

Barth syndrome

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

Emergencies

Danger signs

Pale, sweating, grunting when exhaling, breathless, fainting, unconscious = heart

Sweaty, pale, floppy = low blood sugar. Give sugar/food

Fever = infection

What is your plan in case of emergency?

Do you have a plan for use of an AED (Automated External Defibrillator) if student has one?

Do you have a Care Plan for student?

Call 999

Get help

Start CPR and/or use AED if needed

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 him 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.

Fatigue

Symptoms/Info

Variable – can come and go at any time of the day

Pallor

Some boys might not recognise when it's time to stop

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 him 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 him 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 him to get up and move during long lessons
Allow him 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 him in adapted PE e.g. warm ups and stretches
Help him with tying laces, getting dressed, buttons, zips etc
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 him away from excessive stimuli
Pay attention to where child sits and who sits near him
What type of learner is he? Visual? Kinaesthetic etc?

Social and Emotional

He may be smaller and weaker than his peers and these physical differences become more outwardly apparent as he gets older
Loneliness as peers drift away as they become more independent and mature
Anger, frustration, anxiety about his 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