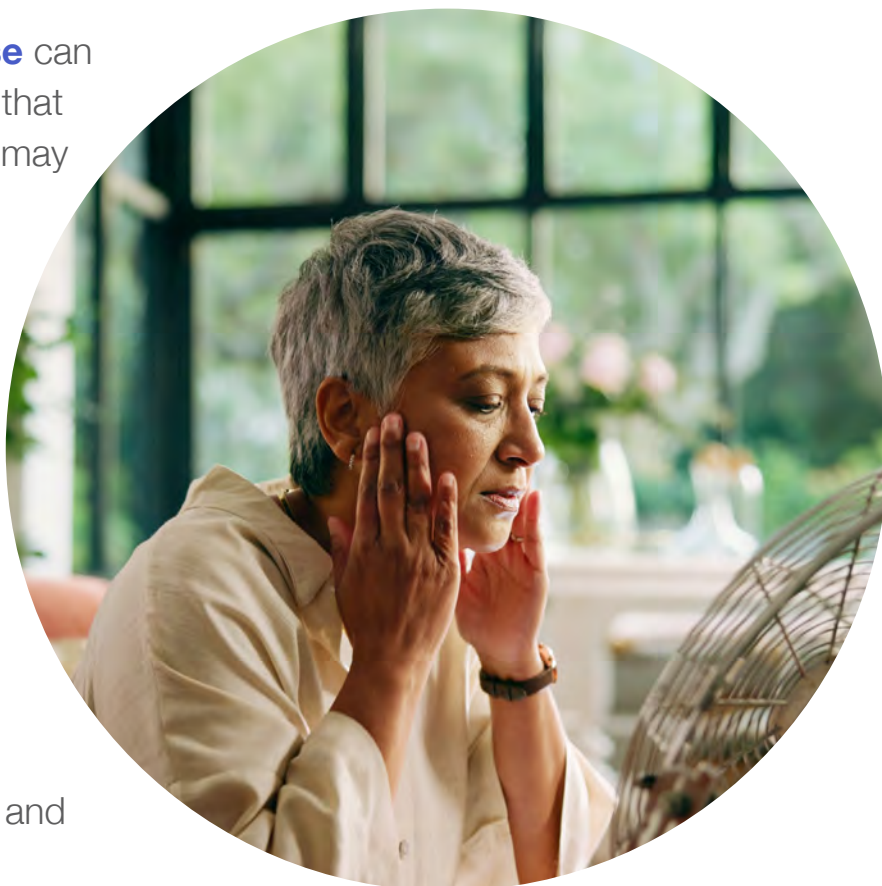


Women's Health in Neuromuscular Disease: Aging, Menopause, Hormone Therapy, and Bladder Health

Living with a **neuromuscular disease** can bring unique and evolving challenges that affect many aspects of health. These may include changes in muscle strength and function, **pelvic floor** health, and bladder and bowel control, which are all areas that can also be influenced by aging and hormonal changes, such as menopause. As these changes occur, it can sometimes be difficult to tell what is related to your underlying condition and what may be influenced by aging or **hormones**. Understanding how these factors overlap is an important step in maintaining comfort, function, and quality of life.



This resource provides practical, accessible information to help you better understand your body and explore supportive strategies. Whether you are experiencing new symptoms or are looking for ways to maintain function and comfort, it is designed to support informed decision-making in partnership with your healthcare team.

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: You and Your OB/GYN

An **obstetrician/gynecologist (OB/GYN)** is a doctor who specializes in women's health in all stages of life. Finding the right OB/GYN can make a meaningful difference in your comfort, confidence, and overall care.

Choosing an OB/GYN

It can be helpful to work with an OB/GYN who is open to collaboration and understands complex or chronic conditions, such as neuromuscular diseases.

Three things to look for in a provider

1. Experience or openness with complex or chronic conditions: Your provider does not need to be a neuromuscular disease expert, but they should be willing to learn and coordinate with your neurologist or specialty care team.

2. Comfort discussing sensitive topics: You should feel at ease asking questions about bladder health, sexual health, **menopause**, or **mobility**-related concerns.
3. Accessibility and accommodations: Consider whether the office is physically accessible and can support your mobility or positioning needs during exams.

Ask questions

Before making an appointment, ask questions to help determine if the doctor and their practice are a good fit for you, such as:

- Have you worked with patients who have chronic or neuromuscular conditions?
- How do you typically coordinate care with other specialists?
- Are there ways we can adapt exams or visits to meet my mobility or comfort needs?

Building a **strong relationship** with your OB/GYN is an important part of your care.



Preparing for your appointment

Taking a few steps before your visit can help you get the most out of your time with the provider and ensure your concerns are addressed.

Before your visit:

- Write down your symptoms or concerns. Include when they started, how often they occur, and anything that makes them better or worse.
- Bring a medication list that includes prescriptions, over-the-counter medications, and supplements.
- Be ready to share your neuromuscular diagnosis, a summary of your medical history, any recent changes, and key members of your care team.

During your visit:

- Be open and honest. Topics like bladder function, sexual health, or menopause symptoms are important parts of your care.
- If something isn't clear, ask your provider to explain it in a different way.
- Discuss your daily life, and share how symptoms affect your routine. This can help guide more personalized recommendations.
- A trusted support person can help you remember information, take notes for you, or ask additional questions.



After your visit:

- Review your care plan. Make sure you understand next steps, treatments, or referrals.
- Follow up if needed, and don't hesitate to reach out if new questions come up after your appointment.

The right provider **will listen to your concerns**, respect your experiences, and work with you to create a plan that fits your needs and goals.

Section 2: Menopause

Menopause is the stage of life when menstrual periods permanently stop, typically occurring after 12 consecutive months without a period. This is due to a decline in the production of hormones, primarily **estrogen** and **progesterone**, that the female body (the ovaries) naturally makes.

Menopause is a natural part of aging, but for individuals living with a neuromuscular disease, it can bring additional challenges. These hormonal changes may affect muscle strength, bone health, mobility, and overall comfort.

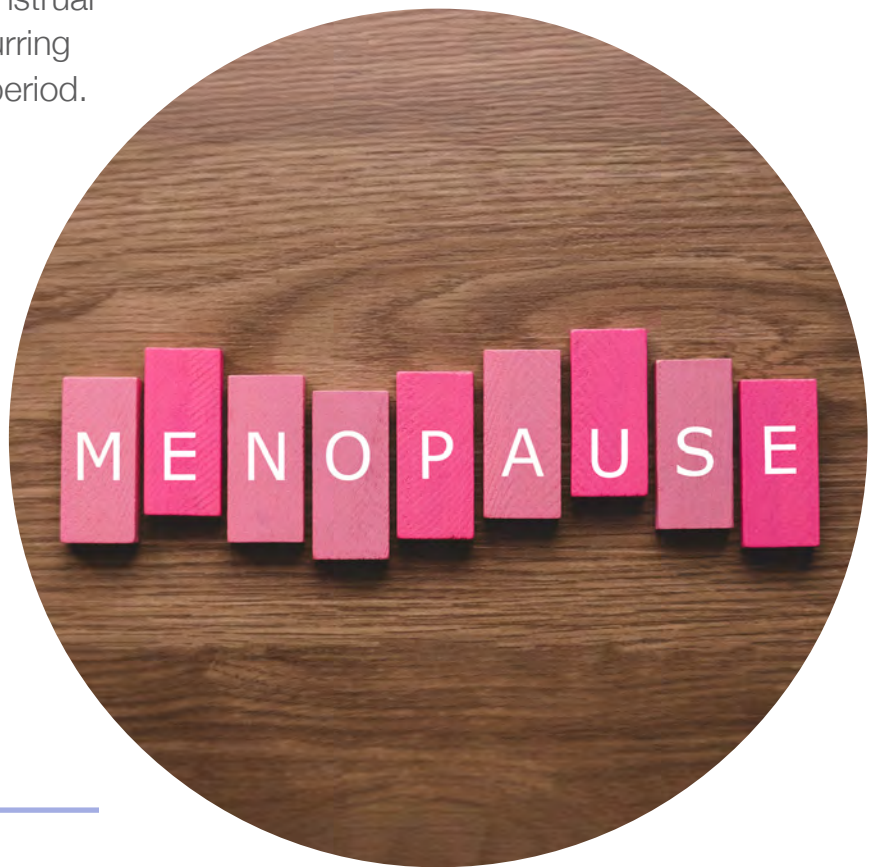
How menopause affects the body

As estrogen levels decline, the body experiences many changes, including:

- Loss of muscle mass
- Increased muscle aches and discomfort
- Decreased bone density
- Higher risk of fractures

These changes are a normal part of aging, but they can be more noticeable for people who already experience muscle weakness or reduced mobility. The body may feel unfamiliar, uncomfortable, or more sensitive to everyday strain.

While menopause officially means the end of female reproduction, the term is often used to include the **transitional phase**, also known as perimenopause, which leads to menopause.



The **menopausal transition** may begin years before a woman hits menopause.

What happens during menopause

Hormonal shifts during menopause lead to a range of symptoms, including:

- **Hot flashes** and **night sweats**
- **Vaginal dryness** or discomfort
- Skin changes (including in the vagina/vulva)
- Increased risk of **urinary tract infections (UTIs)**
- Changes in mood or sleep
- Muscle aches and decreased muscle mass

Bone, muscle, and aging in menopause

For people with neuromuscular diseases, the changes affecting the muscles, bones, and skin may feel more pronounced during menopause. These changes may have a greater impact on mobility, comfort, and overall function.

Muscle changes and symptoms

Muscle-related symptoms during and after menopause may include increased fatigue, muscle soreness or stiffness, and a gradual decline in strength. Menopause can make existing muscle symptoms feel worse. While this can be frustrating, there are ways to help maintain strength and function.

The most important factor in maintaining muscle strength is staying as active as possible within your ability level. This looks different for everyone, but may include **range-of-motion exercises**, physical therapy (PT) or occupational therapy (OT), or assisted movement. Even small, consistent movements can help maintain muscle tone over time.

There is no minimum level of activity required to benefit. What matters most is doing what is safe and sustainable for your body.

Bone health and weight bearing

Bone density naturally decreases with age, and this process accelerates after menopause. For individuals with limited **weight-bearing activity**, this can increase the risk of bone



loss, fractures, and even long-term mobility challenges. Weight-bearing activity, when possible, helps support bone strength. This may include standing, supported walking, or other guided activities based on your abilities.

Skin health

Skin health is essential during menopause. **Barrier creams** or estrogen creams can help protect sensitive skin, reduce irritation, and prevent breakdown, especially in areas exposed to moisture, friction, or **incontinence**.

Section 3: Menopausal Hormone Therapy (MHT)

Menopausal hormone therapy (MHT) can help manage symptoms during the menopausal transition and support overall health for some women.

Deciding about MHT

Hormone therapy is highly individualized, and MHT is not the right choice for everyone. The benefits and risks can vary based on your health history, mobility, and personal goals.

Possible benefits of MHT

Possible benefits include:

- Relief from hot flashes and night sweats
- Improved vaginal and urinary health
- Support for skin integrity
- Protection against bone loss
- **Cardiovascular health** benefits (when started early in menopause)

For people with reduced mobility or decreased weight-bearing activity, maintaining bone health is especially important. MHT may play a role in reducing the risk of bone-related complications.

Risks and considerations

It's important to carefully weigh your specific symptoms against the potential risks with your healthcare provider.

Potential risks may include:

- Increased risk of blood clots
- Increased risk of breast cancer
- Ongoing or irregular bleeding



- Complications in people with liver disease or hypertension (high blood pressure)

Some people with limited mobility may already have an increased risk for blood clots, which should be part of the decision-making process. MHT may not be recommended if you have a history of blood clots. It is also not recommended for people with health conditions such as uncontrolled hypertension, a history of breast cancer, or active liver disease.

Types of therapy for menopause

Each person's experience with menopause is unique, and so are the options for managing symptoms.

MHT types

There are two approaches to MHT, and choosing the right one depends on your specific symptoms and needs.

In **systemic hormone therapy**, treatment is delivered through oral medicine or patches to provide broad symptom relief.

Local (vaginal) therapy is typically delivered as a cream or suppository to primarily target vaginal and urinary symptoms. Localized therapy lowers a person's overall exposure to hormones, which may be a good option if symptoms are primarily related to vaginal discomfort or recurrent UTIs.

Nonhormonal therapies

There are also several nonhormonal medications that can effectively manage specific symptoms, such as hot flashes



and night sweats. These can be helpful for people for whom hormone therapy is not recommended.

MHT used to be called **hormone replacement therapy (HRT)**, but the term has been updated to describe the therapeutic nature, not just the replacement of hormones.

Where hormone therapy fits in

MHT can help reduce some of the bone and muscle loss that occurs during menopause. This may be especially important for people who have limited weight-bearing activity.

Potential benefits include:

- Slowing bone density loss
- Reducing muscle aches
- Supporting overall physical comfort

However, MHT is only one part of the picture. Movement and activity remain essential for maintaining both muscle and bone health.

MHT is generally most effective and safest when started **within the first few years** after menopause and before age 60. Starting therapy later may reduce some benefits, particularly for heart health.

Section 4: Bladder Health

Bladder issues are common and can become more noticeable with age and hormonal changes. For people living with neuromuscular diseases, factors like muscle weakness and mobility challenges can also play a role.

Bladder symptoms can be caused by several factors, including weakening pelvic floor muscles with age or pregnancy, hormonal changes during menopause, effects of neuromuscular disease on muscle strength, and/or mobility or access challenges.

While not all causes are specific to neuromuscular disease, these factors can overlap and increase the impact on daily life.



Bladder health is an important but **often overlooked** aspect of overall well-being.

Urinary incontinence

Urinary incontinence is the most common bladder issue experienced during menopause. Understanding the type of incontinence you are experiencing can help guide the most effective treatment options.

Stress incontinence occurs when pressure in the abdomen increases, causing urine leakage. Common triggers include coughing, sneezing, laughing, exercise, or movement. This type of incontinence is often related to weakness in the pelvic floor muscles, which support the bladder.

Urge incontinence happens when the bladder suddenly contracts, creating a strong, immediate need to urinate. You may notice a sudden urge to go, difficulty reaching the bathroom in time, or leakage before you can get to the bathroom. For individuals with mobility limitations, even a short delay in reaching the bathroom can make symptoms more challenging.

Changes in muscle strength, nerve signaling, and mobility can all impact bladder control, leading to symptoms such as urgency, frequency, or incomplete emptying. Early recognition and simple interventions can make a meaningful difference.

Management and treatment options

There is a range of approaches to managing bladder symptoms, including urinary incontinence. Treatment often starts with the least invasive option. Behavioral strategies, such as scheduled bathroom visits, adjusting or timing fluid intake, and **bladder training** techniques, can be a beneficial starting point.

Pelvic floor physical therapy

The muscles that support the bladder, uterus, and bowel play an important role in bladder control, and weakness or poor coordination can contribute to leakage. **Pelvic floor physical therapy** focuses on strengthening and improving coordination of these muscles.

A trained pelvic floor physical therapist can assess how these muscles are functioning and develop a personalized plan.

Therapy may include:

- Guided exercises to strengthen or relax pelvic floor muscles
- **Biofeedback** techniques, which use sensors and visual or audio cues to help you identify and control your pelvic floor muscles
- Breathing and coordination strategies that support bladder control
- Education on how daily habits and movement patterns affect symptoms



Biofeedback can be especially helpful because pelvic floor muscles are not always easy to feel or control. With this technique, small sensors are placed on the body (or sometimes internally), and a screen or device shows when the muscles are tightening or relaxing. This helps you learn how to use the correct muscles more effectively.

Kegel exercises are a common at-home approach to pelvic floor strengthening. However, they are not always done correctly. In some cases, the muscles may need to relax rather than strengthen.

Working with a specialist can help ensure you are using the correct muscles, performing exercises safely and effectively, and following

a plan tailored to your specific needs and abilities. There are also biofeedback devices available to help continue the physical therapy exercises at home.

Support devices

Some devices can help reduce or manage leakage from stress incontinence by supporting pelvic structures. Options include:

- **Pessaries** — small, removable medical devices that are inserted into the vagina to help support pelvic organs or the urethra. These devices are fitted by a healthcare provider.
- Non-prescription vaginal inserts that provide internal support to help prevent leakage

- Absorbent products, such as pads or liners, that help manage leakage during daily activities

Medications and procedures

For urge incontinence, treatments may include:

- Medications to relax the bladder
- Nerve stimulation therapies
- **Botox** injections to reduce bladder overactivity

In some cases, surgery may be recommended to address structural issues contributing to symptoms.

When to see a specialist

Bladder symptoms are common and treatable. You do not have to manage them on your own. If symptoms are ongoing or affecting your quality of life, it may be helpful to see a specialist.

A **urogynecologist** focuses on pelvic floor and bladder conditions and can provide more targeted care than general providers in many cases. They often work closely with pelvic floor physical therapists to create a comprehensive treatment plan.



Glossary

Barrier cream

A protective cream applied to the skin to prevent irritation and damage, especially in areas exposed to moisture, friction, or incontinence

Biofeedback

A technique that uses sensors and visual or sound cues to help you learn how to control certain muscles, such as the pelvic floor muscles

Bladder training

A method of improving bladder control by following a schedule for bathroom visits and gradually increasing the time between them

Bone density

A measure of how strong and solid your bones are. Lower bone density can increase the risk of fractures

Botox (for bladder use)

A medication that can be injected into the bladder to help relax muscles and reduce symptoms like urgency and leakage

Cardiovascular health

The health of your heart and blood vessels

Estrogen

A hormone that plays an important role in reproductive health, bone strength, skin health, and many other body functions

Hormones

Chemical messengers in the body that control many processes, including growth, metabolism, and reproduction

Hot flashes

Sudden feelings of warmth, often with sweating and flushing, commonly experienced during menopause

Incontinence

Loss of bladder control, which can lead to urine leakage

Kegel exercises

Repeatedly contracting and relaxing the pelvic floor muscles that support the bladder, uterus, and bowels

Local (vaginal) hormone therapy

Hormone treatment applied directly to the vaginal area (such as creams or suppositories) to relieve local symptoms like dryness or irritation

Menopause

The stage of life when menstrual periods permanently stop, confirmed after 12 months without a period

Menopausal hormone therapy (MHT)

Treatment using hormones to help manage symptoms of menopause and support overall health

Mobility

The ability to move freely and easily

Neuromuscular diseases

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

Night sweats

Episodes of excessive sweating during sleep, often linked to hormonal changes in menopause

Obstetrician/gynecologist (OB/GYN)

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

Pelvic floor

A group of muscles at the bottom of the pelvis that support the bladder, uterus, and bowel

Pelvic floor physical therapy

A specialized type of physical therapy that helps strengthen or relax the pelvic floor muscles to improve bladder and bowel control

Pessary

A small, removable device placed in the vagina to support pelvic organs and help reduce bladder leakage

Progesterone

A hormone that works with estrogen to regulate the menstrual cycle and support pregnancy

Range-of-motion exercises

Gentle movements that help keep joints flexible and maintain mobility

Stress incontinence

Urine leakage that happens when pressure is placed on the bladder, such as during coughing, sneezing, or movement

Systemic hormone therapy

Hormone treatment that affects the whole body, usually taken as a pill, patch, or gel

Urge incontinence

A sudden, strong need to urinate that may lead to leakage before reaching the bathroom

Urinary tract infection (UTI)

An infection in any part of the urinary system, often causing pain, burning, or frequent urination

Urogynecologist

A doctor who specializes in pelvic floor disorders, including bladder and bowel control issues

Vaginal dryness

A common menopause symptom where the vaginal tissue becomes less moist, which can cause discomfort or irritation

Weight-bearing activity

Activities that involve standing or putting weight on your legs, which help maintain bone strength (such as standing or walking, when possible)

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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.

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