

Muscle weakness, tiredness and exercise intolerance

Children with heart problems often find it tiring to feed but, in addition to this, a baby with Barth syndrome may also be quite floppy and tire easily because of muscle weakness. Some children are late to crawl, walk or run and may struggle to get up from sitting (a positive Gower's sign). Physiotherapy and occupational therapy are advised from a very early age to help reach milestones.

Many children have "flat feet" and find it helps to get inserts for their shoes or special little boots to help them walk. Some may like a frame to provide more stability. Be reassured that all children eventually walk when they're ready.

There is no evidence of any major cognitive damage, with most children living "normal" lives, though they are often hampered by a lack of stamina. When older, they may find it difficult to run or play sport due to exercise intolerance but younger children usually follow an adapted PE curriculum and usually enjoy this tremendously.