

DIAGNOSIS

Quite a small word – but one that has a massive impact.

You may have suspected for a while that things were not “right” with your child. Something you just couldn’t put your finger on, but as a parent your instincts were alerting you to a potential problem.

Perhaps you had no idea anything was “wrong” until someone else pointed it out.

However it came about, you’ve ended up here, at THE DIAGNOSIS.

You probably sat in a consulting room and heard the words Neurofibromatosis Type 1 and had no idea what it was. You may have left without hearing anything else that was said. You’re sure it’s a mistake. You might even feel some sense of relief that a name has been put on a bunch of symptoms that you have been worrying about for a while.

Whatever your feelings – your world just changed.

You might feel sad, angry, cheated, guilt, disbelief, disappointment, self-pity, denial, the list goes on and on. Everyone feels differently, and everyone deals with these emotions in their own way.

You have a million questions – you want to cry; you want to scream. Whatever you feel you are not alone.

It can feel like the loneliest place in the world – that post diagnosis time. You may think your best resource is the internet, where you will find all the answers. Try not to do this. With Nf1, as with most conditions, the internet will show you the most shocking and worst-case scenarios. Save your questions for the professionals who should be coming into your life now. Write them down as they come to you.

Life may well become a never-ending round of appointments so you should never be short of a professional to talk to. They won’t all know the answers to all your questions, but they should be able to point you in the right direction. You need websites with good solid information, and you need support. Funny Lumps can point you in the direction of both.

Those first few days and weeks post diagnosis can be so stressful for parents. So much information to take in and all you want to do is pretend it’s not happening.

Take your time. Your stress levels will be high in the early stages. Give yourself time to adjust. Most parents will find a strength they never imagined they had. It takes time.

You might find it difficult talking to family and friends and having to explain a condition that you know little about. You might not want to tell anyone. Everyone is different but talking to someone who understands how you are feeling can make a world of difference. Funny Lumps can put you in touch with other families in the same situation. No one understands better than someone who has been there – who is there.

Funny Lumps has online support groups, family events, parties and an Annual Family Workshop Weekend where you can meet other families and gain information and support.

IF YOU ARE READING THIS, YOU ARE NOT ALONE.