normal heart beat, and electrical shocks might be given to try and restart the heart rhythm.

While doctors and nurses work to do everything they can for people and want to follow people's wishes, they do not provide treatment they know will be unsuccessful or cause harm. People with advanced heart failure are strongly encouraged to discuss this end-of-life care decision with their families/whānau, doctors/ nurse practitioners and nurses.

Pain

Pain has many causes and is unique to the individual who is experiencing it. For example, pain can be emotional, spiritual, physical, long term or acute (short-term). Examples of the most common causes of pain in the older person are osteoporosis, osteoarthritis/joint pain, back pain, constipation, dental problems and infections.

A person with advanced heart failure can also develop new causes of pain e.g. skin problems, joint stiffness and weight loss. Untreated or poorly controlled pain has a significant impact on quality of life and can lead to loss of mobility, low mood or depression and changes in behaviour.

A person who is experiencing pain may feel restless, agitated, anxious, depressed and tearful. They may not want to move or do their normal activities, or may appear worried or withdrawn.

Strategies

- Tell the doctor/ nurse practitioner or nurse about any pain or discomfort.

- The doctor/ nurse practitioner or nurse will assess for pain or discomfort and discuss appropriate and individualised treatment which may involve medication, changing a person's positioning regularly, and pressure relief.
- They may ask for advice from Hospice.

Some things family/whānau can do to assist are:

- Provide comfortable clothing that is easy to remove.
- Bring familiar music.
- Using comforting touch. This must be gentle enough to avoid bruising or injuring the skin.
- Spiritual and/ or cultural advisors can offer support and advice.

Other medical conditions

A person with advanced heart failure may also have other medical conditions which can affect their day-to-day health (e.g. diabetes or stroke). These conditions will also be managed by the care team.

Depression is common in people with heart failure. If you or your loved one has a loss of interest in things that they used to enjoy, is tearful, withdrawn or has a reduced desire to eat, discuss this with the doctor/ nurse practitioner or nurse and ask for a mood assessment.

Strategies

There are specialist palliative services available (e.g. Hospice) who can advise the doctor/ nurse practitioner or nurse on symptom management and support the person and their family/whānau.

Eating, drinking and weight loss

When a person has advanced heart failure they very often lose weight in the same way as someone with cancer or other illnesses. As the body is no longer able to get nutrients from food, it makes chemicals that cause weight loss. Nausea and loss of appetite can also be a problem. It can be distressing for family/ whānau members when a person stops eating or drinking, or only manages small amounts of food or fluid, but there are some things that may help.

Strategies

- Care providers will continue to maintain good mouth care to promote comfort.
- Focus on whether the person is hungry, rather than worry about the amount of food that is consumed.
- The symptoms of heart failure are sometimes managed by restricting the amount of fluid a person is allowed. It is usually fine to offer sips of drinks if someone is thirsty, but check with the doctor/ nurse practitioner or nurse if it's okay to give larger quantities than this regularly.
- Small amounts of food or fluid should continue to be offered frequently.
- Family/whānau can bring in favourite foods.
- Protein drinks may be beneficial if appetite and weight loss are problematic. Ask the doctor/ nurse practitioner or nurse if a community dietitian review would be helpful.

Over time these strategies may become less effective. Alternatives such as tube feeding or subcutaneous fluids (fluids given through a tube under the skin) are not usually considered helpful for people with advanced heart failure, as studies show that they do not increase or improve quality of life. These interventions are invasive and can be distressing.

Infection

A person with any stage of heart failure may develop infections more easily. The most common are chest, skin and urinary tract infections. The reason for this is declining health, increasing frailty and reduced ability of the immune system to fight infections.

Strategies

The doctor/ nurse practitioner or nurse may discuss with the person and their family/ whānau whether antibiotics can be helpful.

Skin

As the disease progresses skin may become more fragile. This will increase risk for skin injuries and infections.

A person who has difficulty changing their position in bed is at risk for skin break down (known as pressure injuries or bed sores) especially on the heels, tail bone,

hips, elbows, spine and ears.

Skin changes also occur with weight loss and decreased fluid and nutritional intake.

Strategies

- Staff will check the person's skin regularly and provide skin and wound care if required.
- A pressure relieving mattress or seat may be provided.
- Tell staff about any redness, pain or new skin injuries that you see.



Recognising dying

- A person is dying when they enter the final or ending phase of physical life.
- Most people who have a progressive illness experience gradual deterioration over time and a dying phase at the end. However, this process varies from person to person and can be unpredictable.
- The need for food and fluid decreases. People who are dying can lose the ability to swallow and often don't feel thirsty or hungry. When death is near, the body is no longer able to digest food.
- There is potential for a variety of people to be involved in end of life care. It is important for family/ whānau and friends to be involved at a level that is comfortable for the person. Please discuss any concerns with the staff so that they can provide the best possible care.
- There may be changes in levels of alertness. It will become more difficult for the person to wake up, to respond to talking or physical contact. Some people may still have moments when they recognise family/ whānau members and are able to communicate.

- The person gradually loses the ability to move or lift their head up off the pillow. They will need full assistance with all physical cares (such as washing, or cleaning of the mouth).
- There may be changes in physical appearance that can include purple or blotchy red-blue discolouration of the skin (mottling). Hands and feet may feel cold. There may also be loss of muscle tone, which will cause changes in facial expression.

After death

The person's dignity is of the utmost importance, and their beliefs and values will be respected. Specific cultural, religious and spiritual needs should be discussed ahead of time. Discussing the person's and family/ whānau preferences before death (e.g. choice of celebrant, cremation, or burial) can reduce stress during this difficult time.

The roles of clinical team and family/whānau

Health care professionals use the information provided by the person and their family/ whānau to guide care. This includes the person's values, wishes and activities enjoyed. As well as the registered nurse and doctor there are other people who assist with caring for, or supporting the person and their family/ whānau (e.g. health care assistants, physiotherapists, chaplain, or other religious leaders). Other specialist services such as hospice can also be helpful.

Who makes decisions?

- People make decisions regarding their own care and welfare unless a doctor has assessed that they no longer have the mental capacity to do so. At this point, the attorney specified in an enduring power of attorney (EPOA) for care and welfare or a welfare guardian appointed by a Protection or Personal Property and Rights court order makes decisions on that person's behalf (see legal definition page). If there is no enduring power of attorney or welfare guardian, then a clinician can provide treatment in the person's best interests, provided reasonable steps are taken to find out the person's views.
- Waitemātā DHB advises everyone to consider appointing an EPOA to safeguard their interests should they become unable to act for themselves. If there is no EPOA and a person lacks decision making capacity, their family/whānau or friend can apply to the Family Court, under the Protection of Personal and Property Rights Act 1988, to appoint a Welfare Guardian (and possibly a Property Manager) to make decisions on behalf of the person. These decisions must be in the best interests of the person and would usually be in consultation with family/whānau and the registered nurse and doctor/nurse. Further information on the process is available at the Ministry of Social Development website: ➤ [Link](#))
- Regardless of capacity, a person must still be supported to take part in discussions about their health and welfare. Their preferences and beliefs should be respected and followed as far as possible when making decisions.
- The person in residential aged care, along with their family/ whānau and health care professionals, work together. The family /whānau or friends that will take part in these discussions are chosen by the person wherever possible.

- Should any differences in opinion arise around the appropriateness of care, health care professionals are available to facilitate discussion.
- If conflict arises, the resident with capacity makes the final decision. If the person does not have mental capacity their EPOA/Welfare Guardian makes the final decision.
- Conflict may sometimes arise when there are differences of opinion amongst individual family/whānau members or between families/whānau and the clinical team. If the designated EPOA or welfare guardian does not act in the person's best interest, please contact legal services for specific advice.

It is important to have good communication, and there are agencies that can support the decision-making process (e.g. the Advocacy Service, Mental Health Service for Older Adults (MHSOA), Gerontology Nurse Specialists, a Chaplain, religious or cultural groups).



Supports for family/whānau

There are many organisations that can offer support. Here is a list of some of the organisations that are available:

Community services

Age Concern

Phone: (09) 820 0184

Website: www.ageconcern.org.nz

(Supports vulnerable older adults)

Amitahba Hospice service

Phone: (09) 828 3321

Address: 44 Powell St Avondale

Website: www.amitabhahospice.org

Citizens Advice Bureau

Phone: 0800 FOR CAB (0800 367 222) to find an office near you

Email: www.cab.org.nz

(Helps people to know and understand their rights)

Community Law Centres

There are community law centres throughout the country.

Website: www.communitylaw.org.nz

(Offers all sort of free legal help)

Grief Centre

Phone: (09) 418 1457

Website: www.griefcentre.org.nz

(Offers grief and loss support to children, youth, adults, families, or whanau experiencing any form of significant loss)

Heart Foundation NZ

Phone: 0800 863 375 or (09) 571 9191

Website: www.heartfoundation.org.nz

(Information and support about heart conditions)

Hospice New Zealand

Phone:

North Shore: (09) 486 1688

Hibiscus Coast: (09) 421 9180

Website: Harbour Hospice: <https://harbourhospice>

Warkworth/Wellsford (09) 425 9535

Hospice West Auckland (09) 834 9750

Website: www.wah.org.nz

(Supports anyone with life limiting illness, not just cancer)

Government support services

Advance Care Planning

Website: <https://www.hqsc.govt.nz/our-programmes/advance-care-planning/>

(Planning for future health care and end of life care)

Health and Disability Advocacy

Website: <https://advocacy.org.nz/>

(Supports consumers with concerns about their healthcare to achieve positive outcomes with health and disability providers)

Ministry of Social Development

Website: www.msd.govt.nz

<https://superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/>

Waitematā District Health Board support services

Waitematā District Health Board

Phone: (09) 486 8900 or 0800 809 342

Website: www.waitematadhb.govt.nz

Needs Assessment and Service Coordinators (NASC)

Phone: (09) 442 7171

Email: nascinfo@waitematadhb.govt.nz

There are other supports available such as cultural groups and RSA. Facility staff may be able to advise about local supports.

Appendix

Advance directives

If there is an advance directive in place, the information in this document will be taken into consideration as part of the care planning process.

Advance Care Planning

Advance Care Planning is a process that gives the chance to plan the health care preferences for the person with dementia, their family/whānau and the health care team. It is a way to ensure that the wishes of the person with dementia and their family/whānau have been thoroughly discussed and updated on a regular basis. It does not have to be a legalised formal process, but rather part of the care.

Enduring power of attorney and welfare guardian

An enduring power of attorney (EPOA or EPA) is a legal document where the person appoints an attorney to make decisions if the person becomes mentally incapable. An EPOA cannot be set up once someone has lost mental capacity. An EPOA that was completed when the person was competent is activated once they are assessed by a medical practitioner as incompetent or lacking capacity. This must be written and signed by the medical practitioner activating the EPOA. Ensure that the EPOA is activated by checking with your legal advisor and/or medical practitioner.

If there is no EPOA and the person no longer has capacity to make decisions, their family/whānau should apply to the court for appointment of a welfare guardian under the Protection of Personal Property and Rights Act. This should be a nominated person from the family/whānau or friend who is happy to take on this responsibility for the person. Once in place, care decisions are then made by the welfare guardian in consultation with health care professionals, including the medical practitioner. It is important that the enduring power of attorney or welfare guardian are aware of the person's personal wishes, feelings and values to assist them in making the best decisions on the person's behalf; this can be done using an Advance Care Plan.

Information about this is available through Age Concern:

Website: www.ageconcern.org.nz

Phone: North Shore: (09) 489 4975

Rodney: (09) 426 0916

West Auckland: (09) 820 0184

Glossary

Exacerbation: sudden increase in severity due to infection or other causes

Notes

This document can be downloaded from www.wdwb-agedcare.co.nz



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