We were thrilled to have eight participants in last month’s group call about medical decision making. The discussion was an important window into participants’ management of their illness as well as their expectations for help (vs. going it alone) and coping patterns.

We began by asking the group to consider their criteria for calling the doctor. How do they tell the difference between a “bad” day and a “really bad” day?

What is your threshold?
For one participant, the time to go to the ER is when it is too tiring to walk to the bathroom or kitchen without shortness of breath, in other words, when basic functioning is impossible. Another caller decides when to call the doctor by frequency of nebulizers, every 2 hours or less. For another, the threshold is when it becomes difficult to talk and her Prednisone is already “through the roof.” Others use in-home oximeter values to make the decision, waiting for their pulse ox to drop. Sally Wenzel MD, Director of UPMC’s Asthma Institute, questioned whether participants ever use fever as a sign of needing medical attention.

One participant stated she would call the doctor only when all other resources had been exhausted, and even then may call her PCP before calling her pulmonologist, not wanting to “pester” the specialist. A number of callers expressed concern about going to the emergency department where providers have been unimpressed by their having “just asthma.” One caller stated that while she used to feel that way she has learned to advocate for her symptoms as important and deserving of emergency medical attention. Another caller goes to her local urgent care center where she knows she will get a steroid injection.

One participant, who states she does not de-saturate with exacerbations, has had the experience of ER physicians treating her as if she is not ill. Her pulse ox is high, but she cannot breathe. The physicians told her she was having a panic attack. Dr. Wenzel acknowledged that unfortunately, de-saturation is often the criteria for evaluating severity. Shortness of breath is related to airway constriction or “the work of breathing.” However, air exchange through the lung’s alveoli is sufficient and so a patient will not be found to de-saturate; this does not mean that just the act of breathing is not “exhausting.” There is a need for greater education on this among providers.

According to Dr. Wenzel, if you require increasingly frequent nebulizers or when nebs stop working and every breath is a struggle, you need Prednisone. You should indeed call the doctor if you are producing dark green mucus, a sign of asthmatic bronchitis, or when every step is a struggle. Dr. Wenzel suggested that fatigue from the “work of breathing” was indeed reason enough to call the doctor.

Waiting too long?
We discussed whether participants are waiting too long, either knowingly or perhaps without full awareness of putting themselves at risk? One caller acknowledged that waiting and calling an ambulance is not wise since they do not have steroid shots on the ambulance, and the so the EMTs would only intubate.
Partnering with your doctor

One caller described how when she has an exacerbation she “goes downhill fast” and will call the doctor, typically if she has to do six nebulizers in 24 hours. She has extra Prednisone on hand and has made an agreement with her doctor to “take 40 (mg Prednisone) and then call” [him]. Often she will still call the doctor first. A few participants on the call have made arrangements with their doctor to start or increase prednisone on their own, before calling. Another participant will call her local pulmonologist before calling her PCP. Her most common threshold for going to the emergency room, however, is use of 40-60 mg Prednisone at home and the need for nebulizers very three hours. She also checks her pulse ox at home. Upon further thought, she recognizes that this kind of decline is typically preceded by a two or more days at home doing nothing, with difficulty walking from room to room, what she calls “turtling” or hiding out--so that others don’t see how sick she is. Can a flare improve on its own, without prednisone? According to Dr. Wenzel, it can, but rarely. It is often fine to call and start medication at the same time since a call back from the doctor can take a few hours.

We discussed the dynamic of waiting or deciding when to call the doctor. In Dr. Wenzel’s experience some patients are “poor perceivers” when it comes to recognizing their own exacerbation of symptoms. Others simply feel they should be able to “fix” themselves and wonder if they are sick enough. Unlike other diseases, which have objective criteria for decline, patients with severe forms of asthma are frequently interpreting their own symptoms and setting their own criteria. Deborah Gillman, psychologist with the UPMC Asthma Institute observed that among the callers the decision about when to seek medical attention can become overly personalized, a reflection of how much a patient can push or treat him or herself, in order to stay on track with the rest of their lives.

Dr. Wenzel reviewed some criteria that patients may wish to consider in evaluating their status and/or need to call the doctor:

- Changes in functioning (per above, difficulty walking from room to room, unable to meet a typical level of activity)
- Increase in fatigue
- Changes in sleep or appetite
- Changes in pulse ox on home oximeter

Participants cited Apps that they have used to track symptoms, to avoid using only subjective criteria: See Asthma Sense as one example: [http://asthmasense.com.au/](http://asthmasense.com.au/)