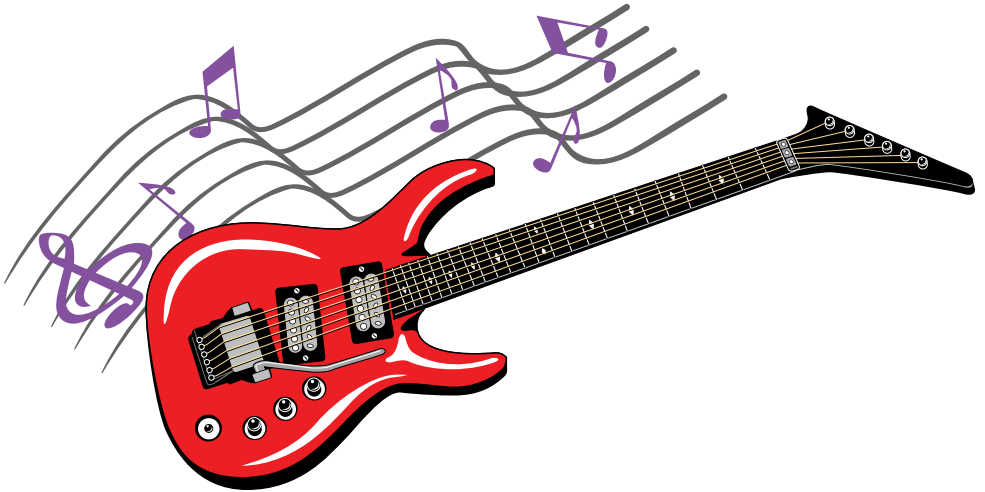


Rocking and Rolling to Independence

*Transitioning from the Pediatric
to the Adult Care Team*



Authors

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A Special Note To You And Your Family:

As a way to help make a smooth transition from pediatric to adult care, we created this booklet to help you learn more about your neuromuscular disease and how to take charge of your cares and health as much as you are able.

We understand that at first, your parents will probably help you to read this and reach your goals. As time goes on, we hope that you will start to use this booklet on your own. This is a great way to build confidence in yourself, and also to let your parents know that you are learning to gain independence in your own health care.

If you use an alternative method of communication, the team will learn that method so that they can communicate with you directly. If you require an adult to assist you with communication, you can choose to have someone come with you or rely on the neuromuscular disease team to understand your unique communication system.

As you learn more about your neuromuscular disease, you can take a lead in your life and your cares.

We wish you well on your journey...



What Is Transition?

To get started, we look to our “old friend” Webster’s dictionary. According to Webster, transition is “the passage from one state, stage, or place to another.” At the University of Wisconsin pulmonary clinic, we see it as moving from pediatric to adult health care in a way that feels safe and smooth to you and your family.

What Is Our Philosophy Regarding Transition?

We are committed to caring for people with neuromuscular disease across their lifespan. Helping young adults and their families move to the adult care team is a big part of our commitment. We believe transition is a rite of passage or a milestone that you and your family will experience. This is a big change. We want you to know that you are not alone and we will be here to help you with this change. We’ll help you throughout your journey and promise to take good care of you along the way. We hope that by working with you early on, the transition will be seamless and something you look forward to as part of moving into the adult world.

With all of the advances in neuromuscular disease care, we are seeing our young adults grow up... get jobs, go to college, get married and have their own families. Other young adults may need assistance throughout their lives, yet they can still be active in decision-making, directing their care and partnering with the health care team. Just like school prepares children for the future, we hope that your time in pediatrics prepares you and your family for as much independence as possible in your adulthood. Our goal for all young adults is to learn about and manage their neuromuscular disease.



What Is the Neuromuscular Disease Team's Policy On Transition?

The neuromuscular disease team has a policy that states that all young adults under the age of 18 will be cared for in the Children's Hospital. It also states that we can provide care to the age of 21. Both the pediatric and adult neuromuscular disease teams expect that the majority of the patients will transition between 18 and 19 years of age. To help you make a smooth transition, we have developed a program to help you learn more about how to manage your neuromuscular disease as you move from pediatric to adult care.

Stages Of Transition

Just as you have to attend elementary school before middle school and middle school before high school, there are times when you are ready to learn new things and take on more responsibilities. We have broken down these times into six stages. We have given you an overview of what to expect during each stage.

Our philosophy is that you will be as active as possible in the decision-making and management of your neuromuscular disease.

We have also included a checklist to help you learn more about your neuromuscular disease. Learning the specific skills in each list will help you to take charge of your life and your cares.



Stage 1

Ages 8-10

The neuromuscular disease team begins to ask you (instead of your parents) questions about your health, medication and therapies. We help you start to understand how your body uses the food you receive to grow and stay healthy. This means we help you to understand what is normal for your body. This will help you to learn more about your neuromuscular disease and start to know why you take medications and do airway clearance treatments.

Checklist:

- Explain what it means to have your neuromuscular disease.
- Understand why some people have your neuromuscular disease and others do not.
- Begin to learn how your lungs work.
- Understand why airway clearance treatments are necessary.
- Begin to learn why good nutrition is important.
- Help parents remember your medications.
- Name your medications (slang is O.K.) and simple reasons for taking them.



Stage 2

Ages 10-12

We continue to ask you questions about your health and medications. Try to answer questions about your health without help from your parents. We also continue to help you to understand your body's respiratory baseline. We help you to see when there is a change in your baseline. For example, we help you think about if there are changes in your breathing. When you begin to notice these changes, you can start to take charge of your own care. This helps you to be more independent.

Checklist:

- Explain what it means to have your neuromuscular disease.
- Continue to learn how your lungs work.
- Recognize when you need airway clearance treatments.
- Continue to learn why good nutrition is important.
- Take medications on your own if you are able.
- Name medications (use proper names) and reasons for taking them.
- Begin to answer questions in clinic.

Stage 3

Age 13

The neuromuscular disease team starts to talk with you and your parents about what will happen when you turn 14 years old.

At that time, we will start to see you alone for the first half of the visit if you are able. We will ask your parents to join you for the last half of the visit to review information, talk about the health care plan and answer any questions or concerns. This helps you to be more independent and to start to build confidence that you can take care of your health.

Checklist:

- Answer questions independently in clinic if you are able.
- Understand your *respiratory baseline* and changes that may occur.
- Recognize when you need airway clearance treatments and identify the steps involved with airway treatment.
- Remain independent with medications if you are able.
- List medications, the amount you take, how you take them, when you take them, and why you take them.
- Understand why you come to clinic on a regular basis.
- Begin to understand the tests that we do and why.



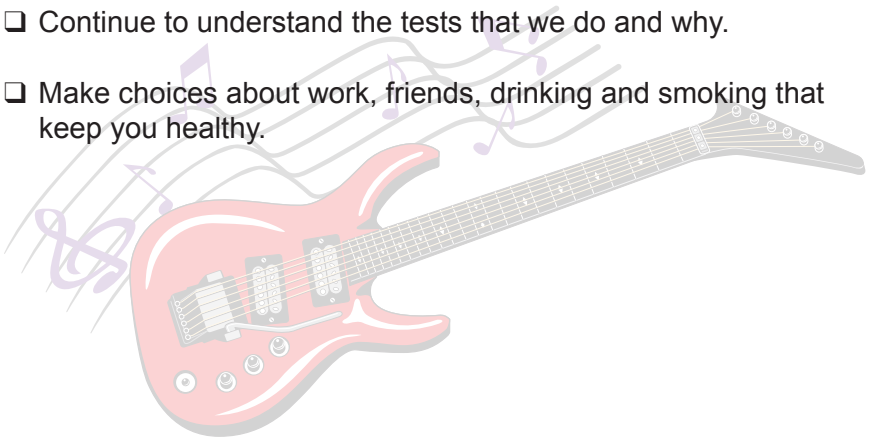
Stage 4

Ages 14-15

The neuromuscular disease team sees you alone for the first half of the clinic visit if you are able. We will ask your parents to join you for the last half of the visit. When your parents join you and we talk about the clinic visit, it helps show what you understand. This builds trust between you and the neuromuscular disease team, as well as between your parents and the neuromuscular disease team. As you start to take an active role in the clinic visits, it helps you to be a part of the decisions that are made about your care. You will be introduced to the concept of transition to the adult care team when you are 16-17 years old.

Checklist:

- Participate with airway clearance treatments if you are able.
- Remain independent with your medications if you are able.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits if you are able.
- Continue to understand the tests that we do and why.
- Make choices about work, friends, drinking and smoking that keep you healthy.



Stage 5

Ages 16-17

If you are able, this is a time when you (instead of your parents) begin to communicate directly with the neuromuscular disease team when there are changes in your health. We will talk about plans after you finish high school and how job and career choices may impact you and your health. **We will talk about when to transition to the adult care team.** You and your family will have a chance to meet with adult team members during a clinic visit. We can also arrange for you and your family to visit the adult pulmonary inpatient unit so you can meet more adult team members.

Checklist:

- Participate with airway clearance treatments if you are able.
- Remain independent with medications if you are able.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits if you are able.
- Continue to understand the tests that we do and why.
- Continue to make choices about work, friends, drinking and smoking that keep you healthy.
- Begin to monitor medication and supplies if you are able.
- Begin to contact the neuromuscular disease team or direct a parent or helper to do so if there are changes in your health.
- Begin to schedule follow up clinic appointments if you are able.
- Begin to understand reproductive choices and the impact on your overall health.



Stage 6

Ages 18-21

This is the stage when transition to adult care takes place. If you are able, we expect you to contact the neuromuscular disease team if there are changes in your health. You manage your own medications and contact the pharmacy and equipment provider when refills or additional supplies are needed. We will talk about how school, work and lifestyles choices impact your health. We will continue to talk about transition, link you with the adult neuromuscular disease team and may also arrange a visit to the adult pulmonary inpatient unit if you desire.

Checklist:

- Participate with airway clearance treatments if you are able.
- Remain independent with medications if you are able.
- Continue to list medications, doses and frequencies.
- Continue independent clinic visits if you are able.
- Continue to understand the tests that we do and why.
- Continue to make choices about work, friends, drinking and smoking that keep you healthy
- Monitor medications and supplies. Contact the pharmacy or equipment provider or direct a parent or helper to do so when refills or additional supplies are needed.
- Contact the neuromuscular disease team or direct a parent or helper to do so if there are changes in your health.
- Continue to schedule follow up appointments if you are able.
- Continue to understand reproductive choices and the impact they have on your health.
- Secure financial coverage or insurance.
- Identify a person to make health care decisions for you if you become unable to do so.
- Begin to identify possible adult care providers

How To Prepare For Transition

What adult family members can do...

1. When your child is age 8, begin talking to him/her about the changes that will happen in clinic. Explain that we will start to ask questions directly to him/her. This will allow your child to get comfortable answering questions while they have a “safety net” of a parent in the room. Your health care team will provide you with an electronic medical home care plan to begin filling out with your child.
2. Work with your child at home to take an active role in his/her care. You can use the checklist that we have provided as a guide. Gently encourage independence, but know that it will take time. If your child uses assistive technology, you will want to consider how the assistive technology device can include health-related screens. For example, the main menu may have a choice, which simply states “health”. When this is selected, a new screen could have choices such as “I want to talk about my health, my medications, my health care providers, my direct care providers” etc. Each subsequent screen could have more detail, which allows your child a chance to explain exactly what he/she is thinking. Being able to express thoughts about one’s care is an important part of preparing for a more independent life as an adult. There could also be screens that allow your child to direct his or her care or make specific requests. Being able to direct one’s care is important in preparing for a more independent life.
3. When your child is 14, encourage him/her to see the neuro-muscular disease team independently for the majority of the visit if your child is able. You can join your child and care providers at the end of the visit to review information and ask any questions or concerns you may have. This will help your child become independent and form a relationship with his/her health care providers. This can also help him/her learn how to form future relationships with the adult care team.

4. Determine continuing insurance coverage into adulthood prior to the age of 18.
5. Find out how your insurance company handles referrals to the adult health care team.
6. If it would be helpful to you, ask to speak to another parent who has a child who has transitioned to the adult care team.
7. Remember, you are not alone and we will be here to help you with this change.

How To Prepare For Transition

What adolescents / young adults can do...

1. As you get older, take on more responsibility for your care.
2. Complete your medical home care plan about how you manage your neuromuscular disease. Keep it in your daypack so that if you are out in the community it is always with you.
3. Learn how to obtain and maintain an appropriate weight through good nutrition.
4. If it would be helpful to you, ask to communicate with another young adult with a similar condition who has recently transitioned to the adult care team.
5. Find out how your health insurance coverage works.
6. Identify a person to make healthcare decisions for you if you become unable to do so.
7. Make a list of questions to ask your future health care provider.
8. Work through the checklists for each of the six transition stages.
9. Remember you are not alone... your parents, and the pediatric and adult care teams will help you with this change.

How To Prepare For Transition

What the health care team can do...

1. Encourage you to meet the adult care team.
2. If you use an alternative communication system, staff can learn your individualized communication method.
3. Provide you with an electronic medical home care plan to help you in organizing your medical information.
4. Encourage you to come to clinic prepared to communicate about your health, medication and supplies.
5. Remind you that you are not alone and promise to help you with the move to the adult care team.
6. The adult care team will answer your questions and ease you into their system.

How Do You Know When It Is Time To Transition?

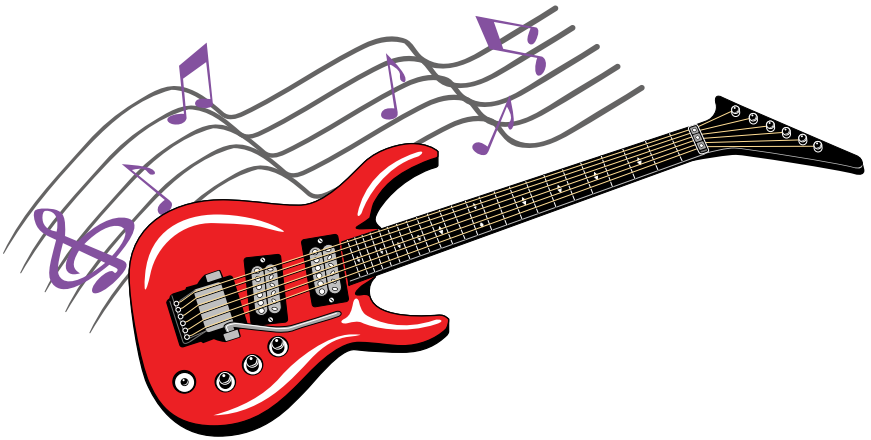
1. Do you take as much responsibility as you are able for your own care?
2. When you give the neuromuscular disease team your health history, does it sound the same as what your parents tell the team? Does your health history match with the neuromuscular disease team's view of your health?
3. If you are able, do you take your medications and do your airway treatments without your parents reminding you?
4. Do you communicate directly with the neuromuscular disease team?
5. Do you know when you need refills for your medication or supplies? Do you contact the pharmacy or equipment provider?
6. Do you have a plan for your future, such as college, work or independent living?
7. Have you met the goals in each checklist?

If the answer to all the questions is “YES,” then you are ready for transition.

If the answer to any of the questions is “NO,” then a plan will be made to help you be more independent with that part of your care. However, answering no to any of the above does not stop you from transitioning to adult care. The adult care team is experienced in helping young adults become independent.

How Does Your Information Transfer To The Adult Care Team?

When you transition from the pediatric to the adult care team, your *medical records* will be transferred as well. We will also include your electronic medical home care plan as a way to provide a quick reference to your current health status. By putting all of your medical information together, we believe it will make for a smooth and organized transition.



Common Questions You Will Be Asked When Calling The Neuromuscular Disease Team:

1. What are your symptoms?
2. How are these symptoms different from your *respiratory baseline*?
3. When did the symptoms start?
4. Do you use *BiPAP*?
5. What are your oxygen saturations on and off *BiPAP*?
6. How often are you doing your *airway clearance protocol*?
7. What do your secretions look like? Color, consistency, blood?
8. Do you have any other cold symptoms?
9. Is your appetite normal and/or are you tolerating your tube feeding?
10. Is your activity normal?
11. Do you have a fever?
12. Are you able to sleep through the night?
13. Do you have any increased work of breathing (*retractions, nasal flaring, increased respirations*)?

Glossary:

Airway Clearance Protocol for Neuromuscular Patients during a cold includes doing the following every 4 hours:

- A. Chest physiotherapy for 12-20 minutes.
- B. Cough Assist Machine, four sets of 5 breaths.
- C. Postural drainage for 15-30 minutes.
- D. Cough Assist Machine, four sets of 5 breaths.

BiPAP stands for bilevel positive airway pressure. This machine delivers high and low pressure air through a mask over the nose and into the lungs. When you inhale, high pressure air is delivered through the mask to inflate the lungs. When you exhale, the machine pressure decreases so you can exhale air easily. The purpose of BiPAP is to rest the breathing muscles during sleep and during illnesses.

Chest PT or chest physiotherapy is a technique used to loosen the secretions in the lungs by clapping on the chest wall using your hands or palm cups while positioning the body to optimally drain the lungs.

Cough Assist Machine helps you clear secretions from your lungs by helping you to cough. With the inhale, the machine gives you air to help expand your lungs. With the exhale, the machine creates a vacuum or sucking force that pulls the air out of your lungs along with any secretions. The rapid change in pressure from inhale to exhale helps you cough more effectively.

Medical Records are documents that contain one's health history, medical diagnoses, and treatments. These records cannot be shared without the individual's written permission.

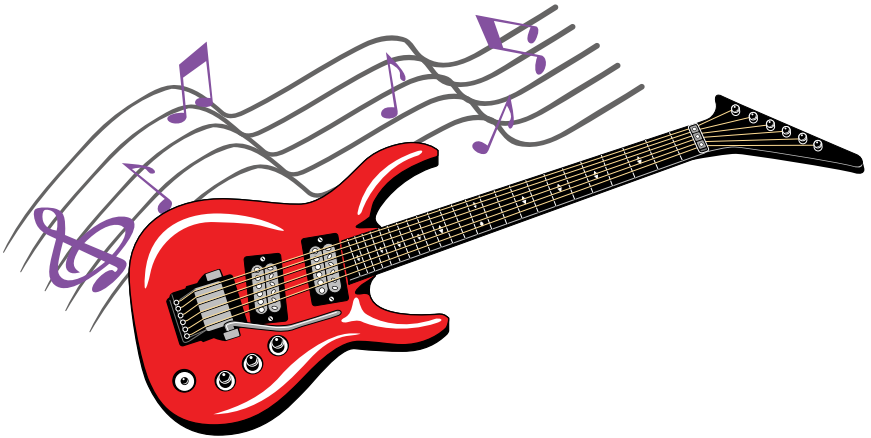
Nasal Flaring occurs with working harder to breathe and is shown by opening the nostrils wider during breathing.

Postural Drainage helps to drain secretions and mucus from the airways of the lungs by using gravity. By positioning with the head lower than the chest, gravity will help move secretions from the smaller airways to the bigger airways where they can be more easily coughed out.

PFTs or Pulmonary Function Tests are breathing tests that measure how much air your lungs hold.

Respiratory Baseline is the level of respiratory symptoms you have when you feel well.

Retractions are an increased work of breathing displayed by drawing in of the neck muscles, chest muscles or rib muscles.



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