My Choices

Anticipatory Care Planning for People with Chronic Respiratory Illness

Please note: This document is not a consent form. It is a note of your wishes and preferences to aid decision making about your care.

Filling in this booklet is optional- you do not have to do this if you do not want to.

The information in this document will not be added to your medical records unless you have discussed and agreed this with your medical professional.

Introduction

What is this document for?

This document is known as an Anticipatory Care Plan (ACP). You are known to have a lung condition that may worsen over time. This plan 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 your condition changes. **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, perhaps with the assistance of your healthcare practitioner, 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 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.

Bring it with you when you visit the doctor or when you are admitted to hospital.

Unless people know what your preferences and priorities are, they may not be able to take your wishes into account.

Treatments and supportive care 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. They may be life-threatening. 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
- Prednisolone
- Antibiotics
- Oxygen breathed in through nasal tubing or mask
- Opiates (usually morphine) 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 non-invasive ventilation (NIV) machine, which supports a patient’s own efforts to breathe. The machine delivers air/oxygen under pressure via a close-fitting mask held in place by straps.

‘Life prolonging’ treatment

Use of mechanical ventilation in the intensive care unit 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. Some of these treatments may not be suitable in the treatment of your disease.

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, in a community hospital (Tippet Hill), 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.

Your decisions may be used to update your KIS (Key Information Summary) record in your electronic medical notes which summarises and guides health care professionals about the limits of treatment that you have decided are appropriate. It sets out limitations to what might be done in the event of a crisis. You will need to let your doctor know about your decisions before they can be added to your KIS.

Bronchodilators

Your reliever inhaler (e.g. Ventolin), will be given to you via a spacer or a nebuliser. Sometimes this type of medication is given through an intravenous line into a vein. These drugs are given to open the airways and make breathing easier. High doses via a nebuliser can result in side effects (e.g. tremors or fast heart rate), making you feel even more anxious.

This will not be restricted if my condition deteriorates.

Prednisolone

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.

I am happy to receive this treatment if my condition deteriorates.

Yes ☐ No ☐

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 and using antibiotics may prolong things.

I am happy to receive this treatment if my condition deteriorates.

Yes ☐ No ☐

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 of more than 2L/min. Do not increase the flow rate when you are unwell, unless you know that it is safe to do so.

This will not be restricted if my condition deteriorates.

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 e.g. lorazepam.

This will not be restricted if my condition deteriorates.

NIV - non-invasive ventilatory support

A machine blows air enriched with oxygen into your lungs through a face mask or nasal prongs. It requires you to co-operate with the machine, and nursing staff are there to support you. If you have not had NIV before, it may seem scary to begin with but most people tolerate it well. It may be better to stop using NIV in someone who is dying if by doing so, they become more comfortable.

I am happy to receive this treatment if my condition deteriorates.

Yes ☐ No ☐

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 given 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. A patient on a ventilator is unable to communicate verbally.

This is unlikely to be helpful in patients with severe lung disease.

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.

General questions:

If you have been experiencing a deterioration in your overall health condition (including your breathing), how do you think these problems are going to affect you and your quality of life in the future?

Example: *I am concerned that I will not be able to get out of the house.*

When you are thinking about your future or about dying, what is it that worries you most?

Example: *I think about how I might die. I worry that I am going to suffocate and it will be a struggle to breathe at the very last.*

Based on your view of how things are developing **or** past experiences you have had, are there any treatments listed above which you would not wish to have in the event of sudden deterioration? Example: *I get claustrophobic when they put a mask over my face. This happened when I was on NIV treatment. It made me much more anxious*
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? Example: *If I get a bad pneumonia and it's definite that I am dying even despite lots of treatment, then I would be comfortable if antibiotics were stopped.*

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

Example: *I do not want to be in a noisy hospital ward. If possible, I would prefer to be at home but that depends on how my family feel. If a place is available, it would be good to be admitted to the hospice.*

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?

Example: *It is really important that I spend time with my daughter and my 2 grandchildren.*

I could visit them if it was possible for the oxygen concentrator to be transported to their house for a weekend.

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

Example: *Knowing that when the end is near, I can get help easily. I live on my own.*

When you are nearing the end, and may not be able to speak or be understood, are there things you would like your family or friends to know?

Examples: *I would like my ex-husband to know that I have forgiven him.*

I would like my son who lives in Australia to know that I love him very much and am very proud of him.

Patient's signature:	**Date:**
Print name:	**__/__/__**

You can make changes to the preferences and priorities that you have written above at any time. When doing so, please strike through the original preference(s) with a single line, then write the new preference underneath with your initial and date beside it. Please ensure that the updated document is shared and/or discussed with those people involved in your care.

My Contacts:

Name:	**Relationship to me**
Address:	**Phone number(s):**
Name:	**Relationship to me**
Address:	**Phone number(s):**
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