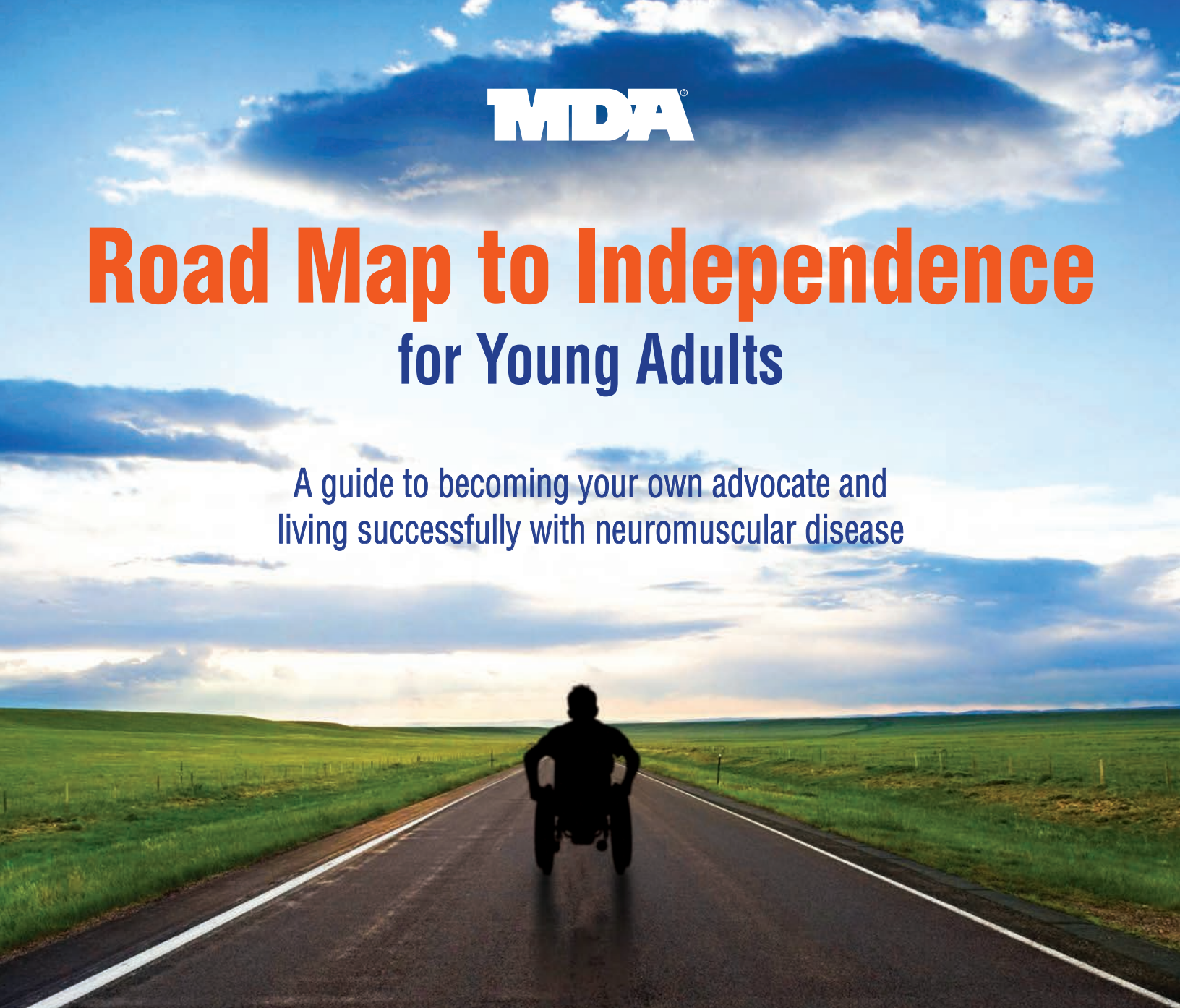




Road Map to Independence for Young Adults

A guide to becoming your own advocate and living successfully with neuromuscular disease



This workbook is brought to you by the Muscular Dystrophy Association and the MDA Transitional Services Task Force:

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For additional information or questions, please contact MDA at (800) 572-1717.

A note to the users of this guide:

This workbook is designed to help you grow up to be as independent as possible. The questions in the book revolve around diagnosis, health and education. They serve as a guide to what you and your family should know and do to achieve successful independence at the end of high school.

Remember, if you have questions about any issue raised in this book or about your care and well-being, your MDA clinic team is here to help you.

This guide is not meant to be comprehensive, and we encourage you to contact the MDA clinic team, your local MDA staff and other families with neuromuscular disease within the MDA community for additional resources.

Remember that you are never alone ...

Your local MDA office and contact person:



Name: _____

Address: _____

Contact information:

Home: _____

Cell: _____

E-mail: _____

Diagnosis: _____

Doctors' names and phone numbers:

Primary care physician (PCP): _____

Neurologist: _____

Cardiologist: _____

Pulmonologist: _____

Rehab doctor: _____

Other: _____

Insurance company, policy number, group number: _____

Parent/Guardian/Caregiver name(s): _____

Date: _____

Your understanding of your neuromuscular disease:

What is your diagnosis? How do you explain it if someone asks?

Do you take any medications? Which ones and why?

Have you had any surgeries? For what?

Your health:

Has a pulmonary doctor (a doctor who specializes in lungs) spoken with you about ways of helping you breathe better?

Has a cardiologist (a doctor who specializes in the heart) spoken with you about your heart?

What are you doing to help yourself stay healthy?

Would you like to speak with someone about nutrition and exercise?

Issues discussed with your doctor today:

Your education:

Will you or did you enter a new school this year?

Do you have an IEP or 504 plan? Do you know why?

Do you know who is responsible for coordinating your school services?

Would you like the MDA team to speak with your classmates or teachers about neuromuscular disease?

Outside of class, what activities interest you?

Where do you see your friends outside of school?

Who is your closest friend?

When you look ahead, what do you most look forward to, and what is your biggest worry?

(Clinic Team Member)

Date: _____

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Would you like the MDA team to speak with your classmates or teachers about neuromuscular disease?

Do you know who is responsible for coordinating your school services?

You may have had a class on topics like relationships, parenting, sex and reproduction. What questions do you have that we can answer?

Outside of class, what activities interest you?

Where do you see your friends outside of school?

Who is your closest friend?

(Clinic Team Member)

Date: _____

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Has a cardiologist (a doctor who specializes in the heart) spoken with you about your heart?

What are you doing to help yourself stay healthy?

Would you like to speak with someone about nutrition and exercise?

Issues discussed with your doctor today:

Your education:

Will you or did you enter a new school this year?

Do you have an IEP or 504 plan? Do you know why?

Do you know who is responsible for coordinating your school services?

Have you studied genetics yet? What questions do you have about genetics and your neuromuscular disease?

You may have had a class on topics like relationships, parenting, sex and reproduction. What questions do you have that we can answer?

Do you plan to drive? If so, when will you start driver's education?

Outside of class, what activities interest you?

Where do you see your friends outside of school?

Who is your closest friend?

(Clinic Team Member)

Date: _____

Your understanding of your pulmonary health:

Are you using any equipment to help your lungs?

Do you know how this equipment is helping you breathe and keep your lungs healthy?

Has a pulmonary doctor discussed any other issues or equipment with you?

Have you been in the hospital this year for pneumonia or any other problems?

Have you thought about the possibility of using more complicated ventilation equipment?

Your understanding of your cardiac health:

What did the cardiologist tell you about how well your heart is working?

Are you taking any heart medications? Which ones and why?

Your education:

What do you think you will do after you finish high school?

What are your thoughts about a career or going to college?

Where will you live?

Is anyone helping you with these plans?

You may have had a class on topics like relationships, parenting, sex and reproduction. What questions do you have that we can answer?

Outside of class, what activities interest you?

Who is your closest friend?

Have you learned how to drive or how to use local transportation services to get around the community?

(Clinic Team Member)

Date: _____

Your understanding of your pulmonary health:

Are you using any equipment to help your lungs?

Do you know how this equipment is helping you breathe and keep your lungs healthy?

Has a pulmonary doctor discussed any other issues or equipment with you?

Have you been in the hospital this year for pneumonia or any other problems?

Have you thought about the possibility of using more complicated ventilation equipment?

Your understanding of your cardiac health:

What did the cardiologist tell you about how well your heart is working?

Are you taking any heart medications? Which ones and why?

Establishing independence:

What do you think you will do after you finish high school?

What are your thoughts about a career or going to college?

Where will you live? Will you need assistance? How will you find it?

Is anyone helping you with these plans?

Have you studied genetics in school? What questions do you have about genetics and your neuromuscular disease?

You may have had a class on topics like relationships, parenting, sex and reproduction. What questions do you have that we can answer?

Have you learned how to drive or how to use transportation services to get around your community?

What thought have you given to working or volunteering in your free time?

Has a physical or occupational therapist spoken with you about equipment that can help with your mobility and independence in everyday activities?

What do you know about advanced directives? Would you like to learn more about advanced directives? Does your family know your wishes?

(Clinic Team Member)

Date: _____

Your understanding of your pulmonary health:

Are you using any equipment to help your lungs?

Do you know how this equipment is helping you breathe and keep your lungs healthy?

Has a pulmonary doctor discussed any other issues or equipment with you?

Have you been in the hospital this year for pneumonia or any other problems?

Have you thought about the possibility of using more complicated ventilation equipment?

Your understanding of your cardiac health:

What did the cardiologist tell you about how well your heart is working?

Are you taking any heart medications? Which ones and why?

Establishing independence:

What do you think you will do after you finish high school?

What are your thoughts about a career or going to college?

Where will you live? Will you need assistance? How will you find it?

Is anyone helping you with these plans?

What activities are you currently involved in?

Who is your closest friend?

Has a physical or occupational therapist spoken with you about equipment that can help with your mobility and independence in everyday activities?

Do you know about laws designed to protect you? Do you know what they do and where to go if you need legal help?

What kind of health insurance do you have now, and will you be able to keep it now that you are 18 years old?

What do you know about advanced directives? Would you like to learn more about advanced directives? Does your family know your wishes?

Have you registered to vote?

Have you registered with the Selective Service?

(Clinic Team Member)

Additional Information and Notes: