

Introduction

Children and young people living with Pompe could benefit from special educational needs and disability (SEND) support. The purpose of this is to help children achieve the outcomes or learning objectives set for them by their school. As parents or carers, you should be involved in this process.

Rights in education

All educational settings, nurseries, schools, colleges, and further education settings must make sure they meet the “reasonable” special educational needs of children and young people they identify as needing extra support.

When an education setting has identified that a child or young person with Pompe has special educational needs, they must make a SEN support plan. This might be called an individual education plan (IEP) or something similar. Parents and carers should always be involved in writing and reviewing the support plan.

The Local Authority provides the funding for schools to pay for specialist resources and equipment as required.

The SEND Code of Practice says that schools should use a ‘graduated approach’ to support a child with special education needs. This graduated approach has four steps: **Assess, Plan, Do, and Review.**

- **Access:** Teaching staff should work with the Special Educational Needs Coordinator (SENCO) to assess your child’s needs, so they can give the right support.
- **Plan:** If the school decides that your child needs SEN support, they must tell you. The school should talk with you about the outcomes that will be set, what help will be provided and agree a date for progress to be reviewed. This is often done through a SEND Support Plan.
- **Do:** Your child’s teacher is usually responsible for the work that is done with your child and should work closely with any teaching assistants or specialist staff involved. The school should tell you who is responsible for the support your child receives.
- **Review:** The school should review your child’s progress, and the difference that the help your child has been given has made, on the date agreed in the plan. You and your child should be involved in the review and in planning the next step.

“It is always a good idea to involve all medical teams when having reviews. This can be your specialist nurse, speech and language therapist, physiotherapist, educational psychologist or whichever team is currently involved with your child.”

You should consider whether your child's special educational needs can be met under SEN support or whether they need an education, health and care plan (EHCP).

What is an education, health, and care plan?

An EHCP is a higher level of support for children with special educational needs, determined by a formal needs assessment.

It offers a way of getting children and young people affected by Pompe specific support at school. Legally, local authorities must provide the support identified in a child's EHCP. Children and young people up to 25 years should get an EHCP if special educational needs support cannot meet their needs.

The purpose of applying for an EHCP is to have your child achieve their full potential and get the special services they need. The EHCP not only assesses the educational needs of the child but also provides an insight into what services they need across their health and care, providing an all-encompassing service. The plan is a legal document.

A request for an EHCP can be made by anyone who thinks an assessment may be necessary, including doctors, health visitors, teachers, parents, and family friends.

If they decide to carry out an assessment, you may be asked for:

- Any reports from your child's school, nursery, or childminder
- Doctors' assessments of your child
- A letter from you about your child's needs

The local authority will tell you within 16 weeks whether an EHCP is going to be made for your child.

Higher education

If a young person affected by Pompe is applying for higher education then they can apply for a disabled student grant to help with equipment, travel, or other things to help make university life easier.

Make sure you have enough evidence and support when applying for either an education plan or EHCP.

TOP TIP: Keep all health assessments up to date and have them ready for reviews or to discuss with the SEND team at school.

My child is leaving nursery and starting school in September. Already the school and nursery are talking and arranging planning meetings so that everything is in place for their first day. They keep me up to date with every step. So don't be afraid to talk to nursery staff and teachers. Arrange a quiet time to ask your questions, write them down if you need to.

TOP TIP: The links below are useful:

www.gov.uk/children-with-special-educational-needs/extra-SEN-help

www.kids.org.uk/contact-us

www.contact.org.uk/

www.councilfordisabledchildren.org.uk/

<https://parents.actionforchildren.org.uk/>

For more information or support around rights in education for children and young people affected by Pompe contact our specialist care advisor. Just email info@agsd.org.uk and we will be in touch!