

Audioscript for Workbook

"Making Choices...The use of intubation and mechanical ventilation for severe chronic obstructive pulmonary disease"

Hello. My name is Susan and I know that the decision about treatment if your lungs can no longer breathe on their own is very difficult and emotional. That's why this program was developed.

I'll be your guide for this workbook, which prepares you for an informed discussion with your doctor about your own values and the pros and cons of intubation and mechanical ventilation for severe chronic obstructive pulmonary disease.

When you hear the following sound...

SOUND

...Please turn to the next page in your workbook. You can stop the tape at any time if you are not ready to go on to the next page.

Let's start by looking at the next page: "This workbook is for you if"

SOUND

Page 4

This workbook was created for men and women who have been told by their doctor that they have severe, long-standing lung disease, referred to as Chronic Obstructive Pulmonary Disease, or COPD. Other terms you may have heard are "chronic bronchitis" or "emphysema".

This workbook is for you if, you want to consider the options available to you if at some time in the future your lungs can no longer breathe on their own. Lastly, this workbook is useful if you want to make your preferences known to your doctor and family members.

In this workbook, you'll learn about:

- Chronic Obstructive Pulmonary Disease or COPD;

- The effects and management of COPD;
- Treatment choices if you can no longer breathe on your own, specifically, intensive care with intubation and mechanical ventilation or supportive end-of-life care;
- The pros and cons of these treatment choices; and
- How to weigh the pros and cons of intubation and mechanical ventilation for you personally.

Let's look to the next page “What is Chronic Obstructive Pulmonary Disease, or COPD?”...

Page 5

COPD is a common, severe, lung disease. With COPD, the air passages in the lungs become narrow, making it difficult for air to move in and out of the lungs. This causes you to feel short of breath or breathless. Another thing that happens with COPD is that you have increased production of mucus in your lungs, causing an increase in phlegm and cough.

While COPD is not curable and may worsen over time, treatment can be given to reduce your symptoms, improve your quality of life, and prevent the worsening of your COPD.

Now, let's turn to the next page to talk about how COPD may affect your life.

SOUND

Page 6

COPD can affect your life in many different ways. The most common things that bother people with COPD are listed below. Please place a check mark in the box next to all the things that bother you.

COPD may cause some problems with your breathing: including

- shortness of breath;
- coughing;
- spitting up, phlegm;
- wheezing; and
- frequent chest colds.

Some people have difficulty with their daily activity and lifestyle. These can include:

- feeling short of breath when walking or exercising;
- having difficulty completing daily activities such as bathing, dressing, and preparing meals;
- having less energy; and
- having difficulty falling asleep or sleeping poorly.

The possible emotional effects of COPD are many, and examples are:

- feeling anxious;
- depressed or unable to cope;
- feeling irritable or angry; and
- feeling embarrassed by having to go out in public with an oxygen tank.

Page 7

Socially, some people report:

- not being able to participate in social activities;
- feeling isolated; and having a
- change in their financial situation because of not being able to work or having increased expenses.

COPD may also cause people to have:

- difficulty concentrating; or
- forgetfulness; this is most often because there is not enough oxygen in their blood.

There may be other effects that COPD has had on your life. Please write them down. You may stop the tape while you add your concerns.

(Pause)

Now, let's turn to the next page to learn about some of the things that are done to manage COPD and its effects.

SOUND

Page 8

Although there are many difficulties to be faced with COPD, there are a number of things which people do to deal with some of these effects. Again,

please place a check mark in the box next to the things that you have used in the past year to cope with or manage, your COPD.

People may use medications prescribed by their doctor to help with their breathing. Some medications are given to open the airways and decrease symptoms such as breathlessness. These medications may include bronchodilators, which are usually inhaled with a puffer, or taken as a pill. Another medication that acts on your airways are steroids that act to reduce the inflammation and swelling in the airways. They may also be taken as a pill or with an inhaler.

Other things may be done to help your breathing. To treat chest colds, you may take antibiotics. Immunizations are strongly recommended to prevent flu and pneumonia. To improve your length of life and breathlessness you can use oxygen breathed in through your nose is often prescribed to raise the levels of oxygen in your blood, which in turn may help you to live longer and experience less breathlessness. The last thing that some people with COPD do to make their breathing better is to not smoke.

Page 9

To adjust to the effects of COPD on daily activity and lifestyle some people may do activities more slowly, reduce the number of activities they actually do or change the type of activities they do. Carrying out regular exercise as recommended by a doctor, and avoiding triggers that make breathing worse such as air pollution, dust, fumes and cold air may also help. Other things that help with daily activity and lifestyle include eating nutritiously and asking for and accepting outside help such as home care.

Some people say that talking about their feelings, learning relaxation exercises, praying or seeking spiritual support, and taking things one day at a time helps them to cope with the emotional effects of COPD.

There may be other things that you do to cope with your COPD. Stop the tape for a moment to write them down (Pause).

Now, let's turn to the next page to learn about how COPD is treated when it gets worse.

SOUND

Page 10

As time goes by, you may have more and more trouble breathing. This may happen gradually, but a common cold or pneumonia may cause your COPD to suddenly worsen, requiring treatment in hospital.

Treatment in the hospital may include medications such as bronchodilators, steroids and antibiotics, some of which may be given intravenously. These medications treat the causes of worsened breathing and relieve symptoms. You may also be given pain relievers such as Morphine to ease your shortness of breath. Oxygen breathed in through a mask may also be used to ease breathlessness.

A machine called a “BiPap”, which pushes air into your lungs through a face mask, is often used if the oxygen is not enough to improve your condition.

As this can be a very difficult and frightening time for you and your loved ones, emotional support and information will also be provided.

Page 11

If these medical treatments are not effective, and you can no longer breathe on your own, it will be necessary to decide whether:

- to receive intensive care with intubation and mechanical ventilation; or
- to receive supportive end-of-life care.

Now let's look to the next page to talk about exactly what is involved in these treatments choices.

SOUND**Page 12**

Intensive care with intubation and mechanical ventilation:

Intubation involves a tube being passed through the mouth and into the windpipe. The tube is then connected to a ventilator, or respirator, which pushes air into the lungs.

When a patient is intubated and being treated on the ventilator frequent tests such as blood tests are done to monitor their condition. Being intubated and ventilated also includes medications to make a patient more comfortable.

Essentially, the goal of care is to control the symptoms of COPD and improve the chances of survival.

Once a patient is intubated and ventilated, they are cared for in the Intensive Care Unit in the hospital.

Page 13

The pros of intubation and mechanical ventilation include the relief of breathlessness, preventing immediate death, and improving survival by a year or more.

The first pro is the relief of breathlessness, which occurs by increasing the amount of oxygen in the blood.

Intubation and mechanical ventilation may also prevent immediate death, depending on how healthy the patient is before they begin having trouble breathing. Look at the top block of 100 faces. This block represents 100 patients who are intubated and ventilated. As you can see, 70 out of 100 patients will come off the ventilator and leave the hospital.

The last pro of intubation and ventilated is that for patients who survive intubation and mechanical ventilation, the treatment may also lengthen their life by a year or more. Looking at the bottom block of 100 faces you can see that of the patients who survive intubation, 30 will come off the ventilator and survive to one year.

SOUND

Page 14

The cons of intensive care with intubation and mechanical ventilation are that patients may not be able to come off the ventilator, the patients may experience some discomfort from being intubated and there are other potential complications and concerns.

The major con of being intubated and ventilated is that the patient may not be able to come off the ventilator.

Let's look at the block of 100 patients who are intubated and ventilated. The 20 patients at the bottom will never come off the ventilator and will die in

hospital. The average stay on the ventilator for these patients is from 7 to 10 days.

Page 15

The second con of intubation and mechanical ventilation is discomfort.

Patients may experience:

- anxiety, a gagging feeling and discomfort in the throat when the tube is being inserted;
- extremely limited movement and activities while being ventilated;
- sleepyness from the medication given;
- difficulty getting a restful sleep;
- an inability to swallow food or drink because of the tube in their mouth; and
- being unable to talk with friends, family and care providers.

The last con of intubation and mechanical ventilation are the potential complications. Patients who are intubated have a high risk of lung infections. Less common complications include damage to the patient's lungs or throat, and bleeding in the stomach.

Two other concerns that should be considered are that “weaning” or coming off the ventilator may cause breathlessness and the patient's COPD will be no better and possibly worse than before intubation and mechanical ventilation.

On the next page we'll summarize the pros and cons of intensive care with intubation and mechanical ventilation.

SOUND

Page 16

In summary, let's look at 100 patients who are intubated and ventilated:

- 30 out of 100 will come off the ventilator and survive to one year;

and the remaining 70 will die within one year of being ventilated:

- 40 out of 100 will come off the ventilator but not survive to one year;

- 10 out of 100 will come off the ventilator but die in hospital; and
- 20 out of 100 will never come off the ventilator and die in hospital.

Look to the next page where we'll talk about what is involved in receiving supportive end-of-life care without intubation and mechanical ventilation.

Page 17

Supportive end-of-life care involves receiving medications, oxygen therapy, emotional support, and information.

The goal of supportive end-of-life care is to control the symptoms of COPD and relieve suffering. Patients are kept comfortable with pain relievers and sedatives, and eventually fall in to a deep sleep and die. This treatment is usually received in a hospital ward, but arrangements can sometimes be made for care in the home.

Let's review the pros and cons of this treatment option.

SOUND

Page 18

One of the pros of supportive end-of-life care is that the treatment is aimed at relieving shortness of breath, pain, anxiety and fear. As well, patients may receive care in their home. Lastly, death will occur, but with a minimum of discomfort and without complications of tubes, tests and other procedures.

Page 19

There are two main cons of supportive end-of-life care:

- patients may be sleepy from the medications used to treat their symptoms; and
- death will occur within a short period of time.

Looking at the block of 100 faces on this page you can see that death will occur within a short period of time for more than 95 out of 100 patients who choose supportive end-of-life care.

Before we go on, let's review the pros and cons of each treatment choice.

SOUND

Page 20/21

First, let's review what would be involved in intensive care with intubation and mechanical ventilation. You would be provided with comfort care such as medications, oxygen, emotional support and information. A tube would be passed through your mouth and into your windpipe, and connected to a ventilator. You would have frequent tests done and be cared for in the intensive care unit.

The pros of choosing intubation and mechanical ventilation are that your immediate death would be prevented, your breathlessness might be relieved and your life might be lengthened by a year or more. (Pause) You may have thought of other pros. (Pause)

The cons of this option are that you might not be able to come off the ventilator, you might experience discomfort and complications, you might be sleepy from the medications you are given, and your COPD would not be any better than before. (Pause) You may have thought of other cons? (Pause)

Choosing supportive end-of-life care would involve everything that has previously been discussed about comfort care. You would receive medications to keep you comfortable, and you might receive care in hospital or in your home. You would eventually fall into a deep sleep and die.

The pros of choosing supportive end-of-life care are that your breathlessness might be relieved, you might receive care in your home, and you would die without the discomfort of tubes, tests and other procedures. (Pause) You may have thought of other pros? (Pause)

The cons of opting for supportive end-of-life care are that you might be sleepy from the medications used to keep you comfortable, and you would die within a short period of time. (Pause) You may have thought of other cons. (Pause)

Now it is time to learn how to weigh the pros and cons in making your decision about your treatment when your lungs can no longer breathe on their own. On the next pages I'll review the five steps to doing this and some questions you need to ask yourself. Then I'll show you how other people have answered these questions for themselves.

SOUND

Page 22

Step 1 asks what are the pros and cons of intensive care with intubation and mechanical ventilation for me?

In step 2, you'll ask yourself: how important are each of the pros and cons of the choices to me? You'll be asked to color in boxes showing how important each one is to you.

Page 23

Step 3 asks you to list any questions that need to be discussed before you decide. What do you need to discuss with your doctor or others before making your decision? Again, you'll be asked to write these down.

Step 4 asks you to check in the box showing who you think should decide about the treatment options. Are you more comfortable deciding **with** your doctor, letting your doctor decide **for** you, do you want to decide for **yourself** or, are you **unsure** at this time?

Step 5 asks you to check your overall leaning about your treatment options. It may help to hear how some other people feel about this decision. I'll describe three different people's decisions and the factors that were important to them.

SOUND

Page 24/25

The first example is Andy's situation. In step 1, he lists his personal pros and cons of intensive care with intubation and mechanical ventilation. Under the first "pro", prevents immediate death, Andy writes that he is afraid of death.

When Andy considers the next pro, relief of breathlessness, he writes that he gets very anxious and afraid when he is short of breath, and if intubation and

mechanical ventilation were necessary to relieve his symptoms, then he would want it.

Under the next pro, may lengthen life by up to a year or more, Andy writes that his son is graduating from University in a year and a half, and he very much wants to live to see that day.

In the next box, Andy considers whether there are other pros of being intubated and ventilated. Andy is a very religious man, and according to his religion everything should be done to keep someone alive.

Moving on to Andy's thinking about the "cons" of intubation and mechanical ventilation, he first thinks about the possibility of not being able to come off the ventilator. This is not a worry for him, so he writes that down.

The next "con", discomfort of intubation and mechanical ventilation is of concern to Andy, in particular not being able to eat, drink, and talk.

Under the "con" of complications of intubation and mechanical ventilation, Andy writes down that he is afraid of lung infections, because he knows that his COPD makes it difficult to get over them.

Andy then moves on to the last box, "other cons". The other concern that Andy has is for his family, who he's sure will be very worried about him if he is so sick in the Intensive Care Unit. He writes this in the box marked "other cons".

Next, in step 2 Andy colors in the weigh scale picture with a pencil to show his values. In each box Andy fills in the amount that shows how important each pro and con is to him. He fills in a large portion of the box if the item is very important, and only a small part if the item is less important. Those things that are not important at all he leaves blank.

On the "pro" side, he thinks about the prevention of immediate death. This is very important to him, so he colors it in completely. He partially colors in the box for relief of breathlessness, which is moderately important to him, because even though he is afraid of feeling breathless, he knows that there are medications that will help. For the pro "may lengthen life by up to a year or more", he colors the box completely to show that it is very important

to him. The last box “other pros” he colors in completely as well because his religious beliefs are very important to him.

When thinking about the cons of intubation and mechanical ventilation, he does not color in the box marked “may not be able to come off the breathing machine”, because this is not of concern to him. He partially colors in the box marked discomfort of intubation and mechanical ventilation because this is moderately important to him. Under complications he colors a small amount because this is slightly important to him. Andy partly colors in the "other cons" box, where he wrote down his concerns for his family because this is slightly important to him.

In Step 3, Andy writes down that he will ask his doctor if there is anything that he can do to stay healthy...he’s wondering if he should start taking vitamins and herbal remedies.

In Step 4, Andy thinks about who should make the decision. He feels most comfortable with a decision made together with his doctor.

In the final step, Andy places his check mark on the row of boxes to show his overall leaning, after considering all the pros and cons, and how important they are for him. He is strongly leaning toward intubation and mechanical ventilation if one day his lungs can no longer breathe on their own. So, he places a check in the box at the end marked yes, intubation and mechanical ventilation.

Let’s look to the next page for Marge's decision.

SOUND

Page 26/27

In step 1, Marge reviews her personal pros and cons of intensive care with intubation and mechanical ventilation. In the first "pro", preventing immediate death, Marge writes that she has lived a full life, and accepts death. In thinking about the next "pro", may reduce breathlessness, Marge writes she is only slightly bothered by worsened shortness of breath, because she has been living with it for so long, and that she has a prescription to help calm her when she feels worse. When Marge thinks about the lengthening of her life by up to a year or more, Marge writes that she would like to have

time to settle all her affairs so that her children will not have a lot to deal with when she dies. The other pro that she writes down is that her children would be relieved to know that everything was being done to keep her alive.

For the first con, “may not be able to come off the ventilator”, Marge thinks back to other times when she has been in the ICU, and writes that she would not want to be cared for in an ICU for a long time. She remembers the other times when she was intubated and ventilated, and that she really didn’t like having to depend on the nurses to care for her. She writes this in the discomfort box. Again, Marge remembers the complications and problems she had when she was on the ventilator before, in particular the infections and bleeding in her stomach, which required treatment with lots of medications and I.V.’s. She is worried that she may have the same problems, and so writes them down. Under "other cons", Marge writes that **quality** of life is more important to her now than **quantity** of life.

You can see by the weigh scale in Step 2 that the possible prevention of immediate death is not important to Marge, and the possible reduction in breathlessness is slightly important to her. Lengthening her life by up to a year or more is moderately important to her. Her childrens’ concerns are slightly important to her. On the "con" side, the possibility of not being able to come off the ventilator and having to spend a long time in the ICU is very important to her, as well as the discomfort and complications of the ventilator. Her concern for quality of life over quantity of life is moderately important to her.

In step 3, Marge identifies two questions for her doctor:

- What should I take if my COPD gets worse? and
- How will I be cared for at home?

In step 4, Marge indicates that she should decide about treatment after considering the opinions of others.

Step 5 shows Marge's leaning: she is strongly leaning toward no intubation and mechanical ventilation.

SOUND

Page 28

After reviewing the pros and cons of the options you may still be unsure which way you are leaning.

Page 29

This may be because:

- you will have questions about treatment;
- you need to discuss treatment options with others; or
- you are still not sure what is most important to you in the decision.

It is important to discuss your decision with your family and physician.

This completes the last part of the workbook. If you're interested in reading more about COPD, its management or advanced directives there is a list of books at the back of the workbook. The references to the studies that were used to develop this kit are also found at the back of the workbook. The members of the research team who prepared this kit are listed in the back of the workbook. Good luck with your decision making and thank you for listening.