

Women's Health in Neuromuscular Disease: Pregnancy and Family Planning

Family planning and pregnancy are deeply personal decisions, and for people living with **neuromuscular diseases**, they can come with additional questions and considerations. The good news is that most people with neuromuscular diseases can have successful pregnancies and build families in ways that align with their goals.



With thoughtful planning, the right care team, and individualized support, you can navigate this journey with confidence. This guide is designed to help you understand your options, prepare for what to expect, and have informed conversations with your healthcare providers.

MDA is here to support you. If you have questions, are looking for additional resources, or would like to connect with others in the neuromuscular community, please contact the MDA Resource Center at **833-ASK-MDA1 (833-275-6321)** or **ResourceCenter@mdausa.org**.

Section 1: Pregnancy

Pregnancy considerations

Pregnancy with a neuromuscular disease requires thoughtful planning and individualized care. Each condition and each person's experience is different, so care decisions should be tailored to your specific needs and health history.

Individualized care matters

No two neuromuscular conditions affect the body in the same way. Even within the same diagnosis, symptoms and severity can vary.

Because of this, pregnancy planning should include:

- A review of your specific diagnosis and symptoms
- Discussion of how pregnancy may affect your body
- Planning for any additional support you may need
- A discussion of genetics and potential for inheritance of your condition

A **maternal-fetal medicine (MFM) specialist** is often recommended. This is an **obstetrician/gynecologist (OB/GYN)** with expertise in managing more complex or **high-risk pregnancies**. Genetic counseling and involvement with a neuromuscular specialist team may also be helpful.

Most people with neuromuscular diseases can have successful pregnancies, especially with **the right care team** and planning.



General pregnancy outcomes

According to the American College of Obstetricians and Gynecologists (2020), individuals with neuromuscular diseases have pregnancy outcomes that are similar to the general population, particularly when their condition is stable and care is coordinated among specialists. (Rudnik-Schöneborn et al., 2014)

- Rates of **miscarriage** are generally comparable
- Many pregnancy-related conditions occur at similar rates
- Most individuals do well with appropriate care and monitoring

While this can be reassuring, it is still important to have a care plan in place that reflects your individual health needs.

How neuromuscular conditions may affect pregnancy

Neuromuscular diseases can affect different parts of the body, including muscles involved in movement, breathing, and, in some cases, heart function or the immune system. Because of this, pregnancy may place additional demands on the body that are important to understand and plan for. Not all individuals will experience these effects, but being aware of them can help you and your care team prepare and provide the right support.

Cardiac considerations

Some neuromuscular conditions are associated with heart involvement. During pregnancy, the body naturally increases blood volume and the amount of work the heart must do. For individuals with existing cardiac concerns, this may increase the risk of complications, particularly later in pregnancy.

Your care team may recommend a heart evaluation before or early in pregnancy, along with ongoing monitoring to help ensure your heart is functioning well throughout pregnancy.

Respiratory considerations

Respiratory muscles may be affected in some neuromuscular conditions. As pregnancy progresses, the growing uterus places pressure on the diaphragm, which can make breathing feel more difficult.

People with preexisting respiratory involvement may notice increased shortness of breath, fatigue, or reduced lung capacity. In some cases, additional monitoring or **respiratory support**, such as breathing devices, may be needed, particularly later in pregnancy or around delivery.

Autoimmune conditions

Some neuromuscular conditions, such as myasthenia gravis (MG) and myositis, are **autoimmune diseases**. The course of these conditions can be unpredictable, and they may change during pregnancy. Some people may experience stable symptoms, while others may notice worsening or improvement.

Because muscle strength, including breathing muscle strength, can be affected, close monitoring is important. Planning pregnancy during a period of stability in symptoms and reviewing medications in advance can help support the best possible outcomes.

Potential areas of increased risk

Some individuals may experience higher rates of certain complications, depending on their condition.

These may include:

- **Preterm delivery**
- Increased likelihood of **cesarean delivery (C-section)**
- Greater need for **assisted delivery** (such as **forceps** or **vacuum**)
- Increased susceptibility or challenges with **anesthesia** management

Fatigue, muscle weakness, and mobility limitations may also affect labor and delivery, as well as influence pregnancy tolerance, and the need for help with infant/child care after birth.

Connecting with the **right specialists** before or early in pregnancy can make a significant difference in your experience and outcomes.

Not all people with neuromuscular diseases experience these challenges, and many have healthy pregnancies. Understanding how your specific condition may affect your body allows you and your care team to plan ahead, monitor appropriately, and respond to any changes that arise.

Monitoring and support during pregnancy

Ongoing monitoring is an important part of care. Your healthcare team may:

- Track changes in strength, mobility, or breathing
- Monitor for pregnancy-related conditions
- Adjust care plans as your body changes

As pregnancy progresses, some individuals may notice:

- Increased difficulty with mobility
- Greater fatigue
- Changes in daily function

Planning for these changes can help you stay safe and supported.

Planning ahead

Having early conversations with your care team will help you prepare for pregnancy and delivery.

Topics to discuss may include:

- Your goals for pregnancy
- Potential risks based on your condition
- How your care team will coordinate support
- If extra infant monitoring, supports, or time in the hospital is likely to be needed

Delivery planning and care teams

Planning for delivery is an important part of pregnancy, especially for people living with neuromuscular diseases. Because needs can vary widely, having a coordinated care team in place ahead of time can help ensure

a safer and more supportive experience. Your delivery plan should reflect your physical needs, and those needs may change throughout pregnancy. It is not a one-size-fits-all approach.

Building your care team

A **multidisciplinary care team** is often recommended to support delivery planning and care.

Your team may include:

- An MFM specialist (often the team lead)
- A general OB/GYN or midwife (often works in conjunction with the MFM)
- A **neurologist** familiar with your condition



- A **cardiologist**, if there are heart-related concerns
- A **pulmonologist**, if breathing or lung function is affected
- An anesthesia team experienced with complex cases
- A pediatrician or **neonatologist** if there are expected to be infant concerns or early delivery

Each provider plays a role in helping plan for a safe delivery that reflects your individual needs.

Planning for mobility needs

Mobility can change throughout pregnancy. Some individuals who do not typically use **mobility aids** may find they need additional support during pregnancy, delivery, and after.

Considerations may include:

- Positioning during labor and delivery
- Accessibility of the delivery room
- Use of wheelchairs and other mobility devices
- Assistance with transfers and movement
- Accessible plan for infant care and sleeping

Discussing these needs in advance allows your care team to prepare the appropriate equipment and support. Additionally, if your partner has mobility needs, these may need to be considered as well.

Anesthesia considerations

Anesthesia planning is an important part of delivery preparation.

Regional anesthesia (such as an **epidural or spinal**) is typically preferred when possible. However, it may be more difficult for some



people, particularly if there are spinal changes, such as **scoliosis** or prior spinal surgeries.

General anesthesia may carry additional risks, including:

- Challenges with airway management (especially if there is jaw/neck or facial muscle weakness)
- Increased sensitivity to certain medications
- Prolonged anesthesia effects related to muscle weakness or paralysis

Some neuromuscular diseases can make people more susceptible to certain types of anesthesia or make them more likely to have complications when used. This makes early communication with the anesthesia team especially important. A consultation before any planned procedure (including during fertility care) and before delivery is key to ensuring that a safe and effective care plan is in place.

Preparing for delivery day

Because deliveries may be more complex, planning ahead can help reduce stress and improve outcomes.

Important steps include:

- Ensuring all team members are aware of your diagnosis and needs
- Discussing a clear delivery plan in advance, but also being prepared if care needs change or unexpected challenges arise
- Identifying any special equipment or positioning requirements

For people with respiratory involvement, there may be a higher likelihood of needing additional monitoring or support. For those using respiratory supports (such as noninvasive ventilation equipment), care for a period of time after birth in an **intensive care unit (ICU)** may be needed.

If the infant is known to also have a neuromuscular disease or could be affected by the medications or therapies you are using, they may need a period of observation or care with the pediatric team. If an early

delivery is planned, this may be the case as well. Discussions about how and where this may occur, who can visit, and how and when feeding will be allowed can help you feel prepared and safe going into delivery.

Breastfeeding

Early delivery, as well as a C-section and differences in upper limb mobility, can all make **lactation** and breastfeeding more difficult. If your baby is expected to have mobility or swallowing challenges related to a neuromuscular disease, this can be an additional issue. Meeting with a lactation specialist to develop a feeding plan, review medication use during lactation, and ensure support during early feeding events can also help you meet your lactation/breastfeeding goals.

Post-delivery planning

Recovery and the **postpartum period** also require thoughtful preparation.

Consider:

- Staying in the hospital longer, if additional support is needed
- Involving the lactation team to help with positioning/support of lactation/breastfeeding
- Planning for help with daily activities after discharge
- Physical or occupational therapy may help with recovery, mobility recovery, and infant care
- Setting up your home environment for safety and accessibility

Caring for a newborn introduces new physical demands, and having supports in place can make a meaningful difference.



Section 2: Fertility and IVF

Understanding fertility and IVF

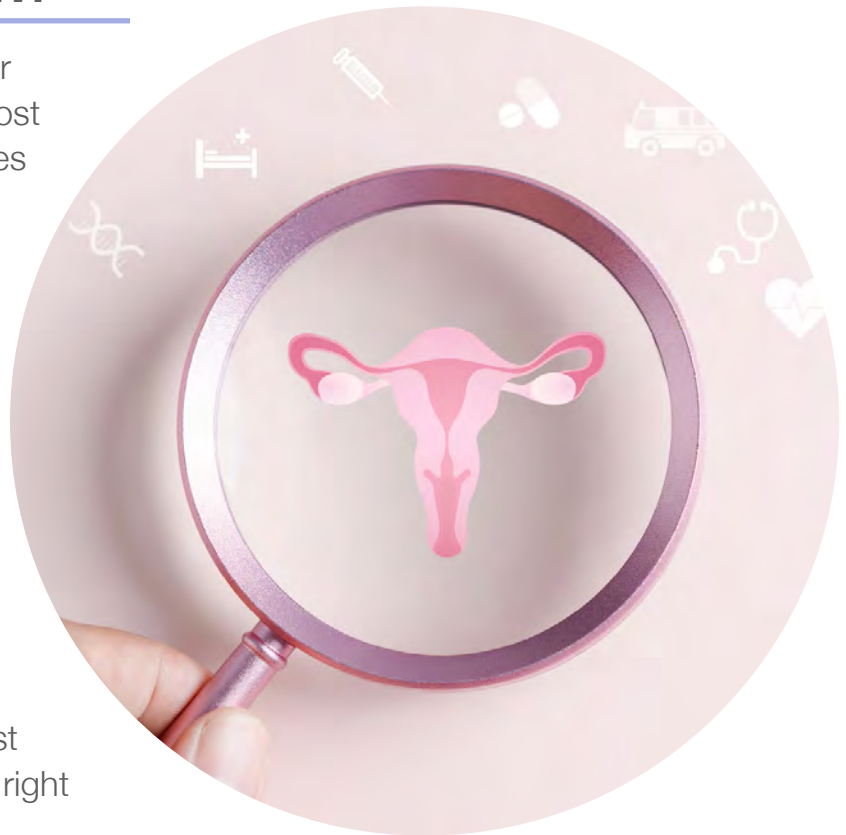
Most people living with neuromuscular diseases can become pregnant. In most cases, a neuromuscular condition does not directly affect **fertility**, but there are important considerations when planning for pregnancy. Some conditions will affect male but not female fertility, or the other way around. Others may not affect fertility but may affect the risk for early pregnancy loss (miscarriage).

Fertility decisions are highly personal and may be influenced by your specific diagnosis, health status, and future goals. Speaking with a specialist can help you explore options that are right for you.

Fertility may be influenced by:

- Overall health and physical function
- Hormonal changes or menstrual irregularities
- Medications that may affect **ovulation** or pregnancy safety
- Genetic considerations, depending on the specific diagnosis

Because of these factors, it is important to begin conversations early with your healthcare team if you are considering pregnancy.



Planning ahead

Preconception planning can help optimize health before pregnancy. This may include:

- Reviewing medications for safety in pregnancy
- Assessing cardiac and respiratory function, if relevant to your diagnosis
- Discussing any mobility or support needs
- Meeting with specialists as needed

Your care team may include a neurologist, OB/GYN, and, in some cases, an MFM specialist.

Open communication with your healthcare team can help ensure that decisions align with your health needs and personal goals.

Assisted reproductive options

If fertility challenges arise or if there are genetic concerns, **assisted reproductive technology (ART)** may be an option.

ART may include:

- **Gonadotropin therapy**
- **Insemination**
- **In vitro fertilization (IVF)**
- Use of **donor eggs, sperm, or embryos**
- **Genetic testing** of embryos prior to implantation
- **Surrogate pregnancy**

These options can help individuals and families make informed decisions about pregnancy while considering both medical and personal factors.

In vitro fertilization (IVF)

IVF is one option many families consider.

How IVF works:

- Hormone medications stimulate the ovaries to produce multiple eggs
- Eggs are retrieved in a small procedure
- Eggs are combined with sperm in a laboratory to create embryos
- Embryos are monitored and graded
- One or more embryos are transferred into the uterus

In some cases, a single sperm is injected directly into an egg to support fertilization, called **intracytoplasmic sperm injection**

There is no one “right” path. Fertility planning should reflect your personal goals, values, and medical needs.

Fertility is not affected by most neuromuscular diseases, but they can affect the ability to get and stay pregnant.

(ICSI). This is commonly done when sperm counts are low, or when sperm has to be removed from the testicle directly (i.e., not from ejaculate) due to certain disorders, including some neuromuscular diseases.

Additional considerations:

- Fertility plans should be tailored to your individual health needs
- Care is often coordinated with specialists, including a **reproductive endocrinologist (REI)** and MFM specialist
- **Genetic counseling** can help you understand the likelihood of passing on a condition. This can be complex depending on the disorder, the genetics of each parent, and the ability to test the embryos and predict effects for the baby. A genetic counselor and REI specialist can help guide you through this discussion and prepregnancy testing.



Glossary

Anesthesia

Medicine used to prevent pain during medical procedures. It may numb part of your body or make you fully asleep.

Assisted delivery

When tools like forceps or a vacuum are used to help deliver a baby during childbirth

Assisted reproductive technology (ART)

Medical treatments that help people become pregnant, such as IVF or insemination

Autoimmune diseases

Conditions caused by the immune system mistakenly attacking healthy body tissues. In neuromuscular autoimmune diseases, the immune system attacks nerves, muscles, or the neuromuscular junction.

Cardiologist

A doctor who specializes in heart health

Cesarean delivery (C-section)

A surgery used to deliver a baby through an opening in the abdomen and uterus

Donor eggs, sperm, or embryos

Eggs, sperm, or embryos from another person are used to help achieve pregnancy

Endocrinology

A branch of medicine that focuses on hormones and how they affect the body, including fertility, metabolism, and growth

Epidural or spinal anesthesia

Types of anesthesia given in the lower back to numb the lower half of the body during labor and delivery

Fertility

The ability to become pregnant

Forceps

A medical tool used to gently help guide a baby out during delivery

General anesthesia

Anesthesia that puts you into a sleep-like state so you're completely unaware

Genetic counseling

A service that helps you understand how a medical condition might be passed down to a child

Genetic testing

Testing that looks at your genes to assess the risk of inherited conditions

Gonadotropin therapy

Hormone treatment used to stimulate the ovaries to produce eggs

High-risk pregnancy

A pregnancy that needs extra monitoring due to medical conditions or other factors

Insemination

A procedure where sperm is placed directly into the uterus to help achieve pregnancy

Intensive care unit (ICU)

A specialized hospital unit where patients receive close monitoring and advanced medical support

In vitro fertilization (IVF)

A process where eggs and sperm are combined in a lab to create embryos, which are then placed into the uterus

Intracytoplasmic sperm injection (ICSI)

A type of IVF where a single sperm is injected directly into an egg to help fertilization

Lactation

The process of creating and releasing breast milk

Maternal-fetal medicine (MFM) specialist

A doctor who specializes in caring for people with more complex or high-risk pregnancies

Miscarriage

The loss of a pregnancy before 20 weeks. Many miscarriages happen early and are often not preventable.

Mobility aids

Devices such as wheelchairs, walkers, or braces that help with movement

Multidisciplinary care team

A group of healthcare providers from different specialties who work together to support your care

Neonatologist

A pediatrician who specializes in medical care for newborns

Neuromuscular diseases

A group of conditions that affect the muscles and the nerves that control them

Neurologist

A doctor who specializes in the brain, nerves, and muscles

Obstetrician/gynecologist (OB/GYN)

A doctor who specializes in pregnancy, childbirth, and reproductive health

Ovulation

The release of an egg from the ovary, which is necessary for pregnancy

Postpartum period

The time after childbirth when the body recovers and adjusts

Preconception (preconception planning)

The process of preparing for pregnancy before trying to conceive. This may include reviewing medications, checking overall health, and meeting with healthcare providers.

Preterm delivery

When a baby is born before 37 weeks of pregnancy

Pulmonologist

A doctor who specializes in lung and breathing health

Regional anesthesia

Anesthesia that numbs a specific part of the body instead of putting you to sleep

Reproductive endocrinologist (REI)

A doctor who specializes in fertility and hormone-related conditions

Respiratory support

Treatments or devices that help with breathing

Scoliosis

A condition where the spine curves to the side.

Surrogate pregnancy (surrogacy)

When another person carries and delivers a baby for someone else

Vacuum delivery

A type of assisted delivery that uses gentle suction to help guide the baby out

This resource was developed with the knowledge and expertise of Lorelai L. Thornburg, MD, from the University of Rochester Medicine.

DISCLAIMER: This resource is meant to inform and educate the community. The information presented is not intended to replace discussions with your healthcare provider and is not and should not be considered to be medical advice. Please consult with your healthcare team for information specific to you/your loved one.

CITED SOURCES: American College of Obstetricians and Gynecologists (2016). Obstetric management of patients with physical disabilities (Committee Opinion No. 675). *Obstetrics & Gynecology*, 128(4), e81–e85. (Reaffirmed 2020)

Rudnik-Schöneborn, S., Zerres, K., & Schoser, B. (2014). Pregnancy and neuromuscular disorders. *Journal of Neurology*, 261(Suppl 1), S81–S89.

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