

# MDA TRANSITION GUIDE: PEDIATRIC TO ADULT CARE

A road map for youth with neuromuscular disease and their caregivers

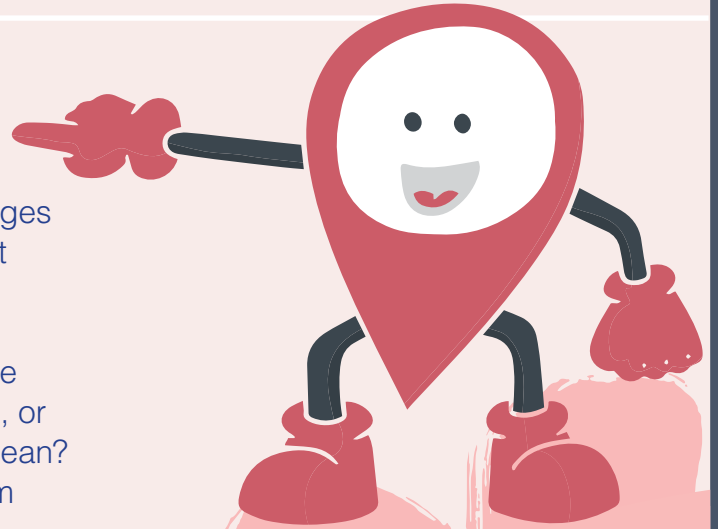
*Hello there, fellow traveler!* I'll be your tour guide as we take a road trip to adulthood. As you use this guide and complete traveler challenges along the way, you will gain stamps in your passport and ultimately feel more prepared to become an independent adult.

Before we embark, we need to know where we are going. You might have heard your parents, teachers, or doctors talk about "transition," but what does that mean?

Transition is the process of preparing to move from childhood into adulthood. Part of that process is switching from pediatric care providers to adult care providers and learning to manage your own healthcare.

This guide will assist you by breaking down your plans into manageable steps, so you will feel prepared and excited for the road ahead.

Now that we know where we are going, let's not delay. Gather your supports and your travel companions, and let's begin our adventure.



This resource is meant to inform and educate the community. The information presented is not intended to replace discussions with medical, financial, or employment specialists, and it should not be considered financial, medical, or legal advice. Please consult with your healthcare provider, employment specialist, or legal advisor for information specific to you.

## Your Travel Checklist

When planning for a trip, you want to make sure you are prepared. This can range from making a packing list to budgeting. The same rules apply to your transition to adult care. Review the list below to help you feel ready for this new and exciting journey.

	Yes!	Halfway to yes!	No, but I want to learn!
I can give my full name, date of birth, and full address when asked.			
I can give the name of my disease and explain what parts of my body are affected.			
I can tell you what my allergies are.			
I know the names of my medications.			
I can tell you what medication helps what part of my body.			
I can tell you the doses of the medications that I take.			
I can tell you which doctor prescribed which medication.			
I know how to refill my medications.			
I understand basic insurance terms, like copay and deductible.			
I feel comfortable speaking during one-on-one time with my provider.			
I feel comfortable speaking openly with my doctor about tobacco, drug, and alcohol use.			
I have discussed issues related to sex with my doctor.			
I know how to prevent sexually transmitted diseases.			

## Your Travel Checklist

	Yes!	Halfway to yes!	No, but I want to learn
I feel comfortable advocating for myself at the doctor's office.			
I feel comfortable advocating for myself in other settings such as my school or community.			
I have access to my medical records or know how to access them.			
I can keep track of my medical appointments.			
I know how to contact my doctor when needed.			
I know who to contact in the event of a medical emergency.			
I have identified a healthcare advocate or someone to speak on my behalf if I cannot make decisions myself. That person is aware of my wishes and healthcare goals.			
I come prepared with questions to my medical appointments.			
I know what type of medical insurance I have.			
I have a support network for my condition.			
I know how to locate mental health support.			



*Congratulations* on earning the **READINESS STAMP!**

By completing the checklist above, you have reviewed important considerations for your journey to adulthood. Be sure to update your checklist whenever you learn a new skill.

Sources: Wood, D. L., Sawicki, G. S., Miller, M. D., Smotherman, C., Lukens-Bull, K., Livingood, W. C., Ferris, M., & Kraemer, D. F. (2014). The Transition Readiness Assessment Questionnaire (TRAQ): Its factor structure, reliability, and validity. *Academic Pediatrics*, 14(4), 415-422. <https://doi.org/10.1016/j.acap.2014.03.008>

# The Lay of the Land

*As you embark* on your journey into adulthood, you may come across words and phrases that are new to you. On this leg of our journey, we will begin learning this new “language.”

Just as it’s helpful to learn basic phrases when visiting another country, it’s important to know the terms below. You might use them to get assistance, advocate for yourself, and accurately communicate your needs.

For more information about the terms below, explore MDA’s Access Workshops at **[mda.org/care/access-workshops](https://mda.org/care/access-workshops)**. These self-guided workshops cover a variety of topics, including insurance, education, medical care, employment, and more.

⇒ **504 plan<sup>1</sup>**: A blueprint for supporting a student with a disability by removing barriers. It gives the student equal access to learning in the general education classroom. Students with 504 plans tend not to need “special education.” These plans prevent discrimination and protect the rights of kids with disabilities in school. They’re covered under Section 504 of the Rehabilitation Act of 1973, the country’s first civil rights law for people with disabilities.

⇒ **ABLE account<sup>2</sup>**: An Achieving a Better Life Experience (ABLE) account is a savings account for individuals with disabilities and their families. They allow eligible individuals or beneficiaries to save for qualified disability expenses without discontinuing financial benefits such as Supplemental Security Income (SSI) and Medicaid, or other benefits programs. Distributions are tax-free if used for qualified disability expenses. To learn more about eligibility, visit the ABLE National Resource Center at **[ABLEnrc.org](https://ABLEnrc.org)**.







⇒ **Advance directive<sup>3</sup>:** A legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions because of a serious illness or injury. An advance

directive may also give a person (such as a spouse, relative, or friend) the authority to make medical decisions for another person when that person can no longer make decisions. There are different types of advance directives, including living wills, durable powers of attorney (DPA) for healthcare, and do not resuscitate (DNR) orders. In the United States, the laws for advance directives may be different for each state, and each state may allow only certain types of advance directives.

⇒ **Appeal<sup>4</sup>:** A request for your health insurance company or the health insurance marketplace to review a decision that denies a benefit or payment. If your health plan refuses to pay a claim or ends your coverage, you have the right to appeal the decision and have it reviewed by a third party.

⇒ **Behavioral health insurance:** This is health insurance that covers treatment and visits with a mental health professional. Your behavioral health insurance supplier may be different than your medical insurance provider. On the back of your insurance card, you should see a phone number for behavioral health services. Call that number to learn how to access mental health providers that are in-network with your insurance.


⇒ **Coinsurance<sup>5</sup>:** The percentage of costs of a covered healthcare service you pay after you've paid your deductible. Generally, plans with low monthly premiums have higher coinsurance, and plans with higher monthly premiums have lower coinsurance.

⇒ **Commercial medical insurance:** A medical insurance plan that does not come from the state or government. Most commercial insurance providers are for-profit companies, although some operate as nonprofit organizations. Policyholders' monthly premiums fund commercial policies. Their premiums and coverage amounts are designed to create a profit for the insurance company.

⇒ **Copayment or copay<sup>5</sup>:** A fixed amount you pay for a covered healthcare service after you've paid your deductible. Copays can vary for different services within the same plan, like drugs, lab tests, and visits to specialists. Generally, plans with lower monthly premiums have higher copays. Plans with higher monthly premiums usually have lower copays.

⇒ **Deductible<sup>6</sup>:** The amount you pay for covered healthcare services before your insurance plan starts to pay. After you pay your deductible, you usually pay only a copayment or coinsurance for covered services. Your insurance company pays the rest. Many plans pay for certain services, like a checkup or disease management programs, before you've met your deductible. Check your plan details. Generally, plans with lower monthly premiums have higher deductibles. Plans with higher monthly premiums usually have lower deductibles.

⇒ **Dental insurance:** This will help pay for the cost of visits to a dentist for basic or preventive services, like teeth cleaning, X-rays, and fillings. Similar to vision and behavioral health benefits, dental benefits may have a different insurance provider.



⇒ **Disability insurance<sup>8</sup>:** These policies provide a portion of your income if you become sick or injured and are unable to work. It can help anyone who depends on their job for living expenses. There are different kinds of disability insurance, but two common types are long-term and short-term. Long-term disability insurance is designed to last for many years — up to retirement if needed — replacing around 40% to 60% of your income if something happens and you can no longer work. Short-term disability insurance is designed to replace your income for a much shorter period — typically a few months up to a year — until you can get back to work.

⇒ **Durable medical equipment (DME):**

This can describe a wide array of medically necessary equipment, from respiratory support to wheelchairs. Your insurance provider may require you to use specific DME vendors to have them pay for the equipment.

⇒ **Family and Medical Leave Act (FMLA)<sup>9</sup>:**

This law entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. Eligible employees are entitled to 12 work weeks of leave in a 12-month period for:

- The birth of a child and to care for the newborn child within one year of birth
- The placement with the employee of a child for adoption or foster care and to care for the newly placed child within one year of placement

- To care for the employee's spouse, child, or parent who has a serious health condition
- A serious health condition that makes the employee unable to perform the essential functions of their job
- A qualifying situation because the employee's spouse, child, or parent is a covered military member on "covered active duty," or 26 work weeks of leave during a 12-month period to care for a covered military service member with a serious injury or illness if the eligible employee is the service member's spouse, child, parent, or next of kin. This is known as military caregiver leave.

⇒ **Flexible spending account (FSA)<sup>10</sup>:**

An arrangement through your employer that lets you pay for many out-of-pocket medical expenses with tax-free dollars. Allowed expenses include insurance copayments and deductibles, qualified prescription drugs, insulin, and medical devices.

⇒ **Genetic testing<sup>11</sup>:** Genetic testing looks for changes, sometimes called mutations or variants, in your DNA. Genetic testing is useful in many areas of medicine and can change the medical care you or your family member receives. For example, genetic testing can provide a diagnosis for a genetic condition such as muscular dystrophy or information about your cancer risk. There are many different kinds of genetic tests. Genetic tests are done using a blood or spit sample, and results are usually ready in a few weeks. Because family members share DNA, if you are found to have a genetic variant, your family members may have the same variant. Genetic counseling before and after genetic testing can ensure that you are getting the right genetic test and you understand your results.

⇒ **Grievance<sup>12</sup>**: A complaint that you communicate to your health insurance provider or plan.

⇒ **HIPAA<sup>13</sup>**: The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law requiring institutions to follow national standards to protect sensitive patient health information from being disclosed without the patient's consent or knowledge.

⇒ **HMO<sup>14</sup>**: A type of health insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO. It generally won't cover out-of-network care except in an emergency. An HMO may require you to live or work in its service area to be eligible for coverage. HMOs often provide integrated care and focus on prevention and wellness.

⇒ **Health savings account (HSA)<sup>15</sup>**: Money in these accounts can be used — without being taxed — for qualified medical expenses. Both individuals and employers can establish these accounts, but only in conjunction with an HSA-qualified high deductible health plan (HDHP). Contributions can only be made while the account holder remains covered by an HDHP. However, the money can be used at any time in the future, even if the person is no longer covered by an HDHP. Money in the HSA that is not used for medical expenses remains in the account.

⇒ **In-network and out-of-network**: Most health insurance plans provide a network of doctors and healthcare facilities that are approved and contracted to cover certain services at a discounted rate. These providers and healthcare facilities are considered in-network. In-network providers (sometimes referred to as participating providers) will not charge you more than the cost that was agreed upon with your health insurance

plan. If a healthcare provider or facility is not contracted with your health insurance plan, they cannot guarantee a rate for services and are considered out-of-network. If you see an out-of-network provider, you can expect to pay more for your care.

⇒ **IEP<sup>1</sup>**: An Individualized Education Program or Plan (IEP) outlines the special education instruction, supports, and services a child needs to make progress and thrive in school. Some people refer to the written document that outlines this plan as the IEP. IEPs were created from the Individuals with Disabilities Act (IDEA), the nation's special education law. IDEA is a federal law that guarantees all students with disabilities access to a free, appropriate public education.

⇒ **Insurance case manager**: This person can help oversee your claims and act as a liaison between you and the insurer. It is helpful to have a dedicated case manager at the insurance company who will learn your healthcare needs and claims over time. If you do not have one, you can call the member services number on the back of your card to request one.

⇒ **Living will<sup>16</sup>**: A type of advance directive that states the specific types of medical care that a person wishes to receive if they are no longer able to make medical decisions because of a terminal illness or permanent unconsciousness. A living will usually has instructions about whether to use certain treatments to help keep a person alive, such as the use of dialysis (kidney machines, breathing tubes, feeding tubes, and CPR). In the United States, the laws for living wills may differ from state to state, and not every state may allow them.



⇒ **Medical records:** A patient's medical history. This may include notes, images, test results, and other pertinent information. This information is also protected by HIPAA. In order to obtain this information or send records to an outside institution, you will need to sign a written consent.

⇒ **Medicaid<sup>17</sup>:** An insurance program that provides free or low-cost health coverage to eligible low-income adults, children, pregnant women, the elderly, and people with disabilities. Many states have expanded their Medicaid programs to cover all people below certain income levels. Whether you qualify for Medicaid coverage depends partly on whether your state has expanded its program. Medicaid benefits and program names vary between states. You can apply anytime. If you qualify, your coverage can begin immediately, any time of year.

⇒ **Medicare<sup>18</sup>:** A federal health insurance program for people ages 65 and older and certain younger people with disabilities. It also covers people with end-stage renal disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD). Medicare isn't part of the Health Insurance Marketplace®. If

you have Medicare coverage, you don't have to make any changes. You're considered covered under the healthcare law.

⇒ **Primary care provider (PCP)/ internal medicine doctor/family doctor:** These terms refer to the doctor who oversees your overall care. You should visit your PCP at least once a year or as directed. They may perform tests or labs and focus on preventative medicine, and they can refer you to a specialist if needed. It is important to have a PCP as they are often needed to assist with referrals or authorizations that specialists cannot complete. For convenience, you can choose one local to you, so you don't have to travel far when you need a visit. To choose a PCP, call your insurance company and ask for a list of in-network options.

⇒ **Peer to peer:** Usually, for a designated period of time after an insurance company has denied a service and/or equipment item, the requesting physician can speak directly with a physician from the insurance company. This usually takes place during a scheduled phone conversation.

⇒ **Power of attorney<sup>16</sup>:** A durable power of attorney for healthcare is a document that allows you to name another person to make decisions about your medical care if you are unable to make these decisions for yourself. (It also may be called a healthcare proxy or medical power of attorney for healthcare.) People often appoint someone they know well and trust to carry out their wishes. This person may be called a healthcare agent, surrogate, or proxy.

⇒ **PPO<sup>14</sup>:** A type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. You pay less if you use providers that belong to the plan's network. You can use doctors, hospitals, and providers outside of the network for an additional cost.





⇒ **Preferred lab:** Your insurance company may dictate where you should have bloodwork done. This is important to know because you may accrue additional costs if you go to a nonpreferred lab.

⇒ **Prior authorization<sup>14</sup>:** Approval from your insurance company may be required before you get a service or fill a prescription in order for the service or prescription to be covered by your plan.

⇒ **Referral<sup>19</sup>:** A written order from your primary care doctor for you to see a specialist or get certain medical services. In many HMOs, you need to get a referral before you can get medical care from anyone except your primary care doctor. If you don't get a referral first, the plan may not pay for the services.

⇒ **Secondary insurance:** A second insurance plan that supplements your primary insurance plan. Depending on the state you live in, you may be able to have Medicaid or Medical Assistance as a secondary insurance. If not, some individuals may choose to purchase additional coverage from an independent source on the healthcare marketplace.

⇒ **Specialist:** A doctor who focuses on a specific part of the body or organ system. They will typically see you or follow you for a specific issue or concern. Examples include neurologist (treats disorders of the brain, spinal cord, and nerves), pulmonologist (treats the respiratory system), and cardiologist (treats heart conditions).

⇒ **Specialty pharmacy:** Unlike your local pharmacy that can fill most prescriptions, this pharmacy is dictated by your insurance company and will supply any specialty medications.



⇒ **Social Security Disability Insurance (SSDI)<sup>7</sup>:** SSDI supports individuals who are disabled and have a qualifying work history, either through their own employment or a family member (spouse/parent).

⇒ **Social Security Income (SSI)<sup>7</sup>:** SSI provides minimum basic financial assistance to older adults and persons with disabilities (regardless of age) with very limited income and resources. Federal SSI benefits from the Social Security Administration are often supplemented by state programs.

⇒ **SSI and SSDI differences<sup>7</sup>:** The major difference is that SSI determination is based on age/disability and limited income and resources, whereas SSDI determination is based on disability and work credits. In addition, in most states, an SSI recipient will automatically qualify for healthcare coverage through Medicaid. A person with SSDI will automatically qualify for Medicare after 24 months of receiving disability payments. Individuals with amyotrophic lateral sclerosis (ALS) are eligible for Medicare immediately.



⇒ **Transfer:** The coordination between two healthcare centers, moving a patient's care from one center to another.

⇒ **Vision insurance:** Similar to behavioral health insurance, vision insurance is often through a different provider that is included with your health plan. This benefit at least partially covers vision care, like eye exams and glasses.

## ⇒ **Vocational rehabilitation:**

Programs in each state that provide support to individuals with physical, mental, and/or intellectual disabilities to obtain access to higher education or employment.

⇒ **Waiver:** Government programs that give individuals with disabilities access to programs, funding, and supports. The name comes from the fact that the federal government “waives” Medical Assistance/Medicaid rules for institutional care so the state can use the same funds to provide supports and services closer to individuals’ homes. There are typically both financial and diagnostic criteria to qualify for a waiver. Some waivers will also give you access to Medical Assistance or Medicaid as one of its benefits.

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# Your Itinerary

*An experienced traveler* knows that creating an itinerary will help you stay organized and ensure you can make time for all your favorite attractions. Just like a travel itinerary, you can use the timelines below as you plan for your transition to adult care.



Keep in mind that along your journey, things may come up that cause you to change your plans. If this happens, don't worry! This is your experience, and it is important to tailor your itinerary to your interests and needs.

Just as you might talk to a travel agent regarding changes to your travel itinerary, you can consult a social worker, member of your medical care team, teacher, or caregiver for support with any of the steps below.

## **Ages 14-16: Practicing**

Schedule time to meet one-on-one with your healthcare providers, including with psychosocial staff such as social workers, to ask questions. You can participate in screenings for anxiety and depression when available.

Ask about your healthcare institution's policy on transitioning to adult care and any resources and supports available for the process.

Learn to answer important questions about your own health, including any allergies and reactions, your medications and why you take them, and which doctor you see for which symptoms.

Begin taking on tasks related to your healthcare, such as refilling a prescription, answering questions at doctor visits, and scheduling appointments.

Expect screenings and discussions regarding transition readiness to become a normal part of your follow-up visits.





## Age 17: Readyng

Ask your healthcare providers what changes will occur when you turn 18. You can complete HIPAA release forms and powers of attorney, if applicable.

Begin to take control of your healthcare visits. Your caregivers can “take a back seat,” allowing you to ask and answer questions and help make decisions about your care. Leverage your caregivers’ help to investigate any changes to your benefits that may occur when you turn 18. If you are required to reapply for services, begin looking into requirements and deadlines.

Use the assessment in the next section to track your progress with transition readiness. Make plans for improvement in areas where you need help or guidance.



## Age 18+: Transitioning

Start making your transition plan. Begin by collecting your medical records and identifying adult providers. Ask potential providers questions such as: “What is your lateness policy?,” “How far out are you scheduling?,” and “Do you specialize in my disease?”

Take charge of the planning process for college, independent living, and/or employment.

Establish a connection with a local vocational rehabilitation organization.

Learn about your health insurance and get information on your coverage and plans.

Apply for eligible government benefits when you turn 18. Your parents’ income can no longer be taken into consideration for social security income (SSI). Even if you have been denied SSI in the past due to income, you can apply at age 18 (or up to 3 months before).

Learn about advance directives. If you’re interested, ask your healthcare team how to create one.

## Transition Plan Guide

Fill out the lines below to get started on creating your road map for success.

### Medical Providers

Provider name and specialty \_\_\_\_\_

Phone number \_\_\_\_\_

Location \_\_\_\_\_

Provider name and specialty \_\_\_\_\_

Phone number \_\_\_\_\_

Location \_\_\_\_\_

Provider name and specialty \_\_\_\_\_

Phone number \_\_\_\_\_

Location \_\_\_\_\_

Provider name and specialty \_\_\_\_\_

Phone number \_\_\_\_\_

Location \_\_\_\_\_

Provider name and specialty \_\_\_\_\_

Phone number \_\_\_\_\_

Location \_\_\_\_\_

### Your medical needs

What are your medications? \_\_\_\_\_

\_\_\_\_\_

What pharmacy do you use? (Include address and phone number) \_\_\_\_\_

\_\_\_\_\_

Who can offer support if you experience problems with your medications? \_\_\_\_\_

\_\_\_\_\_

What is your diagnosis? \_\_\_\_\_

\_\_\_\_\_

What are your symptoms? \_\_\_\_\_

\_\_\_\_\_

Who can offer guidance and support if you experience problems? \_\_\_\_\_

\_\_\_\_\_

## Transition Plan Guide

### Healthcare Essentials

Transportation to medical appointments: \_\_\_\_\_

\_\_\_\_\_

Transportation for personal and recreational purposes: \_\_\_\_\_

\_\_\_\_\_

Educational/vocational supports: \_\_\_\_\_

\_\_\_\_\_

Equipment needs and vendors: \_\_\_\_\_

### Medical Releases/Advance Directives

HIPAA (if applicable)

Completed

Original copy stored in a safe location

Copy sent to providers

Healthcare proxy

Completed

Original copy stored in a safe location

Copy sent to providers

Power of attorney

Completed

Original copy stored in a safe location

Copy sent to providers

### Healthcare Insurance

Insurance provider and plan: \_\_\_\_\_

\_\_\_\_\_

Insurance provider's phone number: \_\_\_\_\_

Secondary insurance provider and plan: \_\_\_\_\_

\_\_\_\_\_

Secondary insurance provider's phone number: \_\_\_\_\_



*Congratulations.* you've earned the **TRANSITION PLANNING STAMP**! This stamp shows that you have successfully created a plan to guide you toward adulthood. Although you've earned this stamp, feel free to come back and visit frequently to update your plans and goals.



## New Roles and Responsibilities

When setting out on a new adventure, it is helpful to have a plan A as well as a plan B, just in case of an unexpected event. As the leader of your journey, it is your responsibility to delegate tasks to your support team to ensure all goes smoothly.

### **Start by making a list of your support people and what each can help with.**

Your support people may offer advice, financial or transportation assistance, emotional support, and more. Be sure to discuss the support you need with the individuals on your list.



Name	Support type	Contact information

### **Next, think about different areas of your life and set goals for what you want to accomplish:**

#### **Housing**

Where do you want to live? \_\_\_\_\_

What will you need to live independently? \_\_\_\_\_

Which support people can help you achieve this goal? \_\_\_\_\_

How are they willing and able to assist? \_\_\_\_\_

#### **Transportation**

How can you get to the grocery store, doctor's appointments, and social engagements?

Is there anyone you can rely on for transportation needs? What if you are in trouble and need quick assistance?

## New Roles and Responsibilities

### Education/employment

Do you want to continue studying after high school? \_\_\_\_\_

What career paths interest you? \_\_\_\_\_

Can you think of someone in your life whose career you would like to know more about?  
(List their name(s) and contact information.)

Do your family and friends have any education or employment connections?

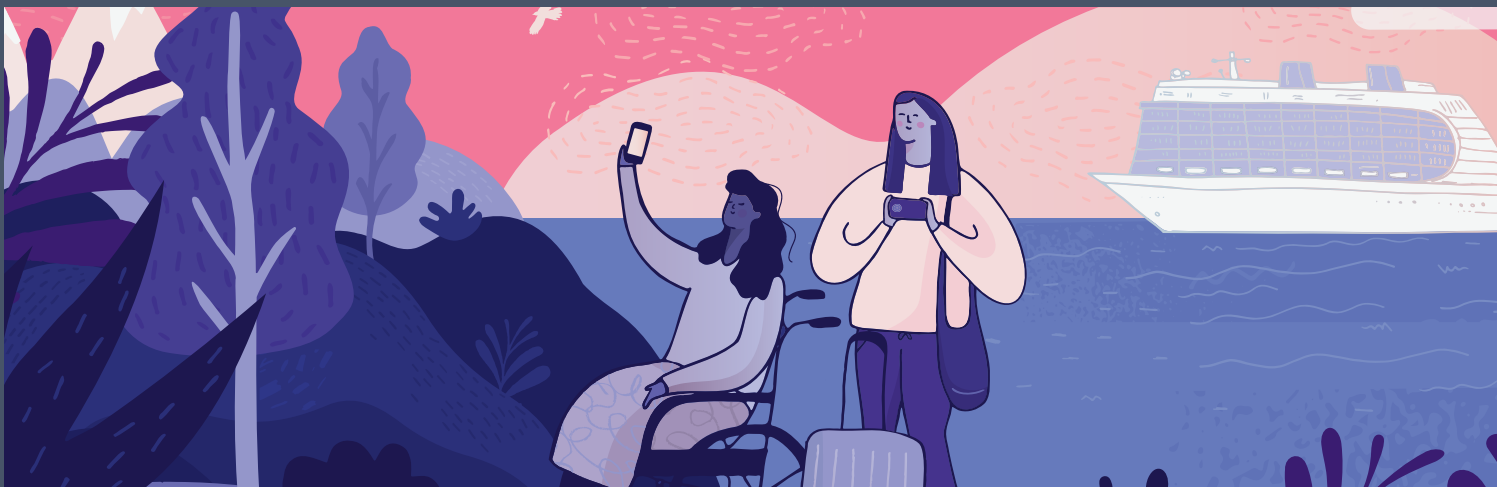
If you don't know anyone personally, brainstorm how you can learn more about these careers.

**Use this chart to jot down goals for school, work, relationships, personal development, and finances.**

Area	Goals
School	
Work	
Relationships	
Personal development	
Finances	
Other	
Other	
Other	



*Congratulations* on achieving the **ROLES AND RESPONSIBILITIES STAMP!** As you can see, there are many factors to consider as you transition to an independent adult. Don't let this overwhelm you! You can rely on your support team — who we will refer to as your fellow travelers — to help you along the way. This includes trusted adults, family members, and educational and medical providers.



## Know Your Stuff

Are you ready to take the wheel? Move from a more passive role to a more active role by completing the following challenges.

### *Challenge 1:* **Set up your next medical appointment!**

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Physician: \_\_\_\_\_

### *Challenge 2:* **Review the questions below and select the ones you would like to ask at your next appointment.**

What is causing my symptoms? \_\_\_\_\_

What can I expect before our next appointment? \_\_\_\_\_

Are there any side effects to my medication? \_\_\_\_\_

Are there any alternate treatments I should consider? \_\_\_\_\_

Do you know of any clinical trials available for me? \_\_\_\_\_

What can I expect when participating in a clinical trial? \_\_\_\_\_

Can you recommend any adult providers? \_\_\_\_\_

How can I transfer my medical records to my new provider? \_\_\_\_\_

When is my next appointment? \_\_\_\_\_

## *Challenge 3:* Refill your medication.

What is your prescription name and number? \_\_\_\_\_

What pharmacy do you use? \_\_\_\_\_

What is your pharmacy's phone number? \_\_\_\_\_

What is your pharmacy's address? \_\_\_\_\_

What would you do if you were traveling and suddenly realized you didn't have your medication?

## *Challenge 4:* Become familiar with online medical technology, such as your MyChart accounts.\*

\*You may have to access multiple online health portals to communicate with providers and access your information. Practice the following steps with each of your online accounts.

Learn your login and password information.

Take a tour of the platform, and jot down any questions you have.

Locate where you update your contact information.

Use the platform to request a medication refill, contact your provider, or schedule an appointment.

## *Challenge 5:* Set goals for your future.

What are your plans after high school? \_\_\_\_\_

How will you meet new people after you graduate? \_\_\_\_\_

Where do you plan to live if and when you live independently? \_\_\_\_\_

What resources do you need to help you live independently? \_\_\_\_\_

Do you want to get married? Have children? \_\_\_\_\_





## *Challenge 6:* Practice taking on more responsibility.

Explore employment opportunities and look up requirements for your target job:

Employment goal: \_\_\_\_\_

Job requirements: \_\_\_\_\_

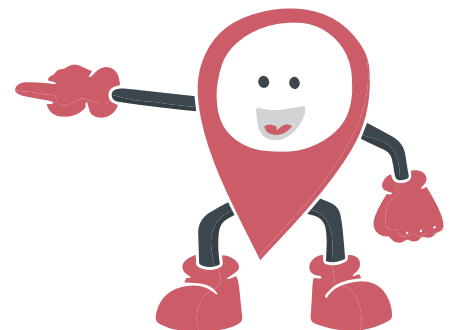
Expected wage: \_\_\_\_\_

MDA's Access Workshops are a great tool to help you learn more about a variety of access topics while being specifically built for the neuromuscular disease community. These self-paced workshops include:

- **Access to Employment**
- **Access to Education**
- **Access to Higher Education**
- **Access to Financial Independence**

Find these workshops at [mda.org/care/access-workshops](https://mda.org/care/access-workshops).

**Remember, you are not on this journey alone, and your fellow travelers want to see you reach your destination successfully. The next sections will help guide your fellow travelers so they can support you on your journey to adulthood.**





## Support Team Guide

### **For Parents and Caregivers**

Teach your child about their condition and medications, and how to schedule appointments, ask questions, and prepare for a doctor's visit.

Children can begin learning about their condition and participating in decision-making as early as 5 years old. See below for a list of suggestions to help foster independence in young children.

### **Ages 5-7: Learning**

- Encourage your child to learn the name of their disease and what part of the body it affects. As a child starts school, it is important for them to be equipped to answer questions and/or understand how to set boundaries.

- It is developmentally appropriate for children this age to notice and point out differences between themselves and their peers. Support your child as they learn to tell their peers about their muscle disease. Role play is a great way to help children practice these conversations.
- Allow your child to ask questions. Caregivers can encourage and answer questions using age-appropriate language. If you are unsure of the language to use with your child, talk with your care team's psychosocial support staff, such as child life specialists or social workers.
- Allow your child to ask the doctor questions if they have them. This will also help you know what your child is curious about regarding their diagnosis.

### **Ages 7-10: Participating**

- Encourage questions. Children will often tell us what they want to know. Respond honestly, even if the answer is, "I don't know."
- Allow your child to participate in their medical care. Children can start by asking their doctor a question or explaining why they are visiting the doctor.
- Doctors can encourage participation during the visit by asking questions the child can answer, such as their name and birthday.
- Ask your child about their conversations with friends and classmates to ensure they have the tools to talk about their differences positively.



## Ages 11-13: Including

- Puberty can be a difficult transition for anybody. Insecurities and challenges with peers and in school may increase during this time. Encourage your adolescent to pursue their interests and help them identify activities or skills that promote self-esteem.
- Consider finding a mental health provider during this time. This may help your adolescent develop coping skills and provide an outlet to discuss frustrations related to their diagnosis or other aspects of life.
- Encourage your adolescent to learn more about their condition and their medical care. They can also participate more in doctor's visits, explaining their symptoms and daily challenges and answering providers' questions.
- Allow your adolescent to be involved in their IEP/504 planning meetings. Remember that students must have access to a fair and equal education. To help them speak up you may ask them questions such as:
  - » "What are the barriers you have in school?"
  - » "Are there rooms that are hard to access?"
  - » "Are there assignments that are harder for you than others?"
  - » "What do you think would help you in school?"

For a list of suggestions for ages 14+, turn to page 11. Additionally, you can educate your teen about what their rights and responsibilities will be in the medical setting once they turn 18. Your teen will be responsible for signing documents at appointments and in other settings that require contracts or consent. Discuss the importance of understanding paperwork before signing. They should read through everything before signing and ask questions if they are unsure of anything.



Consider learning about these topics together:

- **HIPAA:** This law requires medical professionals to keep patients' medical and demographic information private and inaccessible to others. Once a patient turns 18, HIPAA will prevent providers from sharing information with parents and caregivers. The patient will need to request and sign a release of information naming people with whom providers are allowed to share medical information.
- **Consent for treatment:** The patient will be responsible for reading, understanding, and signing consent forms before their medical appointments and procedures.

Provide opportunities for your child to ask for and receive caregiving help from other individuals in their lives. Move from an active role to a more supportive role. Support your teen while allowing them to take charge. Your teen might make some mistakes, but that is the best way to learn.

## For Healthcare Providers

Review conditions, symptoms, medications, equipment, and other related healthcare information with the patient and family. Allow the patient to ask questions and continue to check for understanding.

Facilitate ongoing discussions about health, education, employment, and living as an adult with disabilities. Discuss with the patient the current best practices for their ongoing care as an adult, such as what specialists to continue seeing and how often.

Gradually move from directing questions and information to parents to speaking directly to the patient. Seek to involve the patient more in their own care.

Provide relevant information to help patients make decisions about their future. Connect them to resources that offer support in all aspects of transitioning to adulthood.

## For Schools and Educators

Provide guidance and support for identifying opportunities for higher education. Help students search for universities or colleges that are skilled at providing accommodations for adults with disabilities.

- **Individualized Education Program (IEP):** An IEP is an academic support. This program is offered free of charge to families of kids in public schools and outlines the goals and any support services that may be needed for a child to succeed in school.
- **504 plan:** This plan outlines services, accommodations, and modifications that help students with disabilities participate in educational and school-related activities.

If a student has an IEP, it is required under the Individuals with Disabilities Education Act (IDEA) that they have a transition plan in place by age 16 or earlier. Be sure to mention this ahead of time at IEP meetings. Inform your student of their IEP or 504 plan and help them understand how the school can accommodate them.

When your student graduates, give them copies of IEP or 504 plans and the results of any diagnostic testing. Students will need this information to submit to colleges to request ongoing support and accommodations.

Provide guidance and support with vocational opportunities or training. Schools often have great resources, and many have transitional or vocational programs available for their students who qualify. Additionally, any student with a cognitive impairment can receive public school education until the age of 22.

MDA offers a variety of K-12 educational resources. These printable resources help educators understand the needs of youth living with neuromuscular diseases and offer suggestions for working with students in the school environment:

- **MDA Educators' Flyer—Duchenne Muscular Dystrophy**
- **MDA Educators' Flyer—Myotonic Dystrophy**
- **MDA Educators' Flyer—Spinal Muscular Atrophy**
- **MDA Teacher's Guide**
- **The IEP Process**

Many of these resources are available in English and Spanish. Find these resources at [mda.org/education](https://mda.org/education).

# Making Decisions

*Along your journey*, you may come to a fork in the road. How would an experienced traveler decide which path to take? As the driver on your journey to adulthood, you should feel empowered to make important decisions that help lead you to your destination. Just as a traveler would use tools like GPS, you can lean on your support system to help. But always be sure to remain in the driver's seat, as the final decision is yours to make.



One of the biggest transitions that occurs when a patient turns 18 involves decision-making. Ideally, conversations about decision-making options should start around age 16.

There are *3 main categories* based on an individual's capacity to make decisions for themselves:

1

Low  
level of  
support

## **Becoming your own decision maker**

You can look to others for support, but you ultimately make decisions about your care and how you'd like to live.





Medium  
level of  
support

2

## Supported decision-making options

- **Power of attorney (POA):** This is designated by the person with a disability to appoint someone who can make decisions on their behalf. A POA may give broad or limited authority to make decisions about healthcare or finances. The individual retains their rights.
- **Supported decision-making (SDM):** This option, available in some states, allows an individual with disabilities to retain their rights and appoint individuals who can collaborate and provide guidance on decision-making. You can see which states have SDM laws at [supporteddecisions.org](https://supporteddecisions.org). This website also provides resources and guidelines for using SDM, regardless of whether your state has an SDM statute.
- **Release of information (ROI):** This form authorizes someone else to receive an individual's healthcare information. If you'd like a parent or caregiver to have access to your medical information, you'll need to sign an ROI at each of your providers' offices.

## Financial Support

### Achieving a Better Life Experience (ABLE)

**accounts:** These tax-advantaged savings accounts are for individuals with disabilities and their families. The account owner is the person with disabilities, and anyone can contribute funds to the account. The account owner can use funds from the account for qualified expenses that help improve health, independence, and/or quality of life, which may include education, food, housing, transportation, employment training and support, assistive technology, personal support services, healthcare expenses, and financial management administrative services. Learn more about ABLE accounts on [page 4](#).

### Assistive technology:

Use a name stamp to assist with physically signing documents.

### Authorized signer:

You can add someone to your bank account as an authorized signer, so the authorized signer can assist with deposits, withdrawals, and other financial tasks.

### Joint bank accounts/ trusts:

This type of bank or brokerage account is shared by two or more individuals.

### Representative payee:

A person receiving SSI benefits can designate someone to manage those benefits on their behalf. Contact the Social Security Administration to set up a representative payee. Learn more about SSI on [page 9](#).

3

High  
level of  
support

## Appointing a guardian or conservator

This typically takes place after a psychological or neuropsychological evaluation recommending guardianship based on cognitive impairment. Guardianship or conservatorship takes away an individual's rights by giving someone else the authority to make decisions for that individual. Input from your healthcare team is important because this is a long-term option that can be difficult to reverse or change.

A family applies through a court for a guardianship or conservatorship to be granted. Often, courthouses will have help desks to assist families with pursuing guardianship.

You can also look for nonprofit disability organizations that can assist with this process.

This is a wonderful tool available to individuals and families who need it, but serious consideration and conversations should take place before pursuing guardianship or conservatorship. It should only be done in situations where the individual truly does not have the capacity to make decisions for themselves.





# Making Decisions

## 6 Tips for Selecting Appointees and Support People

- 1 Choose someone who respects your beliefs and values.
- 2 Choose someone who is trustworthy and will listen to you, act on your behalf, and keep your records private.
- 3 Choose someone who will help you advocate for yourself; help you practice speaking up; and help make reports if abuse, neglect, or financial exploitation occurs.
- 4 A guardian or support person could be a parent or stepparent, brother or sister, relative, cousin, aunt, uncle, or close family friend.
- 5 An appropriate appointee should not be your boss or employer or a service provider or agency.
- 6 Avoid selecting individuals who charge you for their help or support or who have committed abuse or a crime in the past.



## Know Your Stuff

*Challenge:* List a few trusted support people you can count on. Be sure to include their contact information.

Support person: \_\_\_\_\_

Role/relationship: \_\_\_\_\_

Phone number: \_\_\_\_\_ Email: \_\_\_\_\_

Support person: \_\_\_\_\_

Role/relationship: \_\_\_\_\_

Phone number: \_\_\_\_\_ Email: \_\_\_\_\_

Support person: \_\_\_\_\_

Role/relationship: \_\_\_\_\_

Phone number: \_\_\_\_\_ Email: \_\_\_\_\_



*Congratulations* You've earned the **SUPPORT STAMP!** Remember, everyone needs help sometimes, and it's OK to turn to a trusted adult with questions along your journey. Support people should understand this journey is new for you, and their role is to help you achieve your goals.

# The Final Stretch

*You've almost reached your destination!* Here are a few more things to consider once you turn 18 years old.

## **Health insurance**

Depending on the state, you will have to transition from child Medicaid plans to adult Medicaid plans. Each state has its own guidelines and processes. If you are insured through your parent, you are eligible to keep their insurance until you are 26 years old. Health insurance is also available to purchase on the marketplace or can be obtained as a benefit through an employer.

Take MDA's Access to Coverage: Insurance workshop to learn more about insurance and overcoming barriers to coverage. Find it at **[mda.org/AccessWorkshops](http://mda.org/AccessWorkshops)**.

## **Disability benefits**

Once you turn 18, you may be eligible for SSI benefits, as your parents' income and assets will no longer count as your income or assets.

Adults may be eligible for other programs offered through the state, such as vocational training, independent living assistance, and personal care attendants (PCAs). Most programs are available through a state's Department of Health and Human Services or Department of Rehabilitation Services. Check your state's website for information on how to apply.

Take MDA's Access to Financial Independence workshop to learn more about disability benefits and other financial programs. Find it at **[mda.org/AccessWorkshops](http://mda.org/AccessWorkshops)**.





## Advance directives

An advance directive is a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor.

Many healthcare teams include access to palliative care professionals. A palliative care team can help you and your family discuss advanced directives, goals for quality of life, and assist in healthcare decision-making that supports the individuals' preferences.

**In addition to your support team, or fellow travelers, you can also contact the MDA Resource Center at 1-833-ASK-MDA1 (1-833-275-6321) or [ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org).**

*Wow, what a journey it's been!*

Thank you for taking the time to travel with me and complete your passport challenges. Remember, when transitioning to adulthood, it is important to focus on the journey, not the destination. This is a very important time in your life and by completing this guide, you are setting yourself up for success.



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