

## Welcome to the Children's Hospital Colorado Ventilator Care Program (VCP)

Learning to care for your technology-dependent child will be one of the most rewarding yet challenging experiences of your entire life. As you continue this journey, our VCP team wants to care for and support your entire family. Thank you for trusting us with your child's care.

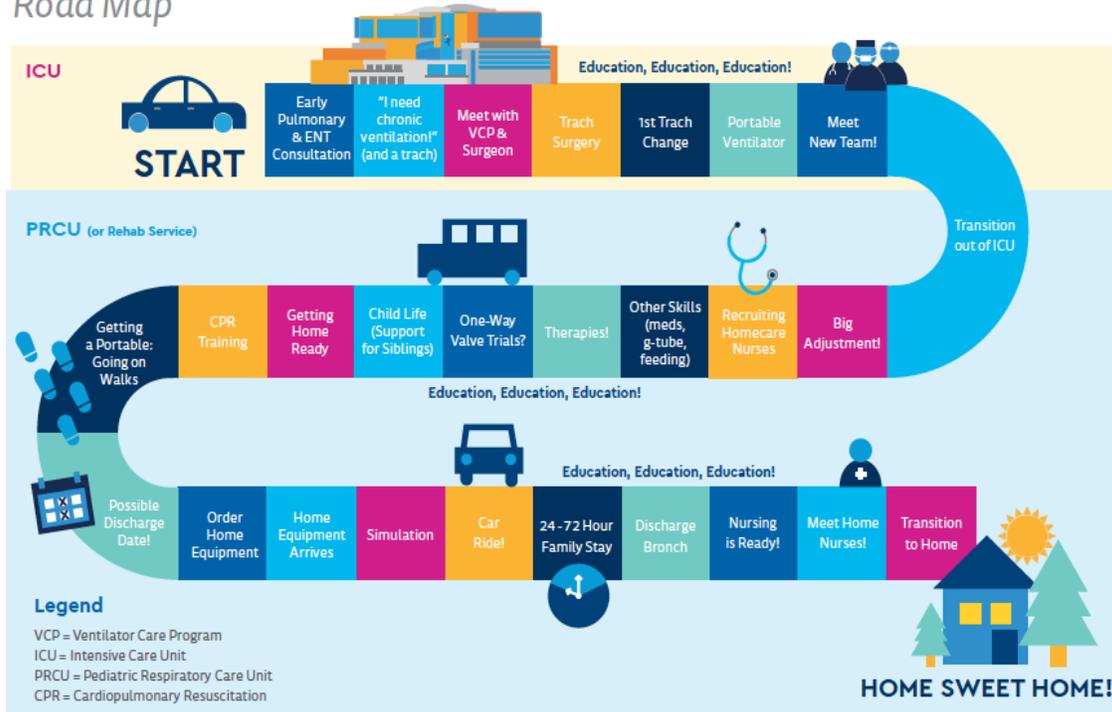
– Dr. Christopher Baker, Medical Director

- These are some of the benefits of chronic ventilation for your child:
  - Breathing – We want all children to be able to breathe as comfortably as possible.
  - Growth & Development – When children breathe comfortably, they can grow and learn new skills such as playing, moving, and communicating.
  - Bonding – A tracheostomy makes it easier to hold and interact with your child.
  - Going Home – We know how important it is for you to be able to take your child home.
  - Extending Life – Chronic ventilation helps some children to live much longer.
  
- **What is the process?**
  - The Chronic Ventilation Road Map below shows you many of the steps you and your child will take on your journey home.
  - As you can see on the road map, teaching you how to care for your child is very important to us. Learning, practicing, and improving your skills are how you keep your child safe.
  - Your medical teams will work together to make plans starting well before the trach surgery.
  - The trach surgery will be done under general anesthesia. Most children will have a feeding tube (aka “g-tube”) put in by surgery around the same time.
  - Recovery from surgery takes about a week. At the end of that week, the first trach change is done.
  - It often takes weeks or months to get your child stabilized and ready to go on the home ventilator.
  - When stable on the home ventilator, your child will be transferred to the 9<sup>th</sup> floor Pediatric Respiratory Care Unit (PRCU). You'll stay there to continue your education and reinforce your skills.
  - Home equipment will be ordered and home nurses will be recruited.

BREATHING INSTITUTE

## Chronic Ventilation

### Road Map



- Who is my team?
  - Your VCP team has many members:
    - Intensive Care Unit (ICU) medical team – the primary team who will take care of your child until the 9<sup>th</sup> Floor transfer
    - PRCU (9<sup>th</sup> Floor) medical team – prepare you and your child to go home safely
    - Nursing and Respiratory Therapy – will complete much of your training
    - Case Managers – help to arrange home care (nursing, equipment, supplies)
    - Social Workers – support you through the many challenges
    - Physical, Occupational, and Speech Therapists – will partner with you to maximize your child's strengths and address developmental goals
    - Dietitians – make sure your child receives proper nutrition to grow and thrive
    - Child Life Specialists – help patients and siblings along the way

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Author: Ventilator | Approved by Patient Education Committee | Valid through 2022

The information presented is intended for educational purposes only. It is not intended to take the place of your personal doctor's advice and is not intended to diagnose, treat, cure or prevent any disease. The information should not be used in place of a visit, call or consultation or advice of your doctor or other health care provider.

## IN CARE OF KIDS

- What are the challenges and how will we help you?
  - This is a HUGE STRESS. – Our entire team will help support you along the way.
  - Education starts in the ICU and continues until you go home – and beyond!
  - Children with a tracheostomy/ventilator at home must have an awake/alert/fully-trained caregiver with them at all times. (For safety, they need this 24/7.)
  - We'll train at least two family caregivers to be experts (other family can also be trained).
  - This takes a LONG TIME. – One of the hardest parts is being here so long.
  - No matter the challenges, we will make a custom plan that fits your family's needs.
  
- When can I go home?
  - Many children will go straight home when they are discharged from the 9<sup>th</sup> Floor. This happens when all the education is complete and a safe plan is in place.
  - In some cases, children may be transferred to the hospital in their hometown after training on the 9<sup>th</sup> Floor is complete.
  - Your insurance and medical teams will have to approve the plan.
  - After going home, your child will return to VCP Clinic for follow-up.
  
- As you can see, the process takes time. The sickest babies and children sometimes have to stay in the ICU for over a year. The step that usually takes the longest is finding home nurses – families often have to wait on the 9<sup>th</sup> Floor for many months. We have worked hard to create an efficient process, but we know that your child's safety is your top priority. Safety is our top priority, too!

### CONTACT US:

**[www.childrenscolorado.org/doctors-and-departments/departments/  
breathing-institute/programs/ventilator-care-program/](http://www.childrenscolorado.org/doctors-and-departments/departments/breathing-institute/programs/ventilator-care-program/)**

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