

FREQUENTLY ASKED QUESTIONS

Q - What and when should I tell my child?

A - As soon as your child is diagnosed it's best to start talking about it. Don't put it off. Answer their questions as honestly / age appropriately as you can. Making their condition part of everyday conversation is much healthier than talking in hushed voices and waiting "for the right time". There really is no "right time". Nf1 is a lifelong condition and it really is easier to make it a part of life rather than a taboo subject. Our "Aaron's Way of Life" booklet is a good place to start an opening conversation with your child.

Q - Does every child with Nf1 have ASD too?

A - No. 1:4 will have autism but many more will have autistic traits and behaviours although never receive an ASD diagnosis

Q - Will my child develop more Café Au Lait patches as they get older?

A - Probably. Although this has no bearing on the severity of Nf1 but most people develop more and more as they age

Q - Should I inform the school my child has Nf1?

A - Yes is the short answer. Many parents feel they should "wait and see" if their child has any additional needs before making school aware. More than 70% of children with Nf1 will experience some learning difficulty and many more will struggle with ADHD/ADD. Combine this with the possibility of difficulties with fine and/or gross motor skills - and the volume of hospital appointments – and it makes sense to make school aware of the condition.

Q - Should children with Nf1 be in mainstream school?

A - The majority of children with Nf1 will do very well in mainstream. However, some children definitely need the additional help offered by ASN schools.