



Te Whatu Ora
Health New Zealand
Waitematā

Advanced Lung Disease

*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 Te Whatu Ora Health NZ - Waitematā.

Our aim has been to write about the issues we have noticed that can cause concern for people with advanced lung disease 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.

Janet Parker: Gerontology Nurse Practitioner, Nga Kaitiaki Kaumatua, Older Adults and Home Health, Te Whatu Ora - Waitematā.

Te Whatu Ora-Waitematā Residential Aged Care Integration Programme

Working Group			Reviewers
Anne Grinlinton	Linda Goodwin	Lisa Smith	Helen Bowen
Anne James	Laurel Winwood	Rebecca Sixtus	Dr Michal Boyd
Bernadette	Claire Parker	Jon Amesbury	Dr John Scott
Rehman	Linda Willetts	Sue Pronk	Peter Groom
Carole Pilcher	Amor Redoble	Emma Venables	Amanda Homewood
Dianna McGregor	Rebecca Marshall	Linda McFadyen	Anne Turner
Hyeonjoo Lee	Liz Webb	Sue Buchanan	Heather Brannigan
Ingrid Harvey	Diane Cooke	Tina Chivers	Consumer
Joan O’Brien	Claire May	Cecily Walley	representatives
Joy Owen	Lyn Askell	Mina Vuorinen	Health Link North Health
Janet Parker	Anne	Margaret Roigard	Literacy Group
Jacque Merciecia	Postlewaight	Lucia Mhinderent	Maori Health Services
Jo Hikaka	Jasper Young		Asian Health
Operations	Susan Mountier		Pacific Health Services
Manager Older			Hospice Representatives
Adults and Home			Claire Hatherell
Health			Trish Fleming
Sue Skipper			Jessica Ponen

We acknowledge and thank the individuals with lung disease and their families who read and gave advice on content

Contents

Acknowledgments	2
Te Whatu Ora - Waitematā Residential Aged Care Integration Programme	2
Introduction	4
Typical Progression of Advanced Lung Disease	5
Principles of care	6
Breathing	6
Breathlessness that causes fear and anxiety	7
Episodes of confusion	8
Managing exacerbations	9
Medicines	9
When is admission to hospital appropriate?	10
Resuscitation	10
Pain	11
Other medical conditions	12
Eating, drinking and weight loss	12
Infection	12
Skin	13
Recognising dying	15
After death	15
The roles of clinical team and family/whānau	16
Who makes decisions?	16
Resources	18
Appendix	20
Advance directives	20
Advance Care Planning	20
Enduring Power of Attorney (EPOA or EPA) and Guardianship	20
Glossary	20
Notes	21

Introduction

This booklet is written for a person with **advanced lung disease** 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 lung disease. Please ask for an interpreter if this is needed.

Lung failure is a progressive disease. There usually comes a time when a person with advanced lung disease becomes fully 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 lung 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 apart from lung cancer that cause damage to lungs e.g. chronic obstructive pulmonary disease, emphysema, etc. These diseases reduce the ability of the lungs to absorb oxygen and this causes breathlessness. This in turn leads to increasing 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 lung disease and past medical history. How people cope varies, influenced by personal skills and life experiences.

There is a lot of information about lung diseases such as chronic obstructive pulmonary disease on the internet and from organisations such as the Asthma Foundation (see resources on page 18).

Although progression of lung disease 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. Identifying this is useful as it supports you and clinicians when planning the goals of your care. As you move through the different stages your goals of care will change.

Typical Progression of Advanced Lung Disease

Modified Medical Research Council Dyspnoea Scale 0 – 4
(measuring breathlessness)

		Goals of Care	Setting
Mild	0: Breathless only with strenuous exercise		
	1: Short of breath when walking on the level or up a slight hill 2: Slower than most people of the same age on the level because of breathlessness, or Have to stop for breath when walking at their own pace on the level	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
Moderate	3: Stop for breath after walking about 100 metres on level ground or After a few minutes at their own pace on level ground	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	Increasing need for home support for person and family
Severe	4: Too breathless to leave the house or Breathless when dressing	Symptom management	Increasing likelihood of residential aged care
Very Severe	Increasing dependence for all cares	Monitoring to reduce exacerbations and prevent deterioration Management of exacerbations (sudden increase in severity due to infection or other causes). Exacerbations ¹ may be more frequent (may not survive exacerbations) End of life/palliative care Follow Advance Care Plan	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. Family/whānau and staff may cooperatively plan this care.

When a person is **dying** from lung disease 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.

Breathing

As the lungs fail, their ability to transfer oxygen to the blood decreases. This will cause the breathing rate to increase. A lot more effort is needed to breathe and use of shoulder, neck and abdominal (stomach) muscles increases. This uses up a lot of energy and often causes fatigue and weight loss. It may also be more difficult to talk.

Strategies

The doctor can review to see if medication may be helpful. Hospice and/or a pharmacist may be consulted.

- Nebulised medicines may be used. Medicines are given through a mask using a special machine
- If oxygen has been prescribed the person may need to use this most of the time: there will be guidance from staff about safe use
- Plan for exertion or activity so that effort is minimised 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
- Let staff know what interventions work best

Note: Support will be given to help maintain independence unless it is causing severe breathlessness or distress.

Breathlessness that causes fear and anxiety

Being very short of breath can be frightening. Anxiety worsens the feeling of breathlessness.

Strategies

- The doctor may prescribe medicines than can help reduce the feeling of breathlessness and reduce anxiety
- Sitting in an upright position or leaning forward can help make breathing more comfortable
- A physiotherapist can teach more effective breathing and relaxation techniques
- Have a good flow of air through the room using a fan or leaving a window open. The use of aromatherapy can be considered
- Have small but more frequent meals
- Plan activity so that there is no over exertion
- Recognise triggers that increase fear and anxiety and reduce or prevent them e.g. If being alone is a trigger have the call bell within reach or have a family member present. Triggers may not be just physical ones; they may be emotional e.g. worrying about family/ whānau
- Familiarity with equipment such as nebulisers, gentle lighting, suitable room temperature, confidence in familiar staff will all assist with reducing fear
- Keep inhalers within reach
- Tell staff about anxiety or fear because they may be able to help
- Let staff know what works best
- Ask staff for assistance and advice





Episodes of confusion

The brain is dependent on an adequate oxygen supply. Confusion can occur when it does not get this. This is known as delirium and can be upsetting for the person and their family/whānau.

Strategies

- Staff will assess if there are other causes for the confusion e.g. infection, constipation or pain, or too many medications
- Care is aimed at keeping the person safe, ensuring they receive regular food and fluids, monitoring bowel and bladder function and treating any reversible causes of the confusion
- It is very helpful for family/whānau and staff to remain calm and gently reorient the person to time and place



Managing exacerbations¹

Usually, lung diseases such as chronic obstructive lung disease have periods of stability and periods of exacerbation and infection. As lung failure gets worse exacerbations may become more frequent.

Strategies

- Having an Advance Care Plan in place will reduce much of the uncertainty about what to do
- The clinical team will discuss options for on-going care with the person and their family/whānau
- The care team may have a plan for medicines and other interventions to be used during an exacerbation

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

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



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 and 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 people's wishes as much as possible, they also will not provide treatment they know to be futile. People with advanced lung disease 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 lung disease 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 lung disease may also have other medical conditions which can affect their day to day health e.g. heart conditions, diabetes 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 lung disease 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 lung 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 developing pressure injuries (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)
- Te Whatu Ora - Waitematā advises everyone to appoint 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 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.

The Asthma Foundation

04 499 459

asthmafoundation.org.nz

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

Cancer Society of New Zealand

0800 CANCER (226 237)

www.cancernz.org.nz

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

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

Te Whatu Ora Health New Zealand - Waitematā
(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 that a person lacks the 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) 8200184

Glossary

Dyspnoea: breathlessness

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

[illegible]

Handwriting practice lines consisting of multiple horizontal dotted lines for tracing and writing practice.



Handwriting practice lines consisting of multiple horizontal dotted lines across the page.



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



Te Whatu Ora
Health New Zealand
Waitematā