SPOTLIGHT: PATIENT CENTRED CARE

Patient commentary: social media provides patients with support, information, and friendship

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When I was diagnosed with systemic lupus erythematosus 32 years ago, aged 15, social media did not exist. After months of diagnostic tests, I was happy to find out that my condition had a name. Six months after diagnosis, I attended my first lupus support group, where the topic for discussion was funeral planning. Questions posed included “what prayers and flowers do you want?”

For me dying was not an option. My mother and I looked at all the treatment options. We told the doctor that I was going to be a long term lupus survivor. My doctor took my mother aside and suggested that was unlikely. Shortly afterwards I found a different rheumatologist. Patients have the right to change doctors, and I did.

My new doctor had a good understanding of the spectrum of illness that lupus can cause. He also knew that when he suggested any change to my treatment that my mother would say, “If your daughter had lupus, would you give this medication to her?” Our doctor-patient relationship lasted 30 years and was one of mutual respect.

When he retired I used social media to find a new rheumatologist and an internist open to respecting patients’ views and exploring alternative therapies as well as conventional medical treatments. Social media not only enabled me to find new doctors. It was also the way I met Tiffany Peterson. Only 48 days after she had lupus diagnosed, Tiffany searched “lupus” on Twitter, and my Twitter profile (@LAlupusLady) appeared. Soon, we were sharing the latest research and our excitement when the first drug specifically designed for lupus was approved by the FDA, and supporting each other through disease “flares.” Having had the disease for many years, I was able to offer her the insight and support that her doctors and other healthcare professionals simply could not.

In 2011, I spoke at the #140 “State of Now” conference in New York (where speakers share stories on how Twitter has changed their world) on “Lupus Awareness is fun, Lupus is not.” It was there that I met and hugged Tiffany in person for the first time. A lifetime friendship had started. We are “lupie sisters.” Lupus may have brought us together, but it’s our passion for sharing and supporting lupus awareness that has made us friends.

As patients, we realise that many health professionals have yet to embrace the powerful tools that Twitter, Facebook, Instagram, and other social media platforms have created. Most doctor’s offices are busy, understaffed, and view social media as a distraction. If only they took a moment to realise the benefit of offering a “patient portal” or posting a monthly blog. Supporting patients with information online would result in healthier patients and could reduce their workload.

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