



News & Views

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In and Around Our World



For many years COPD has been an almost unknown disease. Part of this is the confusion that arose when the medical profession came to the conclusion that both chronic bronchitis and emphysema were basically two different faces of the same disease, and as treatment for both was essentially similar, they

"We want to help educate, not just the individual patients but the general population as well."

Jackie Whitaker

would use the new descriptive phrase Chronic Obstructive Pulmonary Disease, which of course got abbreviated to COPD.

With this new name there was even less recognition of just how common it had become. The good news is that this is changing. The World Health Organisation puts together worldwide statistics on all diseases and the realisation started spreading that this was at least the fifth if not the fourth largest cause of death world-wide and that it is one of the few that are becoming more common. The causes of the disease are being identified and treatments researched and

marketed and finally in the last couple of years COPD is becoming known more and more by the public.

The National Lung Heart and Blood Institute in the US have been pushing for more publicity and well known personalities such as Grace Ann Dorney Koppel in the US and Liz Dawn (the actress who played the part of Vera Duckworth on the long running Coronation Street program) in the UK have gone very public about their disease which all helps to get the message out

In Canada, the Lung Health Framework, which is a collaboration between the Public Health Agency of Canada and the Canadian Lung Association, is attempting to bring together the various needs for lung health of all Canadians (with an emphasis on the various disadvantaged groups) and the "centres of excellence" around the country, to come up with a common agenda that the Provincial/Territorial Health Authorities can sign on to. Some of our directors have even had some input into this, and we do feel that, whatever the immediate outcome, it will at least raise the profile of all the lung disease problems in Canada - and there are many including TB and asthma as well as COPD.

Which brings us to COPD Canada Patient Network which has been started :

www.copdcanada.ca with a mandate to reach as many Canadians living with COPD as possible across Canada and unite them. In Jackie Whitaker's words "We want to help educate, not just the individual patients but the general population as well." We want to advocate for better access to proven and effective treatments; those recommended by the Canadian Thoracic Society but frequently not covered by the individual province's health programs. This should include not only recommended medications but also respiratory rehabilitation. Currently only one in 80 patients are able to get into a such a program due to lack of funding and facilities. We'd also like to pull these folks together, collectively, so that they feel they have a voice and aren't so alone. Together we CAN.

Chris W
Chris Wigley

In The News Mechanical Ventilators

Mechanical ventilators can be life-savers for hospitalised patients, but they can also lead to problems such as lung infections. Now, Canadian researchers have developed a new kind of ventilator that some say may revolutionize intensive care.

The problem with ventilators is that they decide how a patient breathes -- or rather the medical staff who sets it decides. But patients cannot override the system to take a deeper breath for something such as a sigh or a cough.

"The patient is trying to breathe in and the ventilator is trying to breathe out. The patient is fighting it because we've had no way of

synching the two," explains Dr. Arthur Slutsky, the vice-president of research at St. Michael's Hospital in Toronto.

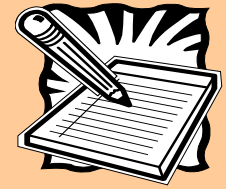
Often patients have to be heavily sedated so that they won't try to fight the mechanical ventilation, which could lead to lung or tracheal damage or cardiovascular stress. But the sedation means the patient must remain bed-ridden, putting them at risk of lung infections such as pneumonia.

Now, a Canadian-developed ventilator senses the signal sent to the diaphragm from the brain and uses that to trigger the ventilator and mimic normal breathing for ventilated patients, even

unconscious patients.

It's technology that may be critically important for premature babies, who are at risk of lung damage if too much air is delivered to their tiny lungs.

Dr. Patrick Bellemare of the Hospital du Sacre Coeur in Montreal says the new ventilator means he will no longer have to guess at how many breaths patients want. Instead, they'll be able to decide for themselves, reducing their stress and complications. Because the patients are not so heavily sedated it should be possible to reduce the length of time patients have to stay in hospital as well as reducing the risk of lung injuries caused by ventilators.



From The Editor's Desk

We hope that you will find this newsletter helpful and of interest. If you have ideas, comments or suggestions we would love to hear from you. This is your newsletter so you need to have input on topics which will be useful to you.

Please email: gwen@copdcanada.c

Member Discounts

Substantial Discount
gelFAST hand hygiene
from Medonyx
www.medonyx.com

10% OFF
OxyView frames &
TTO supplies
www.oxyview.com



Healthy Eating

Here is another alternative for mucus thinning:

Chicken Soup

When University of Nebraska researchers tested 13 brands, they found that all but one (chicken-flavoured ramen noodles) blocked the migration of inflammatory white cells—an important finding, because cold symptoms are a response to the cells' accumulation in the bronchial tubes. The amino acid cysteine, released from chicken during cooking, chemically resembles the bronchitis drug acetylcysteine, which may explain the results. The soup's salty broth keeps mucus thin the same way cough medicines do. Added spices, such as garlic and onions, can increase soup's immune-boosting power.

Your optimal dose: Have a bowl when feeling crummy.

Caregiver's Corner

Advanced Directives



You and your COPD partner have probably thought about or discussed it, but possibly never acted on it. Based on personal experience I feel directives are necessary and need to be dealt with up front. As a “caregiver” “support person” you must be ready to fight for your partner.

An advanced directive (AD) is a document in which a capable person sets out what, how and by whom, health care decisions are made in the event the individual is not capable of making those decisions on their own.

There are two types: Proxy Directives & Instruction Directives

Proxy Directive : An advanced directive in which a capable person, over 19, names a proxy or substitute to make health care decisions for themselves in the event they (the individual) is incapacitated. The directive must be in writing; must be signed by the person who made the proxy directive; and must be witnessed by someone other than the proxy or the proxy’s spouse. The named proxy must be 19 years or older.

Instruction Directive: An advanced directive in which a capable person specifies what health care and treatment he/she wishes to receive or not receive. A substitute decision-maker is not named in an instruction directive.

Now is the time to sit and discuss what you really want to happen in the event of a major exacerbation or surgical procedure. A copy should be on record with your partner, respirologist, general practitioner and surgeon.

A sample form is available at:

www.aafp.org/afp/990201a617.html

In the event of a planned surgical procedure you need to sit with your surgeon to discuss this AD and know from the start who will communicate

with you in the event of complications or the need of unplanned procedures. Although my partner and I had discussed our advanced directive with the surgeon, it was left in a rather ambiguous state as the surgeon felt there would be no complications even though we felt going in that COPD could be a factor or a problem.

Had everything gone as planned for my partner’s surgery, this is where the story would end. However, two days after the surgery, she ended up in the ICU due to breathing difficulties and fever. While sitting bedside after 36 hours of no sleep, a doctor brought forms for me to sign and ensured me that my wife would get the best of care. Basically that is where any of my participation in the decision making process of medical care ended. She was intubated, sedated, and unable to speak. Now my promise to be her voice had to kick in.

I found myself constantly telling medical personnel “her COPD was managed. No, she was not on oxygen 24/7,” and “not only could she function daily, but she walked five miles before surgery.” All falling on deaf ears as they continued to treat COPD as the culprit, taking two weeks to find the exacerbation was as a result of a hospital acquired infection. It was the most frustrating period ever in my life.

I would leave to get rest only to return to a change of procedure or course of action. I asked “if I had to have a psychotic event to have someone listen to me” only to have a social/patient advocate ask me “if I was serious” but “he understood my frustration and would talk to the doctors to make sure they would communicate with me in the future.” Medicine after medicine was added or changed by different doctors. The nurses continued to be evasive, the rotation of doctors continued (this was a teaching hospital) and still no communication. After four weeks we were transferred out of the ICU

and I was finally allowed input in her care.

Based on our experience I would suggest the following:

- 1) Take a look at the sample advanced order.
- 2) Take the time to discuss your wishes and write them down.
- 3) Make sure your personal doctors have a copy of it.

And most of all should you end up in an emergency/intensive situation, demand to see a hospital patient advocate immediately. State what you and your partner have decided, and who has a copy of it. Ask who will be communicating with you as to procedures and courses of actions.

Understand that in the Canadian medical community there is no one individual looking out for your partner’s best interest except you. Your GP is last informed, your respirologist might be called, but it all rests with you as a caregiver, friend or partner. Ensure you’re prepared to stand up and be heard.

Dray.

Dave Raymer

Puzzle Answers:

1. DIAGNOSIS
2. LOX
3. TRANSPLANT
4. BRONCHOSPASM
5. NARROWING
6. SALINE
7. IDIOPATHIC
8. EDEMA
9. DYSPNEA
10. SPIROMETRY
11. ANTIBIOTIC
12. EXACERBATION
13. DIAPHRAGM
14. PLB



www.copdcanada.ca

Puzzle Corner

How to Play: Check the definitions below and decide the correct word. (the number of letters in the word is shown.) The correct word can appear in any direction but always in a straight line. Answers on Page 3

F	W	S	P	I	R	O	M	E	T	R	Y	F	N
I	E	R	T	A	S	N	C	D	N	S	X	C	A
	F	X	C	P	T	I	P	M	A	P	G	K	D
I	M	W	A	X	E	Y	A	G	L	L	M	D	Y
O	S	L	O	C	A	E	N	A	P	J	Z	G	S
P	I	A	B	R	E	W	T	R	S	E	H	N	P
A	S	E	L	F	W	R	I	H	N	Y	J	I	N
T	O	Y	T	I	P	F	B	P	A	W	E	W	E
H	N	I	D	S	N	T	I	A	R	N	Y	O	A
I	G	N	N	H	P	E	O	I	T	D	W	R	J
C	A	D	I	E	D	L	T	D	O	I	X	R	U
L	I	T	Y	E	H	S	I	L	G	B	O	A	B
R	D	B	M	R	P	B	C	R	M	F	L	N	W
M	S	A	P	S	O	H	C	N	O	R	B	P	Y

1. Dx for short (9)
 2. Liquid Oxygen ab. (3)
 3. Tx for short (10)
 4. Tightening of muscles surrounding the airways (12)
 5. Stenosis (9)
 6. A solution made of salt & water (6)
 7. Unknown origin (10)
 8. Swelling (5)
 9. Shortness of breath (7)
 10. A test which measures lung function (10)
 11. A bacterial fighting medicine (10)
 12. Flare-up or worsening of symptoms (12)
 13. The most efficient breathing muscle. Found below the lungs (9)
 14. Pursed Lip Breathing ab. (3)
- Clue:** Most of the info can be found on our COPD Canada website on the Acronyms & Abbreviations page.

