



Waitemata
District Health Board

Best Care for Everyone

Advanced Heart Failure

*Information for residents in Residential Aged Care and their families
to support decision making*

Manaaki Mana Kaumatua

All-encompassing care, respect, dignity of holding our older ones

Acknowledgments

This information booklet has been provided by the Residential Aged Care Integration Programme Work Group and Waitemata District Health Board.

Our aim has been 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 care. We have also suggested some practical ways families/whānau 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 advise what to expect during the final stages of heart disease. Please ask for an interpreter if this is needed.

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.

The registered nurse and doctor are able to support and discuss this information with you and your family/whānau.

Having knowledge of the likely course of heart disease 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 diseases that cause damage to the heart e.g. hypertension (high blood pressure), diabetes, myocardial infarction (heart attack), etc. These diseases reduce the ability of the heart to pump blood around the body. This can cause many different symptoms, but the most common are tiredness, shortness of breath, and fluid retention. This leads to increased difficulty managing personal care, and reduced quality of life which may cause increased stress for a person and their family/whānau.

More important than the diagnosis is the impact it has on a person, their family and friends. Disease progression will vary from person to person influenced by the type of heart disease and past medical history. How people cope varies, influenced by personal skills and life experience. There is a lot of information about heart diseases such as congestive heart failure on the internet and from organisations such as the Heart Foundation NZ (see resources on page 19).

Although progression of heart failure is unique for each person there are usually identifiable 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 deterioration. 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 Advanced 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	Assessment and diagnosis Education of person and family Symptom management Monitoring to reduce exacerbations ¹ and prevent deterioration Management of exacerbations	Community, outpatient and home based services Increasing need for home support for caregiver and person with heart disease as ability to manage physical activities declines
Moderate	Slight limitation of physical activity. Comfortable at rest but ordinary physical activity causes symptoms of heart failure (Breathlessness and fatigue). Examples: Difficulty showering or walking any distance		
Severe/ Very Severe	Marked limitation of physical activity. Comfortable at rest but less than ordinary activity causes symptoms of heart failure. (Breathlessness and fatigue). Examples: Difficulty walking to another room, dressing and undressing Unable to carry out any physical activity without symptoms of heart failure or symptoms of heart failure at rest. Examples: Difficulty getting out of bed or moving in bed.	Support and education of person and family Planning ahead: Advance Care Plan, Enduring Power of Attorney Symptom management Monitoring to reduce exacerbations ¹ and prevent deterioration Management of exacerbations which may be more frequent Symptom management Monitoring to reduce exacerbations ¹ and prevent deterioration Management of exacerbations (may not survive) End of life care/ palliative care Follow Advance Care Plan	Increasing likelihood of residential aged care Collaborative care with hospice

Bereavement care for the family

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 integrates the cultural, spiritual, religious values and beliefs of the person will assist in providing 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 the problems that may arise as part of the natural course of the disease process. 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 limbs, 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 lowest places in the body change when a person lies down. The extra fluid causes weight gain, breathlessness, increased tiredness and strain on an already tired heart.

Strategies

- Raising the legs can assist fluid to return to the circulation and be removed by the kidneys
- Compression stockings or bandages when walking assists with fluid return to the circulation
- Wearing loose and comfortable clothing and socks reduces discomfort
- Promote comfort when sleeping by raising the head and upper body using pillows or hospital bed or Lazy Boy chair
- The doctor may:
 - Review to see if medication may be helpful
 - Advise a low salt diet
 - Advise fluid restriction (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 causing a moist cough. The sputum is usually white and frothy. Oxygen is not helpful for relieving cough.

Strategies

- Sitting in a more upright position
- Breathing exercises may help
- Relaxation techniques may be helpful
- Tell staff if the cough is getting worse
- The doctor can review to see if medication may be helpful

Breathlessness

When the lungs contain more than normal amounts of fluid, 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 can review medications – these can often help reduce both feelings of 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, sleeping slightly upright with several pillows can be helpful
- Let staff know what works best

Fast or irregular heart beat

As heart failure progresses the heart enlarges and the heart rate can become more irregular. Feeling tired is a common symptom of this.

Strategies

- Planning activities to minimise effort
- More rest may be needed especially before meals or activity
- The doctor can review to see if medication may be needed

Dizziness

Blood pressure can be very low in heart failure causing dizziness and feeling faint. Dizziness can also be caused by a sudden drop in blood pressure when there is a position change e.g. sitting or standing up.

Strategies

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



Tiredness

Extreme tiredness is common with any advanced illness. The body tissues, e.g. muscles, are not getting the oxygen and energy they need and this increases feelings of tiredness.

Strategies

- Planning for activities to minimise effort 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, medications that were required to control diseases may no longer be of benefit. The registered nurse and doctor will discuss medications with the person and their family/whānau and reach agreement about which ones to stop. Sometimes a new medication may need to be started, for example to manage anxiety or pain.

Strategies

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



Common medicines used in heart failure

Diuretics e.g. furosemide (frusemide)	Stimulates the kidneys to get rid of fluid
ACE inhibitors e.g. cilazapril, quinapril ARBs e.g. candesartan	Widens blood vessels to reduce the amount of pressure the heart has to pump against. Can cause coughing as a side effect.
Calcium channel blockers e.g. amlodipine, felodipine	Reduces blood pressure and heart and chest pain brought on, for example, by exercise or stress. It widens small blood vessels, so that blood can be pumped around the body more easily. Can cause ankle swelling and headache.
Beta Blockers e.g. metoprolol	Affects the hearts response to nerve impulses reducing how much work it has to do, and its need for oxygen. Can make people feel cold and “slowed down”.
Nitrates e.g. GTN spray	Relieves heart pain (angina) by widening the blood vessels that supply blood to the heart. Can cause headache.
Digoxin	Slows down the heart rate so that each heartbeat is more effective at pumping blood. It also can help to control the symptoms of tiredness, breathlessness and fluid retention.

These medicines can all cause dizziness. The registered nurse and doctor need to know if dizziness is experienced.

Pacemakers (Implantable Cardioverter Defibrillator or ICD)

Some people with heart failure have a pacemaker which keeps the heart in its correct rhythm. Some pacemakers also contain a defibrillator which gives electric shocks to prevent sudden death from cardiac arrest. Pacemakers cannot prevent death that occurs with the disease progression in heart failure. The pacemaker function can continue but it may be appropriate to plan to have the defibrillator part turned off.



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.

How unexpected events are managed will depend on the goal of care for the person. Sometimes going to hospital is necessary to provide treatment which maintains function, or relieves suffering and provides the best possible quality of life. For example a fall may cause a fractured bone which may need treatment, a severe skin tear may need suturing, and a bowel obstruction may need specialist medical intervention.

However in some situations going to hospital may not be in the person's best interest. 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. The clinical team can advise and guide about Advance Care Plans.

Residential aged care facilities provide skilled medical and nursing care. Staff are familiar with their residents' needs and choices and in many situations are able to provide on-going care in the facility e.g. chest infections, wound infections, urinary tract infections can in most cases be treated in the residential care facility.

Making decisions about whether to go to hospital or stay in the facility will be dependent 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 massaged by pressing firmly on the chest, and electrical shocks are usually given to try and restart the heart rhythm.

While doctors want to do everything they can to help people, and want to follow peoples wishes as much as possible, they also will not provide treatment they know to be pointless. People with advanced heart failure are strongly encouraged to discuss this with their doctors if they have concerns or need more information.

Pain

Pain has many causes. For example it can be emotional, spiritual, physical, long term or acute. Examples of the most common causes of pain in the older person are: osteoporosis, back pain, constipation, dental problems and infections but there are many others.

A person with advanced heart failure can also develop new sources of pain for example skin problems, joint stiffness, weight loss etc. 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, and tearful. They may not want to move or do their normal activities or may appear worried or withdrawn.

Strategies

- Tell the registered nurse about any pain or discomfort
- The registered nurse or doctor will assess for pain or discomfort and discuss appropriate and individualised treatment which may involve medication, positioning and pressure relief. They may ask for advice from Hospice or a hospital specialist
- Some things family/whānau can do to assist are:
 - Provide comfortable clothing that is easy to remove
 - Bring familiar music
 - Use comforting touch or hand massage
- 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, stroke etc. These conditions will also be managed by the care team.

Strategies

- There are specialist services available e.g. Hospice, who can advise the doctor 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 dying from cancer or other illnesses. When 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
- It is usually more helpful to ask if the person is hungry or thirsty than to worry about the quantity of food or fluid that is consumed
- Small amounts of food or fluid will continue to be offered frequently
- Family/whānau can bring in favourite foods

Over time these strategies may become less effective. Alternatives such as tube feeding or subcutaneous fluids are not usually considered to be of benefit for people dying from heart failure as we know from studies that they do not prolong or improve quality of life. These interventions are invasive and can be distressing.

Infection

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

Strategies

- The doctor and registered nurse may discuss with the person and their family/whānau the use of antibiotics recognising what is appropriate for the situation

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 (bed sores) especially on their 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 skin when providing hygiene and provide skin and wound care
- A pressure relieving mattress or seat may be provided
- Tell staff about any redness or new skin injuries



Recognising dying

- Dying can be defined as 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 as is the case for anyone at the end of their life. People who are dying can lose the ability to swallow and 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 remains important for family/whānau and friends to be involved at a level that is comfortable for them. Please discuss any concerns with the staff so that they provide the best possible care
- There may be changes in levels of alertness. It will become more difficult 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, cleaning of the mouth etc
- 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

As in life the person's dignity is of the utmost importance. The person's 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 etc. can reduce stress at what is a difficult time.

The roles of clinical team and family/whānau

Health care professionals use the information provided by you and your family/whānau to guide your care. This includes your values, wishes and activities you enjoy. As well as the registered nurse and doctor there are other people who assist with caring for, or supporting you and your family/whānau e.g. health care assistants, physiotherapists, chaplain, or other religious leaders etc. 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 and has activated the Enduring Power of Attorney (EPOA) if one exists. At this point the activated Enduring Power Of Attorney or Welfare Guardian (appointed by the Court under the Protection of Personal and Property Rights Act 1988) makes the decisions. (Emergency treatment may be given by health professionals even if there is no person who has legal authority to authorise it)
- Waitemata DHB advises everyone to appoint an Enduring Power of Attorney 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 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 who will make decisions on their behalf (this can be a lengthy process). 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. Further information on the process is available at the Ministry of Social Development website (www.msdc.govt.nz)
- 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 works together as a team. The family members and/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

- The person and their family/whānau
- Between families and the clinical team

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 for Older Adults team, Gerontology Nurse Specialists, a Chaplain, religious or cultural groups.



Resources

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

Age Concern

www.ageconcern.org.nz

North Shore: (09) 489 4975

Rodney: (09) 426 0916

West Auckland: (09) 820 0184

Advance Care Planning

www.advancecareplanning.org.nz

Amitahba Hospice service

44 Powell St Avondale

(09) 828 3321

www.amitabhahospice.org

Citizens Advice Bureau

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

www.cab.org.nz

Community Law Centres

There are community law centres throughout the country.

www.communitylaw.org.nz

Grief Centre

(09) 418 1457

www.griefcentre.org.nz

Heart Foundation NZ

0800 863 375 or (09) 571 9191

www.heartfoundation.org.nz

Health and Disability Advocacy
advocacy.hdc.org.nz

Hospice New Zealand
www.hospice.org.nz

Hospice West Auckland
(09) 834 9750 (General)
(09) 834 9755 (Patient & Carer line)
www.wah.org.nz

Hospice North Shore
(09) 486 1688
www.hospicenorthshore.org.nz

Hospice Hibiscus Coast
(09) 421 9180
www.hibiscushospice.org.nz

Family Caregiver Alliance (Information for Care Givers)
www.caregiver.org

Ministry of Social Development
www.msd.govt.nz

Waitemata District Health Board
(09) 486 8900
0800 809 342
www.waitematadhb.govt.nz

There are other supports available such as cultural groups, RSA etc. 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 opportunity to plan health care preferences ahead of time. It is a way to ensure that a person and their family/whānau wishes 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.

If the doctor assesses a person has no mental capacity to make decisions about their care the person who holds the EPOA for care and welfare makes these decisions on their behalf and in accordance with their known preferences and values.

Enduring Power of Attorney (EPOA or EPA) and Guardianship

Enduring Power of Attorney (EPOA) cannot be set up once a person has lost mental capacity. An EPOA that was completed when a 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 doctor activating the EPOA. Ensure that the EPOA is activated by checking with your legal advisor and a doctor.

Information about this is available through Age Concern

www.ageconcern.org.nz

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

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



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