

# Jamie

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It has been 6 years since my Mother wrote about my life so far and how we as a family dealt with Pompes. In these last six years a great deal has happened and I'm sorry but recalling every detail would be impossible and would probably bore you half to death, therefore I will try and summarise as best I can the ups and downs I have encountered living with Pompes and being on Enzyme replacement therapy as a teenager / young adult.

My philosophy has always to live life to the fullest, to enjoy every moment without thinking negatively "We pass the time of day to forget how time passes". I am lucky enough not to be too physically disabled and therefore can forget that I have Pompes disease and I try to do things that any healthy person could or would do (within limit). I am fully aware of the fact I could progress in the future but at present I am stable and healthy and for that I am grateful.



*Jamie taking a shot.*

After my spinal operation in 2005 I gradually started to get back into tennis where I could rebuild some strength and the enzyme replacement therapy thereafter may have helped or at least stopped the progression of the disorder. About six months after the back operation I felt nothing, no pain or discomfort and was eternally thankful for what the Doctors and my parents had made happen. Those few months of agony and stress were all worth it in the end – I have a more or less straight spine and never have any back problems (touch wood).

Soon after this I started college and took a number of Art based subjects to progress and widen my education with a view to study film production in the future. For two years I studied Photography, English, Music technology and Fine Art. Here I met some wonderful likeminded friends that I still spend time with even though we all went to different universities. Throughout college my ERT was never a problem, I would take an afternoon off every two weeks, which unfortunately would usually be photography (my favourite subject). Also I tended not to tell people why I would be absent but as people began to ask I did slowly reveal the truth. Whenever I imagine telling my peers about things like I have ERT or I use a bi-pap at night I always imagine an onslaught of "Oh my god your so weird" or similar negative responses but I have come to realise that the majority of people feel sympathy for you and do not want to hurt your feelings. I think my imagination is great at delving into dark areas of my psyche and convincing me that my friends secretly think I'm weird because I have this illness but in fact I have come to believe that it is actually quite the opposite. I would now like to think that I'm unique instead.



*At a Tiger temple in Thailand, just north from Bangkok.*

University was then a similar story of slowly trying to break it to my housemates that I use a bi-pap and have a medical condition, which needs treatment every two weeks. I imagine it felt similar to "coming out of the closet" although I am not interested in men so cannot say for sure. The tension builds and builds and the longer you put off telling them the worse it feels and once you do that relief is the greatest feeling in the world. When I did there was a small amount of silence then " ah ok, that's fine". Once that was over I then remember they quickly moved on to talk about other things totally oblivious to my anxiety.

Whilst at university I also made lots of friends and enjoyed the experience thoroughly. I am lucky in that I have inherited the need to talk to strangers and make conversation from my mother and therefore tend to find it easy making friends.

My course *Film production* was highly practical and meant that I could make films rather than just study them, which was my main objective in taking the course. This did mean that more lifting of heavy camera and lighting equipment was involved though it never phased or stopped me from doing anything and I never wanted help or assistance. Going to university and suffering from Pompes also enabled me to gain a free laptop and printer through a disability scheme our UK government has.

Throughout these three years of university I did a small amount of exercise but regret not making more time for it. I tried vibration therapy for around 2 months which was great fun but too expensive for me to keep up. I also joined a gym and had a few sessions but I have never been dedicated enough to keep at it. To sum up university it was a great experience meeting people, creating lots of portfolio work and living independently. There are a few things I probably shouldn't have done involving alcohol and the other substances that go with the territory but I came out of it all unscathed whilst living with Pompes disease.



*Filming is quite heavy.*

Currently I am working on a number of film projects whilst still having the fortnightly infusion through homecare. I am working with my father on a feature length documentary for the charity under my new business Jamiemuirfilms ([www.jamiemuirfilms.com](http://www.jamiemuirfilms.com)), which aims to make music videos, commercials and short films.



*With my mother in Spain.*

I enjoy traveling and have been to spent time in Thailand and Ecuador taking photos ([www.jamiemuir.com](http://www.jamiemuir.com)).

I make sure that my Pompes disease doesn't get in the way of my life and what I can achieve. In my career I dream and try to make those dreams a reality and I think that is what we should all try to do with regard to our illnesses. I am sure none of us will ever reach that dream of being perfectly healthy but it is the journey and pursuit that is exciting and makes life worthwhile. Do not give up and live your life!



*Abseiling off Guys Tower Hospital in London.*

**Jamie Muir, United Kingdom**