Two Reasons for a Patients’ Association

1. An Effective Patient Voice Needs Organizational Support

It is still true that most decisions in health care systems are made by experts: professionals, disease based organizations, policymakers and politicians. All are there to promote the interests of patients, but their views often differ from each other and form that of patients. As patients have become more capable of speaking for themselves, it is natural for them to join the discussion about the future of their healthcare.

Patients, like others at these discussions, should come with organizational support. The Patients’ Association of Canada provides such support for patients and families who want to bring their perspective to issues of patient care, service delivery, and policy. We aim to make your experience count.

2. A Deeper Historical Reason for a Patients’ Association

Modern health care systems emerged in the late 19th Century from the ascendance of scientific medicine. The major killers at the time of Robert Koch and Louis Pasteur were infectious diseases such as anthrax, tuberculosis, and typhoid fever. These scientists were among the first to identify the microorganisms that cause such disease and then to develop vaccines to prevent them. Their success spurred the construction of the modern acute care hospital. The professionalization of scientific physicians and nurses and led to other elements of modern health systems such as rigorous experimental science, replicable testing, definitive treatment protocols, and research on the prevention of diseases.

Because most infectious diseases are clearly identifiable, there was little or no ambiguity that required patients to be engaged. Once this paradigm was established in the early 20th Century typical patients gave their bodies over to the system and, once admitted to the hospital, contributed little or nothing to their treatment. These health care systems were enormously successful. Between 1900 and 1970, the system achieved much of what it set out to do. On the way we developed an expert-based system that provides acute care using clear and evidence based protocols with very little patient participation. The hope was that all diseases would ultimately be dealt with in this way.

Today, comparatively few deaths result from acute illness caused by microorganisms. Instead the vast majority result from chronic non-communicable conditions, with multiple causes, long periods of development, and episodic acute events. The course of chronic illness is far more ambiguous. It can vary considerably from one person to another, and in the same person from one time to another. Clinical intervention is only one aspect of managing a chronic condition; it also depends on many other factors. Particularly noteworthy is the vital need for making the patient and family experience count in the prevention and management of chronic conditions. What makes the situation even more complex, and contrasts it even more from identifiable and expertly treatable acute infectious disease, is the fact that at least a third of those who suffer from chronic illnesses have more than one such condition.

Because it is based on acute infectious diseases, our system is not structured to respond well to the uncertainty surrounding chronic illness, or to accept a partnership with patients. The system continues to seek rigorous identification and protocol-driven treatments. Therefore the nature of chronic disease results in intense frustration for researchers, practitioners, managers, and policymakers, who hope for formulaic responses to every condition, and who are not trained to understand the patient and family experience, nor to see their participation as a vital contribution to treatment.

3. Here are some conclusions:

1. A health care system appropriate to current circumstance must make patient and family experience count at every level: in direct care, in planning services, and in forming policy.

2. Providers need to learn how to listen to and understand patient and family experiences, and then make those experiences play a significant role in decision-making toward system change.

3. Just as all who now work in the system have organizations which inform and support their members, patients also need organizational support to help bring their perspective forward and affect system change - they cannot do it as individuals. The Patients' Association of Canada fills this void. To make your experience count, become an e-member. Go to www.patientsassociation.ca and join!