

# Glycogen Storage Disease (GSD) and School



## Please note:

Every child is different and there are many different types of GSD. Not all the information below will be relevant to every child with GSD.

GSD should prove no barrier to a good education. To ensure a child with GSD gets the most from school, however, it is important that the right support is in place. In most cases, this support can be set up before a child starts school. In cases where a child is diagnosed with GSD after starting school, the support should be put in place before the child returns to school.

This leaflet provides an overview of the different support measures required for children with GSD during their school years. All children with GSD should have a detailed individual health plan that is discussed and agreed by the child's family, the Specialist Metabolic Centre, the school and any local healthcare providers involved in the healthcare of the child.

In most cases, schools will be unfamiliar with GSD and the same may be true of local healthcare professionals. Discussions with the child's family and the specialist metabolic team are extremely useful in terms of understanding both GSD and the specific needs of the individual child.

## General Information

### Health need

#### Information on GSD

Teacher and staff should understand the condition including:

- What the condition is
- Treatment needed (feeds, starch)
- When treatment is needed

#### Emergency treatment

Teacher and staff should be aware of what to do if a child with GSD becomes unwell at school.

- Signs of illness (pale, sweaty, asking for food)
- What treatment is needed if unwell (Glucose polymer/glucose gel)
- Who to contact
- When to take to hospital/ call 999 (unresponsive or continually vomiting)

#### Adequate staff support

The school should be able to provide additional support to monitor and provide feeds when needed.

### Who can help

The **Specialist Metabolic Team** nurse can provide written information on this.

The **Specialist Metabolic Team** nurse can provide written information on this including emergency protocols.

The school **Special Educational Needs Co-ordinator (SENCO)** will assist with staff allocation.



## Dietary Information

### Health need

#### **Feeds:**

Feeds can sometimes be tailored to fit into a child's school regimen.

#### **Tube feeding:**

It is best that 2-3 people are trained. This allows cover to be provided in the event of teacher sickness or leave.

#### **Supplying meals/foods:**

- Starch should be supplied in measured containers (water in separate containers)
- Milk/ liquid feed should be supplied in measured, labelled containers.
- Snacks

### Who can help

The **Specialist Metabolic Team dietitian** can ensure the feeds plan is appropriate for school.

The **school** allocate a key person to ensure that feeds are given correctly and on time

**Local community nurses** should be able to provide training to the school staff and competency documents.

**Parents/carers** should provide pre-mixed and labelled foods/feeds for the school.

