

An Introduction to Home Ventilation

Name:

Home ventilation for your child

Welcome to the Starship Life Support Longterm Ventilation (LTV) Pathway. Having a child on home ventilation has many implications for your family. You will be pleased and relieved that your child can breathe and is working towards getting home from hospital. However, you may experience grief brought about as a result of change in lifestyle, restrictions or even changes in the dreams and goals you held for your child.

Some people can feel overwhelmed by the things they will need to learn, however you have a healthcare team to help and support you. We understand that this is a big responsibility. It is important that you understand and feel happy about providing all aspects of care for your child before you leave the hospital.

This booklet explains all about home ventilation and shows you the Pathway to getting home. It gives information and advice on managing your child's ventilation once you return home. It is used together with other Starship Child Health parent teaching books to provide families with information in order to help you care for your child in the best possible way in hospital and at home.

Your child's primary health care team will work together with you and your family to help guide and teach you all the important things you will need to know about the medical and nursing aspects of your child's care. Working with you is a very important in this partnership as it allows you to teach us about your wishes and needs, what is important for your family, and who you and your child are. This in turn helps us hold you and your child safely while in the hospital and with your transition safely back into the community.



Home ventilation: The Children's Therapy team

Medical and Nursing Team

Your child's care is best achieved with a team of people that are the experts in meeting your child's needs. Different people will be involved at different times of your child's journey but there will always be a core team of people to work with you. You will meet many people from the medical and nursing teams but there will always be an assigned primary doctor and nurse who will be the consistent people you see. Other people that may become familiar to you are

respiratory physiologists that will help you manage your home ventilator equipment

Someone from the consult liaison team who will help you along this challenging journey

allied health (physiotherapists, occupational and speech language therapists) who will ensure your child develops as best they can

social workers who are familiar with the community support available to parents of children with complex health needs

the community agency coordinating the carers that will help support you to care for your child when you get home.

Everyone will work with you so that you can care for your child in your home. To do this we will provide you with the education and training in a staged process that allows you to build up your confidence. We want to ensure that your child spends no longer in hospital than is necessary but also want to make sure that both you and your child are ready to transition to that next step safely. Sometimes that next step is home and sometimes it is to a hospital that is closer to where you live. Whatever that next step is we want to make sure that the community teams know your child well so that they can provide high quality healthcare. Eventually you will get home and you will be able to be a family again. We know you will have many moments of happiness to look forward to.



