Making Choices:

The Use of Intubation and Mechanical Ventilation for Severe Chronic Obstructive Pulmonary Disease (COPD)

A Decision Aid for Patients

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Welcome!

This workbook and cassette tape will provide you with the information you need to have a meaningful discussion with your physician about treatment choices if in the future your lungs can no longer breathe on their own.

Instructions:

1. Set aside 30 - 45 minutes.
2. Have a pencil ready to use.
3. Place the cassette in a tape recorder.
4. Press the play button.
5. Stay on the page until you are asked to turn to the next page.

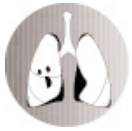
Please Note:

Research studies that support statements made in the workbook are referenced by number in the text. A complete list of these studies appears at the back of this workbook.

This Workbook is for you if:

- You have severe, long-standing lung disease, referred to as Chronic Obstructive Pulmonary Disease or COPD.
- You want to consider the options available to you if your lungs can no longer breathe on their own.
- You want to make your preferences known to your doctor and family members.

You will learn about:

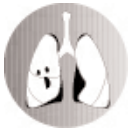


Chronic Obstructive Pulmonary Disease (COPD)
The effects and management of COPD.

Treatment choices if you can no longer breathe on your own.

The pros and cons of these treatment choices.

How to weigh the pros and cons of the choices for you personally.



What is Chronic Obstructive Pulmonary Disease or COPD?

- Common, severe, lung disease.

Narrowed air passages

▼

Difficult for air to move in and out of the lungs

▼

Feel short of breath.

Increased mucus production in the lungs

▼

Causes increased phlegm and cough.

- COPD is not curable and may worsen over time.

How can COPD affect your life?

Common things that bother people with COPD are listed below. [1-3] Please check ✔ all the things that bother you.

Breathing

- ❑ Shortness of breath
- ❑ Coughing
- ❑ Spitting up phlegm
- ❑ Wheezing
- ❑ Frequent chest colds

Daily Activity & Lifestyle

- ❑ Short of breath when walking or exercising
- ❑ Difficulty with daily activities
- ❑ Less energy
- ❑ Difficulty falling asleep or poor sleep

Emotional

- ❑ Feeling anxious
- ❑ Feeling depressed or unable to cope
- ❑ Feeling irritable or angry
- ❑ Feeling embarrassed

Social

- ❑ Unable to participate in social activities
- ❑ Feeling isolated
- ❑ Change in financial situation

Thinking

- ❑ Difficulty concentrating
- ❑ Forgetfulness

Others…

Are there other effects that COPD has had on your life that you are aware of?

Managing your COPD

Some of the things that people do to manage COPD are listed below. Please ✔ those you have used in the past year:

Breathing

Medications:

To open airways and decrease symptoms:

- ❑ Bronchodilators – inhalers or pills.
- ❑ Steroids – to reduce inflammation and swelling in the airways, pills or inhalers.

For chest colds:

- ❑ Antibiotics – to fight chest colds.
- ❑ Immunizations – to prevent flu and pneumonia.

To improve length of life and breathlessness:

- ❑ Oxygen – to raise oxygen levels in the blood.

Others:

- ❑ Not smoking.

Daily Activity & Lifestyle

- ❑ Do activities more slowly.
- ❑ Reduce number of activities.
- ❑ Change the type of activities you do.
- ❑ Do regular exercise.
- ❑ Avoid triggers which make your breathing worse.
- ❑ Eat nutritiously.
- ❑ Ask for and accept outside help.

Emotional

- ❑ Talk about feelings.
- ❑ Learn relaxation exercises.
- ❑ Pray or seek spiritual support.
- ❑ Take things one day at a time.

Others…

Are there other things that you do to manage or cope with your COPD?

When COPD gets worse. . .

- As time goes by, you may have more and more trouble breathing.
- Common cold or pneumonia may cause sudden worsening, requiring treatment in hospital.

Treatment in hospital may include:

- Bronchodilators, steroids and antibiotics.
- Pain relievers to ease shortness of breath.
- Oxygen breathed in through a mask.
- A “BiPap” machine, which pushes air into your lungs through a face mask to help you breathe.
- Emotional support and information.

Treatment Choices

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

1) To receive intensive care with intubation and mechanical ventilation

+

or

2) To receive supportive end-of-life care

The next pages will describe these treatment choices...

Intensive care with intubation and mechanical ventilation

What?

- Tube passed through the mouth, into the windpipe.
- Tube connected to a ventilator, air is pushed into your lungs.
- Frequent tests done.
- Includes medications for comfort care.
- Goal to control symptoms and improve chances of survival.

Where?

- Intensive Care Unit in the hospital.

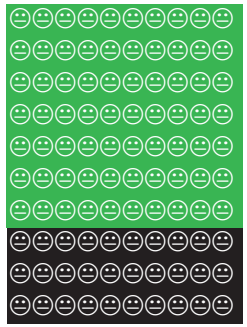
Pros of intensive care with intubation and mechanical ventilation

May relieve breathlessness:

- Increases oxygen in the blood.

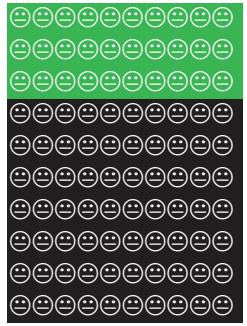
May prevent immediate death:

- **70 out of 100** patients will come off the ventilator and leave the hospital[4-14].



May lengthen life by a year or more:

- **30 out of 100** patients will come off the ventilator and survive to 1 year[5-10,12-14].



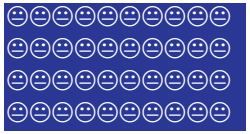
Cons of intensive care with intubation and mechanical ventilation

May not be able to come off the ventilator:

- **20 out of 100** patients will never come off the ventilator. They will die in hospital[9,14-17].

- **10 out of 100** patients will come off the ventilator, but they will die before leaving hospital.

- **40 out of 100** patients will come off the ventilator and they will leave the hospital alive, but they will die within one year.



- The average time spent on the ventilator is 7 to 10 days for all patients.

Discomfort of intubation and mechanical ventilation:

- May have anxiety, a gagging feeling and discomfort.
- Movement and activities limited.
- May feel sleepy from medications.
- May have difficulty getting a restful sleep.
- Unable to swallow food or drink - fed through a tube that goes into the stomach.
- Unable to talk.

Complications of intubation and mechanical ventilation[17]:

- Risk of lung infections – high
- Damage to lungs – less frequent
- Damage to the throat – less frequent
- Bleeding in the stomach – less frequent

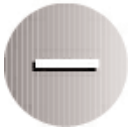
Other concerns:

- Weaning or coming off the ventilator may cause you to be breathless.
- COPD will be no better, and it could possibly be worse than before intubation and mechanical ventilation.

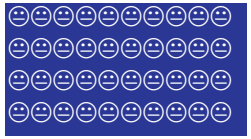
Summary :

What happens to 100 people who choose intubation and mechanical ventilation

- **30 out of 100** patients will come off the ventilator and survive at least 1 year.



- **40 out of 100** patients will come off the ventilator and leave the hospital but they will die within 1 year.



- **10 out of 100** patients will come off the ventilator but they will die in hospital.

- **20 out of 100** patients will never come off the ventilator and they will die in hospital.

Supportive end-of-life care

What?

- Goal to control symptoms and suffering.
- Kept comfortable with pain relievers and sedatives.
- Eventually fall into a deep sleep and die.
- Death will likely occur within a short period of time. You have less than a 5% chance of surviving if you choose this option.

Where?

- Most likely care is provided in a hospital ward.
- Arrangements sometimes made for care in the home.

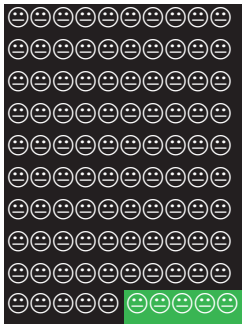
Pros of supportive end-of-life care.

Treatment aimed to relieve shortness of breath, pain, anxiety and fear.

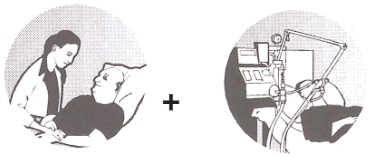
- May receive care in your home.
- Death will occur, but with minimum of discomfort and without complications of tubes, tests and other procedures.

Cons of supportive end-of-life care

- You may be sleepy.
- Death will likely occur within a short period of time.
- More than **95 out of 100** patients who choose supportive end-of-life care die within a few days.



Summary of Choices

Choice	What's involved	Pros	Cons
Intensive care with intubation and mechanical ventilation 	• Comfort care: medications, oxygen, emotional support, etc. • Tube passed through the mouth, into the windpipe & connected to ventilator. • Frequent tests done. • Receive care in ICU.	• Prevents immediate death. • May relieve breathlessness. • May lengthen life by a year or more.	• May not be able to come off the ventilator. • Discomfort • Complications • May be sleepy from medications. • COPD will be no better than before & perhaps worse.
Supportive end-of-life care 	• Comfort care: medications, oxygen, emotional support, etc. • Kept comfortable with medications. • Receive care in hospital or home. • Eventually fall into a deep sleep and die.	• May relieve breathlessness. • May receive care in your home. • Death without discomfort from tubes, tests & procedures.	• May be sleepy from medications. • Death will occur within a short period of time.

5 Steps to Making Your Choice about Treatment

1. What are the pros and cons of intubation and mechanical ventilation for me?

2. How important are each of the pros and cons of the choices to me?

3. What questions do I need to ask or discuss before deciding?

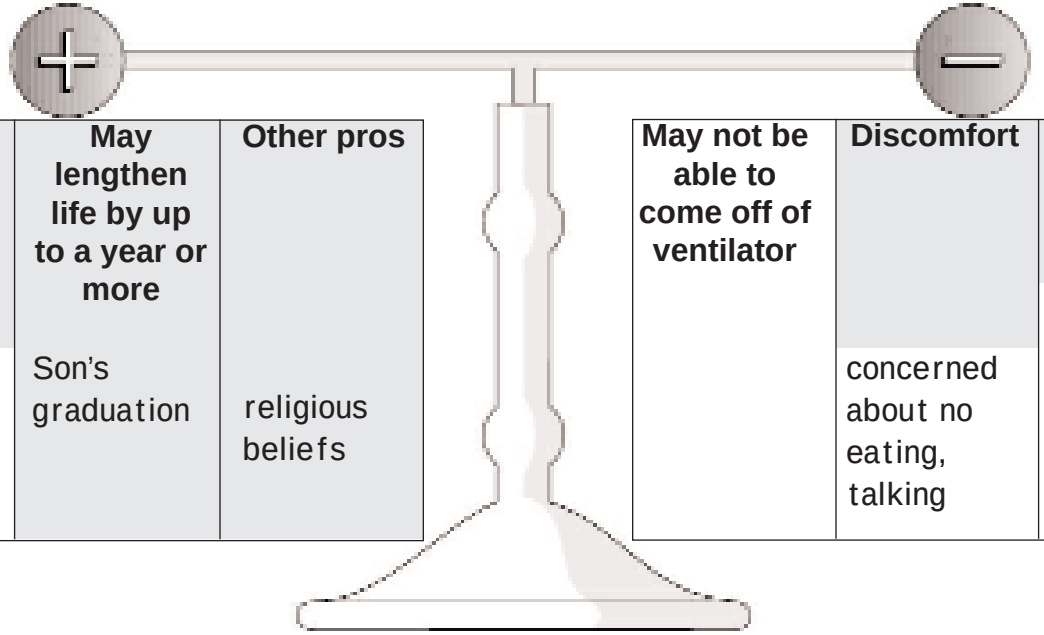
4. Who should decide about the treatment choices?

5. What is my overall “leaning” about my treatment choices?

Example #1

1 My pros and cons

2 Colour my values



Prevents immediate death	May relieve breathless-ness	May lengthen life by up to a year or more	Other pros
afraid to die	anxious and afraid	Son's graduation	religious beliefs

May not be able to come off of ventilator	Discomfort	Complications	Other cons
	concerned about no eating, talking	lung infections	worried about family

3 My questions

What can I do to stay healthy?

_____

_____

_____

_____

4 Who should decide about this treatment?

- ☐ I should decide after considering opinions of others
- ☑ My doctor and I should decide together
- ☐ My doctor should decide
- ☐ I'm not sure

5 My leaning

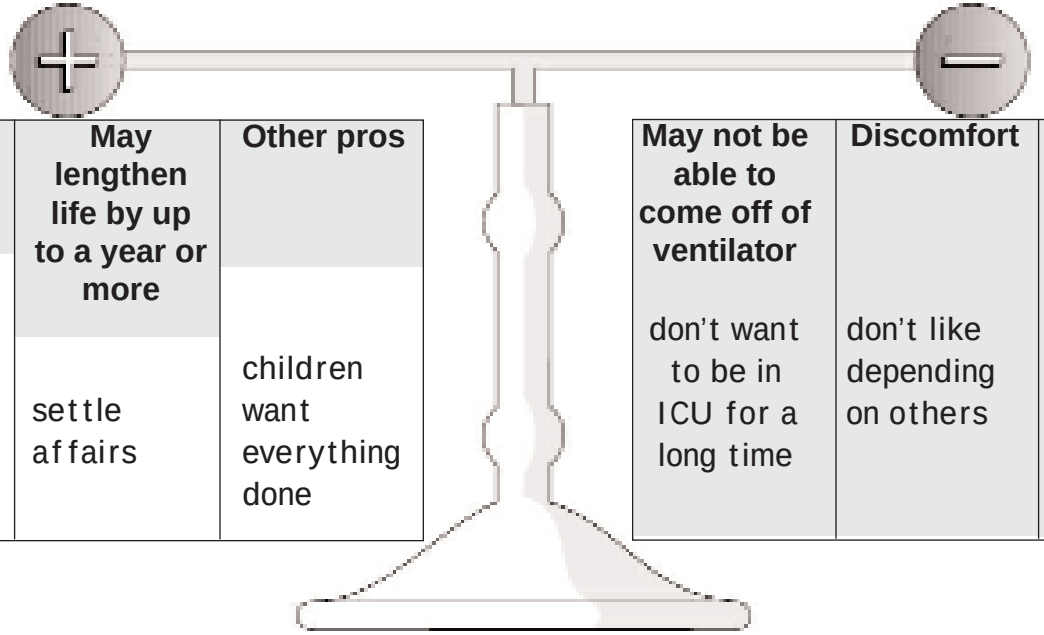
☑ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Intubation & Mechanical Ventilation — Unsure — Supportive end-of-life care

Example #2

1 My pros and cons

2 Colour my values



Prevents immediate death	May relieve breathless-ness	May lengthen life by up to a year or more	Other pros
accept death	lived with it a long time	settle affairs	children want everything done

May not be able to come off of ventilator	Discomfort	Complications	Other cons
don't want to be in ICU for a long time	don't like depending on others	infections and bleeding	quality of life important

3 My questions

What should I take if my COPD gets worse?

How will I be cared for at home?

4 Who should decide about this treatment?

- [x] I should decide after considering opinions of others
- [ ] My doctor and I should decide together
- [ ] My doctor should decide
- [ ] I'm not sure

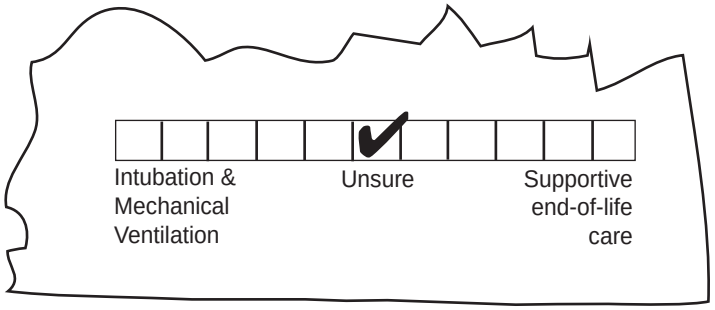
5 My leaning

										✔

Intubation & Mechanical Ventilation — Unsure — Supportive end-of-life care

You may be unsure...

- After considering the pros and cons, you may still be unsure



- This may be because:
  - You still have questions about treatment
  - You need to discuss treatment options with others
  - 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.

Suggested Readings

Diane Bracuk
Coping with COPD: Managing and Living with Chronic Obstructive Lung Disease. Toronto: Grosvenor House Press Inc., 1994.
This manual explains what COPD is, how to control its symptoms and what treatments are available. This manual offers positive and practical advice on living and coping with this chronic illness.

Madeline H. Barrow & Nancy R. Hull
To Air is Human: A manual for people with chronic lung disease (COPD). Atlanta: Pritchett & Hull Associates, Inc., 1995.
An easy-to-read guide describing chronic lung disease, its treatment and how to become an active participant in its management.

William Malloy & Virginia Mepham
Let Me Decide. Toronto: Penquin Books, 1996.
An easy-to-follow living will written in plain language. It features clear explanations of treatment options, a convenient pull out form, and a completed sample directive.

Other Contacts:

The Living Wills Registry
93 St. Vincent Street North
Stratford, Ontario N5A 6H5

University of Toronto
Centre for Bioethics
88 College Street
Toronto, Ontario M5G 1L4
(416) 978-2709

The Department of Clinical and Organizational Ethics
613-737-8899, ext. 19338
ethics@ottawahospital.on.ca

<u>Power of Attorney Information</u>
The Public Guardian and Trustee
595 Bay Street, Suite 800
Toronto, Ontario M5G 2M6

Ontario Lung Association
201-573 King Street East
Toronto, Ontario M5A 4L3
1-800-668-7682

Scientific Readings

1. Guyatt, G.H., Townsend, M., Berman, L.B. & Pugsley, S.O. (1987). ***Quality of life in patients with chronic airflow limitation.*** British Journal of Diseases of the Chest, 81, 45-54.

2. Viramontes, J.L. & O'Brien, B. ***(1994). Relationship between symptoms and health related quality of life in chronic lung disease.*** Journal of General Internal Medicine, 9, 46-48.

3. Anderson, K.L. (1995). ***The effect of chronic obstructive pulmonary disease on quality of life.*** Research in Nursing and Health, 18, 547-556.

4. Martin, T.R., Lewis, S.W. & Albert, R.K. (1982). ***The prognosis of patients with chronic obstructive pulmonary disease after hospitalization for acute respiratory failure.*** Chest, 82 (3), 310-314.

5. Witek, T.J., Schnater, N., Dean, N.L. & Beck, G.J. (1985). ***Mechanically assisted ventilation in a community hospital.*** Archives of Internal Medicine, 145, 235-239.

6. Gillespie, D.J., Marsh, H.M., Divertie, M.B. & Meadows, J.A. (1986). ***Clinical outcome of respiratory failure in patients requiring prolonged (>24hours) mechanical ventilation.*** Chest, 90 (3), 364-369.

7. Kaelin, R.M., Assimacopoulos, A. & Chevrolet, J.C. (1987). ***Failure to predict six-month survival in patients with COPD requiring mechanical ventilation by analysis of simple indices.*** Chest, 92 (6), 971-978.

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12. Stauffer, J.L., Fayter, N.A., Graves, B., Cromb, M., Lynch, J.C. & Goebel, P. (1993). **Survival following mechanical ventilation for acute respiratory failure in adult men.** Chest, 104, 1222-1229.

13. Brochard, L., Mancebo, J., Wysocki, M, Lofaso, F., Conti, G., Rauss, A., Simonneau, G., Benito, S., Gasparetto, A., Lemaire, F., Isabey, D. & Harf, A. (1995). ***Noninvasive ventilation for acute exacerbations of chronic obstructive pulmonary disease.*** New England Journal of Medicine, 333, 817-822.

14. Seneff, MG., Wagner, DP., Wagner RP., Zimmerman, JE., Knaux, WA. (1995). ***Hospital and 1-year survival of patients admitted to intensive care units with acute exacerbations of chronic obstructive pulmonary disease.*** JAMA, 274, 1852-1857.

15. Bradley, R.D., Spencer, G.T. & Semple, S.J. (1964). ***Tracheostomy and artificial ventilation in the treatment of acute exacerbations of chronic lung disease.*** Lancet, I, 854-859.

16. Jessen, O., Kristensen, H.S., Rasmussen, K. (1967). ***Tracheostomy and artificial ventilation in chronic lung disease.*** Lancet, 2, 9-12.

17. Nava, S., Rubini, F, Zanotti, E., Ambrosino, N., Bruschi, C., Vitacca, M., Fracchia, C. & Rampulla, C. (1994). ***Survival and prediction of successful ventilator weaning in COPD patients requiring mechanical ventilation for more than 21 days.*** European Respiratory Journal, 7, 1645-1652.

18. Pingleton, S.K. (1988). ***Complications of acute respiratory failure.*** American Review of Respiratory Diseases, 137, 1463-1493.