

My name is Jane O'Keeffe, I am a 38-year-old mother of one from Cork. I will begin by giving you a brief outline of how I became an amputee.

Roughly three years ago I was out walking my then five month old baby in the buggy, when my right hand started to get a bit sore. After a few weeks I decided I'd go to the physio and get it looked at. She said she could feel something there but the physio was giving it some relief and it wasn't very painful so we both felt it was just from excess walking while pushing the buggy and laughed it off.

As the week went on I started to wake every few nights for a few minutes with a sore hand, kind of like a burning feeling but nothing too drastic but I decided I would get it looked at by my GP. I went to my GP in August and my hand looked exactly like my left hand. There was very slight swelling, but he said he would send me for an MRI just to be on the safe side, even though he felt it was probably a ganglion cyst, if anything at all.

I am in no way medically minded, but even I realised when I saw the MRI image that there was something more going on. It turned out there was a 3.9 cm tumour in my right hand that had perfectly filled the gap between the bones and the tendons.

Over the coming weeks I was sent to a plastic surgeon who luckily had seen many cases of sarcoma before. The first time I met him and he saw my imaging was the first time I heard the word I mention of the word sarcoma. He said it may be a sarcoma or a giant cell tumour, which sounds awful, but is actually benign.

I was then sent for a biopsy, which was the most painful thing I've ever had in my life. The results of the biopsy took quite a while to come back which made me feel that maybe we were dealing with something serious. In fact, the biopsy had to be sent to London for specific testing given the rarity of my tumour.

At the end of November, we found out I had Clear Cell Sarcoma. Sarcomas make up about one percent of cancers and Clear Cell Sarcoma makes up less than one percent of sarcomas so to say this is rare is an understatement. About 1 and 6.5 million people are diagnosed with this.

Given the rarity of Clear Cell Sarcoma CUH in Cork, reached out to UCL in London for advice as how to proceed with my care. Clear Cell Sarcoma does not respond to traditional therapies like chemotherapy and radiotherapy so on December 10th 2021, the day after my daughter's first birthday I was told I would be having my right hand amputated four days later.

Life after the amputation has been a new world of learning how to do everything I took for granted before. Simple things like dressing myself, tying up my hair, tying a pair of jeans, changing my daughter's nappy, dressing her, chopping a pepper, making dinner, and of course, obviously learning how to drive.

I've driven a manual car my whole life, so obviously I needed to change to an automatic car and get it adapted seeing as I only had one hand. On leaving hospital I had been told that I would qualify for the Primary Medical Certificate, however it became apparent that I would not qualify because in fact I only had one hand amputated and not two. The cost of my car was approximately €30000 and adaptation was €1800, which with help of my husband and family I managed to do. I obviously didn't have a spare €32000 lying around my bank account or I would've been one serious holiday before my cancer diagnosis.

I absolutely feel the stringent criteria of the primary medical certificate discriminate against single arm amputees and contravenes, the UNCRPD directly. The purpose of the UNCRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disabilities. There are 26 points to the UNCRPD and the stringent criteria of the PMC contravenes many of these including accessibility, equal recognition before the law and personal mobility to name but a few.

Unfortunately, my cancer has returned and I am now stage four. I do not know what the future holds for me or how long more I will have. However, I feel so strongly about the primary medical certificate that I have been willing to give up a day of my life to come up to Dublin to stand with my other single arm amputees to try and obtain something that should have been given to us initially day one without any argument.

What I would like you to take from today from my speech is if you could go home tonight, set your alarm for an hour and try do everything with one hand. Try do everything for an hour that we do all of our lives, make the dinner, cut that pepper, tie those skinny jeans that button in the middle, tie up your hair, change a nappy. Then tell me that we shouldn't be entitled to the Primary Medical Certificate. Thank you.