



STARSHIP LONG-TERM VENTILATION PATHWAY

THIS IS HOW WE SUPPORT YOU
THROUGH THIS JOURNEY.





STARSHIP LONG-TERM VENTILATION PATHWAY

1

MEET YOUR CHILD'S TEAM

From the time long term ventilation is considered for your child a multidisciplinary team will meet with you and support you. The team will support you through the decision of whether your child should have long term ventilation, through the process of starting ventilation and into the community after you go home. The multidisciplinary team includes specialist medical teams, nursing, allied health, primary care and community based teams.

4

START LEARNING ABOUT YOUR CHILD'S FUTURE NEEDS

Children who require long term ventilation often have multiple needs. Each of these needs may require special care or equipment that you will need to learn to use. We provide a training program for you and your child's carers to ensure you are confident and your child is safe. Over time you will gradually learn to care for your child in a series of small steps. The training includes practical "hands on training". Over time you will provide more of the care while your child is in the hospital in preparation for the transition to home.

7

MEET THE PEOPLE WHO WILL HELP YOU AT HOME

Children on long term ventilation need looking after 24 hours per day. It is not safe for you to try and do this on your own. You may have family support and you will likely need support from paid home support workers. You will also get support at home from your local homecare nurse and community team. Identifying the carers who will help you at home can take a long time. We will work with you to introduce you to people who can help in this process and support the carers with training so that the transition between the hospital and community is successful.

We start this process as soon as possible in your child's admission to ensure there are no delays. One of the first steps in this process will be participation in a Needs Assessment & Service Coordination (NASC) process. It is through this process that recommendations will be developed regarding the package of care required to support your child in the community safely.

2

MAKE DECISIONS ABOUT THE RIGHT CARE FOR YOUR CHILD AND WHĀNAU

Starting long term ventilation is a complex decision and deciding to start ventilation must be in the best interests of the child. To ensure this occurs we have a careful process to support decision making. The multidisciplinary team will meet with you to discuss what is best for your child and support you through this decision.

5

YOUR CHILD IS STABLE ON THEIR VENTILATOR

Children who need long term ventilation are often quite unwell and can be medically unstable for some time. Often children need operations or procedures before they are stable enough to consider going home. It may also take a little time to get the settings right on the home ventilator. Once your child is stable on the ventilator we will encourage you to gain confidence by taking walks out of the PICU, firstly around the hospital, then out of the hospital and then taking trips home or into the community.

8

YOU AND YOUR CARERS FINISH TRAINING

You will have been gradually learning to look after your child's new needs all the way through the admission. By this stage you may be doing all the cares yourself with the nurses only supervising. Now we need to make sure you have learned all the skills you will need. At this stage your carers and community nurses may need to go through similar training. As a final step we will run through scenarios where you will practice managing your child in an emergency.

3

START LONG-TERM VENTILATION AT STARSHIP

Some children require a tracheostomy tube for ventilation. This is a special tube in the neck that helps a child breathe and is placed in a small operation. Other children use a mask. A ventilator is attached to the tracheostomy or mask to deliver the air your child needs. After the operation your child will be cared for in the pediatric intensive care unit (PICU) and placed on a ventilator. Once your child is stable on a ventilator they will be transferred to a ventilator specially designed for home use. We will help you learn to use your child's ventilator.

6

WE'LL MAKE SURE YOUR HOME AND SUPPORTS ARE READY

Your home needs to be suitable for your child's needs and those of other family members, including any siblings. A care package for home and employment of carers can't be approved until you have a suitable home to go to. The home needs to accommodate the equipment required to care for your child and for carers to come and work there. A home assessment will occur in partnership with members of the community team. You may not have a suitable home, or changes may need to be made to your home to make it suitable. This can be a lengthy process so assessing your home occurs soon after your child is stable on their ventilator.

9

COMPLETE THE JOURNEY TO HOME AND WHĀNAU

As you gain confidence in caring for your child you will begin gaining independence from the hospital until eventually a date for discharge is agreed. Getting home is important for everyone in the immediate family as you will be able to do family things and together create a family life. Once you are home the LTV team and the community team will continue to support you. We will need to see your child regularly at Starship to check the tracheostomy and the ventilator settings and ensure all is well with the plan that was put in place to support your child and family.

