

Dear Family,

Our lives may never be quite the same, A.D. (after diagnosis). In a perfect world, I wouldn't have COPD. But we can both try to seek more joy, derive more pleasure, from what we are fortunate enough to have... one another. Let's make the most of our time.

In a perfect world, you wouldn't have to wonder how I was feeling, and wonder what you might be able to do to help me. You wouldn't find yourself on the receiving end of my reactions to the episodic depression spells to which I am prone. Nor would you have to puzzle over the fact that I seem to have good days, and then unexplainably, so many bad days.

You must be terribly disturbed by my shortness of breath, and by the fatigue that nibbles at me all day, every day. And I can guess that you are as upset and embarrassed as I am by the fits of coughing that sometimes seize me, especially out in public.

You know that the compromises to my lifestyle that are demanded of me are upsetting. It's hard for me to ask for help, when I find that I can no longer do something on my own. It hurts my pride, and I can see in your eyes that it hurts you, too.

But it isn't a perfect world, is it? I do have this disease, and so far there is no cure for it. I must learn to cope with it. We all must. So, even though the world is less than perfect, particularly so since my diagnosis with chronic lung disease, these issues do exist. I want to find a way to help you as you try to help me.

That's why I'm writing this letter to you now. Sometimes it's just easier to write things down than it is to say them out loud. Especially things that cause this big lump in my throat, even as I write.

You are my loved and cherished family. And it seems to me that the family members are often hit as hard with the realities of COPD as the patient. Maybe even harder. It pains me to see you struggle with solutions for us as we fight the battle of illness together. I know you want to help.

So here is my fantasy of what our nearly perfect world can be, in spite of COPD:

Our lives cannot help but be affected by the fact that I have this disease. But I have learned that COPD is not a death sentence... nor does it have to be the end of our quality of life. The better I become at managing my own illness, the more effective and happier our time together will be. Maybe if we establish some suggested ground rules to get us through the rough patches, we'll adapt more easily and with less stress on us all. Here's my list of seven suggestions:

- Suggestion #1 It is important for me to remain as independent as possible to preserve my self-esteem. Try not to rush to help me before you know whether or not I can accomplish a task on my own. I really want to try; not only to spare you, but also to help me with my independence and self esteem, both of which will erode significantly with every thing that I learn I can't do.

There is a fine line that you, my dear ones, must walk in balancing between coming to my aid, or just taking over for me, (which can be interpreted as enabling me to become a cripple). This is important for so many reasons, like the need to keep my body and muscles as conditioned and toned as is humanly possible under these circumstances. Like the need that I have to feel useful, again -- to help guard against a loss of self esteem.

- Suggestion #2: Try to not judge me if I'm having a bad day. It is possible that a lung infection could be brewing in my body, and you may be aware of it sooner than I can be myself. You know the signs... increased shortness of breath and coughing up dis-colored sputum. Perhaps fever, but maybe not. Less energy to expend on the simple chores of daily living.

Some of the folks in my lung support group have expressed their frustration when their family leaps to the conclusion that we are hypochondriacs who complain a lot about feeling bad. I think that this just isn't so; we aren't constant complainers. The COPDers I've come to know are a pretty brave lot, all in all. Most of us who have some form of COPD do not want our loved ones to see us as "sickly" or making excuses. As a result, however, many of us hedge about the problems we are having.

- Suggestion #3: Please help me by overseeing that I am complying with my doctor's prescribed treatment plan. I don't expect you to be a nurse, but I will appreciate it if you gently remind me to take my afternoon puffs on my inhalers, or to check to see if I remembered to take my evening pills.

Help me to be a compliant patient by helping with my oxygen equipment when we go out. It's good to know that I have a portable filled with enough supplemental oxygen to get me comfortably through our schedule. It's also good to have help getting in and out of the car. And especially helpful to have an arm to lean on going up stairs, if I need it. The more comfortable we both are with the oxygen and equipment that I need, the sooner it will be accepted and not questioned by the general public.

- Suggestion #4: Help me to stay socialized. Do not let me become isolated from friends and other family members. We COPD folks do have a tendency to stay at home, rather than digging down deep for the energy to get up and out! You can encourage me to accompany you to lunch, or even to the market. You can inspire me to go to a movie, or to have guests in for bridge, scrabble or cribbage. Your encouragement can make the difference for me---desiring to see people, and for people to see me!
- Suggestion #5: In this nearly perfect world, we need to have and show respect for one another. I promise that I won't talk about you as if you aren't in the room, if you'll do the same for me. My feelings are currently worn very close to the surface; I can hear perfectly well what you've said to someone about how fast the disease is progressing, or about how futile our efforts to fight it may seem. You and I can certainly discuss these issues between ourselves, and keep them within the family circle.
- Suggestion #6: Encourage me (but please don't nag me) about getting my exercises in each day. Some days it is just so hard to commit to even 10 minutes of active exercises. If I'm too sick to do them myself, try to help me with just some stretching exercises like yoga or T'ai Chi. These gentle movements can help to keep my body conditioned, even when I'm suffering from an exacerbation. And they aren't that taxing of my strength or energy. You, of course, no matter how hard you try, can not fully understand how I am feeling because you don't have my lung disease. But your encouragement brings me added strength; your emotional support brings me peace from the trauma of being sick.
- Suggestion #7 Nutrition is an important part of helping my body with its special needs. You can help by making sure that I'm eating right. A diet high in protein will help build up my immune system and body strength. We can plan the week's menus together. I pledge to try and tell you what items seem to taste best to me.

That's it... I'll stop with Lucky #7. I don't wish to make our lives more difficult with suggestions and rules. I simply want to express myself on the subject of how you can help me. I don't want to sound as though I am whining or complaining. I am reaching out with all the love that is in my heart for the help that I know you want to provide. And if you have your own list of suggestions, please share them with me.

It is true that our lives may never be quite the same. But we can work together to preserve and enhance what we are fortunate enough to have... one another. Help me to continue to fight on, to become stable, to endure what I will not let bring me down. Let's make the most of our time.

From my heart to yours,
Your person with COPD

