

Charlie Croft – Biography for NICE

When first diagnosed with Crohn's, at Great Ormond Street Children's Hospital, I was just about to begin my first year of GCSEs. I had experienced several months of chronic fatigue and severe pain, which meant I gradually gave up most of my non-academic activities, particularly sport. The treatment, which was a combination of immunosuppressants and diet replacement, was unable to prevent these recurrent bouts of illness, or to prevent the disease having a significant impact on my life. I began on azathioprine and pentasa, which was increased to a high dose of methotrexate and azathioprine. At no time was my Crohn's in abeyance. Additionally, the need to fast for 6 weeks at every flare up, followed by periods of restricted diet, had a big impact on my life with my peer group. I was constantly tired, well beyond the normal levels of my peers; I often felt nauseous, and was very susceptible to any cold, cough or sickness that happened to cross my path. In four years, I had seven flare ups, with all that they entailed, including the 6 week fast.

All this had a very adverse impact on my academic studies. I missed a lot of school and without tremendously supportive teachers I would probably have got poorer grades than I obtained.

It was during another flare up that I started to use adalimumab. At the time, I had just returned from a trip to France and was embarking on an internship at Shakespeare's Globe in London. I would not be exaggerating if I said that the effects were almost instantaneous. Overnight, I practically ceased to have any of my previous symptoms, including intestinal pain, bad wind, nausea and fatigue. My internship went so well they have since employed me on a temporary basis, until I go off to university, which is another thing I would have been unable to contemplate without this treatment.

Part of my Gap year has been spent retaking exams, as I had a flare up during my A2 modules. My Maths results leapt from the 30s to the 90s, despite the fact that I had had no lessons for six months. Equally, I expect my French marks to have improved significantly, since I feel the exams went well, even after a year without lessons.

I am a different person since I started taking adalimumab. I am less despondent, less insular and much more optimistic. I have a positive outlook on my life and future. I am more my old self, and have to attribute this to the drug and all that it has given me: a sense of self worth, freedom and the joy of living again. Clearly, adalimumab has been a miracle drug. Without it I would probably have been unsuccessful in my retakes, I would have had frequent absences from work and been unable to travel abroad. I now have the prospect of going to a good university where I intend to get a good degree. I am able to look forward to

studying again, and am really motivated to dispel the shadow of my disease. I had previously been advised to apply for Disabled Living Allowance, but now I believe it would be entirely inappropriate as I feel completely healthy.

For me, the best things about adalimumab, apart from its efficacy, are:

I don't need to go to hospital to receive an infusion. I can decide to take my injection and be finished within a few minutes at home, with no travelling, no need to fit into a schedule, no need to request time off or any support. Constantly visiting hospital only serves to remind me of my ill health and makes me feel dependent. As a young person I hate to think of myself this way.

I am free to travel and work abroad and take the drug with me. No-one else has to know about it, which is again important to my self-image as young person. Although I don't hide my illness, it isn't something I'd choose to reveal by way of an introduction.

Because adalimumab is fully human derived, I understand there is a lower chance of my developing an immune response. Again, being young, I want to minimise any additional future problems with my health. Personally, I can see no downsides to taking this drug, especially when comparing it to other treatments, such as surgery, steroids or Infleximab.

If I consider the possibility that this treatment was no longer available, I would have to compare the last year of my life to how it was before. I can safely say that, having reached an almost promised land, I have no wish to go back. The chance that I wouldn't have the years of health that I hope to have would be crushing.