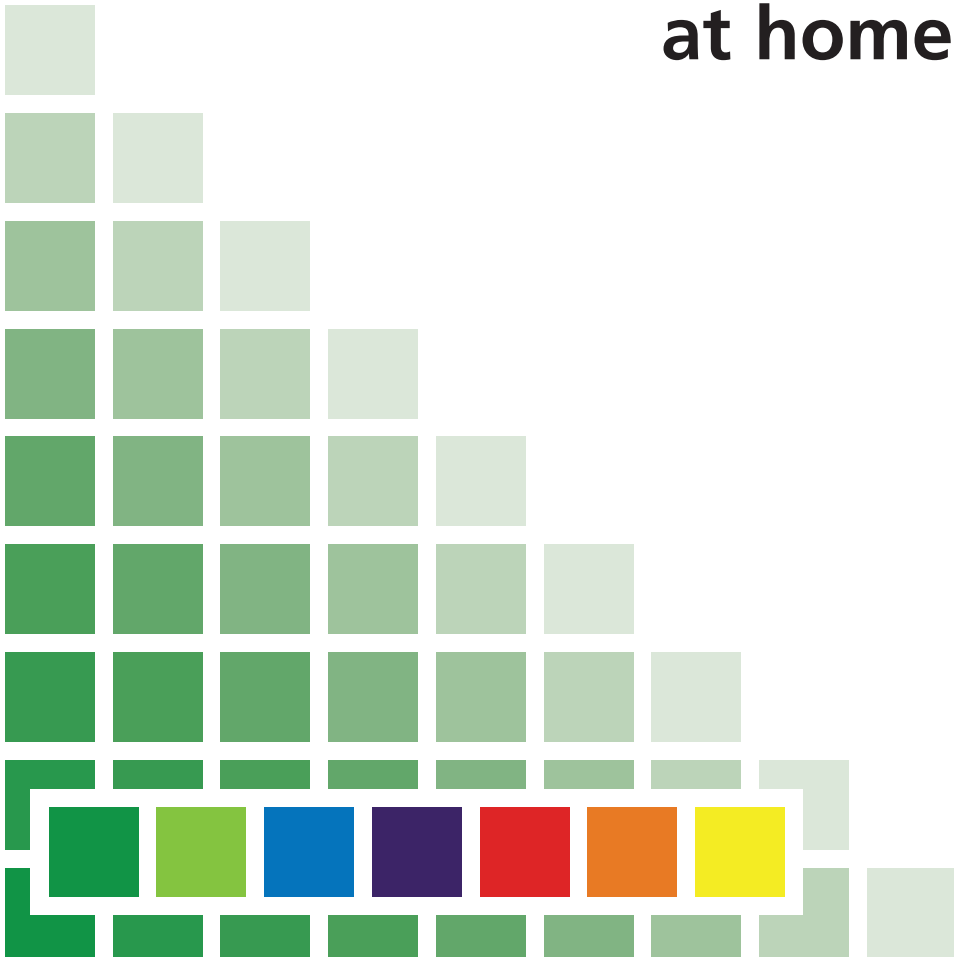


Children on long term assisted ventilation at home



Contents

Introduction	3
Healthcare teams	3
Space, access and storage	4
Properties with two or more levels	5
Cots and beds	5
Bathing	5
Hoists	6
Seating	6
Prams	7
Contact	7

If you have concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call PALS on 020 7349 7715 or email pals@rbht.nhs.uk. This is a confidential service.

Introduction

With the right amount of support, children on long term assisted ventilation can do well in their daily activities. However, the need for ventilation and equipment can restrict their access to certain rooms and areas at home.

This leaflet is a general guide to help carers and healthcare teams work together to plan the space and equipment to use at home. It does not replace the need for personal advice from a qualified healthcare professional. Please ask us if you have any further questions.

Healthcare teams

Occupational therapists help patients and families adapt to changes in everyday life and overcome practical problems. They can recommend the equipment you may need and how to make changes or alterations at home.

Community nurses can also give advice and can tell you who to contact locally to help meet the nursing needs of your child.

Carers and healthcare teams should communicate with each other and share the responsibility for any difficulties with equipment or housing issues.

Regular home assessments are needed as your child's health needs will change over time. Assessments will cover:

Space, access and storage

You should be able to store all the equipment needed for long term assisted ventilation in your child's bedroom as it may be needed in emergency situations.

The long term ventilation equipment should be stored next to the cot, preferably on a mobile trolley or something similar. Spare medical equipment, such as suction catheters and the spare ventilator, should also be kept in the same room.

Ventilators and suction and sats machines need to be plugged into wall sockets. Multi-socket extensions are sometimes used, but please ask your community nurse to check if this is the case in your area.

There should be enough space for carers to reach a child from both sides of the bed. In some routine and emergency procedures, two people may need to assist your child.

If an overnight carer is needed, there should be enough space for a comfortable chair.

The type of pram needed will usually be larger and heavier than average. Parents and carers should think about how the pram will get into the house and where it will be stored.

Think about whether there is enough space for a day room, family living area or separate play area. It is important for your child to have regular breaks from the bedroom, especially if it is not possible to go outdoors.

Properties with two or more levels

A professional risk assessment is necessary to address any issues that may arise when living in a property with multiple levels.

If the bedroom, bathroom, kitchen or other functional rooms are on different floors, it is important to think about how easy it is for your child to get to these rooms.

Cots and beds

Both sides of the cot or bed should be collapsible so that two carers can help your child when needed.

The height should be adjustable for the health and safety of the carers. If your family has a team of regular carers, the cot or bed can be set at a particular height to suit them.

A tilt function can help with managing secretions and reflux.

Bathing

Water should be kept away from the ventilator.

If your child needs 24-hour support on ventilation, a risk assessment for bathing is needed.

If your child needs supportive seating, it should also be considered for bathing.

Carers may need bathing facilities that are height adjustable for their health and safety.

A mobile bath may be better if the bathroom is small.

Hoists

Standard mobile hoists are generally easy to use and can fit into any home with enough storage space.

Ceiling track hoists are a great space-saver, but are a more permanent option.

Portable hoists combine the ability of being a semi-permanent structure, usually over beds, and do not take up too much space.

Seating

Sitting up can be useful for managing secretions.

When children on ventilation have spent a long time on intensive care and the ward, it can cause weak muscles and difficulty with sitting independently.

Children needing ventilatory support can also have other medical conditions that impact on their motor skills and sitting.

Different activities, such as playing and mealtimes, will sometimes need different types of seating.

If your child needs extra support for sitting, then this support may be required when considering a pram.

Prams

As a ventilated child's voice is affected by a tracheostomy, it is important that the chair is rear facing so you can see your child.

There needs to be enough clearance between the seat and the storage tray for the ventilatory equipment to sit and be easily accessed.

If your child needs help to sit up, the seat would need to have additional postural support.

Ventilated children are often less than a year old and would need a pram with a smaller seat.

The pram should have extra weight and space capacity, because of the extra equipment needed.

Brakes should be easy to reach when the pram is loaded with equipment and need to be effective with the extra load.

Prams are not crash tested when loaded with ventilatory equipment or when the seat is positioned rear facing. This means that your child and the equipment need to be removed from the pram when travelling in a car.

Specialist prams need accessories such as rain covers.

The local Wheelchair Service should be able to provide a customised pram to cope with your child's medical needs.

Contact

If you have any questions, please contact our occupational therapy team on 020 7351 8961.

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إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosürteki bilginin Türkçe tercümesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercümenin gerçekleşmesini en kısa zamanda ayaracaktır.