

# ADAM'S STORY

## LIVING WITH A RARE DISORDER

By Michelle, Adam's mum

This is a snapshot in time of the current care and supports in place for Adam. Adam is 15 and has a rare chromosome disorder known as 1q44 deletion, along with 5q34q35 duplication. Adam's specific rare chromosome disorder is ultra-rare (<1 in a million) and possibly unique.

It is not a fixed/static snapshot, as things can change often. With the onset of puberty changes have come about, including a recent diagnosis of probable ADHD (high hyperactivity/impulsivity). We are currently trialling medicine to see if it will help to allow Adam to be able to focus on things better and help with some of his behaviours.

Adam has high needs, so this does require constant supervision, as well as assistance/support for daily tasks such as personal cares. His moderate intellectual disability impacts on his daily life and can present a lot of challenges.

My biggest support in terms of his rare chromosome disorder is through Facebook. I belong to a worldwide group specifically for his deletion where we share information, ask questions and support each other. From there I can gain relevant information that I can then bring up when Adam has a paediatrician appointment for example.

Juggling the coordination of care for Adam is time consuming. The attention needed for Adam does have a big impact on your life – both physically and mentally. You become someone who wears many hats to help Adam navigate the world.

