**Care Plan for**

**Introduction**

The details in this Care Plan are provided by parents/guardians for use by teachers and those caring for their child. They should be readily accessible for any supply teacher or peripatetic teacher. If the child is taken to hospital the Care Plan should accompany them.

Please be certain that you have the complete document at all times. Contents are listed below.

* Name and details of child
* Contact details of parents
* Authorised Emergency Contact details
* Doctor Information
* Medical Condition: Barth syndrome
* Symptoms - Contact parent if any appear
* Essential Care Information
* Academic Issues
* List of Medications

**Notes to parents and/or guardians**

This form has been designed to act as a template and, as such, it may not be wholly accurate when describing your child’s specific symptoms. Please add any specific information as you, your doctors and teachers see fit. If you need any help with this form, please contact Barth Syndrome UK. This Care Plan form can be downloaded from the BSUK website for you fill in, save a copy on your computer and update it when necessary.

Please keep a spare copy at home and also include one in your child’s school bag.

*DISCLAIMER: This fact sheet is designed for educational purposes only and is not intended to serve as medical advice. The information provided here should not be used for diagnosing or treating a health problem or disease. It is not a substitute for professional care.* *Barth Syndrome UK cannot be held responsible for the accuracy of the information it contains.*

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[www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk).

**Care Plan**

**Full name of Child:** **School Year:**

**Hospital Number:** **Condition: Barth syndrome**

**Today’s Date:** **Date of Birth:**

**Allergies:**

|  |
| --- |
|  |

**Contact Information**

|  |  |
| --- | --- |
| **Primary Contact’s Name:**      **Relationship to child:**      **Home Tel:**      **Work Tel:**      **Mobile Tel:**      **Email:**       | **Primary Contact’s Name:****Relationship to child:****Home Tel:**      **Work Tel:**      **Mobile Tel:**      **Email:**       |

**Home Address/es of child:**

# Authorised Emergency/Alternate Contacts

|  |  |
| --- | --- |
| 1. **Name:**

Home Tel:       | Relation to child:       Mobile Tel:       |
| 1. **Name:**

Home Tel:       | Relation to child:       Mobile Tel:       |
| 1. **Name:**

Home Tel:       | Relation to child:       Mobile Tel:       |

**Doctor Information**

1. **Paediatrician:**

Name:

Address:

Tel:

Fax:

Notes:

1. **Paediatric Cardiologist:**

Name:

Address:

Telephone:

Notes:

1. **General Practitioner:**

Name:

Address:

Telephone:

1. **NHS Specialist Service for Barth syndrome:**

Please contact the Clinical Nurse Specialist for Barth syndrome who can direct your call to the appropriate member/s of the team (which includes dietetics, physiotherapy, occupational therapy, psychology etc)

Telephone: 07795 507 294 (Tues-Fri)

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/other-services-in-bristol/barthsyndromeservice/contacts/>

**Hospital of choice:**

**Special Notes:**

**Medical Condition: Barth Syndrome**

Barth syndrome is a rare and serious lifelong genetic condition that usually affects males.

Symptoms consist of the following in varying degrees:

**Infection risks (neutropenia):** Weakness in the immune system, specifically a reduction in the number of “neutrophils”, a type of white blood cell that is most important for fighting bacterial infections. Neutropenia places Barth children at an increased risk of acquiring serious infections. Minor infections in healthy children can be much more serious for children with Barth syndrome.

**Heart problems (cardiomyopathy):**Heart muscle weakness. This, combined with a weakened immune system, represents the greatest threat to children with Barth syndrome. There is a known risk of sudden cardiac arrest or arrhythmia so all caregivers should be trained in CPR and you should have ready access to a defibrillator.

**Heart Transplant:** some individuals with Barth syndrome need a heart transplant.

**Muscle Weakness and General Fatigue:**All muscles, including the heart, have a cellular deficiency, which limits their ability to produce energy, causing extreme fatigue during activities requiring strength or stamina, from walking to writing to growing.

**Failure-to-Thrive, Growth Delay and feeding problems:** Most children with Barth syndrome are also below average in weight and height, often substantially so. The poor growth is often assumed to be evidence of poor nutrition or other secondary effects of a chronic illness, a situation termed “failure to thrive”. This is rarely the case, and the common nutritional treatments for failure to thrive are usually not needed, and in some cases contra-indicated for Barth syndrome children. There is often dramatic growth during late teenage years when children reach or even exceed their predicted adult height (average shift from 4th centile up to 16 years to 80th centile by the age of 19/20)

**Special Notes:**

**Contact parent if any of the following symptoms appear:**

**Possible signs of heart failure/arrhythmia:**

Grey pallor

Persistent cough

Persistent sweating

Increased irritability

Grunting when exhaling

Chest pain or tightening in chest

**Possible signs of infection:**

Fever

Diarrhoea

**Possible signs of hypoglycaemia (low blood sugar):**

Sweating

Pallor

Floppy/listless

(Give sugary drink, followed by complex carbohydrate (e.g. cheese sandwich). If it is hypoglycaemia, symptoms will disappear within minutes of eating and drinking.)

**Other:**

Vomiting or nausea

Extreme fatigue

**NEVER:**

**Prevent child from eating or drinking when requested**: this may cause hypoglycaemia and/or dehydration

**Force child to exert themself when feeling unwell**

**Force child to eat** asthis may worsen their condition

**Forbid child to contact parents when they state they don’t feel well:** they know their own body and will be at a heightened awareness of symptoms that may not be apparent to others.

**Stop them from going to the toilet:** Medications and actual condition may cause them to need to go to the toilet frequently and urgently.

**Essential Care Information**

* Child is at risk for sudden cardiac arrest – a staff member fully trained in resuscitation & defibrillator use should always be on hand.
* Take special care during any PE lessons and make sure child is included where possible but to a degree which does not place undue stress on them physically. Many Barth children have reported being pushed to run during a PE lesson and then needing 1-2 days to recover from the subsequent fatigue and muscle pain.
* Keep child away from other children who appear to be ill. Children who have Barth syndrome are at increased risk of infections. Even a small cut or graze needs to be disinfected as soon as possible to prevent infection.
* All areas should be kept thoroughly clean, especially eating areas, toilets etc.
* Please ensure that child washes their hands after going to the toilet and before eating.
* Keep child under close supervision when in a crowd (on playground/climbing stairs etc) as poor muscle tone and poor sense of balance can cause injury.
* Try to ensure child does not get overheated or exposed to extreme cold.
* Child may need a supportive chair with arm rests, extra sets of books to avoid carrying heavy loads, help with moving around the school grounds etc.
* Please allow child to rest when needed.
* If any IV rehydration fluids are given (after bouts of diarrhoea/vomiting etc), electrolytes need to be monitored carefully and often after starting IV, otherwise severe cardiac failure can be induced.
* No rectal temperatures to be taken due to neutropenia (this is not usually done in the UK).

**Special Notes:**

**Academic Issues**

* A Statement of Special Educational Needs or IEP (Individual Education Plan) is often needed with specific provisions and adaptations made to the curriculum, premises, services or equipment as required to ensure access to education and safety whilst at school.
* A child with Barth syndrome will be at an increased risk of missing more time from school than their peers. They may need extra time to finish a task or test. Please remain in close contact with parents about these issues.
* These children are often reported to be prone to increased attention deficits. Please evaluate and introduce strategies for improving concentration where appropriate, e.g., allow child to remain close to teacher to limit distractions.
* Frequent parent teacher conferences are recommended to maintain a unified effort in child’s academic endeavours.
* Self- limiting physical exercise may be allowed however this varies from child to child. Competitive sports should **never** be forced and in many cases are considered potentially harmful to the child. Please discuss this matter with parents.
* Children often struggle with writing and may benefit from adaptive technology such as lap top computers, scribing, audio books, voice recognition software etc.
* A consistent regime of occupational therapy and physiotherapy exercises may be helpful.

For more information about Barth syndrome please visit [www.barthsyndrome.org.uk](http://www.barthsyndrome.org.uk). There is also a comprehensive [Education Guide](https://www.barthsyndrome.org.uk/userfiles/Factsheets/BarthSyndromeEducationGuide2019forschools.pdf) on our website.

**List of Medications:**

**PLEASE NOTE THAT THESE DOSAGES CHANGE FREQUENTLY – CHECK WITH THE HOSPITAL / GP IF IN DOUBT**

**HOSPITAL NUMBER:**

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| --- | --- | --- |
| **Name of medicine** | **Dosage (milligrams/micrograms)** | **Frequency** |
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| **Name of medicine** | **Dosage** | **Frequency** |
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| **Name of medicine** | **Dosage** | **Frequency** |
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