Alpha-1 antitrypsin deficiency

Help, support and guidance for children and families

My child has just been diagnosed with Alpha-1 antitrypsin deficiency - what now?

Finding out that your baby or child has alpha-1 antitrypsin deficiency (A1ATD) can be a big shock and it is normal to worry. On this factsheet you can find quick answers to some frequently asked questions.

What is A1ATD?

A1ATD is a genetic condition. It usually affects adults but can sometimes cause liver problems in babies and young children.

It is diagnosed by looking at a protein in your child's blood and by looking at their genes.

There are different types of A1ATD caused by different combinations of genes. Your child's medical team should explain what genes your child has and what this means for their care.

How serious is A1ATD in children?

For most children, the jaundice caused by A1ATD gets better by age 2.

They will need to have ongoing monitoring from their local hospital and a specialist liver unit. But otherwise most will go on to live normal lives.

In adulthood they will need to avoid smoking, alcohol and becoming overweight. Having A1ATD makes all these things even more risky.

In rare cases it can be a very serious condition. In the most serious cases children can need a liver transplant.

Because it is so rare it is hard to give exact numbers on how many children become seriously unwell.

Registered Charity England and Wales 298858, Scotland SC042140

What happens next?

Your child should be referred to a specialist centre. This usually means travelling to a hospital further away from home.

The specialist team will be experts in the condition. They will look after your child while they are unwell.

They will also follow up and monitor your child until they become an adult and move to an adult service.

What treatment will my child have?

There is no specific treatment for A1ATD in children. Care will focus on:

- managing any symptoms
- making sure they get all the nutrients they need to grow

In very severe cases a liver transplant is sometimes needed. It is a big operation. But the outcome for children with A1ATD who have a transplant is very good.

Where can I get more information?

How your child is affected will be very individual to them. The best source of information will be your specialist A1ATD medical team.

You can also find lots more about A1ATD on the Liver UK website using the link and QR code at the bottom of this sheet.

How we can help

The Liver UK support team are here for you and for your family and friends. Find out more more at **liveruk.org/support**

Call our helpline to talk to one of our team: **0800 652 7330**

LIVER UK

For more information about A1ATD sydrome and links to support visit liveruk.org/A1ATD or scan the QR code.