

SHOULD I TELL MY CHILD?

THE SHORT ANSWER IS YES!!!

It's likely your child will be attending hospital appointments at the very least. They may be worrying. They may be worrying why their parents are upset.

Talking to your child about their diagnosis can be difficult for you, as a parent, but your child will probably feel better knowing what is happening.

Keep the information you give age appropriate. Don't give overly long explanations and be wary of using complex medical terms. Answer any questions truthfully but don't give information not asked for.

Your child will most likely benefit from knowing that there is a reason behind what is going on with them. Perhaps they are having difficulties at school. They might find some things difficult i.e. tying their shoelaces, riding a bike, catching a ball or making friends – and now there is a reason.

Try to make their condition something they feel they can come and ask about at any time. If a child feels this is a subject which upsets mum or dad then they will be less likely to approach you with questions. If they feel comfortable with it then they will start to feel comfortable with their diagnosis. Learning about Nf throughout childhood is much better for everyone than having to have a difficult conversation later, perhaps in teenage years.

For young children, Funny Lumps' booklet "Aaron's Way of Life" can help prompt a conversation about Nf1 and let your child see that they're not alone. This booklet was written by a 7-year-old and his mum about how Nf1 affects him. Reading this together can open a dialogue between you and your child

Always be sure your child understands and is comfortable with any information you give. Let them know they can come to you at any time with questions. If you don't know the answer to their questions then be honest – tell them you don't know but you will try to find out. Never lie to your child about their condition.