June 2010: Patient/Doctor Relations

The June Asthma Institute Support Group took on the topic of patient/doctor relations and communications in the care and management of severe asthma.

Participants shared their not uncommon difficulty communicating with providers about how best to treat their asthma, particularly in the E.R., when meeting a doctor for the first time. Several participants have had the experience of not being believed when their symptoms did not mirror ‘textbook’ asthma exacerbations; others have been told they must not be taking their medications.

Sally Wenzel, MD, Director of the UPMC Asthma Institute responded that many doctors do not appreciate the complexity of symptoms in severe asthma. There is currently no ‘gold standard’ test for severe asthma, and so many doctors struggle with their own uncertainty and frustration at not being able to treat a patient effectively. This can lead some (not all) physicians to question a patient’s report, rather than view the patient as the expert on their own illness. As a result, an episode of care can turn into a battle of wills.

The group addressed the challenge of communicating their asthma expertise in a way that would engage providers as allies. We discussed the need for everyone to carry an ER Intro Letter to share with new providers. Dr. Wenzel advised that these letters be comprehensive but also brief, with the most important information presented clearly, for the benefit of busy physicians.

Sample ER Intro Letter for Severe Asthma

- Summary statement about the severity and duration of illness, any history of intubations, recent test results: (“Bad asthma 10 years, 3 intubations, last FEV1 42%”)
- Responds best to (State medications)
- Best management of side effects (e.g.“Needs Solumedrol as vomits with high does of prednisone”)
- Current home treatment regimen (e.g.“Advair 500/50, Singulair, Albuterol 5x per day + Prednisone from 10-20mg/day”)
- Last hospital admission date
- Name and contact of primary physician and whether they may be called when.

Several participants have been using variations of letters like this for years. We discussed how the pressures of record keeping—one demand among the many associated with managing chronic and severe illness—may also be usefully shared with one’s care partners. Spouses or other family members should have copies of this information at hand when possible.
Additionally, participants have found it helpful when the doctors who know them best call hospitals in advance of their arrival. We discussed whether participants’ doctors have made themselves available by phone in the event of an emergency, and whether patients feel they can call their physicians, even on evenings or weekends. The availability of a doctor who knows you well has clearly made a difference, even when new providers must get involved. Group members were encouraged to confirm their doctor’s availability.