



Ups and downs

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I was first diagnosed with chronic lymphocytic leukemia (CLL) back in 2002 when I went for a routine cholesterol check and the doctor called me to tell he had a bit of bad news.

While my symptoms at the time of diagnosis were mild, I had found it difficult to fight colds and flu my whole life. I wasn't a stranger to CLL as my sister also had it and passed away back in 2005. That said, **I didn't know a lot about the disease but I did know that it was a blood cancer.** From what my family said about my grandmother's passing, I strongly believe she also had leukemia but as it was the 1920s, it wasn't diagnosed. When I was diagnosed, I was referred to a hematologist who said that **I might never need treatment and that I could lead a normal life but they would need to keep an eye on it with blood tests every six months.**

I kept working but moved to a less stressful job as a taxi driver. I didn't want to tell anyone that I had leukemia as I didn't want everyone ringing me asking me questions about my condition. **I know that might have been hard on my family but it was my way of not letting it impact my life too much.** The doctors told me that if I noticed any changes in my condition, like my lymph nodes swelling, I'd need to let them know. In 2004, I started showing these symptoms. I had a big lump under my arm, my lymph nodes were enlarged and changes also showed up on my routine blood test. **As a result of these changes I had my first round of chemotherapy tablets.**

Again in 2005, the lymph nodes and the blood tests changed so I was sent for another round of treatment with tablets. **In 2006, my blood cancer became far more aggressive.** My neck swelled up and my wife affectionately told me that I looked like Fred Flintstone as my neck was as wide as my face – there was no difference between the two! I was unable to work and others were noticing a deterioration in me. As a result, I was put on an intravenous chemotherapy treatment for about six months in three-week cycles in the hospital. During this period of treatment, I was tired and I had diarrhea. **But the important thing is the treatment worked and I went into remission for five years.** During those five years I was completely better and didn't even take one tablet.

Unfortunately, in 2012 I relapsed and my CLL returned despite me feeling fit and well. I went for my usual blood tests and my consultant noticed a change in the cells in my blood, I had too many lymphocytes. I had also developed a complication called the P53 deletion which meant I might not respond well to chemotherapy. My consultant told me about a new clinical trial and asked if I wanted to be part of it as he felt it was my best chance and I agreed to participate. However, I wasn't put on the new therapy in the trial and unfortunately didn't respond well to the standard therapy that was given. **My health deteriorated and led to me having a mild heart attack.** I came under

the care of a cardiologist who identified that I had several blockages in my heart and I had three stents fitted.

In 2013, my symptoms got much worse. I was losing weight and my lymph nodes were enlarged and I looked really pale, almost gray. This time around it was difficult for my consultant to treat. They tried several different chemotherapy treatments but I seemed to be getting worse. At this point my health was quite poor. My diarrhea was really bad, I had terrible night sweats, I couldn't sleep, eat or walk – **as my wife said I was 'melting away' because I had lost so much weight.** In January 2014, my consultant told me my CLL was at an advanced stage and **I was given 12 weeks to live.** Thankfully due to the improvements seen by patients on the other therapy in the trial **I was transferred over to that treatment.**

After that my symptoms quickly subsided, **I also started to gain weight for the first time in a year.** I'm still on that therapy today and continuing to live a full and happy life with my wife. I did have to come off my therapy recently when I had to have a minor procedure and my CLL symptoms came back quickly so I know my disease is still there and I'll receive treatment for the rest of my life. It's been a journey of ups and downs but what remained consistent was **the support of my wife.** I had to build a lot of mental resilience against my CLL and I did that **by staying active and keeping to my normal routine as much as possible.**

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