



**Heather's Story - Australia**  
**Age of Diagnosis 9, Current Age 28**  
**Time to diagnosis – 5 years**

**Living with Chronic Illness: Primary Sclerosing Cholangitis**

It is often hard to explain to others, especially healthy people, what it is like to live with a chronic illness such as Primary Sclerosing Cholangitis (PSC) or Ulcerative Colitis (UC) - let alone what it is like to live with both of these conditions as well as another auto-immune disease, Erythema Nodosum (EN), that is sometimes seen in conjunction with PSC and UC. This EN was the first visible sign that something was seriously wrong, causing swelling in my feet and ankles, as well as painful lesions that appeared on my legs, ultimately leading to the diagnosis of UC at the age of six and eventually PSC at the age of nine, after a long period of eliminating other possibilities.

PSC is a progressive disease that effects the bile ducts of the liver where inflammation causes scarring, strictures and narrowing of the bile ducts which eventually causes serious liver damage and ultimately liver failure. Unfortunately, both as a young child and as a teenager, I required several hospital admissions, numerous tests, procedures and treatments, not to mention the regular clinic appointments (every three months). Due to my impaired immune system I also got sick more often and for longer duration than other people - and I still do. This meant I also had to take time off school more often than most other students and my Mum had to take time off work to be with me at appointments, during hospital stays and to care for me while I was sick - things for which I will be forever grateful for, but all things that added to personal and family pressures.

Being diagnosed at such a young age I have come to see a lot of the daily struggles as "normal", because they are normal... for me. However, until recently, a lot of the really scary outcomes, the big, life changing outcomes have always been something I would have to face in the future... except now the

future feels a lot closer than before. I was lucky enough to be relatively symptom free for an interim period of about 6 years and remain free of the EN symptoms, but this year my life is changing and I've become gradually more and more symptomatic with PSC and UC, with multiple hospital admissions and a list of medications that seems to grow longer with each clinic appointment and that all come with long lists of side effects.

Having medical conditions like PSC and UC has forced me to come to terms with a lot of things that healthy people rarely need to consider at such a young age, including my own mortality. Each day, because I get tired and worn out very easily, I have to pick and choose carefully what I will spend my limited energy on and it has been hard to come to terms with the fact that I can't "do it all" like I once could. I have also, at times, been unable to work or even look for work, which has been one of the hardest parts of all this, for the obvious reasons of income and independence, but also, unfortunately there are those who have judged me both unkindly and unfairly for this, and maybe that is because in the past I have been reluctant to tell others about my experiences and be open about living with chronic illness for fear that it will seem like I am making excuses for myself, which is where the importance of awareness about chronic illness such as PSC or UC comes in, because it is easy to make assumptions about people when there are sometimes no obvious outward symptoms of illness.

At present the only curative treatment for PSC is Liver Transplant, and as I have read in medical journals, heard first hand from other PSC sufferers and been told by my doctors, one day I will likely face the reality of needing a liver transplant myself. In fact, at my hepatology clinic appointment just two days ago I was told that there are generally only two outcomes with PSC, the first being the development of Cholangiocarcinoma (Liver Bile Duct Cancer), and the second being cirrhosis of the liver requiring liver transplant.

I try every day to stay positive and look after my body as best I can, but symptoms of abdominal and liver pain, fatigue, chronic itching, and more recently the fevers that make whole body tremble uncontrollably which accompany the recurring infections in my bile ducts (just to name a few) often make that challenging. I also wonder whether I will be able to have children or if that will put too much pressure on my body. As a result, I also often struggle with anxiety and depression, but despite the fears I have about the future and what the outcome of all of this will be, I am trying as much as possible to live my life to its fullest and if living with chronic illness has taught me anything it is to not take anything, or anyone for granted because at the end of the day, I am still thankful for the life that I have and the people I share it with.