

The high life

Osteogenesis imperfecta, two very big words, with a million words behind it. This is my story.

It sounds really scary; I can still remember being first diagnosed and being scared to death, like I was being diagnosed with some life threatening disease. I was so wrong; I can honestly say with the help and expertise of the children's hospital OI team I have never ever been worried about my condition, they are the best group of doctors and nurses I have ever met, but let's get on to the real story.

I was diagnosed at the age of four after many unknown breaks and fractures; it's annoying I'm pretty sure all my other fellow OI sufferers hate the first moment when your told you have 'fractured once again'.

I'm lucky I only suffer with type one, the mildest type, I'm still susceptible to breaks and fractures, but really I am nothing compared to how bad some people have the condition, I don't know how some of the worse type patients put up with knowing that even the slightest knock could fracture or damage a bone. That's why when I was asked to put something together about my condition for other people to read I didn't think I was really special enough to write about the condition, as I know there are thousands of people all around the world in a much worse predicament than me.

I have had the honour to meet some really special people through having OI, the people that really do have it bad, but still somehow manage to keep a smile on their face and enjoy their lives, they are the people who have really beat the condition.

Fractures have really come heavy through my life, from the age of four onwards I've either been in a cast or about to be put in one, from the heart I can truthfully say there's really nothing worse than them great big bulky casts, god they have caused some real telling offs on my part, I remember the one time I actually got hold of a screw and tried to make a hole in it, don't think I've ever had or will have a talking to that bad by the plaster technicians and my parents ever again. Once I've somehow managed to make my millions in life, I make a promise to all the OI patients in the word that I will devise a special tool which fits perfect down your plaster cast to itch them really itchy places, you know them places which the ruler really can't reach.

I've also had my fair share of operations thus having: K wires, eights plates and three Nancy nails inserted into me, I tell you what, I really do give them airport security guards a fright when I walk through them metal detectors, anyone would think I'm a terrorist with all the components my body is packing.

Over the years I have found that the best way to cope with OI is to change your mind set from 'I wonder when I will break again' to 'it's been ages since I last broke', I find if you're always expecting a break then the most likely thing is that you're going to break. 90% of the time I literally forget I even have the condition and enjoy life, yeah I don't go out and play rugby (that really wouldn't end up well), but I still manage to give it all when I play other sports (preferably the ones where there is a smaller chance of me ending up in the back of an ambulance.)

Having OI has the lows, well actually quite a lot of lows, I've recently just found out that having the condition can lead to hearing loss, but then look at the highs, with that hearing less I can pretend to not hear some things for example 'Lewis come do the washing up' or 'do the vacuuming please' somehow I may just manage to hear most things except them!

Some of the younger kids who have the condition, if there's one thing you take away from having this is to be never ever scared of a hospital, they are probably one of the safest and friendliest places I have ever been to, can't beat three hot meals a day and a nurse, best bit is by far the little remote you get with the 'call for assistance' on it, I've had some fun with that little button. Oh and another thing, remember to tell your parents you really do deserve a treat after an operation, as you can easily point out there are usually many fast food places near the hospital, don't hesitate in asking for a good old big mac or KFC, you deserve it.

OI will never go away or disappear, unless a cure is found (note to Dr Shaw, hurry up and find one), but I don't really mind that, I will always live with it, but that doesn't matter I know it sounds ridiculous because it has made me the person I am today. Without OI I wouldn't have met half as many amazing people I have met through them ever so famous coffee mornings, with the all you can eat biscuits, that's not the only reason I go don't worry!

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