Te Whatu Ora
Health New Zealand
Waitematā

Advanced Lung Disease

Information for residents, families and whānau

Acknowledgement

This information booklet was updated in 2024 and has been provided by the Residential Aged Care Integration Programme Working Group and Health New Zealand Te Whatu Ora Waitematā. We acknowledge everyone who supported the development of the original version; staff in residential aged care facilities, experts in the field and residents, their families and whānau.

This booklet has been developed to inform you, your family and whānau on what to expect during the final stages of lung disease. It is important that you understand this information and your registered nurse and/or doctor/nurse practitioner can discuss and explain this information to you. Please ask if you would like an interpreter or some other support to help you better understand.

Look for this symbol in the booklet for practical ways you, your family and whānau can help with your care.

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Gerontology Nursing Service
Ngā Kaitiaki Kaumātu
Health New Zealand Te Whatu Ora Waitematā

Contents

Introduction

Lung failure occurs when the lungs are damaged. Lung disease is progressive and can be caused by many diseases (e.g. lung cancer, chronic obstructive pulmonary disease (COPD), emphysema, asbestosis) that reduce the ability of the lungs to absorb oxygen, making breathing hard and causing breathlessness (dyspnoea). Breathlessness makes it harder to manage everyday tasks, reduces the quality of life and can be very stressful.

A diagnosis of lung disease impacts the person, their family and whānau. Disease progression will be different for each person and is impacted by the type of lung disease and the person's medical history. The way people cope with a diagnosis of lung disease is influenced by personal skills and life experiences.

In most cases there comes a time when a person's lung disease becomes advanced and they become fully dependent on others for even the most basic things in life. Through the progression of the disease, the person's goals of care will change. Having knowledge of the likely course of lung disease gives you and your care team an opportunity to plan your future care, for example you, your family and whānau may have preferences about end-of-life care, discussing these with your care team now gives the opportunity for these preferences to be honoured.

Although progression of lung disease is unique for each person, there are usually identifiable stages. The information on the next page will help you, your family and whānau to identify and understand which stage you are currently in.

Note: There is a lot of information about lung disease on the internet and available from organisations such as the Asthma & Respiratory Foundation (see resources on page 13) if you would like to know more.

Typical progression of advanced lung disease

Modified Medical Research Council Dyspnoea			
Scale 0-4		**Goals of Care**	**Setting**
	0: Breathless only with strenuous exercise		
Mild	1: Short of breath when walking on flat ground 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 flat ground	– Assesment and diagnosis – Education of person and family/ whānau – 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 flat ground or after a few minutes at their own pace on flat ground.	– Support and education of person and family/ whānau – 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/ whānau
Severe	4: Too breathless to leave the house or breathless when dressing.	– Symptom management – Monitoring to reduce exacerbations[1] and prevent deterioration – Management of exacerbations (sudden increase in severity due to infection or other causes) – Exacerbations may be more frequest (may not survive exacerbations) – End of life/ palliative care – Follow Advance Care Plan	Increasing likelihood of residential aged care Collaborative care with hospice
Very severe	Increasing dependence for all cares		
Bereavement care for family and whānau			

Principles of care

When a person is dying from lung disease it is especially important to consider quality of life and to plan for any challenges that may arise. Some of the most common areas of care to consider are discussed on the following pages.

Providing care with dignity is a priority. Developing a care plan with your care team, which integrates any cultural, spiritual and/or religious values and beliefs you may have, will help to provide individualised nursing care. Family and whānau may have input in developing the plan if you wish.

Breathing

As the lungs fail, their ability to transfer oxygen to the blood decreases, causing the breathing rate to increase. A lot more effort is needed to breathe, and shoulder, neck and abdominal (stomach) muscles will need to be used more. Breathing will take a lot of work and energy and often causes fatigue and weight loss. It can also make it harder to talk and move around.

Your doctor/nurse practitioner can review your condition to see if medication could be helpful. Hospice and/or a pharmacist may also be consulted.

Inhalers used with a spacer can help reduce breathlessness. Nebulised medicines may be used in some cases, these are given through a mask using a nebuliser machine. The decision to use a nebuliser will depend on the individual residential care facility.

If oxygen has been prescribed you may need to use this most of the time. You will be taught by staff how to safely use your oxygen machine.

Here are some things you can do to help

- Plan for exertion or activity so that effort is minimised e.g. it may not be necessary to shower every day, but on the day that you do shower plan to have a rest or a quiet day.
- Avoid rushing and allow more time to complete tasks.
- Allow for a rest between activities.
- Let staff know if you are struggling and what help might work e.g. having help with showering.
- Tell staff if your breathlessness is getting worse.

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

Breathlessness (dyspnoea) that causes fear and anxiety

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

Your doctor/nurse practitioner may prescribe medicines than can help reduce the feeling of breathlessness and to reduce anxiety. Your physiotherapist may also be able to teach you effective breathing and relaxation techniques if appropriate.

Here are some things you can do

- Sitting in an upright position or leaning forward can help make breathing more comfortable.
- Keep your inhalers and spacer within easy reach and use as prescribed.
- Have a gentle flow of air through your room, using a fan or leaving a window open. The use of aromatherapy can sometimes be helpful.
- Have small, but more frequent meals.
- Plan activities so that there is no over exertion.
- Familiarity with equipment, gentle lighting, comfortable room temperature, and confidence in familiar staff can all help with reducing fear and anxiety.
- Recognise triggers that increase your fear and anxiety and reduce or avoid them if possible e.g. if being alone is a trigger, have the call bell within reach or have a family member or whānau stay with you. Triggers may not be just physical ones; they may be emotional (e.g. worrying about your family and whānau can make you anxious).
- Tell staff about any anxiety or fears you are experiencing, they may be able to help.

Managing exacerbations

Usually lung diseases, such as chronic obstructive lung disease, go through stages where the disease is stable (does not worsen) and periods of exacerbation (sudden increase in severity due to infection or other causes). As lung failure progresses, exacerbations may become more frequent.

Your clinical team will discuss options for ongoing care with you and include your family and whānau if you wish. They will have a protocol for medicines and other interventions that can be used during an exacerbation.

Here are some things your family and whānau can do

- Talk to you, and continue to give comfort and reassurance.
- Hold your hand or offer light gentle massage if you enjoy this.
- Consider having an Advance Care Plan (see Appendix page 16) in place, this will reduce much of the uncertainty about what you want to do when things get worse.

Pain

Pain has many causes and can be long term or acute (pain that comes on suddenly caused by something specific e.g. injury or infection) .Some common causes of pain in the older person are osteoporosis, osteoarthritis, back pain, constipation, dental problems, and infections, but there are many others. Pain can also have emotional, spiritual and physical elements.

A person with advanced lung disease may develop new causes of pain e.g. skin problems, joint stiffness or 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 be restless, agitated, anxious and tearful. They may not want to move or do their normal activities, or may appear worried or withdrawn.

Here are some things you can do

- Tell your registered nurse about any pain or discomfort you are experiencing. Your registered nurse or doctor/nurse practitioner will assess you, and discuss appropriate and individualised treatment to manage your pain, this may include medication, positioning and/ or pressure relief. In some caes they may ask for advice from hospice or a hospital specialist.
- Some things your family and whanau can do to help are:
  - provide comfortable clothing that is easy to remove
  - bring in familiar music or scents, that are enjoyed by you to help relax you
  - use comforting touch or hand massage
  - avoid applying direct heat or cold (e.g. wheat bag or cold pack) directly to the skin as this can damage it
- Let us know if a spiritual and/or cultural advisor can offer you support, comfort and advice we may be able to help.

Eating, drinking and weight loss

When a person has advanced lung disease they often lose weight in the same way as someone dying with 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 and whanau when a person stops eating or drinking, or only manages small amounts of food or fluid, but there are some things that can help.

Here are some things your family and whānau can do

- Bring in favourite foods and drinks.
- Offer small amounts of food and fluid frequently. Don't worry about the quantity of food or fluid consumed.
- Use a straw for fluids or make ice popsicles of favourite drinks and chop up food into small bite sized pieces.
- Nutrition supplements can prescribed by the doctor/nurse practitioner if required. Discuss this with your care team.
- Your care team will continue to maintain good mouth care to ensure your comfort. If you would like to help with this ask your registered nurse to show you how.

Over time these strategies may become less effective. Alternatives such as tube feeding or subcutaneous fluids (fluids given through a needle under the skin) are not usually helpful for people with lung failure; studies show this does not prolong or improve quality of life, and these interventions are invasive and can be distressing. If you are concerned please discuss with your care team.

Infection

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

If you do get an infection the doctor/ nurse practitioner and registered nurse may discuss with you and your family and whānau whether antibiotics would be helpful.

Skin

As the lung disease progresses, skin may become more fragile increasing the risk for skin injuries and infections.

A person who has difficulty changing their position in bed is at risk of developing pressure injuries (bed sores) especially on their heels, tail bone, hips, elbows, spine and ears.

Skin changes also occur with weight loss and a decreased intake of fluid and food.

Staff will check your skin when providing personal cares (e.g. showering or dressing) and provide skin and wound care if required. A pressure relieving mattress or seat may be provided.

Here are some things you can do

- Tell staff about any redness or new skin injuries you notice.
- Lip balms (like Vaseline or Pawpaw) can be helpful to keep lips moist.

Episodes of confusion

The brain always needs a supply of oxygen. If the brain does not get enough oxygen then confusion can occur - this is known as a delirium and it can cause physical agitation or periods of disturbed sleep. Plucking at the air, attempting to get out of bed, pulling at bed clothes, fidgeting, moaning, crying or calling out are also possible signs of confusion. These episodes can be upsetting for the person and their family and whānau.

If you experience a delirium staff will assess if there are other causes, apart from lack of oxygen, causing the confusion (e.g. infection, constipation, pain or too many medications).

Care during a delirium is aimed at keeping you safe, ensuring you receive regular food and fluids, monitoring bowel and bladder function, and treating any reversible causes of the confusion.

Here are some things your family and whānau can do

- Gently reassure you that you are safe.
- Remain calm and gently reorientate you to time and place.
- Try not to correct things said that may not make sense or are incorrect, as this can cause frustration and anxiety.
- Create a calm environment that may include music or familiar scents that you enjoy.
- Hold their hand, or offer light gentle massage if you enjoy this.
- Spiritual and/ or cultural advisors can be contacted to offer support and advice if you wish.

Medications

In the last days or weeks of life, medications that were used to control other conditions may no longer be helpful. The registered nurse and doctor/nurse practitioner will discuss your medications with you, your family and whānau to decide if those that are no longer of benefit should be stopped. Sometimes new medication may need to be started for new symptoms e.g. to manage pain. Your doctor/nurse practitioner can answer any questions you may have.

As a person becomes weaker, swallowing is harder and the taking of medication by mouth becomes more difficult, often eventually not possible. The care team may make changes in the way medication is given so that relief from symptoms can continue.

Hospice can be involved in cases requiring complex symptom management, e.g. pain, breathlessness and restlessness, and there may be other health professionals consulted for advice on how best to manage symptoms (e.g. physiotherapist or pharmacist).

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 or diabetes). These conditions will also be managed by the care team.

There are specialist services available (e.g. hospice) who can advise your doctor/ nurse practitioner on symptom management and support for you, your family and whānau.

When is admission to hospital appropriate

Unexpected events such as falls, fractures, stroke or infection can occur in anyone's life. For people in residential care the decision to go to hospital will depend on the nature of the event, and what the resident's goals of care are; do they want to go to hospital and think it is necessary or not, will it be of benefit for their overall well-being and to maintain function e.g a broken bone which may need a cast, or a serious cut that needs stitches.

In some cases, it may not be helpful for the resident to go to hospital. Moving a person from their familiar surroundings can cause anxiety, disorientation and future decline in their physical function.

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 treatment of chest, , wound and urinary tract infections). Making decisions about whether to go to hospital or stay in the facility depends on where the most appropriate care can be provided, and your wishes.

An Advance Care Plan can help guide everyone concerned about when going to hospital is appropriate, and when it is not what you want. Your care team can advise and guide you about completing an Advance Care Plan (see Appendix page 16).

Resuscitation

Resuscitation is also known as cardiopulmonary resuscitation (CPR). It is used when a person's 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 medical professionals want to do everything they can to help, and want to follow a person's wishes where possible, they will not provide treatment they know will be unsuccessful or cause harm.

People with advanced lung disease are strongly encouraged to discuss their wishes regarding resuscitation with their doctor/nurse practitioner and to raise any concerns or need for more information with their care team.

Who makes the 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 activates an Enduring Power of Attorney (EPOA), if one exists.

If there is no EPOA and your decision-making capacity is assessed as diminished, your family and whānau can apply to the Family Court under the Protection of Personal and Property Rights Act 1988 to appoint a welfare guardian and, if appropriate, a property manager who will make decisions on your behalf. Any decisions made on your behalf must be in your best interests, and would usually be in consultation with family and whānau, the registered nurse and doctor/ nurse practitioner involved in your care.

Health new Zealand Te Whatu Ora Waitematā advises everyone to consider appointing a EPOA to safeguard their interests should they become unable to act for themselves.

For more information regarding enduring power of attorney and welfare guardianship please refer to the appendix of this booklet on page 15 or visit the Ministry of Social Development website (www.msd.govt.nz) and/ or consult a solicitor.

Regardless of your mental capacity, if you are in residential aged care you must still be supported to take part in any discussions about your health care and welfare. Your preferences and beliefs should be respected and accommodated, as far as possible, when making decisions. Should any differences in opinion arise around the appropriateness of certain care or treatment, your care team are available to give advice and help facilitate any discussion.

It is important to have good communication and there are other agencies that can support the decision making process (e.g. Advocacy Service, Mental Health for Older Adults team, gerontology nurse specialists, a chaplain, religious or cultural groups). Let your care team know if you want to be put in touch with any of them or if an interpreter is required..

Recognising dying

Dying is 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. Although it can be hard to tell when someone is going to die, there are signs that indicate things are changing.

Signs of approaching death

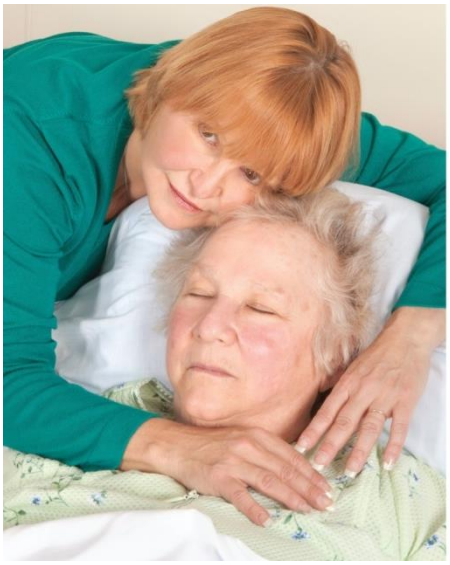
People who are dying can lose the ability to swallow and often don't feel thirsty or hungry. Their need for food and fluid decreases. When death is near, the body is no longer able to digest food.

There may be changes in levels of alertness. It may become more difficult for the person to wake up, respond to talking or physical contact, although some people may still have moments when they recognise family and whanau 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 care (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 and there may also be loss of muscle tone, which can cause changes in facial expression.

There is potential for a variety of people to be involved in end of life care. It is important for your family, whanau and friends to be involved in your care at a level that is comfortable for you. Please discuss any concerns with the staff so they can provide the best possible care.



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 your and your family/ whānau's preferences before death (e.g. choice of celebrant, cremation or burial) can reduce stress during this difficult time.

Resources

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

The Asthma & Respiratory Foundation

Offers useful information for people wanting to know more about managing respiratory disease.

Phone: 0800 100 506 or (04) 499 4592
Website: asthmafoundation.org.nz

Age Concern New Zealand

Offers a wide range of information and support to older adults in Aotearoa/ New Zealand.

Phone: 0800 65 2105
Website: www.ageconcern.org.nz
or:
North Shore and West Auckland: (09) 489 4975
Rodney: (09) 426 0916

Advance Care Planning

Provides information about advance care planning for future health and end of life care.

Phone: 0800 275 742
Website: www.advanceareplanning.org.nz

Amitahba Hospice Service

Offers free practical home help and compassionate companionship and spiritual friendship.

44 Powell St Avondale
Phone: (09) 828 3321
Website: www.amitabhahospice.org

Cancer Society of New Zealand

Offers support and advice.

Phone: 0800 226 237 (0800 CANCER)
Website: www.cancer.org.nz

Citizens Advice Bureau

Provide free, confidential, independent information and advice to anyone.

To find an office near you:
Phone 0800 367 222 (0800 FOR CAB)
Website: www.cab.org.nz

Waitematā Community Law Centre

Community law centres throughout the country offer free legal advice.

Phone: (09) 835 2130
Website: www.communitylaw.org.nz

Grief Centre
Offers grief and loss counselling services. WINZ subsidies and other funding may be available to eligible people.

Phone: (09) 418 1457
Website: www.griefcentre.org.nz

Health & Disability Advocacy Service
Offers free independent and confidential advice and support to help resolve issues with health and disability services.

Phone: 0800 555 050
Website: advocacy.hdc.org.nz

Hospice New Zealand
Hospice provides end of life palliative care in inpatient facilities and the community.

Website: www.hospice.org.nz

Hospice West Auckland:
Phone: (09) 834 9750,
Email: info@hwa.org.nz

Harbour Hospice North Shore: Phone: (09) 486 1688:
Email: infonorthshore@harbourhospice.org.nz

Harbour Hospice Hibiscus Coast:
Phone: (09) 421 9180
Email: infohibiscuscoast@harbourhospice.org.nz

Harbour Hospice Warkworth Wellsford
Phone: (09) 425 9535
infowarkworthwellsford@harbourhospice.org.nz

NZ Carers Alliance – Carers NZ
Offers informtion, advice, learning and support for carers.

Phone: 0800 777 797
Website: Carers.net.nz

Ministry of Social Development
Offers advice and support to people with problems involving income, housing, ill health, childcare and transport.

Contact phone numbers on website below.
Website:www.msd.govt.nz

Health New Zealand Te Whatu Ora Waitematā

North Shore and Waitakere hospitals and community services.

North Shore Hospital:	0800 809 342 or (09) 486 8900
Waitakere Hospital:	0800 809 342 or (09) 839 0000

Website: www.waitematadhb.govt.nz

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

Appendix

Advance directives

An advance directive is a statement signed by a person setting out in advance the treatment wanted or not wanted in the event of becoming unwell in the fiuture.

Advance Care Planning

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

An EPOA is a legal document where the person appoints an attorney to make decisions for them if they become mentally incapable. An EPOA cannot be set up once someone is assessed as having lost mental capacity by a medical practitioner (doctor).

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. To check that the EPOA is activated by contact the person's legal advisor and/or medical practitioner.

If there is no EPOA, and the person has been assessed as no longer having mental capacity to make decisions, the family/whānau should apply to the Family Court for the appointment of a welfare guardian under the Protection of Personal and Property Rights Act 1988 (PPPR Act). If appropriate a property manager can also be appointed. This can be the same person as the welfare guardian or someone different. The welfare and property guardians should be a nominated person from the family/whānau or a friend who is happy to take on this responsibility for the person. Once in place, care decisions would then be made by the Welfare Guardian in consultation with family, whānau and health care professionals including the medical practitioner. Any decisions made must be in the best interests of the person.

It is important that the EPOA or Welfare Guardian are aware of the person's wishes, feelings and values to assist in making the best decisions on their behalf and this can be done using an Advance Care Plan (see above).

Information about this is available through Age Concern
www.ageconcern.org.nz
North Shore and West Auckland: (09) 489 4975
Rodney: (09) 426 0916

Notes

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

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