

Diagnosing Uterine Fibroids

Women with fibroids can experience delays in diagnosis due to stigma around menstrual disorders and normalization of symptoms by both patients and their health care providers.

3.6

Average number of years before a woman seeks treatment

32%

Of women waited > 5 years before seeking treatment

25%

Sought treatment within the first year of experiencing symptoms

42%

Of women visited ≥ 2 providers before being diagnosed

Some women find it difficult or embarrassing to initiate conversations with their health care provider about period-related symptoms like heavy and irregular bleeding. Because fibroids can run in families, symptom normalization may be passed down through generations of women. Misconceptions about what constitutes normal menstruation may also lead some women not to seek timely care.

Diagnosis may also be challenging because common fibroid symptoms such as heavy or irregular menstrual bleeding, pelvic and back pain, and frequent urination may overlap with symptoms of other gynecological conditions such as **endometriosis** and **adenomyosis**.



Sometimes uterine tissue can grow within the muscle of the uterus (the myometrium), causing a related condition called **adenomyosis**. **Endometriosis** is when tissue that resembles the lining of the uterus (endometrium) grows outside the uterus on surrounding pelvic organs.

These conditions can be mistaken for fibroids or might also occur in a woman who has fibroids. Ask your doctor about evaluating your symptoms for the presence of endometriosis or adenomyosis too.

How Are Fibroids Diagnosed?

To diagnosis fibroids, your health care provider can conduct a routine **pelvic exam** to look for irregularities in the shape of your uterus. This method may miss smaller fibroids, so your provider may order an **ultrasound** to confirm their diagnosis and to locate and measure the size of any growths.

Sometimes, providers may order additional tests to gather more information about your fibroids in order to better guide treatment decisions:

- ▶ **Magnetic resonance imaging (MRI)** provides detail on the size, location, and potential abnormal features of growths, as well as blood flow to fibroids.
- ▶ **Hysterosonography** is an ultrasound that uses fluid inside the uterus to look for fibroids in the lining.
- ▶ **Hysterosalpingography** uses X-ray to look for blockages in the uterine cavity and fallopian tubes.
- ▶ **Hysteroscopy** uses a small telescope to view fibroids in the uterus.
- ▶ **Shear wave elasticity imaging (SWEI)** is an emerging technique that uses ultrasound to determine the stiffness of fibroids in uterine tissue.

Your health care provider may also order blood tests to determine whether you have anemia (due to significant blood loss from heavy periods) or to rule out other potential disorders like thyroid problems.

Talking to Your Health Care Provider



Open communication with your health care provider is the best way to ensure you get a timely diagnosis. Your provider will need to know about your symptoms and their impact on your daily life. Give descriptive examples of how your symptoms affect your ability to function at work, school, and home. If you are uncomfortable verbalizing your experience, try to write it down in advance and share it with your doctor.

Preparing in advance for your health care appointments can help you better articulate your concerns and advocate for your own health. To assist your health care provider in understanding your fibroids experience, consider bringing the following to your visit:

- ▶ A record of your menstrual cycle and related symptoms (such as in a journal or an app)
- ▶ Your history of symptoms and, if applicable, past diagnoses or misdiagnoses
- ▶ A list of priority goals for care
- ▶ A record of past gynecological surgeries, tests, and treatments
- ▶ A list of your current medications
- ▶ Family history of fibroids or undiagnosed symptoms
- ▶ Names and contact info for other health care professionals who provide you with care
- ▶ A support person (such as a spouse, family member, or friend) who can help you take notes and advocate for you



Many providers use secure online patient portals, such as My Chart, that allow you to submit this information and message between visits. If you have access to such a platform, be sure to learn all about it and use it to communicate with your health care team. However, if there is no platform, a **Doctor's Visit Worksheet** is provided in the Appendix of SWHR's Uterine Fibroids Toolkit for you to fill out and take with you when you visit your health care provider.

Questions to Ask Your Health Care Provider

Researching and compiling a list of questions to ask your health care provider may help you to feel more prepared to engage in discussion around your diagnosis and treatment. Questions may vary depending on whether you are being evaluated for the first time or receiving ongoing treatment, as well as whether you are seeing your primary care physician, gynecologist, or other specialist. If you do not have time to discuss all of your questions, be sure to follow up, possibly using your patient portal messaging system.

Initial Evaluation

- ▶ How do I know if what I am experiencing is fibroids?
- ▶ Do I need to have an ultrasound, MRI, or another procedure to diagnose what is going on with my body?
- ▶ What other conditions cause similar symptoms?
- ▶ What medical treatment options are available?
- ▶ What kind of surgical or minimally invasive treatment options are available?
- ▶ What are the risks and benefits of each treatment you have proposed?
- ▶ Which treatment option(s) or plan do you recommend that I try first? Why?
- ▶ Are there any helpful strategies or practices I can do at home to assist with managing my symptoms?
- ▶ Can you provide me with additional resources to learn more about fibroids?

You can help foster clear communication with your doctor by asking direct and specific questions. Don't be afraid to restate what your doctor has told you or to ask clarifying questions to ensure that you understand the answers.

Ongoing Management & Care:

- ▶ How many fibroids do I have, how big are they, and where are they located? (If you've already undergone procedures to determine this.)
- ▶ What are the chances of fibroids returning after treatment?
- ▶ What alternative or complementary treatments (e.g., acupuncture, yoga) might be worth trying?
- ▶ What dietary suggestions can you offer to help with my symptoms?
- ▶ How might fibroids and the treatments affect my fertility?
- ▶ How often do I need follow-up visits?

