

## Barth syndrome

**Children with Barth syndrome may have heart problems, muscle weakness, fatigue, reduced resistance to infection, eating problems and learning/attention difficulties**

### Emergencies

#### Danger signs

- Pale, sweating, grunting when exhaling, breathless, fainting, unconscious = heart
- Sweaty, pale, floppy could mean low blood sugar. Give sugar/food
- Fever = infection

#### What is your plan in case of emergency?

1. Do you have a plan for use of an AED (Automated External Defibrillator)?
2. Do you have a Care Plan for student?
3. Call 999
4. Get help
5. Start CPR and/or use AED if needed

#### Symptoms to look out for:

- Extreme fatigue
- Heart problems – including risk of sudden cardiac arrest and heart failure
- Muscle weakness
- Susceptibility to bacterial infections
- Concentration problems that are not simply linked to fatigue (higher than expected diagnoses of ADHD, ASD within Barth population, so consider assessments where indicated)

### Communication

Communication is key and will create an optimal learning environment, better management of the condition and a better quality of life. Consider talking to other teachers, parents and the child to make sure the workload is manageable and realistic so that you can set their up to succeed.

Schedule a meeting with the young person/parents once a year to make a plan about what needs they have and to discuss necessary amendments etc.

## Quick Checklist for Teaching Staff

- Keep a diary of food /drink at school and share with parent daily (needed to prevent hypoglycaemia)
- Keep a diary of activity times (needed to combat extreme fatigue)
- Keep child away from other sick children (to prevent infection)
- Help child if needed with toileting and ensure high standards of cleanliness to combat risk of infection, wash hands well after toileting
- Clean and disinfect any cuts and scrapes immediately to prevent sepsis
- Consider a MedicAlert bracelet/chain
- Regular OT and Physio visits at school
- Use Flash Cards or flip chart on desk for child to signal when feeling unwell/tired/hungry etc

## Fatigue

### Symptoms/Info

- Variable – can come and go at any time of the day
- Pallor
- Some children might not recognise when it's time to stop and rest

### Suggestions

- Provide a quiet, comfortable place to rest
- May need a rest/drink/snack/stretch/toilet break at varying points during day or lesson – make a plan to minimise class disruption but avoid placing them at rear of class far away from teacher.
- Prioritise a task and reduce work load to ensure he achieves the key objectives of each lesson
- Find out what time of day is best – for some it is afternoons, not mornings
- Give extra time to complete task or test
- Creative timetabling with disapplication from non-core subjects and study periods for homework
- Plan for absences due to illness/fatigue/physio/hospital appointments
- Send home any missed work quickly
- Fill a separate box for home (or use a virtual online mailbox) each half term with info about current curriculum
- Electric wheelchair/someone to carry heavy books

## Physical Adaptations

- Keep an eye on them during periods of physical exertion, PE and movement times
- Angled writing board/table
- Appropriate grips for pens and pencils
- Easy grip or self-opening scissors
- Adapted toilet with hand rails and/ or foot box
- Specialist chair with arms (Brookfield chair) with foot rest for stability and good posture
- Buggy/wheelchair for longer distances and trips
- Allow them to get up and move during long lessons
- Allow them to leave before rush in corridor
- Lightweight notebook, laptop, memory stick
- Timetable lessons in classrooms that are close to each other
- Balance timetable to ensure physical lessons are preceded and followed by non-physical lessons
- PE – include them in adapted PE e.g. warm ups and stretches
- Help them with tying laces, getting dressed, buttons, zips etc
- Dance Mat Typing (BBC Bitesize) or something similar to teach touch typing
- Lunch and play times – he may take longer to eat and need help cutting up food when younger. Provide info to dinner ladies and playground staff

## Concentration

Boys may have problems with concentration and focus. Both short and long term memory may be affected.

### Suggestions

Keep them away from excessive stimuli

Pay attention to where child sits and who sits near them

What type of learner are they? Visual? Kinaesthetic etc?

## Social and Emotional

They may be smaller and weaker than their peers and these physical differences become more outwardly apparent as they gets older

Loneliness as peers drift away as they become more independent and mature

Anger, frustration, anxiety about their condition, the demands and pressures of school and home life.

### Suggestions

Need a holistic team approach between tutor or main teacher, subject teachers, SENCO, child and parents to balance work load

Identify parts of lesson that the child can actively and fully access

Keep a close eye for any problems -increased absence, poor performance etc

Assemblies or Sharing exercises for general awareness

Appoint a mentor to be responsible for overall well-being and have regular meetings with parents and child