

## 1. THE BEGINNING OF THE JOURNEY

### **\*Persevere - and Get What You Need\***

The time may come when an illness requires surgery. Should this happen to you or to someone you love, you will want and need to be prepared.

Throughout my life, I have taken extremely good care of myself. Unfortunately, the critical day came when I was told that I must have surgery. As a Licensed Massage therapist, Jazz Ballet instructor and Tai Chi Master, diet and health care have been a top priority in my daily regimen. During production of a nationally syndicated series on Tai Chi for PBS television (Public Broadcasting Service), I began to experience some unusual symptoms such as mild abdominal swelling and heartburn. These escalated over six years into migraine headaches, chronic insomnia due to acid reflux, a small hiatus hernia, and loss of appetite. Although my eating had diminished, my dress size went from a size 5 to 12 in the last two years of this six-year stretch!

As a supporter of alternative health care and conventional medicine, I left no stone unturned. My only inclination was a twenty-year old diagnosis that I had a genetic disease called PKD (polycystic kidney disease with secondary cysts on my liver). However, subsequent testing found these organs were functioning normally. Upon further examination, my general practitioner (GP) discovered that my liver was enlarged and could be pressing on my stomach. He referred me to three specialists - a gastroenterologist, hepatologist (liver specialist), and nephrologist (kidney specialist). The first found a small hiatus hernia with no other abnormalities; the second was bewildered and offered no advice; the third said even if it is the liver causing these symptoms, there are no adequate surgical procedures to resolve the problem. Needless to say, these unhelpful meetings left me discouraged and frustrated. It appeared that the medical community was stumped.

My Irish boyfriend, Ian, would say with his charming, leprechaun accent, "There must be someone who can help you." Ian was born and bred in Belfast, Northern Ireland, and has the stubbornness and loyalty of a 'Taurus' (his astrological sun-sign), which benefited me greatly during this time. Fortunately, he would not give up and commenced a search on

the Internet, which eventually led to the Polycystic Kidney Foundation. They provided literature with a caveat that their organization primarily dealt with polycystic kidneys. Fortune was shining upon me, as the first pamphlet I received advertised an audiotape on “Polycystic Liver Condition” by a nephrologist at the Mayo Clinic Rochester. You can only imagine what incredible joy and relief I felt when finally, a doctor accurately described my condition and its accompanying symptomatic nightmares. The search was over; I had found my pot of gold! Research studies indicate that a small percentage of PKD patients will manifest difficulties with liver cysts and the rarity of this condition had baffled the medical profession.

The next stage in the campaign was to get my HMO (Health Maintenance Organization) to approve a consultation at the Mayo. In order to convince my HMO, I had to have a referral from my GP to whom I gave a copy of the audiotape. Fortunately, he granted my request, but my HMO insisted that I exhaust all possibilities in Florida first. Dutifully, I went to see a hepatologist associated with a liver transplant clinic but, true to form, he was unfamiliar with my condition. He did however recommend a test that would require a special wire to be inserted into my stomach to monitor my bile and acid levels for a 24-hour period.

After one month of trying to secure the appointment for this test, I found out that it could not be performed until my hepatologist gave the specifications with regard to the depth of the wire insertion. I then realized that all my efforts thus far had been futile. Disappointment and frustration erupted, but I was resolved to battle forward! Subsequently, I called the hepatologist to tell him that all I really wanted was to go to the Mayo Clinic where I had found a doctor familiar with my illness, but that my HMO insisted I must first explore all possibilities in Florida. He fully supported me by saying that I should not be denied what I need and that he would contact my HMO with this recommendation. Little did I know, *How to Rehearse Before You See the Nurse* was just beginning!

The moral of the story is no matter how long you have to wait, how hard you have to search, how emotionally and physically demanding the situation - persevere and get what you need.