



The Hidden Costs of Lupus

There are a surprising number of hidden costs on the road to a lupus diagnosis and of your treatment. The examples I give come from my own experience, my clients and others I have met in the lupus community. I was reminded recently with price shock when I got to the blood laboratory of this issue. The purpose is not to scare you or give you anxiety but to make you aware of things that you will need to budget for, even if you live paycheck to paycheck.

Some laboratory tests are not covered by OHIP. Lupus anticoagulant or antiphospholipid antibodies blood test \$70, food sensitivity/allergy immunoglobulin IgE and IgG (such as those done by LifeLabs using Rocky Mountain Analytical) blood test not skin pricks varies from \$100 to \$400, T3 and T4 if your TSH is in the normal range, free T4, PSA for men, etc. The point is to ask your health care practitioner when they give you a laboratory requisition if any of the tests are not covered by OHIP. This also applies to some diagnostic imaging, x-rays, ultrasound, CT, MRI, bone density, mammogram, PAP test, etc. depending on the frequency of testing your doctor is asking for. This also applies to a number of eye tests used in lupus especially when taking Plaquenil. The OHIP rules constantly change on time frames so ask when you book your appointment if the test is covered. Some people are able to claim these tests through an extended health insurance plan, however, for many people it is another out of pocket cost.

Co-payments on prescription medications and medication delivery devices. I have found this to range from a few hundred dollars a month to a couple thousand dollars a month. I also found that banks, trust companies and cooperatives will not lend money for medical expenses. Many lupus patients I have spoken with have to make daily decisions between food, rent and medication. Pharmacy filling fees and the co-payment amount are usually lower at independent pharmacies compared to chains. This will depend on where you live. There are a number of medications that are not covered at all by ODB the Ontario Drug Benefit or private health insurance. You can ask your pharmacist before you fill a prescription if the medication is covered by any of your plans. One example of this for me was in the 1990s where it cost \$35,000 a year for interferon alpha. I am still recovering from that debt 30 years later. Name brand Plaquenil was not covered and was \$400 a month. Many vaccines are not covered so ask the price before you schedule the appointment. It does not do you any good to pay for a vaccine if it leaves you with no money for food for several weeks.

Lost time at work. There is a limit to the number of sick days and vacation days that employers allow you to take. Some workplaces have short term disability plans while others have nothing. The provincial sick benefits are for a very short duration and the time frames and report requirements are frequently updated. For many of us that means days to years off of work without pay. Some people who quit their job due to lupus are able to get ODSP the Ontario Disability Support Program which has some medication, dental and travel to appointment benefits which are assessed on an individual basis.

Loss of tuition for post-secondary education. Most institutions I have spoken with do not reimburse tuition for illness, however, many will offer extended project deadlines or longer times allowed for tests and exams. You are still responsible for your student debt even if you cannot continue in the program or to work.

Co-payments on medical devices. The example that I have run into several times is there is the co-payment on the actual main part of the device but no coverage for the related components under ADP the Assistive Devices Program. One example is CPAP and CFLEX machines which are covered in part but you may have a \$300 or more copay and the head gear is not covered at all which can be an extra \$250 to \$350 every couple of years when the head gear wears out. Also the consumable supplies it uses such as filters, distilled water, and cleaners are not covered. These are only covered by a few extended health care plans. Many lupus patients have developed diabetes after long term steroid use and the cost of monitors, test strips and needles may need to be added to your budget. Oxygen equipment is not covered under ADP if you fall just outside the covered ABG %. This can be \$500 per month. Some devices are not covered at all. Most equipment purchased through ADP is eligible for replacement on a 5 year cycle. Another uncovered expense is maintenance on wheelchairs, scooters and walkers.

Body Therapies, Counselling, Etc. OHIP does not cover physiotherapy, chiropodist, chiropractic, osteopathy, cranial sacral therapist, acupuncture, laser therapy, TENS treatments, massage, reflexology, naturopath, homeopath, homeopathic remedies, special diets, herbal products, energy therapy (therapeutic touch, reiki, shiatsu, qi gong, etc.), psychologist, social worker, art therapy, life skills coach, health coach, paralegal, personal shopper, and many others. If you have extended health insurance that covers any of these, great as these treatments can usually improve your quality of life. If you don't you need to build it into your budget.

It is important to have a discussion with your family about finances and how lupus affects your overall budget. It breaks my heart when I talk to people with lupus who cannot get most of the medication and treatments they need. I ask you, even if you are a household of one person, to sit down and take a serious look at your finances and plan for extra costs. Put your plan down on paper and review it once per year or when your health changes.

The bottom line, "BE PREPARED".