Patient Story 2 – Female, aged 39 when diagnosed with CLL

In 2011 at the age of 39 I was diagnosed with chronic lymphocytic leukaemia.

The diagnosis came after a couple of years of frequent sinus/chest infections followed by a particularly long bout with a red eye (episcleritis).

Some tests were ordered and the day that I went to receive my results I felt physically good and expected to get a clean bill of health. I dropped my youngest child off at play school and went alone to the consultant's office. When he saw me in the waiting room he asked if I'd brought anyone with me.

That was my first clue.

He explained that my blood results showed I had Chronic Lymphocytic Leukaemia, that he himself was not a specialist in that area and would refer me onto someone who was. The rest of the conversation and the days that followed are a blur as I tried to figure out what this was going to mean for me and my family.

Those early days were beyond frightening.

There was a waiting list to see my new consultant, my GP though sympathetic, admitted that she did not know much about CLL and there was no information out there about living with CLL in Ireland. So my husband and I turned to the internet and to the American and UK online support groups. The friends we made there offered hope and support and information throughout the journey and continue to do so today.

Fortunately my haematologist is a specialist in CLL and is informed and proactive when it comes to treatment options. The timing of my diagnosis coincided with the development of newer targeted treatments that represented an amazing paradigm shift in the treatment and prognosis of CLL. From early on we had hope that the newer agents would offer me a shot at leading a 'normal' life. The wait to access the newer drugs would prove to be arduous and frustrating.

Shortly after my diagnosis I became symptomatic of my disease.

I had enlarged nodes in my neck, abdomen, underarm and an enlarged spleen. I had 80% infiltration of CLL cells in my bone marrow. Frequent infections and fatigue took their toll on my quality of life and that of my family (four children under 11 then) .We consulted with a child psychologist at the time for advice on how/when to tell the children. That issue was difficult since it seemed like a lot of the advice out there at the time was really for people trying to explain an acute cancer but since my cancer was chronic and incurable we really needed to think about how we explained that in both realistic and hopeful terms.

We found out that I needed regular immunoglobulin infusions since I was one of the small number of CLL'ers who also had hypogammaglobulinemia (low immunoglobulins). There were hospitalisations for pneumonia and then ITP and then AIHA. We tried a few 'milder' treatments always thinking and hoping that the newer drugs would be available soon.

There was a particularly scary 'blip' on the journey when the biopsy of an enlarged node in my neck appeared to suggest a transformation to something more serious. Luckily it was virus mimicking this result in the lab and the issue was resolved. But there were some sleepless nights at the time.

My Irish haematologist encouraged us to seek out a second opinion in the UK. He referred me a CLL expert in Leeds UK. The professor took on-board that I was young for CLL and the added complications with the ITP meant that chemotherapy would have been a difficult/ inappropriate treatment option for me. He put me on a waiting list for the upcoming ibrutinib trial. I waited for 10 months for the trial to open and there were times when it looked as though I might have to abandon the idea and just go ahead and take my chances with the chemotherapy.

The support and warmth that we received at that time from extended family, friends and neighbours was heart-warming and something we'll always be grateful for.

Finally in September 2014 [after a long summer of waiting and juggling family life and fatigue] I started ibrutinib.

There was some hardship involved financially and the travelling was tiresome in those early days. The bone marrow biopsies were sore but the trials team agreed to sedate me for those and the hospital were extremely cooperative and accommodating to us where possible. It was a testing time. Since ibrutinib works slowly at the start and usually WBC goes up before it comes down I was closely monitored initially. Side effects of the drug for me included joint pain, heartburn, infections and bruising easily.

Gradually I began to feel less fatigued and my blood counts started to normalise. I had a few challenges around needing some minor surgery and having to stop taking the drug and bleeding issues. After my first year taking ibrutinib I was feeling almost back to my old self.

I continue to take three capsules every morning and for the most part I don't think about my CLL much for the rest of the day. I travel every six months to Leeds for a check-up now and I continue with iVIG regularly. I have a very small amount of CLL detectable on tests and it's likely that at some point in the future I will need to pay attention to it again and perhaps look at other treatment options.

As a by-product of this CLL journey, my husband and I have made many new friends and have become interested in patient advocacy for CLL patients in Ireland.

I would encourage anyone newly diagnosed with this disease to seek out a CLL specialist and to get informed and arm themselves with information so that when the treatment options are presented they will be in a better position to decide what's right for them and their loved ones. I would remind them that though currently incurable it is possible to live long and well with CLL. I intend to prove it.

Jan Rynne, 39 at diagnosis, female.