

Loreen Smith

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My name is Loreen and before I'm anybody, I'm mummy to the most gorgeous little girl in the world, Gracie, who is one, and who suffers from epilepsy. Gracie was five months old when she started having seizures (tonic clonic), and that was just last year. And after the rollercoaster of the tests, the not knowing, the tears, and the drama, uncertainty and fear, we finally got a diagnosis that she suffers from epilepsy.

Due to the nature of epilepsy, you don't know if you're going to grow out of it or how it's going to develop. It's just a guessing game and a waiting game. As a single parent, and not having a lot of awareness of epilepsy, I searched the internet to try and understand what was going on.

There is nothing worse than the helpless, sinking feeling knowing that your child is ill and there is nothing that you can do to fix it, or make it better, or make it go away - and I blamed myself. Gracie was premature and I thought to myself maybe if I'd held on a little longer and things like that. Obviously, there's nothing you can do that can change these things and you just have to learn to deal with it. So I took it upon myself to start Gracie's epilepsy appeal because I live in Fife and there is no form of support services within Fife for paediatric epilepsy. We have a field worker, Gaye Kelly, who works for Quarriers but other than that there is nothing.

I started a Facebook campaign called "Gracie's epilepsy appeal" and the response was phenomenal. We were on the STV news and a local paper, the Dunfermline Press, has followed our every footstep. The response from Fife alone was again, fantastic and the amount of, not just families, but mothers and parents, and young people as well who have got in contact because they themselves have been diagnosed and they have nowhere to go and no shoulder to cry on.

They don't understand what is happening with them and how their life is going to play out, because there is only a certain amount of clinical time that you can have with a specialist or a consultant and there is only so much they can tell you.

So my role in Fife is that I'm trying to change things and build a substantial support service within Fife to support paediatric epilepsy, and support families and children and also young people. Many teenagers have contacted me looking for support, and the basic thing is just having someone to talk to, someone who is going through what they are going through, someone who understands. Sometimes just a listening ear is all it needs, to make so much more of a difference to bring epilepsy home. The key is support, and the lack of support within Fife in my opinion is pretty terrible. So I will endeavour hence forth to do everything I can to change that.