

Growing and Thriving With Respiratory Support

A Family Education Manual

Edited by

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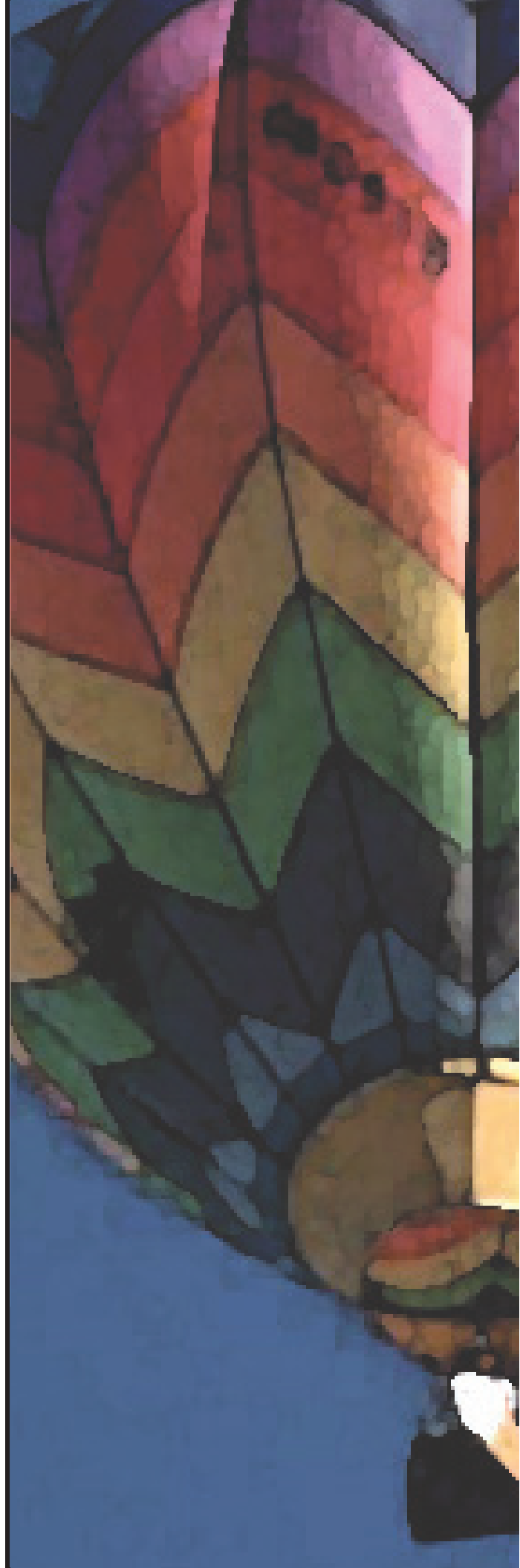
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With 17 contributors

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As you begin your journey to becoming a Parent Expert...

Dear Parents and Families:

This manual is the first step toward becoming an expert in your child's care. Right now you are just learning that your child will need special care at home.

Families in this situation react differently to these first few days and weeks. Rest assured that you are not alone in your feelings. There have been many families who have experienced these same feelings.

The purpose of this manual is to cover basic information. The following chapters will cover important topics such as the respiratory system, breathing machines, insurance, nursing care, nutrition, feeding and ways to cope with this sometimes overwhelming situation. There is plenty of room for you to write down specific information such as the reason your child needs a breathing machine, settings for your child's breathing machine and specific nutrition needs your child may have. This book is designed to go along with the teaching provided to you by the hospital staff.

Children on respiratory support have been growing and thriving at home for more than 20 years. Health care professionals now know that these children do better at home than in the best hospital. You and your family will indeed, in time, provide this expert care to your child.

Our warmest regards as you begin your journey.

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Chapter 1

Learning Your Child's Care

Cathy Lewis, MS, RN

Transitional (Stepdown) units

Many hospitals have **transitional units**. These units may be called, “**stable ventilator units**” or “**stepdown units**.” The goal of these units is to get families ready to go home. It is a big change for patients and families to move from the intensive care setting to a stepdown unit. Keep in mind that this is also a very good sign that your child is making progress and ready to work toward discharge home. The staff on these units is experienced in caring for ventilator-assisted children and in teaching families to provide that care at home.



Preparation for Discharge

Once your child arrives on the stepdown unit the focus of care is to help you and your child adapt to life with a ventilator and to return safely to your life outside the hospital. The environment and services are designed to help children move into a normal daily schedule and activities and to help families participate in their child's care.

There are three major goals of care as your child moves toward discharge:

1. To keep your child stable and get him/her to the best level of function possible.
2. To train the family caregivers in all of their child's care.
3. To complete the discharge planning and find resources for care at home.



Remember the entire health care team is dedicated to helping you and your child return home safely.

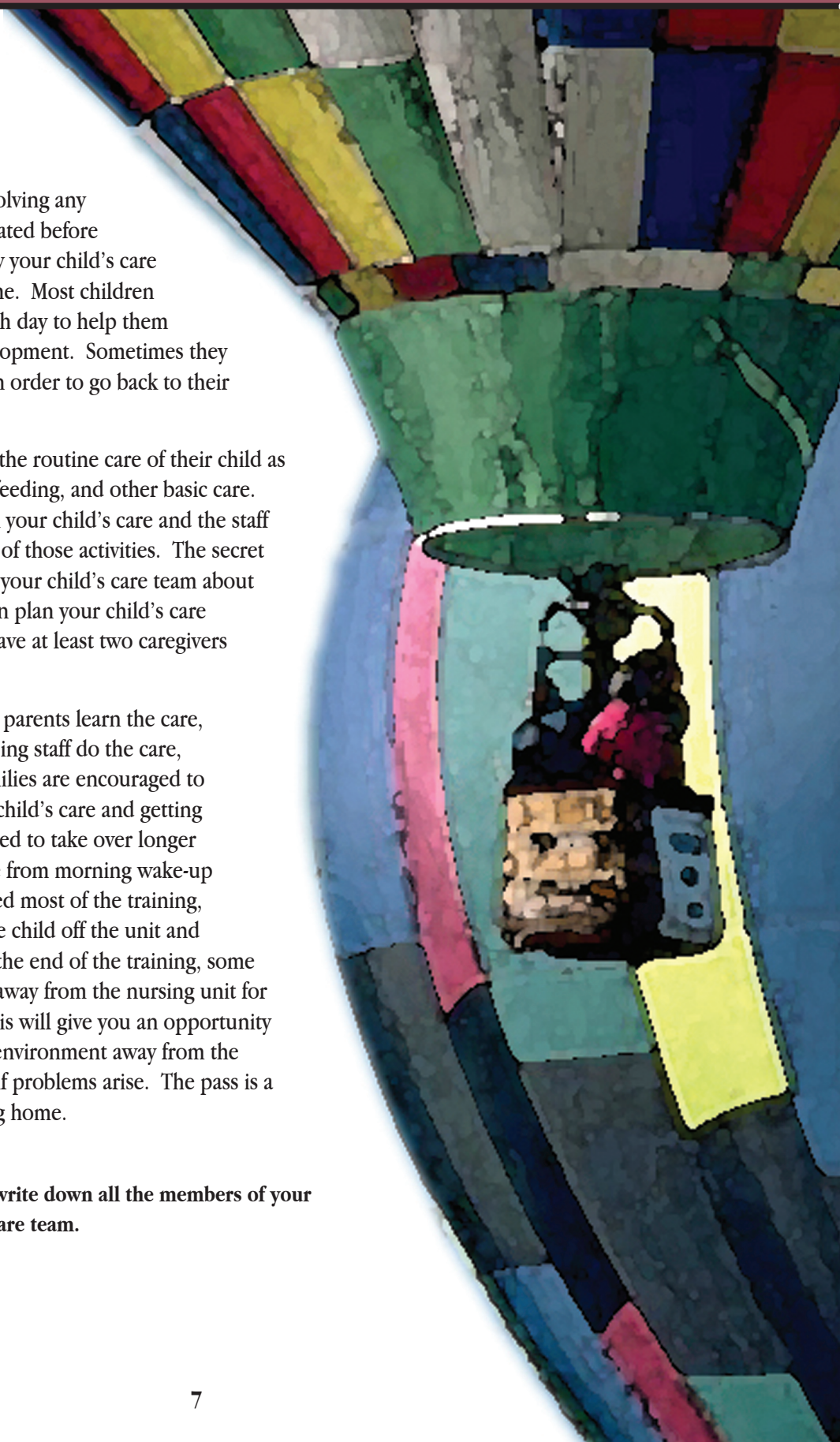
Medical Issues

Medical and nursing staff will work at resolving any medical problems that still need to be treated before discharge and will look at ways to simplify your child's care and make it easier to provide in your home. Most children will have a busy schedule of therapies each day to help them regain function or to continue their development. Sometimes they need to learn to do things in a new way in order to go back to their activities at home.

Families are encouraged to participate in the routine care of their child as soon as possible. This includes bathing, feeding, and other basic care. There will be many new things to learn in your child's care and the staff will help you gradually get involved in all of those activities. The secret to all of this is good communication with your child's care team about when you plan to be here, so that they can plan your child's care and your training. Each child needs to have at least two caregivers trained in his/her care.

The staff will use a variety of ways to help parents learn the care, including written materials, videos, watching staff do the care, and practicing hands-on techniques. Families are encouraged to learn in stages by helping staff with their child's care and getting lots of hands-on practice. You will be asked to take over longer stretches of your child's care, for example from morning wake-up to bedtime. When families have completed most of the training, some institutions encourage trips with the child off the unit and short passes out into the community. At the end of the training, some institutions will set up an overnight pass away from the nursing unit for the child and both parents/caregivers. This will give you an opportunity to take over all of your child's care in an environment away from the hospital, but close enough to come back if problems arise. The pass is a good dress rehearsal before actually going home.

Please refer to Appendix 1 for a space to write down all the members of your child's health care team.



Chapter 2

The Respiratory System

Ann Marie Ramsey, MSN, RN, CPNP

Understanding the Respiratory System

The purpose of the respiratory system is to bring oxygen into the body and remove carbon dioxide. Oxygen enters the body as we inhale air into the lungs. Carbon dioxide is the waste product that leaves the body when we exhale.

There are many parts we use to breathe (figure 1). Air enters the body through the nose and/or mouth then travels down the back of the mouth to the larynx (voice box). The larynx contains the vocal cords. Below the larynx is the trachea or windpipe. The trachea is held open by rings of soft bone called cartilage. About half way down the breastbone the trachea splits off into two smaller windpipes called right and left main stem bronchi.

Each main stem bronchus attaches to a lung. There are two lungs, one on the right and one on the left. The right lung is divided into three lobes, upper, middle and lower. The left lung is divided into two lobes, upper and lower. The inside of the lungs looks like an upside down tree. Picture the trunk of the tree branching to large branches, which branch into medium branches, which then branch into tiny twigs. In the lungs, at the end of each tiny twig, there are sacs called alveoli. These sacs have many blood vessels around them (figure 2). Oxygen in these sacs seeps into the blood. This is how the lungs deliver oxygen to the body. The reverse occurs when the body is removing carbon dioxide. The carbon dioxide in the blood seeps into the sacs and back through the branches and out through the nose/mouth. The whole process of oxygen going into the blood and carbon dioxide coming out of the blood is called gas exchange.

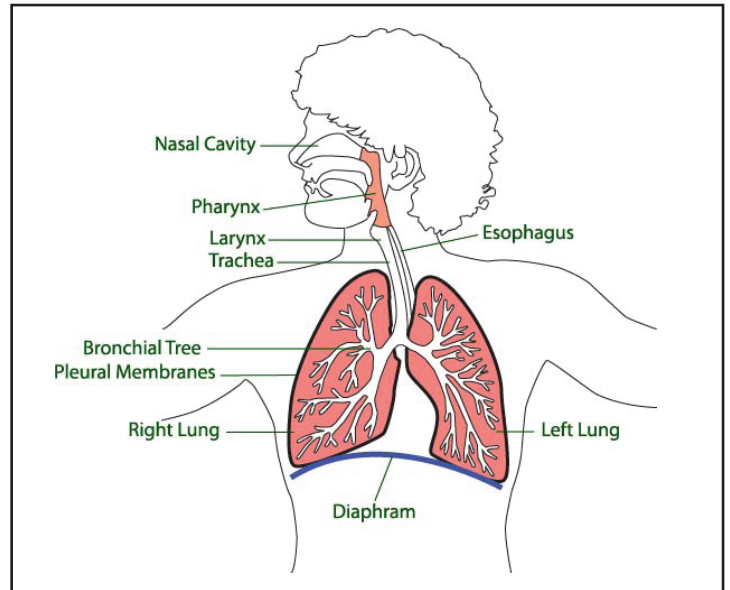


figure 1

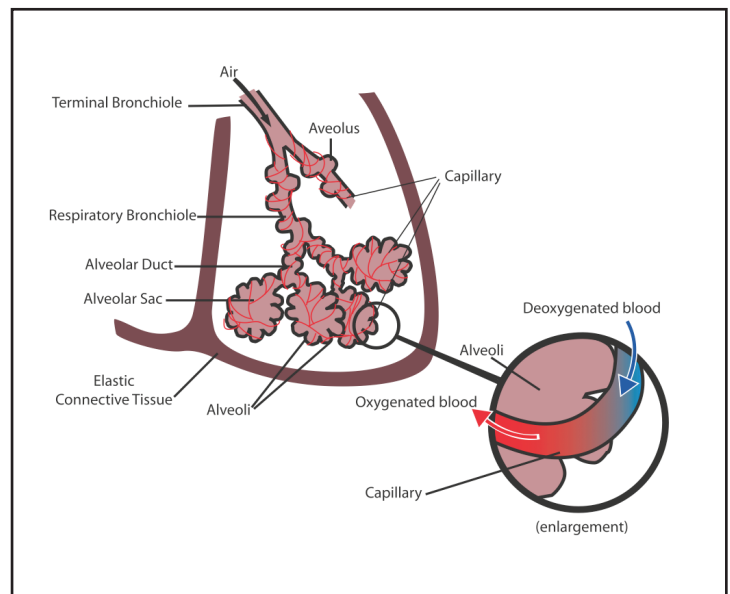


figure 2



How Breathing Works

If you were to hold a lung in your hand you would notice it feels smooth and rubbery. Lungs are made to stretch like a balloon. The rib cage forms a box like structure around the lungs. When you inhale, the muscles around your ribs, called intercostals, and a muscle between the chest and the abdomen, called the diaphragm, work to make the rib cage box bigger. When this happens air is drawn into the lungs. Take a deep breath now. Notice how you pick up your chest and shoulders making the rib cage bigger. We exhale by relaxing these muscles and allowing the air to easily escape.

Reasons Why Children Need To Use Ventilators

There can be many reasons why children may need a ventilator to assist in breathing. These can be placed into one of four categories. Your child may have one or a combination of these problems:

1. **Problems with the airway.** The cartilage that holds the trachea or the main stem bronchi open may be very soft making the airway floppy. This is called “malacia”. This floppy airway cannot stay open when the child tries to inhale. A ventilator is used to give constant airflow to keep the airway open. In most cases the airway gets stronger as the child grows.
2. **Problems with the chest.** In children with muscle weakness or problems with the spine (such as scoliosis), the rib cage and/or the muscles in the rib cage may not work right. These children cannot inhale deeply enough for the lung to expand all the way and fill the sacs with air. Children with this problem are said to have “restrictive lung disease.” The ventilator helps by using pressure to push the air into the sacs which would not inflate with the child’s own breath.
3. **Problems with the part of the nervous system that controls breathing.** Nerves coming from an area of the brain called the brainstem control breathing. Any damage to the brainstem or damage to the nerves in the spinal cord that control breathing can cause breathing to be too shallow or stop all together. Children who have high spinal cord injuries and brain tumors or brain malformations fall into this group. When the brain does not tell the lungs to breathe, this is called “central apnea.” In these cases the ventilator will do the breathing for the child.
4. **Problems with the lungs.** Lung tissue can be damaged in many ways. Damaged lung tissue is not as stretchy as healthy tissue, so air cannot move in and out as easily. The lining of the air sacs can get thickened, making movement of oxygen and carbon dioxide more difficult. Some medical diagnoses that fall into this group are BPD (bronchopulmonary dysplasia) and bronchiectasis. For these children, the ventilator pushes air into these stiff lungs allowing them to breathe better.

Notes

Reasons my child needs a ventilator: _____

Chapter 3

Home Respiratory Support Machines

Kathleen Barnum, BS, RTT and Ann Marie Ramsey, MSN, RN, CPNP

Ventilation

The action of air moving in and out of the lungs is called “ventilation.” Machines that help with the movement of air in and out of the lungs are called ventilators. Ventilators help children breathe by pushing air into the lungs. In this way the machine gives or “delivers” a breath of air to the child. When this air is delivered through a tracheotomy tube, this is called “invasive” ventilation. We will discuss invasive

ventilation in the next few pages.

The air can also be delivered using a facemask or nasal type device. This is called “noninvasive” ventilation. Special machines called BiPap® or CPAP machines are used for these children. **If your child is going to use BiPap® or CPAP please go to part II of this chapter on page 14.**

Part I - Invasive Ventilation

Ventilators have a variety of settings which are used to “customize” how the machine helps your child breathe. Let’s talk about those settings.

Support Settings on Ventilators

Understanding ventilators can be hard. To try to make this explanation a little easier we have chosen to compare ventilators to cars. Cars can operate in two-wheel drive or four wheel drive. Ventilators are similar.

Assist Control: setting means that every breath your child takes is going to be fully assisted by the machine. This is the “four wheel drive mode”. The work of breathing in this setting is minimal, and the machine is mostly in control. Most children use assist control when they first go on the ventilator and will continue using this setting until they heal and grow enough to take on some more of the work of breathing.

SIMV-stands for “Synchronized Intermittent Mandatory Ventilation.” In this setting the ventilator expects your child to assume some of the work of breathing. This mode demands that your child do more work by taking spontaneous breaths on his/her own. Children are changed to the SIMV mode when they are stronger and ready to do more work during breathing.

Types of Ventilation

Volume Ventilation:

Volume refers to a set amount of air delivered to the lungs. Think of volume like filling the gas tank of your car. If you have a 20-gallon gas tank you must put in 20 gallons of gas to fill it up. This is the “volume” of gas need to fill your gas tank. Lungs have volume too. Lung volume is related to age and weight. A two-year-old child weighing 24 pounds has a lower lung volume than a 10-year-old child weighing 75 pounds. The volume mode of ventilation refers to the ventilator giving a set amount or set volume of air to the lungs.

Pressure Control Ventilation:

Pressure refers to the flow of air to the lungs. Think of having to inflate a flat tire with air. Depending on how low the tire is will determine on how much air you will need to add to fill the tire fully. In pressure ventilation, the ventilator will use as much flow as it needs to inflate the lungs to the pressure that is set on the machine.

Settings on the Ventilator:

Rate is the number of breaths the machine is preset to give your child per minute. The rate is the minimum number of breaths the machine will deliver. Your child may also be able to breathe more than the preset rate.

Inspiratory Time is the length of time measured in seconds that the machine delivers the breath. Remember the breath can be a volume breath, a set amount of air delivered over this time, or it can be a pressure breath, which is a set pressure delivered over this time.

Positive End Expiratory Pressure (PEEP) is a pressure that is maintained in the ventilator tubing and lungs at all times. This keeps the small air sacs in the lungs from collapsing completely when the child breathes out. Healthy lungs normally have PEEP.

Tidal Volume is the volume or amount of air the machine is set to deliver. In volume ventilation we set the “tidal volume” so each machine breath is the same.

Pressure Control (PC) is the amount of pressure the machine is set to deliver. In pressure ventilation we set the pressure control so the pressure for each machine breath is the same.

Sensitivity refers to how easy or difficult it is for the ventilator to sense the child is starting to take a breath.

Pressure Support (PS) is the pressure offered during a spontaneous breath to help decrease the work of breathing.

Alarms

Ventilators have two main types of alarms:

Low pressure means that air may be leaking from the ventilator tubing. The ventilator tubing becoming disconnected from the child or the tubing coming apart most often causes this. This can also be caused by water in the ventilator tubing.

High Pressure means that air does not easily pass through the ventilator tubing into the lungs. This is most often caused by something blocking the flow of air, such as a need for suctioning of the tracheotomy tube, a mucus plug in the tracheotomy tube or the child laughing or coughing into the tubing.



Table 1
Quick Guide to Understanding the Modes of Ventilators

Mode	Pressure Ventilation	Volume Ventilation
Assist Control -All breaths are machine assisted	Every breath gets delivered at a set pressure	Every breath gets delivered at a set volume
SIMV - Breaths given at preset rate are assisted, breaths child initiates are independent	Machine breaths (rate) delivered at a set pressure, Patient initiated breaths pressure varies	Machine breath (rate) delivered at a set volume, Patient initiated breaths volume varies

Specific Settings for My Child:

The ventilator my child will be using: _____

My Child will be in (circle one) mode Assist Control SIMV

My Child will use which type of ventilation (circle one) Volume Pressure

My Child's settings are (not all fields will be filled in)

Rate _____

Inspiratory Time _____

Pressure Control _____

PEEP _____

Pressure Support _____

Volume _____

Oxygen used in liters per minute _____



Please remember: Settings on the ventilator are specifically set for your child by your doctor and respiratory therapist based on your child's medical condition. **Ventilator settings are not to be changed by you, family members, or home care staff without specific orders from your child's doctor.**

Learning about your child's ventilator

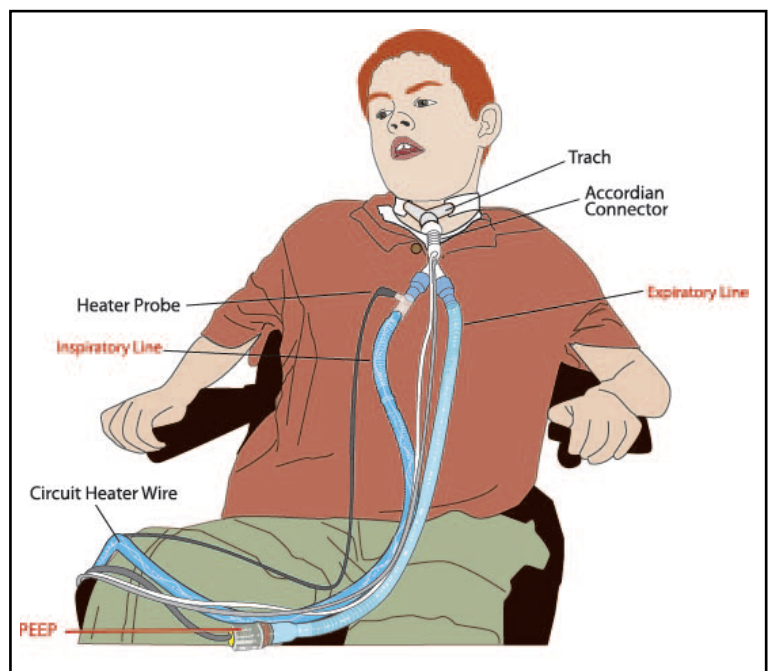
Each child has a ventilator chosen specifically to meet the unique medical situation and type of breathing support needed. Ventilators are constantly changing and improving, so it is not possible for this book to cover the specifics of each type of home care ventilator. Your child's respiratory therapist will go over the specifics of your child's home ventilator with you.

Some general concepts:

All ventilators deliver air to the patient through tubing attached to the machine and to your child's tracheotomy tube. This tubing is also called a circuit. In general, all circuits have the following parts:

1. Inspiratory line: The tubing in which air goes from the machine to your child.
2. Expiratory line: The tubing which allows exhaled air to escape to the environment
3. PEEP valve is used when PEEP is ordered. This fits on the end of the expiratory line and is set by twisting the adjustment knob.

Circuit Diagram



Notes about specific ventilator:

Part II - Noninvasive Positive Pressure Ventilation

Noninvasive Positive Pressure Ventilation (NPPV) means that the air is delivered to your child with a device that fits on the face. There are many types of face devices. As a group these devices are called “interfaces.” The air enters the nose (and sometimes mouth) with this device which is connected to an NPPV machine.

There are two main types of NPPV:

Continuous Positive Airway Pressure (CPAP) provides one constant pressure to the interface.

Bi-level Positive Airway Pressure (BiPap®) provides two different pressures:

- **IPAP-Inspiratory Positive Airway Pressure** refers to the higher-pressure set when your child breathes in.
- **EPAP-End Positive Airway Pressure** refers to the lower pressure that is maintained when your child breathes out.
- **Rate:** Is an optional value that can be set on certain BiPap® machines. The rate is the minimum number of breaths your child can receive.

Interfaces for NPPV machines:



Nasal Masks:

Nasal masks fit over the nose of the child only. They are secured with a headgear.

Full Face Mask:

Full facemasks fit over both the nose and the mouth. They are also secured with a headgear.



Nasal Aire ®

This device is large nasal prongs that fit in each nostril. It looks like an extra large nasal cannula that is used to deliver oxygen. Nasal Aire ® does not require the head gear like nasal pillows or mask.

Nasal Pillows:

Nasal pillows are soft pieces of rubber that look like little funnels that fit into each nostril and are held in place with a headgear.



Specifics about my child's NPPV

My Child uses (circle one)

CPAP

BiPap®

Interface: Type _____ Size _____

Settings –not all will be filled in

CPAP _____ IPAP _____

EPAP _____ Rate _____

Helpful Hints for Using NPPV at home

Here are some common complaints that your child may have and some hints on how to fix them:

Complaint: Air leaking out of mask.

Cause: Loose fitting mask.

What to do:

1. Adjust mask with child lying down.
 - Make sure mask is centered on face.
 - Turn machine on and check for leaks at top of mask toward eyes. It is OK if mask leaks slightly at the bottom of mask.
2. Adjust headgear, it should keep mask in place without being too tight on the child's face.

Complaint: Skin redness and breakdown

Cause: Headgear too tight OR dirty mask

What to do:

1. Check headgear fit as stated above
2. Wash mask daily with mild soap and water and dry well before placing on child
3. Place hydrocolloid dressing (Duoderm®/Restore®) on reddened area of child's face. Place moleskin on the mask at the pressure point site.
4. Bag Balm® may also be applied to the reddened area of child's face.

Complaint: Nasal discomfort and dryness.

Cause: Drying of nasal tissues from airflow of NPPV

What to do:

1. Speak to your doctor about getting a humidifier that attaches to the machine.
2. You may use over the counter nasal saline spray as needed for nasal discomfort.



Additional Notes _____

Chapter 4

Paying for All This Care - Insurance

Amy Jo Herndon, LMSW and Kelly Krawcke, BSN, RN

Insurance policies are hard to understand because most people are not familiar with the terms. This confusing situation is made even more difficult because all these big words and dollar amounts have a direct impact on your child's health. In this chapter we will present some common types of insurance policies and help you to understand some of the terms used when talking about insurance.

Commonly used terms:

Preferred Providers-Some insurance companies require companies they have selected to be used for equipment, supplies, and home care. To know if you have preferred providers with your insurance, check with your insurance company or your hospital discharge planner or social worker.

Private insurance-This is insurance paid for by an individual or group. If someone works and has health insurance provided by their employer, this is considered "private insurance." Some people buy insurance as individuals and that is also considered private insurance. Blue Cross and Blue Shield, Aetna, and Health Maintenance Organizations are examples of private insurance.

Public Insurance- Generally, this is insurance that is paid with national, state and local tax dollars. It is primarily for people with low income and/or with ongoing health problems. Medicaid is an example of a public insurance.

Intermittent Skilled Nursing- This refers to a short home visit by a registered nurse. The nurse comes to provide specific services like weighing and measuring your child, checking heart, lungs, dressings, tracheotomy and gastrostomy tubes and teaching you about your child's care.

Hourly Nursing/Private Duty Nursing- This is care provided by a registered nurse (RN) or licensed practical nurse (LPN) over many hours. This is similar to a nursing shift in a hospital.

Skilled Care- is a term used to describe care that is complicated and must be provided by a person with certain education and licensing.



Custodial Care- is a term used to describe basic care that can be provided by an average person with no special education. Giving a bed bath, changing diapers, feeding and positioning are examples of custodial care.

Durable Medical Equipment (DME)- This is equipment that your child needs. Examples of DME include ventilators, suction machines, wheelchairs, and feeding pumps.

Supplies- are disposable medical items your child needs. Examples of supplies include tracheotomy tubes, suction catheters, and gloves.

Medicaid Eligibility- This means that the child is able to get Medicaid either because his/her family has a limited income or because the child has a severe disability that qualifies the child to receive Supplemental Social Security Income (SSI).

Insurance Riders- Most private insurance plans do not cover the needs of children on ventilators, particularly when it comes to nursing care in the home. Sometimes insurance companies will do a “rider” that allows for services not normally included in the insurance plan to be covered. This benefit is said to be “outside of the plan.” A rider is a special plan developed specifically for your child.



Financial Resources

Type of Insurance	Eligibility	Length of Coverage	Cost	To Access
Private	1. Employer sponsored 2. Self Purchased	1. Length of employment 2. Disenrollment 3. Policy dollar cap reached.	Varies per insurance plan and coverage type	Contact hospital social worker or discharge planner or insurance company directly
Medicaid-State Program	1. Low income 2. Receiving SSI benefits	Disenrollment	No cost to family unless spend down required	Contact hospital business office or local Department of Human Services/Department of Social Services
Children's Special Health Care Services (CSHCS) State program	Based on medical diagnosis	Until 21st birthday	Possible premium dependent upon family income	Contact hospital social worker
Family Support Subsidy (State Program)	Evaluation by local or intermediate school district as SCI or SXI or AI	Until 18th birthday	No Cost	Contact hospital social worker or local or intermediate school district. Applications available at all county community mental health programs
MI Choice Waiver	1. Over 18 years of age 2. Medicaid Eligible 3. Patient requires nursing facility level of care		No Cost	Contact www.michigan.gov/mdch then click on care coverage, services to seniors, MI Choice waiver program
Local Community Mental Health	1. Medicaid Eligible 2. Developmental Disability		No Cost	Contact local community mental health agency. Directory available at www.machmh.org
Adoption Support Subsidy and Adoption Medical Subsidy (State Program)	For children in foster care in Michigan prior to adoption			Contact you adoption worker to learn more.

Note: The State programs outlined above are for Michigan only, however most states have similar programs. Check with your medical social worker about programs in your state.

Financial Resources for Private Duty Nursing

Type of Insurance	Eligibility	Length of Coverage	Cost	To Access
Private	Employer Sponsored Self Purchased	1. Length of employment 2. Disenrollment 3. Policy dollar cap reached	Varies per insurance plan and coverage type.	Contact hospital social worker or discharge planner or contact insurance company directly
Auto Insurance	Need for services for injuries due to motor vehicle collision. Must have Michigan Auto insurance at time of injury	Lifetime	No Cost	Contact hospital discharge planner or social worker or contact auto insurance directly
Children's Special Health Care Services (CSHCS) Private Duty Nursing Benefit State Program	Medicaid Eligible	Ongoing or until Medicaid disenrolled.	No Cost	Contact hospital social worker or discharge planner
Children's Waiver (State Program) Habilitation Supports Waiver	Community Mental Health Client	Until 19th birthday or until no longer meets community mental health criteria.	No Cost	Contact hospital social worker or discharge planner or contact local community mental health agency

Insurance eligibility and services provided either by private or state funds change frequently. It is very difficult for the professionals who work with these programs daily to keep up with the changes. It is even more difficult for families who try to understand all this information while trying to deal with their child's medical problems. You will get to know the staff at the hospital who will help you with insurance issues. Make sure to write down their names and phone numbers and make a point to keep in touch with them, even after your child is discharged.



Chapter 5

Help at Home: Home Nursing Issues

Cathy Lewis, MSN, RN and Kelly Krawcke, BSN, RN

From Finding Funds to Finding Staff

The social work and discharge planning staff will help you find a funding source for home care. After the funding source is found, the team will work with them to get approval for a number of hours of nursing care each day. Families usually receive approval for about 8 to 16 hours per day of care, depending on the funding source, the home care needs of the child, and the amount of nursing support the family needs.

Once the hours of care are approved, you will need to decide, as a family, how you want to use those hours for help with your child's care. This help can be used during the day, at night, or a combination of both. It will be important to think about the times of the day when you may be busy with other family chores, away from home, or sleeping and need skilled staff who can take over your child's care for you.

The discharge planning staff will contact home care nursing agencies in your area to find staffing for your child's care. The biggest delay in discharge is finding agencies that have available, qualified staff. There is a shortage of home care nurses in every state and many agencies do not have nurses with experience in caring for children with special needs. It often takes 4 to 6 weeks or more to find enough staffing for a reasonable amount of help to begin care at home. It may not be possible to find enough staff to cover all of the hours that have been approved



Travis and his home nursing staff

Orientation for Home Care Nurses

The hospital and durable medical equipment company staff will offer to help orient any of the home care staff to your child's care. It will be important for you to help orient the home care nurses to your child's care after you return home. You will be able to help them understand how your child responds to the care and how you and your child like to have things done. There may be new nurses added to your staff at home and these nurses will look to you for guidance.

You may not have enough staffing to cover hours when nurses are ill or on vacation. That is why it is very important for you to be well trained in all of your child's care. You will always have the responsibility for your child's care. You must know your child's care better than anyone and be able to take over your child's care at any time.

The Secret is COMMUNICATION!!

While it is important for you to have help at home with your child's care, it is also very stressful having new people in your home for hours every day. Keep in mind that your home is just that: your home. The goal is to keep it a home – not make it into a mini hospital! Clear, honest communication is the secret to getting along with all of this outside help.



Tips for successful home care relationships:

- Decide where to have the main area of care for your child. A more central room may work best (family room, living room, dining room) vs. the child's bedroom, especially if other siblings share that bedroom. Consider making your child's room in a living area. This will give you more family privacy when nurses are in the home.
- Give nurses access to a kitchen area, bathroom, a place to chart, and adequate light (especially at night).
- Be specific about your child's care. Be available to answer questions for new staff.
- Be flexible. There is more than one way to do most care. The outcome for your child is what matters.
- Use a communication book/log to exchange messages with the staff and between nurses.
- Set reasonable ground rules. For example: where staff should park their cars and store their lunches, break times and quiet times for the household.
- Be open-minded about new staff. It is very important to realize that you probably will not "like" all of the nurses caring for your child. Concentrate on the care they are providing.
- If you are going to be away from home, be sure to return on schedule so that nurses can leave at the end of their shift.
- Do not ask nurses to care for other children in the family. They are there to care only for your child with special health care needs.
- If problems arise, try to talk honestly with the nurse right away or call the supervisor at the agency. Don't let little problems grow into big ones.



School and Vacations

The school system is responsible for providing care for your child while she/he is being transported on the bus and during the school day. The school may choose to use staff from an agency or school staff to provide your child's care. The hospital team will contact your school before discharge to help them understand your child's care needs and to suggest ways to meet those needs safely. Most ventilator assisted children attend school regularly.



Sometimes families can use approved hours of care and agency staffing while they are away for a few days. However, this depends on availability of staff and there must be a trained adult responsible for your child in your absence. Families are often able to take their ventilator assisted child with them on vacations. The home ventilator team can assist you in planning for those adventures after you adjust to a care routine at home.



Remember: All this is worth it. Home is Best!

Chapter 6

Nutrition

Amy McCoy, RD

Nutrition is important for ventilator assisted children. Studies show that good nutrition leads to better growth and development, fewer infections and illnesses, and healthier lives for these children.

Growth

The way a child grows is a good guide to his or her nutrition. Growth charts show us a picture of how a child has been growing. Growth velocity, or speed at which a child gains weight and length, helps us to know how much food your child needs. Younger children grow faster than older children. Some children will need to grow faster than this to achieve “catch-up” growth. Ask your dietitian for a copy of your child’s growth chart.

Typical Growth Rates in Children

Age	Weight Gain (gm/day)	Length Gain (cm/month)
Less than 3 months	25-35	2.6-3.5
3-6 months	15-21	1.6-2.5
6-12 months	10-13	1.2-1.7
1-3 years	4-10	0.7-1.1
4-6 years	5-8	0.5-0.8
7-10 years	5-12	0.4-0.6

Lung Function and Nutrition

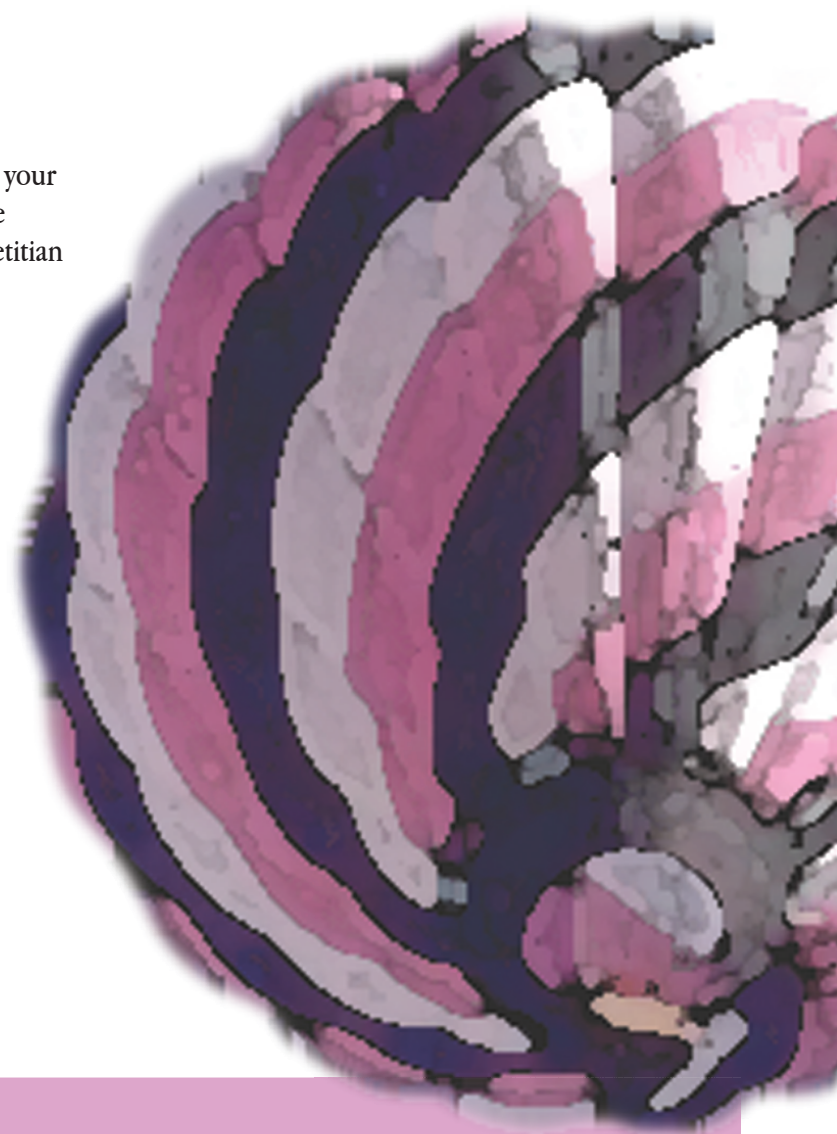
Lung function plays a large role in the amount of calories your child needs in a day. Children with lung problems need more calories because they work harder to breathe. Kids who use respiratory assistance most or all of the time need fewer calories because they do not have to work as hard to breathe. Calorie needs are also affected by age, gender, weight, activity level, diagnosis, lung size and development, time on the ventilator, and degree of ventilator support.

Getting the right amount of calories, protein, and other nutrients is the key to good nutrition. Not getting enough of these can result in increased time on the ventilator, increased risk for infections and illnesses, as well as poor growth. Getting too much, on the other hand, can result in decreased lung function as well as a variety of problems linked with obesity.

Nutrition Plans

The following diet recommendations can help you to provide your child with the foods to best meet his or her needs. Follow the suggestions next to the checked box. Feel free to ask your dietitian for other suggestions.

- ☐ High Calorie Diet-see box 1 in appendix 4
- ☐ Lower Calorie Diet-see box 2 in appendix 4
- ☐ High Fiber Diet-see box 3 in appendix 4
- ☐ Sources of Vitamins and Minerals-see box 4 in appendix 4

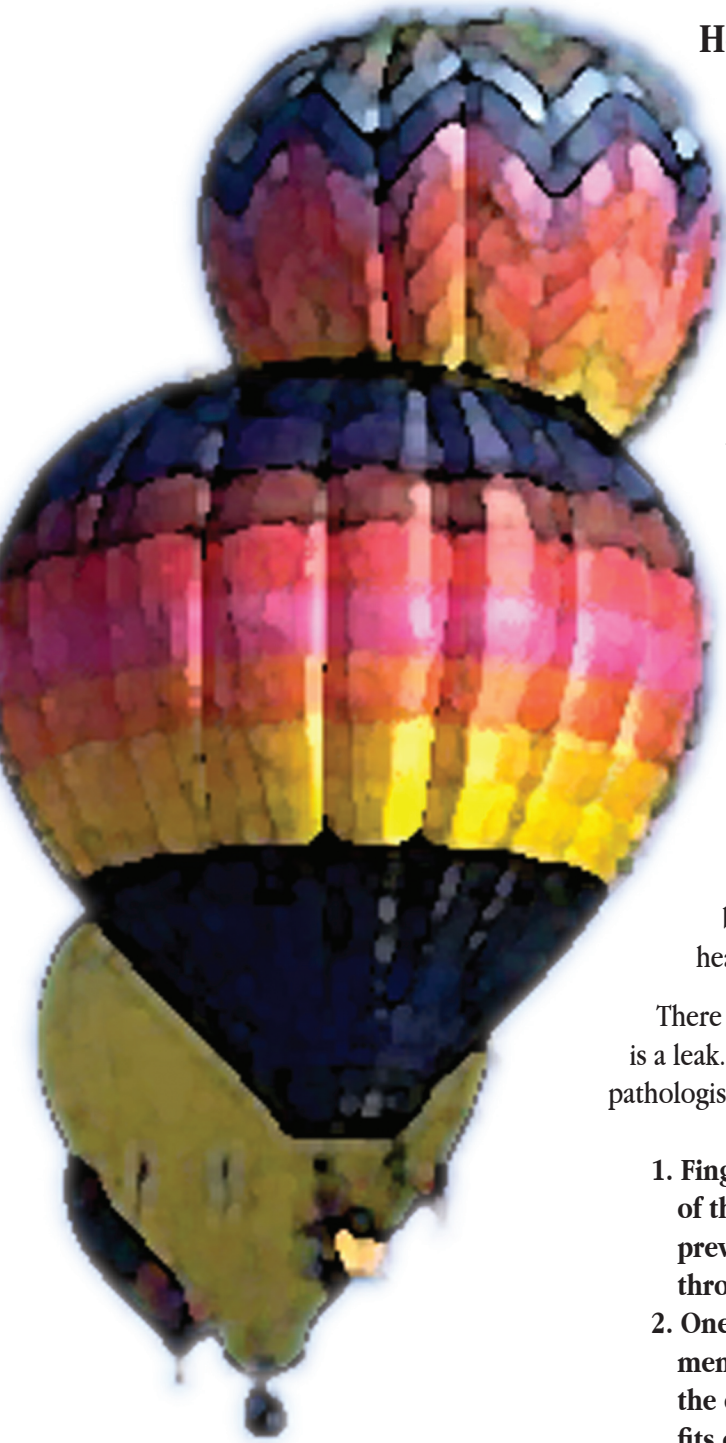


Notes on Nutritional Plans for my child:

Chapter 7

Speech and Communication

Lynn Driver, MS, SLP - CCC, S. Dale VanDenise, MA, SLP - CCC and Trish Mozdierz, OTR



How we Produce Voice

When we talk, airflow travels from the lungs up through our vocal cords. This airflow causes the vocal cords to vibrate as it passes through them, producing sound (our voice) that we use to talk.

Why can't my child talk?

When children with a tracheostomy tube attempt to talk, the airflow that they generate flows out of the tracheostomy tube in their neck before it reaches the vocal cords. When children with a tracheostomy tube on a ventilator attempt to talk, the airflow supplied by the ventilator also goes through the tracheostomy tube on both inhalation and exhalation.

What can be done to help my child with a tracheostomy talk?

If there is enough space between the tracheostomy tube and the tracheal wall, some air may pass up around the tracheostomy tube and reach the vocal cords, allowing your child to talk. This is called a leak. If there is not enough pressure behind the air leak, your child's voice may still be too weak to be heard easily.

There are several ways to make your child's voice louder when there is a leak. The best choice will be determined by your speech-language pathologist and your child's medical team.

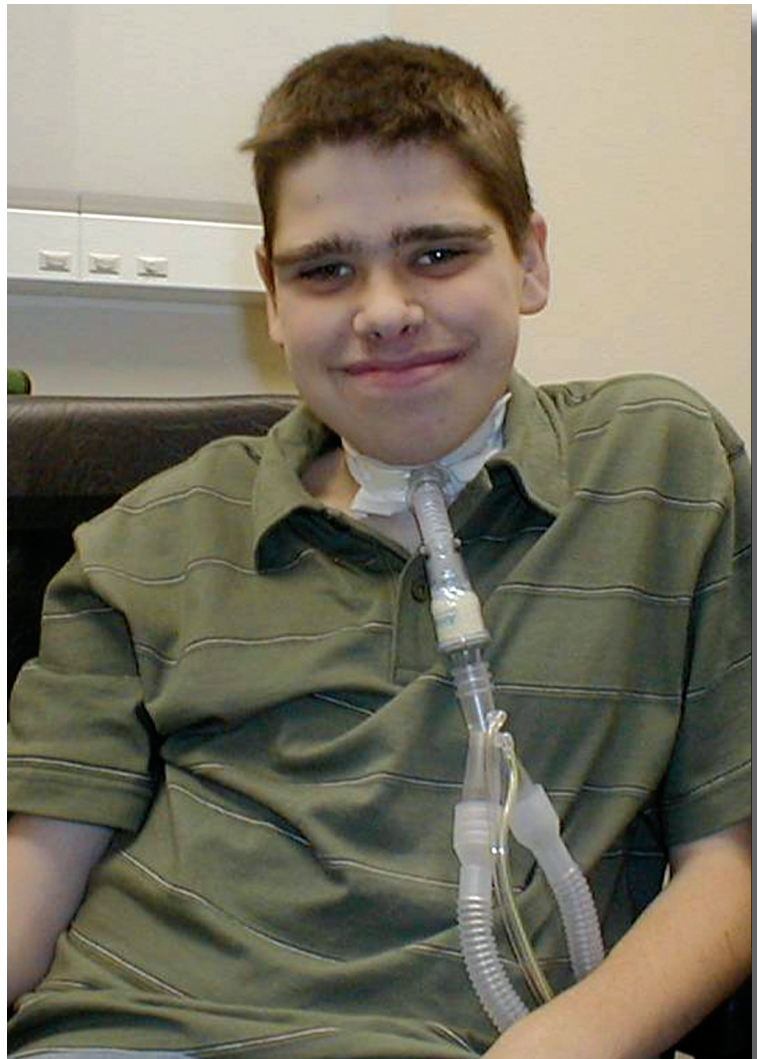
1. **Finger occlusion:** this involves placing a fingertip over the end of the tracheostomy tube when your child is talking. This will prevent air leakage out the tracheostomy tube, and direct it up through the vocal cords.
2. **One-way speaking valve:** this is a valve with a thin, silicone membrane that opens as the child breathes in and closes when the child breathes out, forcing air up through the vocal cords. It fits over the end of the tracheostomy tube.
3. **Cap:** This is a solid plastic cap that is placed over the end of the tracheostomy tube, forcing both inhalation and exhalation through the mouth and vocal cords.

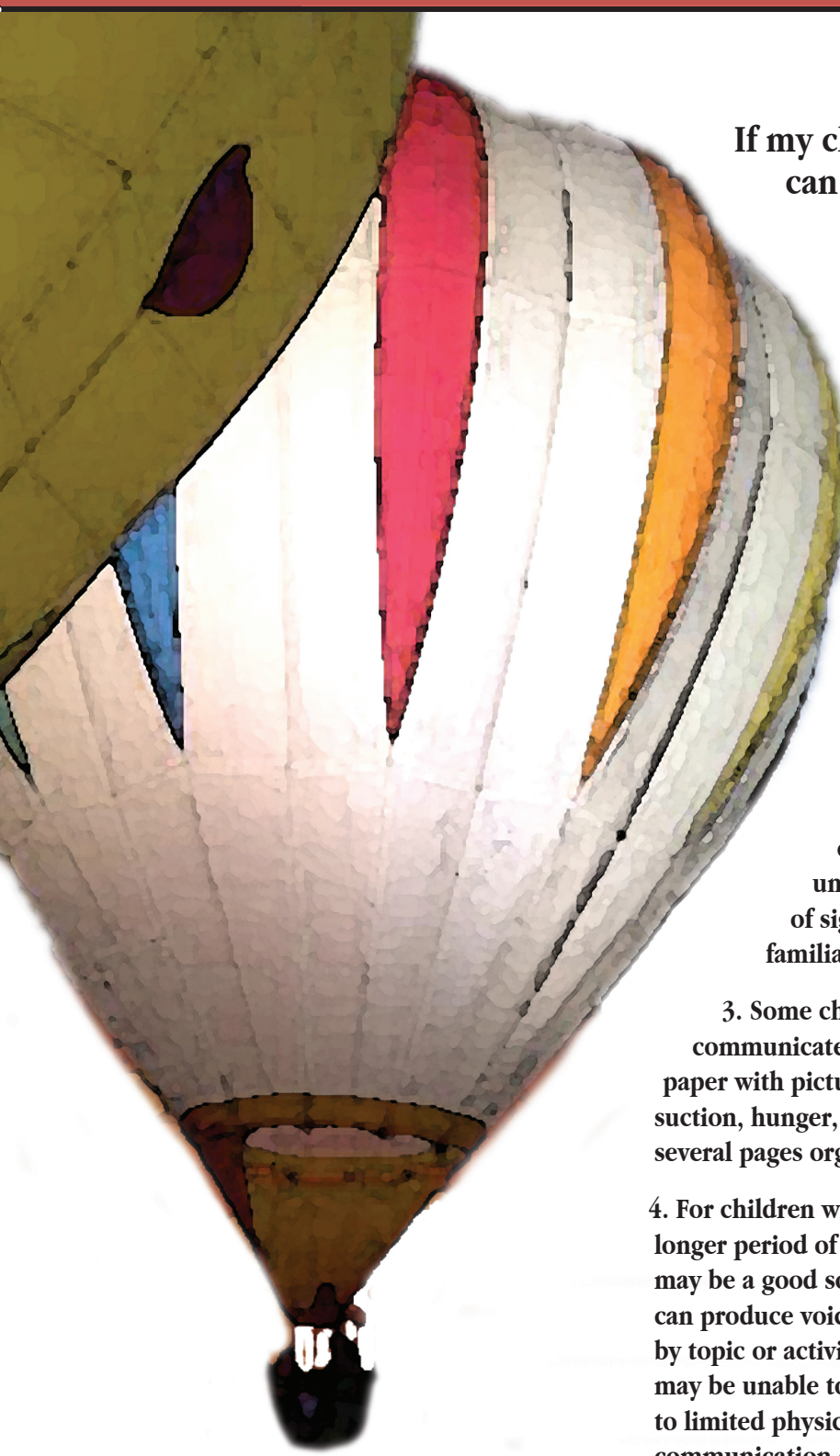
What can be done to help my child with a tracheostomy and ventilator talk?

When the ventilator pushes the air through the tracheostomy tube and into the lungs, some of it may leak around the tube and reach the vocal cords, producing voice. Because of the extra air pressure provided by the ventilator, it is easier to achieve a strong voice.

There are several ways to make your child's voice louder when there is a leak. The best choice will be determined by your speech-language pathologist and your child's medical team.

1. **Cuff deflation:** Some tracheostomy tubes have balloons, or cuffs at one end. These can be inflated to help keep air leakage to a minimum. If your child's tracheostomy tube has a cuff, this can sometimes be partially deflated to allow for more airflow up through the vocal cords, or a bigger leak.
2. **Ventilator adjustments:** A child is able to talk when the ventilator delivers a breath. By making changes in the ventilator settings, the medical team can increase the amount of time your child has to talk with each breath.
3. **One-way speaking valve:** this is a valve with a thin, membrane that opens with inhalation and closes with exhalation, forcing air up through the vocal cords. It fits in the ventilator circuit.





If my child is unable to make sounds, how can I help her/him communicate?

In some cases children are not able to move enough air around the tracheostomy tube to produce voice. For children in these situations, your child's speech-language pathologist will work with you to provide other ways for them to communicate.

- 1. Some children are able to mouth words well enough for others to read their lips and understand them. This is the easiest and most efficient way for them to communicate, because it requires no extra equipment, and it will help them keep practicing oral motor movements for speech while unable to voice.**
- 2. Some children already know sign language, or are able to learn enough basic signs to communicate their basic needs and wants while unable to speak. It is helpful to provide a glossary of signs at the bedside for caregivers who may not be familiar with signs.**
- 3. Some children may prefer using a picture board to communicate. This can be something as simple as a sheet of paper with pictures to represent basic needs such as toileting, suction, hunger, thirst, etc., or it can be more elaborate, with several pages organized by topic or activity.**
- 4. For children whose ability to talk may be interrupted for a longer period of time, an augmentative communication device may be a good solution. This is a portable electronic device that can produce voice when a button is pushed, and is programmed by topic or activity, much like the picture board. Some children may be unable to use any of the above ways to communicate due to limited physical movement. For these children, augmentative communication devices that can be operated using a switch to make selections may be provided.**

How will I know if my child is communicating age-appropriately?

Your child's communication may be interrupted or late in starting due to the tracheostomy. The tracheostomy may also temporarily delay development of spoken language skills. Your child's speech-language pathologist will be able to give you some ideas for working with your child to increase verbal communication, as well as recommend formal speech therapy, if needed.

Who will help me determine my child's communication needs and answer my questions about communication after I go home?

As part of your preparation for going home from the hospital, your child's speech-language pathologist will ask your permission to contact a speech-language pathologist from your local school or community to review your child's communication needs and make a referral, if needed.



Chapter 8

Feeding Issues

S. Dale VanDenise, MA, CCC-SLP and Trisha Mozdierz, OTR

Normal Swallowing

Infants are born with reflexes that allow them to drink and swallow safely. When drinking, the infant must be able to coordinate sucking, swallowing, and breathing. The infant does not have to think about doing all these things in order. The baby's reflexes make this all happen automatically.

As infants grow and develop, some of these reflexes are lost, although older children and even adults have some reflexes that serve to protect the airway when chewing and swallowing, including a gag reflex and cough reflex. As a person swallows, the airway is closed off so food or drink does not go into the lungs (called aspiration). If a person aspirates, she/he will cough to push the material out of the airway.

How using a ventilator affects swallowing

Having a tracheostomy and requiring mechanical ventilation can interfere with normal swallowing. The tracheostomy tube can slow the swallow, especially if the tube is cuffed. In addition, the lack of normal airflow through the nose reduces your child's ability to smell food. This can affect how food tastes. The use of a ventilator can alter the swallow-breathe pattern, especially for an infant who relies on reflexes to swallow safely.

Special needs my child may have

The feeding specialist may recommend that your child be on a Level 1/Level 2/Level 3 Dysphagia diet or that your child can safely take a general diet with or without restrictions. The Dysphagia diets are described in Appendix #4 with specialized nutritional plans.

Oral Aversion

Sometimes children on ventilators develop an oral aversion. An oral aversion means that the child does not like touch or texture in or around the mouth. They may not eat at all or only eat certain types of foods. The reaction may be mild such as the child refusing to open his mouth for food. The reaction may be as severe as gagging at the sight of food or a spoon!



An oral aversion can be caused by many factors. It may occur after having bad experiences happen to the face and mouth area. Unpleasant experiences may include having naso gastric tubes placed and taped onto the face, having tubes placed into the mouth for ventilatory support, or from the mouth being suctioned again and again. Having a tracheostomy and all of the issues that come along with it (such as frequent suctioning with coughing or gagging) can also be an unpleasant experience.

Some children are too sick to be able to start eating through their mouth when they are newborns or as an older baby. If eating by mouth is not started when a baby is young, an oral aversion may occur. Also, if a baby has not added solid food to a liquid diet during early life, he may become unwilling to accept solid food from a spoon.

The Dysphagia Team

If you think that your child is not eating because of an oral aversion, you can ask your child's doctor to send a referral to the dysphagia team. The dysphagia team is made up of occupational therapists and speech-language pathologists who are experts in the areas of feeding and swallowing.

The Treatment Plan

Once the team has seen your child, the therapist will set up a treatment plan. It may be made up of a number of different techniques. One technique is called oral play.

Oral play is the act of presenting pleasant experiences in and around the mouth in order to help make the lips and mouth feel better about being touched. This can be done with the use of toys, teethingers, fingers, toothbrush and sometimes food items. Oral play needs to be fun and exciting! Your child's therapist will give you specific ways to play. Another technique is to provide facial massage with your hands or massage with a vibrator. Becoming used to touch around the cheeks and lips will help to decrease the hypersensitivity.

Playing with food is also a way to introduce new textures of food to the child. There are ways to play with food that can be fun and appealing. Your child's therapist can teach you many different ways to help your child be a good eater!

Additional Notes:

Chapter 9

Coping with Your Child's Care

Amy Jo Herndon, LMSW

This is the chapter that is about you—the parents, caregivers and families. Having a child with medical problems is very difficult for many reasons. Just trying to understand all the medical terms and trying to figure out what this means for your child and your family can be overwhelming. In this chapter we will talk about common reactions families have and ways to cope.

Although each child and family is unique, most families have similar reactions to learning that their child has a long-term medical problem and needs to have a ventilator at home. These include:

- **Shock, disbelief, and numbness**—it wasn't supposed to be this way. Everything was fine.
- **Anger**—It's not fair. Why does everything have to be so complicated? Who are all these people? I just wanted to be a parent.
- **Scared**—There's too much to learn. These are professionals and they expect me to be able to do this? What if I do something wrong? What if I hurt my child?
- **Sadness**—I had so many plans and dreams.
- **Frustration**—health care team can't predict, not enough people to help care for child, everything takes so long.
- **Guilt**—I must have done something wrong.



EXERCISE: Make a list of the feelings you have had since you learned your child will go home with a ventilator

As this information sinks in, families often begin to make changes to fit this new situation into their family. This is called “adjustment”. Making changes takes time. Be patient with yourself and those around you. Think about how things are the same:

- **We’re still a family.**
- **We’re still doing what is best for our child.**
- **The sun comes up each morning and the moon each night; the seasons change.**

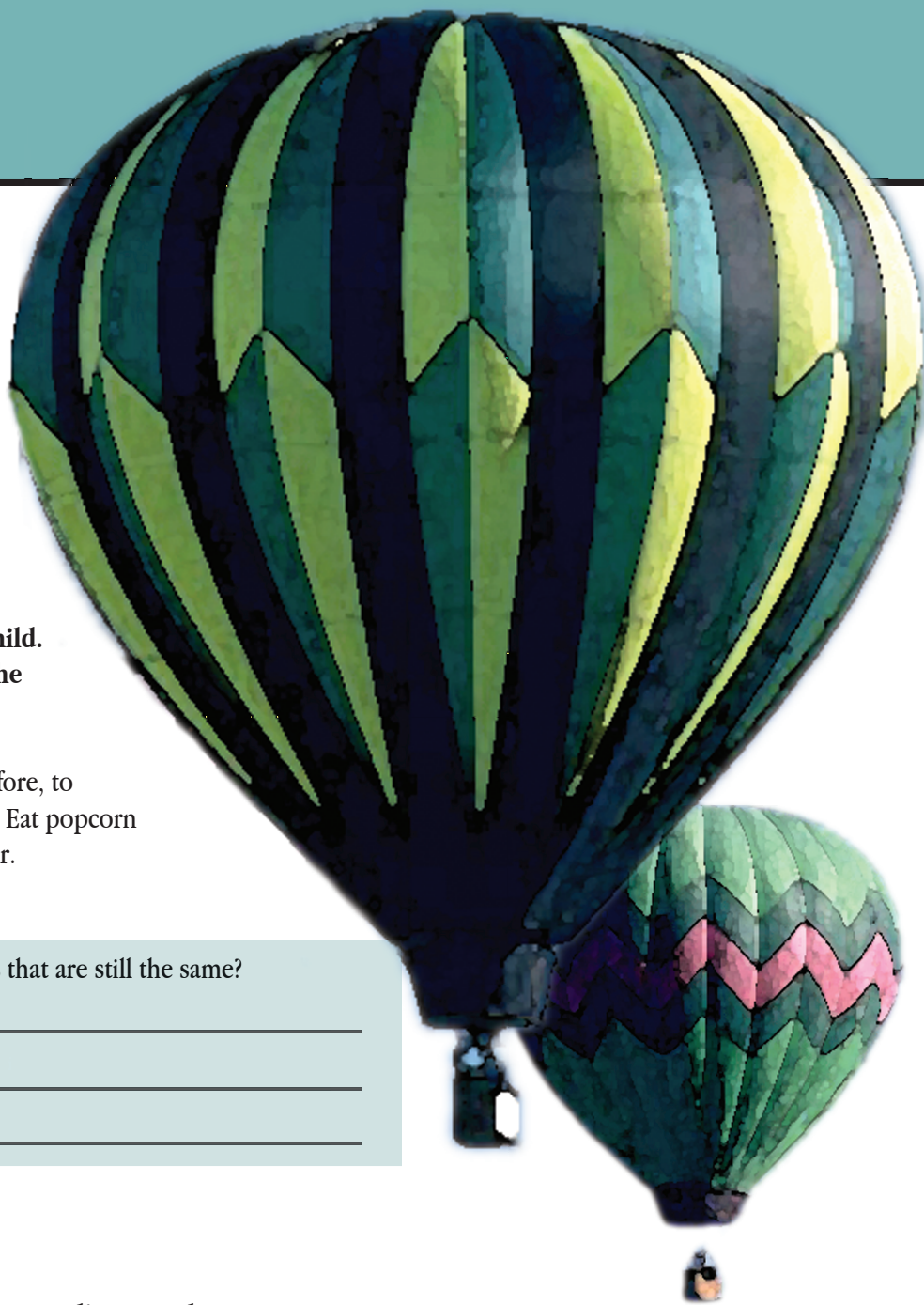
EXERCISE: Do something like you used to before, to remind yourself that some things are the same. Eat popcorn and watch a movie, or have your favorite dinner.

EXERCISE: What are examples of other things that are still the same?

B. Think about how things are different:

- **Home has more stuff in it!! Equipment, supplies, people.**
- **It’s hard to do things on the spur of the moment, to be spontaneous—things have to be planned out, it takes longer.**
- **Seems like we’re never alone, there’s always someone here!**

EXERCISE: What are examples of other ways that things are different?



There are many positive things that can come out of this new situation. Think about some of the remarkable things that have happened such as:

- **I can do things I never dreamed I would be able to do--suction, change a tracheostomy tube, take apart and put together a ventilator.**
- **I realize that there are professionals dedicated to me and my child around to help, I just have to ask.**
- **My child is more precious to me than I knew.**
- **I have a wonderful family and good friends who want to help. If they cannot take care of my child, maybe they can run an errand, go to the grocery store or make a meal.**

EXERCISE: Ways I could let other people help me:

All families adjust. Each family member may have a different way to cope with the situation. Coping techniques vary—all are generally in the range of normal:

- **Some people want to talk about how they feel**
- **Some people show how they feel**
- **Some people don't want to talk about it, don't show how they feel and want to be left alone**

EXERCISES Positive ways to cope

Take a few minutes for yourself--go for a walk, take a hot bath, go out for a picnic, read a magazine, go to a movie.

Spend a few moments with your partner--eat a meal together, go on a date, watch a movie, and talk to each other. Each day tell each other two things about your day that were important to you.

- **Get some exercise.**
- **Each night before sleeping, try to think of one good thing that happened that day.**
- **Eat meals. Healthy foods will help to maintain your energy better than "junk foods."**
- **Introduce yourself to other families. You might meet someone with interests similar to yourself and someone you would feel comfortable talking with.**
- **Keep a daily journal, it will help you see change over time.**

Most families feel some degree of stress. Stress will lesson or increase with changes in your child's condition. If your child gets more sick or you receive some "bad" news, you will feel more stressed. Sometimes stress builds out of frustration with the length of time in the hospital or lack of progress. Listed below are some symptoms of high stress levels. If you are experiencing any of these things, you might want to talk to your social worker or try some of the things suggested earlier.

- **Trouble sleeping or sleeping a lot.**
- **Trouble paying attention or listening when people are talking to you.**
- **Trouble remembering things.**
- **Overreacting to things, fighting with people around you.**
- **Trouble keeping track of things.**

Remember that every family faces stress, frustration, sadness, fear and anxiety as they work though their child's medical situation. It is important to take time to take care of yourself and other members of your family. You are your child's most important resource and you must take care of yourself to be able to provide care for your child. Parents often report feeling guilty about taking some time away from the hospital. It is important to realize that this "me" time is crucial to allowing yourself to refuel and refresh and to come back to the bedside ready to face another day.



Chapter 10

Follow Up Care

Ann Marie Ramsey, MSN, RN, CPNP

Follow up care allows the professionals on your child's health care team to keep working with you to keep your child as healthy as possible. Right after discharge you will probably need to bring your child back for frequent appointments. As your child gets into a home care routine, the visits will not be as often.

Primary Care:

Every child needs a primary care doctor. This can be a pediatrician or family physician. This doctor will be the person who will come to know your child best. This doctor will see your child for well checkups, which include getting immunizations, and for sick visits. Ideally, this doctor should be close to home.

Specialists:

Each child will see specialists based on medical need. In general, children need to see:

1. **Otolaryngology-sometimes called an ENT doctor.** This doctor may check your child's tracheotomy and ears. Children on ventilators may have a higher risk of getting fluid in the ears and having hearing loss. It is important to have your child's hearing checked at least yearly.
2. **Pulmonologist-lung doctor.** This doctor will check your child's lungs and manage the ventilator.
3. **Pediatric Surgeon-this doctor may place a feeding tube or tracheotomy tube in your child.** These tubes and the skin around the opening need to be checked to make sure it is healthy and the tube is the right size. Growing children will need to have tube sizes increased as they grow.
4. **Physical Medicine and Rehabilitation doctor** will check your child's development and help with any physical needs such as braces and wheelchairs and therapy services.

Interdisciplinary clinics

Some hospitals have home ventilator programs. These programs often bring teams of professionals together for your clinic visits.



Getting the most out of your visit

Bringing your child to doctor visits is a lot of work, so it is good to be prepared to get the most out of your visit.

Some common hints:

1. **Bring another adult with you.** This allows for 2 adults to hear what was said during the visit. It also provides another set of hands to care for your child if needs arise when you are speaking to a team member.
2. **Bring a list of medications.** Write down all your child's medications, name of medicine, strength, dosage, and when you give the medicine. Also bring the name and phone number of your pharmacy. Write down all the medications you need refilled.
3. **Write down all your questions for the visit and bring extra paper to write on.** Visits can be busy and hectic, causing families to forget important questions only to remember them after the visit is over.
4. **Bring any paperwork you need filled out for school, insurance and the like.**

Planning ahead and being organized will help you get the most out of your follow up appointments.

Appendix



Members of the Care Team

Hospital Attending Doctor: _____

Resident Doctors(s): _____

Surgeon: _____

ENT doctor: _____

Neurology doctor: _____

Gastroenterology doctor: _____

Orthopedic doctor: _____

Lung Doctor: _____

Rehabilitation Doctor: _____

Clinical Nurse Specialist : _____

Respiratory Therapists: _____

Social Worker: _____

Dietitian: _____

Physical Therapist: _____

Occupational Therapist: _____

Speech Language Pathologist: _____

Recreational Therapist: _____

Rehab Engineer: _____

Psychologist: _____

Discharge Planner: _____

Home Ventilator Program Coordinator: _____

Home care contacts: _____

Other Professionals: _____

Home Modifications

Ramps

Department of Human Services
Civic Groups (Lions, Kiwanis, Elks, Jaycees, etc)
Lumber companies
United Way

- Children With Special Needs Fund—To qualify, child must be eligible for Children's Special Health Care Services. Often provides at least partial payment for things not covered by insurance. Phone 800-359-3722
- Michigan Adoption Subsidy
- Children's Waiver Program—Person must be under 18, developmentally disabled and meet criteria for ICF/MR level of care, must have Medicaid eligibility, and be using at least one waiver service.

Durable Medical Equipment, Toys, Car Seats, Vans

- Used equipment donated to hospital, or school or community agency "loan closets"
- Internet options—ebay, other search engines such as Google®
- Quest, magazine published by the Muscular Dystrophy Association (MDA) that has interesting articles and advertises various types of equipment. It is published 6 times a year by MDA. Publication is free to those with any neuromuscular diseases in MDA program. MDA, 3300 East Sunrise Dr., Tucson, Arizona, 85718-3299. email address: www.mdausa.org.

Car Seats

Safe Kids, www.safekids.org, Jaycees

Vans

- Mobility Monthly, publication that advertises vans, lifts and other mobility systems for sale,
- publication available through local Center for Independent Living
- General Motors, Ford, Chrysler all have modification packages
- Children with Special Need Fund as described above

Psychosocial Resources

- Mental Health resources are available in most counties on a sliding fee scale at local Catholic Social Services, Child and Family Services, and Community Mental Health
- Internet chat rooms
- Other Internet resources, such as Exceptional Parent magazine, or www.exceptionalparent.com
- School district child attends may have support groups

Respite

Funds are quite limited. Check with local Department of Human Services, Children's Special Health Care, Community Mental Health

School Special Education Services

- Ventilator assisted kids go to school, with precautions
- Homebound only when child is sick
- Kids need socialization and other adult role models

Services school must provide

- Education in least restrictive environment
- Transportation to and from school
- Additional services directly related to the child's education such as nursing services, physical, occupational and speech therapies and assistive devices.
- National Dissemination Center for Children with Disabilities provides information on educational services for children with disabilities. www.nichcy.org or 800 695.0285

Initial Contact with school

- Ask hospital social worker to contact the school as soon as a determination is made that child might be appropriate for special education services. Family can also make initial contact.
- Contact should go to local Early On program or the Director of Special Education Services for your local school district.
- Helpful resources: www.earlyonmichigan.org or www.Michigan.gov, Department of Education, Info for families. These two websites also have many wonderful links.
- If your child is doing inpatient rehabilitation following an injury, it is very helpful to have school personnel involvement in rehab stay to help calm their fears and increase their understanding.
- If school personnel cannot talk with therapists, a video of the child's care and the child in therapies can be very educational for the school.

Individual Educational Planning Committee (IEPC)

- Meeting with school representatives can include director of special education, principal, teacher, counselor, nurse, occupational therapist, physical therapist, speech therapist, members of the rehabilitation team, physician and family, family support person and/or advocate.
- Primary goal is to develop an individualized educational plan (IEP) for the child based on evaluation and recommendations of school personnel.
- Family can appeal decision of evaluation team.
- IEPC can provide an opportunity to educate school personnel.
- IEPs are developed each year. Both school personnel and parent must sign for plan to go into effect.
- Parent does not have to sign the plan at the initial meeting. Parents can think about it and consult with advocates or other support people before signing. When signed the plan becomes a binding document.
- Parents and/or school personnel can request a new IEP whenever necessary.
- Preparing for the IEPC
 - Provide medical documentation
 - Therapists' reports
 - Copies of any testing done
 - Previous school reports

Tips Along The Way

- Make all requests in writing
- Keep copies of notes from all meetings
- If you call someone and they cannot help you, ask them if they have any suggestions about whom you might call for help. It is amazing what you can learn that way.

Wish Granting Organizations

- Make a Wish Foundation of Michigan www.wish.org, Telephone: 800-722-WISH
- Rainbow Connection PO Box 46879, Mt. Clemens, MI Contact: Suzanne Jones at 810-783-9777
- Kids Wish Network-Phone 888-918-9004
- Starlight www.starlightmidwest.org 30 E. Adams Suite 1020, Chicago, IL 60603, Phone 312-251-7827
- Sunshine Foundation www.sunshinefoundation.org

Advocacy

- Children's Special Health Care Parent Hot Line—This is a hotline for parents, staffed by parents and can provide lots of information and referrals for children with special needs. Phone 800-359-3722
- Michigan Protection and Advocacy Service 800-288-5923
- Michigan Department of Labor & Economic Growth, Office of Financial & Insurance Services (OFIS). Phone: 877-999-6442 Website: www.michigan.gov/cis/. This office can address insurance issues and concerns.
- Parent Participation Project (PPP) 800-359-3722. Program to connect parents of children with special needs with one another. Administered through Children's Special Health Care Services (CSHCS) of Michigan Department of Community Health (MDCH). CSHCS is part of MDCH's Bureau of Children & Family programs
- National Dissemination Center for Children with Disabilities, provides assistance to families regarding school issues. www.nichcy.org or 800.695.0285

Energy Assistance

- Department of Human Services-contact local office
- Charitable organizations—Salvation Army, Red Cross, United Way, etc
- DTE Energy 800.477.4747 or www.dteenergy.com
- Consumer's Energy www.consumersenergy.com
- Michigan Home Heating Credit: Assistance may be available for heating season if qualifications are met. Forms are available from Michigan Department of Treasury website: www.michigan.gov/treasury, or by calling 800-367-6263 or Consumer's Energy bill payment offices.
- Heat and Warmth Fund 800.866-THAW (8429) www.thawfund.org
- Earned Income Credit—Federal income tax, schedule EIC required. These can be obtained by contacting the internal revenue service.
- U.S. Department of Health and Human Services, Administration for Children & Families, Low income Home Energy Assistance Program (LIHEAP) www.acf.hhs.gov/programs/liheap
- Website for government benefits that you may be eligible to receive: www.GovBenefits.gov

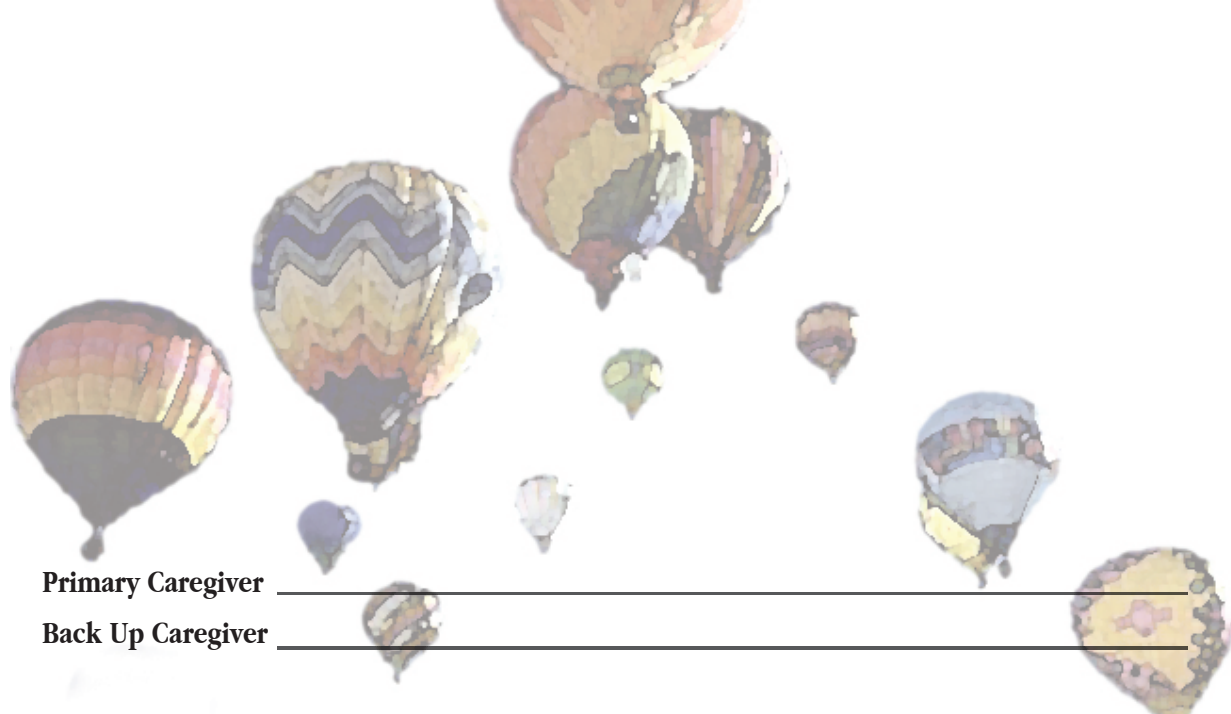
At Least *Two* Caregivers Required

Primary Caregiver _____

Back Up Caregiver _____

Family Training	Primary Care	Date	Back Up	Date
Completed tracheotomy teaching				
Can suction and use resuscitation bag				
Have changed tracheotomy tube 3 times				
Has completed education on respiratory system				
Has completed education on pathophysiology specific to child				
Completed hospital vent training				
Can do bronchodilator therapy, NMT or MDI				
Completed training on all equipment used in the home				
Completed CPR training				
Can use all portable equipment, including vent and battery				
Can do cathing/bowel program				
Can do daily therapies (range of motion, apply braces, etc.)				
Has done care at bedside for 12 hour period of time				
Have taken patient outside vent room without staff				
Has done care for 24 hours Leave On Pass (LOP)				
If LOP and respiratory training are completed more than 1 month prior to discharge, document "refresher"				
Completed training in all patient's nursing care (see Teaching List for Home Care)				
Completed training from therapists.				
OT				
PT				
Speech				
Other				

Appendix Three • 2 - Discharge Checklist



Primary Caregiver _____

Back Up Caregiver _____

Funding	Date
Home vent/BIPAP®/C-PAP system	
Home nursing	
Prescription meds	
Wheelchair/stroller	
Car seat	
Hospital bed	
Bathing equipment	
Other equipment	
Therapies OT, PT, SLP	

Home	
Electrical system adequate to support mechanical ventilation	
Accessible	
Telephone	

Equipment/Supplies	
Completed vendor in-home vent training	
Respiratory equipment set up in the home	
Equipment is set up to be portable for transport	
Portable equipment delivered to hospital (vent suction machine)	
Feeding supplies delivered to the home	
Wheelchair/stroller delivered to the hospital	

Home Care	Date
Adequate home nursing in place for safe discharge	
Enough trained caregivers for child to be managed at home safely	
In home/Outpatient therapies (OT, PT, Speech) arranged	
Skilled nursing visits arranged	

Community	Date
Nursing care plan completed	
Primary Care Physician Contacted	
Discharge medication prescriptions filled	
Handicap parking sticker application provided	
Letter to local electric company for priority electric restoration	
Letter to local EMS notifying of high risk child in service area	
Referral made to WIC	
Discharge Transportation arranged	
Referral made to Early On/School	
Car seat available	
Equipment/Supplies list compiled	

Signatures of Professionals Completing Discharge Checklist		
Initials	Name	Title

Examples of Specialized Nutritional Plans

High Calorie Diet: Some children with lung problems need more calories to grow.

- Add butter, margarine, oil, mayonnaise, sauces, salad dressings, cheese, sour cream, whipping cream, peanut butter, and/or sugar to the foods your child already eats
- Choose higher calorie foods—whole milk, red meat, nuts, eggs, & protein bars.
- Try milkshakes and oral supplements such as Carnation Instant Breakfast®, Pediasure®, Ensure/Boost®, Mighty Shake®, Scandishake®, Resource Fruit Beverage®, or Boost Breeze®
- Try calorie supplements such as Benecalorie® or Duocal®
- Talk to your dietitian about increasing the amount or calorie density of your child's formula/tube feeding

Lower Calorie Diet: Some children and teens on vents may have lower calorie needs and may be at risk for becoming overweight or obese.

- Decrease or eliminate concentrated sweets including soda pop and juices
- Increase fiber foods in your diet, including fruits, vegetables, whole grains
- Choose lower calorie versions of foods, including skim milk, low fat yogurt, and low fat cheese
- Avoid condiments—mayonnaise, cheese, salad dressings and dips
- Do not skip meals—eat 3 meals and 1-2 snacks daily & monitor portion sizes
- Keeping track of food intake in a food journal can help you to identify patterns that may be leading to overeating

High Fiber Diet: Some children may have problems with normal bowel function. A diet high in soluble fiber (cereals, beans) and insoluble fiber (crunchy fruits and vegetables) can help children with constipation. Soluble fiber can help children with looser stools.

- Eat at least one serving of fruits and vegetables at each meal
- Choose cereals with at least 3 grams of fiber
- Try high fiber snacks such as trail mix, celery with peanut butter & raisins, or veggies and dip
- Drink plenty of water—ask your dietitian for guidelines
- Ask your dietitian for a list of fiber content in foods.
- For children with tube feedings, talk to your dietitian about fiber supplements

Vitamins and Minerals: It is important for children to get the right amount of vitamins and minerals to grow.

Sources of Iron: red meat, eggs, beans, fortified cereals

Sources of Calcium: milk & dairy products, green, leafy vegetables, canned salmon

Sources of Vitamin A: eggs, milk, red/orange/yellow fruits & vegetables

Sources of Vitamin D: milk, eggs, fish, exposure to sunlight

Over-the-counter vitamin supplements:

Children Under 3: 1 ml Poly-vi-sol

Children Ages 3-4: ½ chewable multivitamin

Children Ages 4+: 1 chewable multivitamin

Liquid multivitamin/multimineral supplement: Centrum® Multivitamin/Multimineral

Dysphagia Diets

Diet Type	Description	Examples of Foods Allowed
Level 1 Dysphagia Diet	Mashed, pureed smooth or creamy foods	Cream of wheat, pudding, custard, applesauce, strained fruit, oatmeal, mashed potatoes, smooth yogurt (no fruit pieces)
Level 2 Dysphagia Diet	Moist and soft foods requiring minimal chewing	Macaroni and cheese, omelet, chili, scrambled eggs, fruit yogurt, meat lasagna, diced fruit, hamburger with no bun.
Level 3 Dysphagia Diet	Soft, non-chewy foods that do not have small pieces	French toast with syrup, canned fruit halves, egg, tuna salad sandwich, tender cooked meats, baked fish, tater tots, apple crisp, soft bread products, cooked vegetables

