The Importance of Uniting COPD Patients

by RUSSELL WINWOOD

Why and How to Unite Patients

Australia, where I'm from, is many miles from where the majority of chronic obstructive pulmonary disease (COPD) patients live — in the United Kingdom, Europe and the United States.

I am a world away from people I consider great friends. Not friends because of our history or a family relationship, but friends because our disease unites us.

COPD and Isolation

While I'm writing this article, I am also thinking of the countless number of patients I've come across who live in isolation. Isolated from family, friends and quality health care.

As the world moves more towards total dependency on the World Wide Web we need to remember those who have no access to the age of technology. I recently read an article stating there is over 65 million COPD patients worldwide — mind boggling.

When you consider online COPD support groups only number in the thousands, how do the millions connect?

I know the online world is only a part of how patient groups connect and there is no doubt walking, singing and better breathers groups play an important role. However, all these groups put together only account for a very small number.

So, what happens to the millions of disconnected patients? I don't know the answer yet but it's a topic I rarely see discussed.

I know from personal experience financial pressures can restrict some patient’s ability to access the internet, which limits their ability to connect to the COPD community.

For those of us who have access to connect online with patients and health care professionals we benefit from this vast pool of knowledge and experience. I have learned much from the experience of other patients — united, we provide a valuable resource.

The Benefits of Unity

Whether it's in business, sports or family and friends, there is no doubt a united team is a strong team. The internet is playing a vital part in bringing us all together to form a strong team.

You may think, “What's he talking about? A team?”

Challenging Ourselves

In the time I have been a COPD patient I have seen a definite swing in patient's mindset, from a sedentary lifestyle to a more active lifestyle.

We are challenging ourselves and how we perceive our disease. This has come about through sharing experiences from patient to patient, active lifestyle advocates and healthcare professionals.

From my perspective, in the early days I often wondered if all the exercise I do would have a negative outcome on my health. Then I read a post from COPD veteran Jim Nelson talking up the benefits of being active and how it can improve your quality of life.

While patients don't have the level of expertise of healthcare professionals, we do have the benefit of experience. When it's late at night, you're breathless, anxious and need some support or advice, you can log on to your favorite support group and know someone will be there to lend a hand.

Giving Us a Voice

As we know, COPD struggles to have a voice and I suspect part of this is because we have a silent majority. What I mean is we have more patients disconnected rather than connected.

There is little doubting the stigma surrounding COPD being a smoker's disease and the belief if you are a smoker you deserve this disease. This assumption is one we need to change, as poor lifestyle choices account for many chronic diseases and not all COPD patients contracted their disease from smoking.

Recently a fellow patient told me they were ashamed to go out in public, as they didn't want to be seen with their oxygen machine and struggling to breathe. Personally, I like it when people ask me about my oxygen concentrator and why I need it.

Inquiring minds give us the opportunity to educate people about our disease. Educating the population will help change the stigma of COPD — and the more patients we have doing this, the stronger our voice will become.

Educating the Public

We shouldn't be ashamed of having COPD and we shouldn't hide ourselves away from the world. If one smoker decides after seeing you in public with your oxygen machine they're going to give up smoking, then you have made a difference.

Educating the public can start with your family and friends, as it's important for the people most close to you to be aware of your disease and how it affects you.

Through a united voice we can highlight the plight of our disease and how it affects our day-to-day lives as patients. This can change the mindset of our policy makers and hopefully open the doors to more funding for our disease.

Funding for COPD research is key to help treat not only existing patients, but to treat the millions who will be diagnosed in the years ahead. In the meantime, we can help prevent people succumbing to this disease by communicating what the major causes are.

Get Involved

Remember with any disease, prevention is part of the cure. COPD is one of the most preventable diseases and we need to share this with other people.

Quitting smoking, avoiding pollutants and asthma management are just some actions people can take to avoid

contracting COPD. As patients, it's our duty to identify at-risk family and friends so we can help reduce the numbers of newly diagnosed patients.

A useful tool to demonstrate a COPD patient’s ability to breathe is a simple straw. Have your family and friends breathe through the straw while pinching their nose — this can often change the way they view your disease.

If you are in an isolated area or don't have access to the internet, then you need to be proactive. Consult your doctor or visit your local hospital to see what patient programs are available in your area.

If no programs are available, talk to local lung association about starting a group yourself. Walking and singing groups are becoming more and more popular, and provide not only a way to exercise, but a social network as well.