

Volunteerism in COPD Patients and Families in the Community Hospital Setting

Non-Involvement of COPD Patients, Families,
and Caregivers Symposium
Columbia-Presbyterian Medical Center
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Thank you for asking me to share my findings and my thoughts on volunteerism. In preparation for my remarks I recently asked a group of sixteen pulmonary rehab program leaders in my State of Michigan to share their thoughts on what they believe leads to non-involvement of pulmonary patients and families in volunteering.

Here are their responses:

- There is often a message from the physician, directly spoken, or not, that this is indeed for patients, the end of involvement and level of activity as they know it. This advice is given with no alternative to what *can* be done. There is basically information regarding what *can't* be done.

- There are decreased activity and energy levels in this population due to:
 - Family coping taking a lot of energy
 - Guilt (because of cigarette smoking) being a huge factor

- The overall COPD demographic is generally patients whom are older in age and there are limitations for many when it comes to the use of a computer / the Internet, thus less awareness of COPD and volunteer opportunities.

- Depression

- Overall there is also little awareness in the general population. The recent article in TIME magazine, “The Other Lung Disease,” and other public awareness campaigns as discussed at the COPD meeting in November 2003 should help.

- The lack of organization about where potential volunteers would go, even if they should seek involvement
 - “They want to help, but they don’t know where to go to start.”
 - “The American Lung Association (ALA) has seemed to become much more focused lately on asthma and is putting less emphasis on COPD.”

- Community acceptance for people with COPD is still low.
 - One RT sighted an example that in her community, a relatively young person wearing oxygen was not allowed to work for fear of something happening to that person, while they were actually perfectly capable of doing the job safely and effectively. So, this would be fear the disease itself and the people with it on the part of the general populace.

- There is not a high level of involvement of COPD patients in the schools due to fear of infection on the part of patients.

It was mentioned, however, that recently in one community, participation by pulmonary patients at a “Relay for Life” event was significant. It was noted also, that this was a specific event with a well-defined purpose, start, and finish. There were clear-cut jobs to do, including sedentary activities that could

be performed by participants with significant physical limitations. Of course, “Relay for Life” is a cancer-related event, cancer being a much more well-known disease.

Areas in which I have found success in patient volunteerism:

- Helping with “Asthma Education Day” at the registration table.
- Emphysema patients going into our local high school and telling their stories about starting smoking, the addiction, the illness, and life today. This program has been a part of our high school’s “Working With Wellness” curriculum for 4 years now. The name of the program is, “That Will Never Happen to Me!” and is very powerful.

Areas in which COPD patients volunteer in the Saginaw, Michigan region are:

- “Breath of Life” Walk, helping with both fundraising and actually walking.
- The Asthma Walk, making phone calls and driving others to the event.
- Members of the Better Breathers’ Club asking their physicians to come to a meeting and speak. This has been very successful, with physicians seeming less inclined to decline an invitation extended from their own patients.
- Sharing computer skills with other members of the support group.

One way to help others who find themselves with similar problems-- something very near and dear to my heart -- is sharing stories. People with COPD are very eager to share their stories. This is something they can all do, and something they feel confident in doing. Of course not in every case is a patient comfortable talking in front of a group, but every patient does have something to say one-on-one and they feel strongly compelled to share it.

I realized this completely in the writing of my book for COPD patients and families. My experience in asking people to participate in sharing their stories for the book was that they were, oh so eager to do so, and when we got together, they said that they would do *anything* to help educate young people, especially, about the dangers of smoking. A dream-come-true for anybody who needs volunteers: *People were asking me what they could do!*

No matter what people can or cannot do, no matter what talents they think they have or don't have, there is one thing they can do. And that is to tell their story. I was amazed at how willing they were to do this and this is mentioned in the section of my book that explains how the book came to be. Sharing with others and telling a story...it is often very cathartic and it can also be a step to other avenues of volunteering. Several contributors to my book have gone on after sharing their stories to volunteer and reach out to others with chronic lung disease. One has offered to write grants, and some others are advocating for smoke-free environments.

Now, bear in mind that these are folks who have demonstrated a true understanding of, and have learned to cope with many of the emotional issues associated with life with COPD. They could be considered models of emotional balance and achievement.

Back to the informal survey of Pulmonary Rehab leaders. We learned there that several of the barriers to involvement are directly related to the following emotional issues associated with living with COPD.

- Patient and family coping with diagnosis and change
- Guilt
- Depression
- Embarrassment

We must never underestimate the impact of these emotional issues, because I believe, as I have seen in my own experience, that they are at the heart of most of the problems associated with living with COPD, including the lack of volunteerism.

Please allow me to share my thoughts on this, my findings as a result of years of sitting and listening at length to people living with COPD.

To the person with chronic lung disease, their whole life is in a state of upset. Their life as they knew it is gone for good. Their entire world has been turned upside down and yet we, as health professionals, don't always address this as an issue, *as a real issue*. For those physicians and health care professionals who have that first appointment with diagnosis last at least half an hour, do a depression screen and make counseling available, kudos to you!

But, for the most part, we perform tests and prescribe medications and oxygen and expect this to make things better. We tell the patient to come back in three months or so and expect, well, I don't know what we expect.... We expect everything to all be alright then? As if by prescribing an inhaler they are magically and coherently and perfectly going to adjust to having a terminal diagnosis?

I don't really want to say we ignore the emotional issues, because in order to ignore something you have to consciously realize it is there, but we *fail to recognize* that without the resolution of many of the emotional upsets and setting into motion the beginning of learning effective coping skills for living with

chronic lung disease, the most carefully and expertly prescribed treatment is not going to do much good at all.

For you health care professionals here, this may seem like the millionth person with chronic lung disease who has come through the doors of your facility and into your care. But we must remember this: Even though we've treated many people, for each person, it is the first time, the very first time that they have experienced, as Jo-Von Tucker so poignantly called it, "The devastation of the diagnosis." It is very frightening and confusing, and it is, of course, life changing.

I once heard an American president talking about families getting the news that their loved one was killed in the line of duty. He said that we can't toss about casualty facts without thinking about each and every family. When a family sees those military officials walk up to their front door, their worst nightmare has just become real. *That is the war to them. That moment – and their loss -- is the whole war, and it could not possibly get any worse.* It has affected them as close as it can come, and *it is their whole world.* Their world has come crashing down upon them in a most horrible way.

We might say that being given the diagnosis of COPD is similar in nature. For the COPD patient who has received the diagnosis of a terminal disease, their life—their world, at that moment, is spinning out of control. In a chronic, terminal disease situation, the real help, *to oneself as well as others*, begins in dealing with and coping with disease and with this changed life – this new life -- on an emotional level. We all know that a patient, even with severe limitations, can make much progress with improvement of quality of life and compliance when he or she works through these many emotional issues/ stages, and balance (alignment) is achieved.

The main issues leading to non-involvement and efforts toward solutions can be summed up by looking at the four “A’s.”

- **Awareness** -- Public awareness. The COPD Coalition meeting was a great start. The public at large must become more educated and comfortable being around people who have COPD, as well as just talking about pulmonary disease. Efforts in this regard are underway. When there is awareness and a person is diagnosed, then they already have some information—some history of what this disease is. Most people who are now diagnosed have never heard of COPD. I am puzzled by patients who come into my program who have been given a diagnosis of COPD weeks, or even months, earlier and they *still* have no idea what it is.
- **Attitude** – There needs to be a more positive attitude on the part of physicians and health care professionals that life for the COPD patient is not over with diagnosis. This is not a death sentence. It is a new journey. Only with sharing our own confidence and positive attitude over and over and over again, that something *can* be done and that life – a good life – can go on, will patients, as John Walsh says, “Take up the charge.
- **Alignment** – Patients need to be given the tools to cope successfully with their diagnosis, becoming educated about the disease and working through the layers of emotional issues that so often accompany COPD. Most patients and families are willing to work for a cause only after they have faced a diagnosis and begun to regain some balance and control in their lives. When one’s life is spinning out of control, that person cannot begin to think about volunteering.
- **Asking** -- There is not enough asking for volunteers (myself being the worst culprit) going on, and not enough specific tasks being asked to do. *Just ask.* Hockey great Wayne Gretsky said that he

was guaranteed to miss 100% of shots he didn't make. Likewise, we will be at a loss for volunteers 100% of the times we don't ask for help.

But then, finally, and perhaps most importantly, when the physical state can no longer change or improve, and there is nothing more that can be "done," that is the time when there absolutely *has to be more*; when volunteering can actually help a person go on. I have been asked, face to face, as I am sure you all have, many times, for the "more." "Jane, what else can I do? There must be *something*."

And as health care professionals we are left standing there and know that it – *the more* – just has to be there. *It just has to be*, and that is what this is all about. About making life richer and more fulfilling when the diagnosis is new, and helping others all the way down the line to when there is "nothing else" that can be done, and at every point in between. Again, life with chronic lung disease is not a death sentence. It is a journey. It is a walk. And when you're walking a path you've never been on before, it sure does help to have some friends with a map.