

The Issue of Compliance

By Jo-Von Tucker
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When I attended the Long-Term Oxygen Consensus in Washington, DC last fall, I was struck by hearing the researchers and pulmonologists report, time after time, on how difficult patient non-compliance [patients not following doctors' orders] made their jobs of trying to help COPD patients. The percentage of patients who were not complying with the treatment program provided by their doctors – especially related to the prescribing of supplemental oxygen use – was astounding! And upsetting.

I even raised my hand at one point and naively asked Dr. Tom Petty (who is easily considered to be the guru of the pulmonology world) to what he attributed the noncompliance. His answer, and others expressed during the course of those discussions and presentations, involved many issues faced by COPD patients and their caregivers. But the one fact that imprinted itself indelibly onto my own psyche was **the issue of education – or a lack of it – about the disease and its process.**

Bottom line: people who are prescribed supplemental oxygen as a vital part of their treatment program are never really educated about how it will help them. They are not often told what it will - and will not - accomplish for them, why they should adhere to the exact usage as prescribed, and the basic physiology of the patient's own body and its requirements of the respiratory system.

The question remains... Who is responsible for educating patients? It cannot be the doctors themselves; they simply do not have the time (or the inclination) to do this. Some pulmonary rehabilitation courses cover these subjects well, but many do not. Most of them focus only on exercises and the conditioning of the patient, which are of vital importance. But a lack of general knowledge about the illness may allow those participants to fall back into old habits after the course has ended.

More questions arise... How do you keep patients who have graduated from pulmonary rehab courses actively involved in managing their illness? How can the rate of compliance with prescribed treatment programs be improved upon? How can patients learn to better help themselves? How can patients' quality of life be improved? How can mortality rates be changed?

I believe that the answer to all of these issues is **education.**

Somehow we must find better ways to teach patients who have lung disease about what's going on with their bodies. Someone has to be able to help newly diagnosed patients comprehend the results of active and conscientious management of COPD. Patients must be informed on ways to remain as stable as possible, fending off the usual progression of this debilitating chronic illness.

Since, at the moment, there are no ready volunteers for taking up the role of responsible educator, it is up to the patient to find answers about their questions. We must find ways to self-educate! Not an easy task, as there is still very little help available for us. But find answers, we must! Support groups provide more information than just about any other source. Problem is... some support groups are very good about this, while others are not.

We need to know *why* we should be compliant patients. *Why* we need to take our medications exactly as they have been prescribed – not in rote fashion, but with an understanding of the help the meds provide in the treatment program.

We should thoroughly understand why our bodies require supplemental oxygen – what role oxygen plays in providing strength and conditioning to our major muscles. And what happens to those muscles when they are deprived of sufficiently oxygen-rich blood. Yes, we need to grasp the overall physiological basics of how the respiratory system works; and know how the conditioning of our bodies affects the breathing muscles, which are the support system for pulmonary function.

One of the problems in getting COPD patients involved in learning how to manage their own illness probably has to do with the fatigue that we all suffer from. It's very hard to get motivated to exercise, or even to read a book about lung disease, when we are so tired that we feel our mind isn't even functioning properly. Fatigue is, however, a way of life for us — a constant and sometimes nagging companion. We have to exist in spite of the exhaustion we feel, and we must stay active in spite of it. So where does all of this questioning of methods of education about COPD lead us? Do I have answers to put forth to help in some way? Or am I just blowing off steam about the inequities of life for those of us with lung disease?

Hmmmm... there might be a method to my madness, after all.

I do, in fact, have four suggestions to offer you:

1. Buy a copy of the book I co-authored with Drs. Nicotra and Carter, ***Courage and Information for Life with Chronic Obstructive Pulmonary Disease***. And read it! (Please pardon the commercial. I'm not recommending that you purchase this book for my financial gain. I'm pushing it because it does provide *lots* of information, help, and encouragement for COPD'ers.)
2. Find out if there is a pulmonary support group in your area, and plan right now to attend the next meeting. You will learn a lot and meet others with similar concerns.
3. Be good to yourself. Rest when you are tired, but don't give in too easily. Eat right, providing your body with the right nutrition. Maintain your exercise regimen. Try to learn for yourself all the reasons why you should be a compliant patient. And then follow your doctor's orders, or find yourself a different doctor if you don't agree with the treatment plan. Give your body and mind a break by meditating, or if you prefer, by praying. Stay active and socialized, and try to keep yourself in good spirits – sometimes we COPD'ers can be very trying to be around.
4. Reach out and help someone else. Bring them in to the support group. Help them to learn about the disease. Talk to them about pulmonary rehabilitation and its possible long-term rewards. Encourage them to help themselves. "Do unto others..." as the Bible says. Think long and hard about how you want to be treated as a human being with a disease that takes a high toll on patience, understanding and perseverance. And treat your fellow COPD'ers exactly in that way.

And please remember, strict compliance with your treatment program will benefit you as you battle day-to-day with lung disease and all of its ramifications. But no one can do this for you! You must implement the plan yourself, not relying on a spouse or caregiver to regulate the management of your illness. Only you can do this effectively!

*Jo-Von Tucker passed away in late 2003 from complications following surgery. Her book, **Courage and Information for Life with Chronic Obstructive Pulmonary Disease**, is available in the BBLW Bookstore on this website. Her advice on starting and running a support group can be found in the chapter on lung support groups in **Breathe Better, Live in Wellness: Winning Your Battle Over Shortness of Breath**, also available in our online bookstore.*