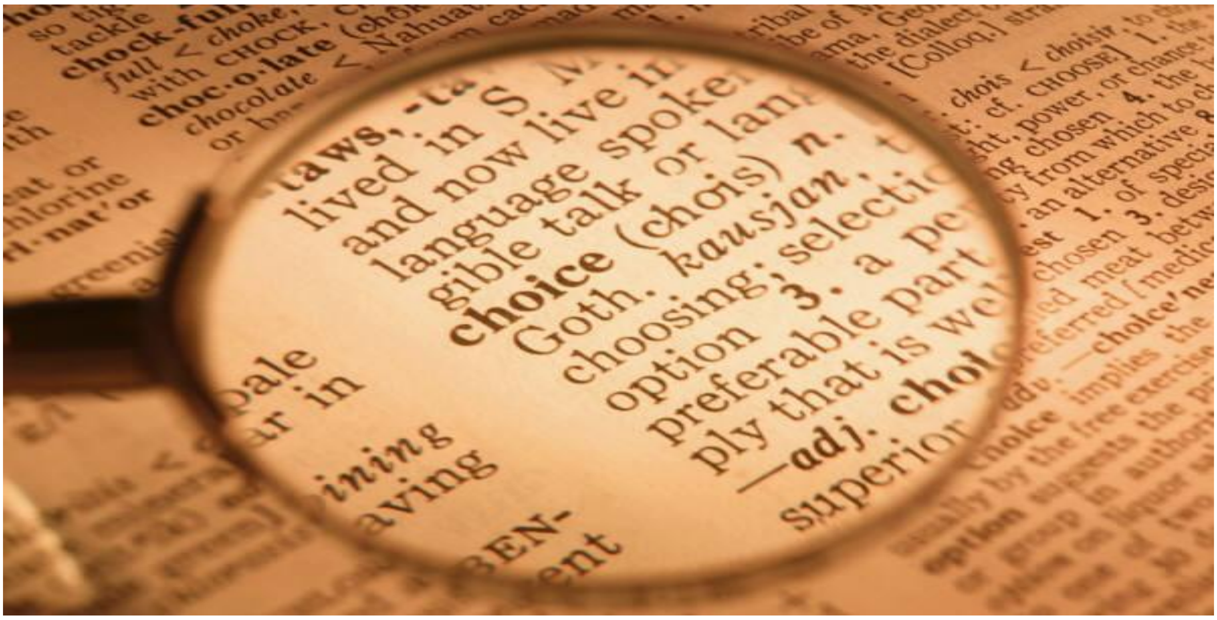
Southern District
Health Board

Making Choices



Advance Care Plan (Otago)

for patients with chronic respiratory illness

INTRODUCTION

What is this document for?

This document is known as an Advance Care Plan (ACP). It is designed to help you make choices about your future care. It provides you and your family with the opportunity to discuss and write down your preferences and priorities for care as you approach the end of your life. **You do not need to do this if you do not want to.**

We will guide you through the document, explaining treatment options and possible choices available to you. Although talking about these things can sometimes be uncomfortable, it can be extremely helpful to family, friends and health professionals to understand what is important to you when planning for future care.

Should a time come when you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will try to take into account anything you have written in your ACP.

You can change what you have written at any time. It would be advisable to review your ACP regularly to make sure it still reflects what you want.

Should I talk to other people about my ACP?

Most people find it helpful to talk about their future care with family (whānau) or friends. Your professional carers (such as doctor, nurse or social worker) can help and support you and your family in this.

Sometimes this can be difficult, as much for them as for you, because it might be emotional or people may not agree. Usually it is worth the effort.

Will my preferences and priorities be met?

What you have written in your ACP will, as far as possible, be taken into account when providing care in the future.

Remember

It is helpful if you consider these issues when no-one is under pressure, bearing in mind that you are free to change your mind as experience or circumstances change. When you have completed your ACP, you are encouraged to keep it with you and share it with anyone involved in your care.

<u>BRING IT WITH YOU IF YOU ARE ADMITTED TO HOSPITAL.</u>

UNLESS PEOPLE KNOW WHAT YOUR PREFERENCES AND PRIORITIES ARE, THEY MAY NOT BE ABLE TO TAKE YOUR WISHES INTO ACCOUNT.

END OF LIFE CARE AND TREATMENTS IN RESPIRATORY DISEASE

Chronic respiratory disease may be due to bronchitis and emphysema (known as COPD), bronchiectasis, cystic fibrosis, or lung fibrosis.

When respiratory disease gets worse it becomes increasingly hard to breathe and manage daily activities. Common colds or chest infections may cause sudden worsening of your condition and you may require hospital treatment. These admissions to hospital may become more frequent and recovery is often harder and slower. The stress and strain of a hospital admission may add to the struggle with breathing that comes with respiratory failure itself.

Treatment in hospital may include:

‘Standard’ treatment

- Bronchodilator medication, e.g. Ventolin, aminophylline
- Prednisone
- Antibiotics
- Oxygen breathed in through nasal tubing or mask
- Opiates and anti-anxiety medication to ease shortness of breath
- Emotional support and information

Or depending on the situation, one of the two following treatments may be added to the standard treatment.

‘Aggressive’ treatment

Use of a 'BiPap' machine, which supports a patient’s own efforts to breathe.

‘Life prolonging’ treatment

Use of mechanical ventilation may be offered to patients who have a good chance of recovery.

Detailed Treatment Information

The various treatments outlined below do not all have to be used. It is important to realise that everyone is different and has individual values, beliefs and wishes.

A selective approach is often best. Some patients may choose all the options - the objective being to live longer. Others may choose a ‘supportive care only’ approach with the option of being looked after at home, in the hospice, or in hospital.

There are no right or wrong decisions, and the choices and treatments can be many and varied. Not all patients want to make these decisions by themselves and may ask their doctors for guidance about choice of future treatment.

Medical and nursing staff in the respiratory service, or your GP, will be happy to assist you with any question or concern you may have.

A ‘Ceiling of Care’ document may be used in your hospital notes to summarise and guide health care professionals about the limits of treatment that you have decided are appropriate. This document, if completed, will be attached at the end of the care plan.

Bronchodilators

Your reliever inhaler (Ventolin, Duolin, Respigen), will be administered to you via a spacer but usually more puffs are given more often. Sometimes this type of medication will be given through an intravenous line into a vein. These drugs are given to open the airways and make breathing easier. Side effects include increased heart rate and tremor with feelings of anxiety.

Prednisone

This is given to decrease inflammation in the lungs and reduce airways congestion. It is usually given at a high dose for a few days tapering off over a week or more, in some cases. Side effects include difficulty in getting to sleep and fluid retention.

Antibiotics

These are given if you have a bacterial infection causing a flare up of your lung disease. At the end of life pneumonia may occur (‘the old man’s friend’), and using antibiotics may prolong things.

Oxygen

This may be helpful in relieving breathlessness if the oxygen level in your blood is low. It can be dangerous if it is given at flow rates >2L/min.

Opiates and anti-anxiety medicine

Drugs we would usually associate with pain relief (morphine) can be given to decrease breathlessness and change your perception of breathlessness. Medications can also be given to decrease the anxiety that often accompanies being breathless.

BiPAP – non-invasive ventilatory support

A machine blows air enriched with oxygen into your lungs through a face mask. It requires you to co-operate with the machine, and nursing staff are there to support you. If you have not had BiPAP before, it may seem scary to begin with but most people tolerate it well. Talking and communicating is more difficult when the mask is on, but a microphone in the mask can be added to assist with this. It is usually better to discontinue BiPAP in someone who is dying.

Mechanical ventilation

This is designed to be a life prolonging treatment, and is not a suitable choice for most patients with long-standing respiratory failure. You are administered drugs to cause unconsciousness and a tube is passed into your wind pipe and connected to a ventilator machine that breathes for you. This is done to rest the lungs until infection or other complications are brought under control and you are able to recover.

CPR – cardiopulmonary resuscitation

This is not commonly used if there is evidence of long-standing respiratory failure. However, you may wish to consider whether this should be performed in the event that your heart should stop beating unexpectedly. **CPR is rarely successful when respiratory disease is advanced.**

PERSONAL DETAILS AND QUESTIONS

Your Name……………………………………………………………………………

Your Address…………………………………………………………………………

DOB or
National Health Number ………………………………………………………

Name of GP…………………………………………………………………………..

You may appoint somebody to make decisions on your behalf if you are unable to make decisions for yourself, using enduring power of attorney. Enduring power of attorney and your will can be set up in consultation with your lawyer or a trustee corporation such as the Public Trust. If you have registered an enduring power of attorney, please provide the details below.

Name of POA holder…………………………………………………………….

Address………………………………………………………………………………

Phone…………………………………………………………………………………

Relationship …………………………………………………………………………

Even if you have not registered an enduring power of attorney, is there anybody you would like to be consulted about your care in the event that you are seriously ill?
"People who know me well and understand what is important to me are:"

Name……………………………………………………………………………………..
Address…………………………………………………………………………………..
Relationship ………………………………………………………………………

Name……………………………………………………………………………………..
Address…………………………………………………………………………………
Relationship…………………………………………………………………………

“My faith or belief system that is important to me is **.......................................**”
“In the event of deteriorating health, receiving spiritual support (e.g. from a minister, priest or rabbi) would be helpful to me.” YES /NO

If yes, who? ………………………………………………………………………..

Relationship ………………………………………………………………………..

Address or telephone if available……….…………………………………

“I have made a will.” YES / NO

If yes, where is it held? ………………………………………………………….

If no, would you like to discuss how to make a will? ……………………….

GENERAL QUESTIONS

If you have been experiencing deterioration in your overall condition, including your breathing, how do you think these problems are going to affect you in the future?

When you are thinking about your future or about dying, what is it that worries you most? For example, do you worry about not managing at home, being alone, or struggling to breathe?

Based on your view of how things are developing OR past experiences you have had, are there any treatments which you would **not wish** to have in the event of sudden deterioration?

Under what circumstances would you want the goal of medical care to switch from actively attempting to prolong your life to focusing on supportive / comfort care?

Where would you prefer to spend your last few weeks or days? What would be your ideal surroundings at this time? How could this happen?

Are your goals affected by your present state of health? Are there ways in which help might be provided so that you **can** accomplish your goals?

What would help you live your life better from now on?

Signature……………………………….

Date…………………………………….

You are welcome to make changes to the preferences and priorities that you have written above. When doing so, strike through the original preference with a single line, then write the new preference underneath with initial and date beside. Ensure that the amended document is circulated and/or discussed with those people involved in your care.

CONTACTS

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