

## The Right to be forgotten:

When my daughter with CMN was in year 3 we happily agreed to photo shoots and interviews with the local paper to raise awareness and money for Caring Matters Now and the condition. An 8 year old cannot give 'informed' consent so that came from me as the parent. I realised with the hindsight that came later that I was not fully informed however. Social media and my understanding of the impact of the 'digital revolution' grew as she did. As a teen she realised that if she googled her name there were pictures online that she no longer wanted peers to see so easily. Googling each others names in ICT was clearly a 'thing'. She came home upset and asked me to "get those photos off the internet Mum". I felt responsible for her being upset and it really challenged how freely I had said yes to her image and identity being shared. I did not really realise until that moment that a photo on the internet is on there forever and is so hard to track down and remove. I also did not really understand or anticipate that giving permission on her behalf when she was 8, how she would feel when older and what that meant for her privacy.

It took a lot of research and waiting for a response. So I will explain how I managed to sort it out and hopefully save you time if you face the same issue...

Her image was in the local paper. They flatly refused (quite rudely) to remove the image or her name that linked her to the image when I requested it. This is when I realised how powerless I was – we did not own the right to her image, the newspaper did and they would not edit archived materials. The other websites I contacted were much more courteous and removed the image and article within a few weeks of my request by email and wished us well. However, the photos attached to the articles still popped up on other sites with no contact details or any way that I could find to contact the sites. The photo and article had been picked up and linked to all over the place. Feeling increasingly guilty and panicked that I had agreed to something without thinking through the long-term consequences that would keep affecting her I did more research I discovered the 'right to be forgotten'.

"In May 2014, the European Court Of Justice ruled that EU citizens have a "Right To Be Forgotten," that they could request that search engines remove links to pages deemed private, even if the pages themselves remain on the internet."

Below are the links to the forms to make this request for each Search Engine:

Google: <https://tinyurl.com/y87ojljk>

Bing: <https://tinyurl.com/omukx37>

Yahoo: <https://tinyurl.com/y9bb9cb4>

You submit ID with your form (passport) and give a reason for the request i.e : "This URL links to an article which reveals medical information about X and an image which she never gave her permission to be public. It breaches her right to privacy."

I repeated this process for each link (and I had to repeat the request when it took too long to happen). The links are now gone and she feels less anxious about it (and has stopped giving me grief about it!). The photos and articles are still there but you would only be able to find them if you knew the address and to look for them in the first place.

If I went back in time with the knowledge I have now I now know that once you agree to your photos being taken and used, you no longer own or have control over how that image is used. So, I would suggest first name only attached to the image and information used for awareness raising and fundraising if possible. I would also urge parents to try to think ahead to their children's teens and adulthood to imagine how they will want their digital footprint to look and have control over. They should have the right to change their mind over which images of themselves are out there and who, when and how they tell about their condition. It is also worth noting that this applied to EU citizens so it is not clear what the situation will be post-brexit.