



Living with XP



Hi - I am Richard.
I am 27 years old
I am a Junior Doctor and
I have xeroderma pigmentosum

I was diagnosed at 8 years old and here are my thoughts about living with XP from my perspective.

What are the most challenging aspects of living with XP?

As a young adult with or without XP a major source of worry is appearance. This applied not only to my actual skin and freckles but the clothing and visor that goes along with it. I have now got to the stage where I am comfortable with wearing whatever I need to in order to be safe. I am much less concerned about the staring, questions and comments. I think appearance is an issue the majority of people let themselves be weighed down by too much, XP or no XP.

XP is like any other health condition really. There are many aspects of your life you will have to adapt around it but this is by no means impossible; you can find ways to do whatever it is that you want to do. Also note though, no matter how positive you are there will be times when it becomes too much and there is nothing wrong with taking some time to let it out; in whatever form is helpful to you. Whether this is pouring your soul out to your parents or a friend or bashing a puck with a hockey stick. **We are all human and you shouldn't feel weak or ashamed when it gets too much.**

How did XP impact you as a child?

As a child, all I understood was that I shouldn't be outside. This meant I couldn't play football with my friends, without wearing all my protective gear which made the game very difficult as the visor fogged up very fast. This upset me a lot when I was much younger but luckily for me my two sisters adopted the same routine and we always found things to do inside; meaning my sisters are two of my best friends. I also have and continue to have a circle of friends who are very considerate of me and always fit plans around me without a hint of irritation.

How did having XP influence your career choices?

XP means a lot of hospital appointments with a lot of different types of doctors; mostly skin specialists. When you're on the way to visit these specialists you're reminded of the seriousness of your XP and its immensely worrying thinking about what you may be told. Therefore, the impact it has knowing you have such dedicated people looking out for you is immeasurable. Not just from a physical health perspective but a psychological one also.

I knew from a very young age that I wanted to be one of these people and provide others with this incredible service.

I am a doctor today because of having XP.

Are there positive things that come from living with XP?

Living a more indoor based lifestyle, allowed me to discover my favourite sport of ice hockey. This provides an invaluable stress relief as there is a very high level of physicality involved in this sport.

XP also meant I am very close with my two sisters, mum and dad; perhaps more so than other families. XP affects the way I think also; generally I'm much more relaxed about the little things as I have come to realise that most things are not really that important in the grand scheme.

How does XP affect relationships and how others treat you?

If and when it does, I try to discourage it as actively as possible. **The most annoying thing is when people say how much they feel sorry for me.** I have no time for this negative response.

Ultimately, what is on the inside is what is important. Looks don't matter although obviously this is all easier said than done and as a young person there is a lot of worry over meeting a girlfriend / boyfriend which the majority of people mistakenly believe revolves around you're appearance.

XP has influenced the way I think and what I value in others, for the better.

What advice would you give to a child living with XP or other rare disease?

My dad always tells me; "you can't eat an elephant all at once". In other words take XP one step at a time. Focus on doing whatever it is you want to do or achieve and make sure XP is not something which gets in the way of it.

XP may help to shape you, but it certainly doesn't define you.

