

Helping Adam to defy health barriers!

Visit our website to read more stories!

Adam is 22 years old. Unlike most young men his age, Adam has Allan Herndon Dudley syndrome. This is a rare brain development disorder that only occurs in males.

The condition causes learning disabilities and mobility issues. It's left Adam with a variety of complex care needs including cerebral palsy, low muscle tone, dystonia and epilepsy.

He also has severe breathing problems that require overnight ventilation and often has swallowing issues that means he has to be PEG-fed, receiving suctioning and is nil by mouth.

Life before our involvement

While Adam attended a special educational needs school, healthcare professionals were still puzzled by his condition.

It took a lot of tests and hospital visits before he was diagnosed with Allan Herndon Syndrome at the age of nine.

This was difficult to manage as a family, but even more so when Adam's dad and grandad sadly passed away in quick succession.

This left Anne, Adam's mum, to look after Adam and his care alone whilst also managing her own grief.

Anne said, *"It was exhausting. I was having to be up all day with him and most of the night because Adam doesn't sleep and often contorts."*

"I had to give up work, so I had little adult interaction, and life became very fast paced for me."

On top of this, Adam was in and out of hospital. His health conditions mean he is more susceptible to chest infections and lung aspiration when eating.



This continued after his PEG line was fitted and he experienced several cases of severe pneumonia. It was a lot for Anne to manage alone.

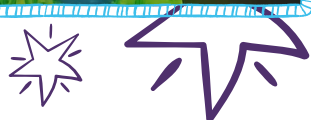
From reactive to preventative

A few years ago, Adam was in hospital for almost two years. After a scoliosis operation, he developed an issue where his bowels would collapse every five to six weeks.

When this happened, he had to go into hospital to have his bowels drained and to have IV fluid.

The hospital suggested Adam begin total parenteral nutrition (TPN) feeding. This is a method of getting nutrition into the body through the veins while avoiding the bowels.

But during his hospital stay, he got septicaemia.



This prompted the medical team to remove the TPN line, and his nursing care package stopped.

But after two long years of lengthy hospital stays, it was evident Adam and Anne needed extra support.

A nurse practitioner at the hospital recommended the **Children's Complex Care team at Voyage Care** as a solution to support Adam at home.

Expert support that works

Adam receives 2:1 care and support from us throughout the day and night. This includes mobility support, pain management, ventilation care, PEG-feeding and suctioning.

To ensure Adam receives the best possible care, the Children's Complex Care team at Voyage Care work closely with his GP and other healthcare professionals to manage the clinical governance of his care package, so his needs are always met.

As well as healthcare, we support Adam with his social and community needs. The team ensures he has his top ready for when Manchester United play and do lots of sensory engagement through arts and crafts.

We also help him to attend a community day centre. We support with escort during transportation and ensure his safety whilst there, so Adam can socialise with his friends and enjoy days out.



“Above all, the best thing you’ve done is kept Adam out of hospital. Which you’ve done fantastically well so far. Plus you’ve helped me too, by giving me some respite.” Anne, Adam’s mum.

Adam’s overhead hoist broke a while ago. Every time Anne tried to get it fixed, she was met with obstacles and this became stressful.

This was not only impacting Adam, but also posed a real health and safety risk to those caring for him.

We stepped in to support Anne to contact Adam’s equipment servicing team so this was fixed as quickly as possible.

Undeniable determination

Since we’ve supported Adam, we’ve been blown away by his undeniable determination and how he refuses to let anything stop him from doing the things he loves the most.

Our main priority is to ensure Adam receives high-quality, personalised care so he can remain healthy.

But we can’t wait to help him achieve his next goal, whatever that may be.



Visit our [website](#) to find out more about complex care for children and young adults.

About Us

We provide nurse-led care and support for people under the age of 25 who have a variety of complex care needs.

Our personalised care helps individuals remain at home with their families and within local communities – **where they belong.**



Get in touch

Contact our friendly enquiry team to discuss how we can support your child, young person or client.



020 7407 7704



CCCreferrals@voyagecare.com



www.voyagecare.com

CHILDREN'S COMPLEX CARE by
voyagecare

