

“Informal” Caregiver

By Lynn Butler, Support Coordinator, Capital District

At Caregivers Nova Scotia, we are sensitive to the use of language when it comes to caregiving. The caregivers with whom we deal tell us that words *do* matter, that it is important to them that the way others describe what they do makes a real difference between feeling validated or demeaned in the demanding responsibilities they have taken on.

One term caregivers particularly dislike is “informal caregiver”. This term is sometimes used by people in professional fields. The implication, caregivers tell us, is that they are “just” family, friends, neighbours, or other well-meaning folk who provide “informal support” or “informal care”. It is the doctors, nurses, occupational therapists, physiotherapists, social workers, and home care workers who are paid for their services who provide the “formal” (that is, the “real” support).

Those who use the term “informal caregiver” are no doubt doing so with no intent of insult, but we would ask them to think about how the phrase is perceived by caregivers. How do they perceive the work that they do? How many of them would refer to the work they do, the duties and tasks they perform, and the responsibilities they have as “informal support”?

Caregivers quickly become expert at providing care to their loved ones. Most soon become well educated about the disease or health condition of their care recipient, be it frailty, cerebral palsy, Parkinson’s, MS, dementia, cancer, or any of a myriad of other disorders. Caregivers know their loved one better than anyone else including the activities with which they may need extra help and support.

Caregivers organize complex care and medication routines. They talk with a range of professionals, including physicians and pharmacists, to better understand the health conditions and learn what exactly needs to be done. They work alongside homecare workers, assisting and orienting them to the unique challenges of their care recipient’s case. Caregivers frequently research community and government supports, and they may even be searching for clinical trial opportunities. It is caregivers who are the first responders in a crisis. It is typically they who recognize when something isn’t right and that immediate attention is needed.

The responsibilities and duties of caregivers are anything but informal. How can we begin the process of banishing a term that offends the people on whom we, as a society, are so dependent? Let’s start by recognizing the extraordinary service they provide to the country. At last count—in 2012—there were over 8 million Canadians, family and friends, who gave care to another person dealing with a chronic or acute physical or mental health condition or with aging related problems. Without unpaid caregivers, the health care system in this country could probably not function: it is unsustainable without them.

So the next time any of us starts to speak the words “informal caregiver” or “informal support”, let’s stop and think how would the caregiver likely respond. What term best shows the value we place on their indispensable efforts, only essential for their care recipient but invaluable to Canada as a whole? So, let’s all adopt the phrase caregivers prefer: family and friend caregiver.