

# Fibromyalgia:

## A Toolkit for the Male Caregiver



educating...  
empowering...  
supporting...

# Toolkit Contents

Being a caregiver isn't always easy. Each day can throw new challenges your way. With that in mind we've designed this toolkit to provide insight, tips and tools for the male caregivers of patients with fibromyalgia.

We hope that you find this toolkit to be a helpful resource in navigating the waters of caregiving.

The toolkit includes:

- ➔ **A Guide to Caregiving**
- ➔ **Fibromyalgia Fact Sheet**
- ➔ **Live a Healthy Lifestyle with Fibromyalgia**
- ➔ **Strategies For Seeking and Optimizing Care**
- ➔ **Caregiver Communication Strategy, Tips, and Family Plan**
- ➔ **Tips for Talking to Your Loved One's Healthcare Provider**
- ➔ **Frequently Asked Questions**
- ➔ **Caregiver Resources and Tools**
- ➔ **A Caregiver's Voice**

# A Guide to Caregiving

Almost one-quarter of American households provide care to relatives or friends. An estimated 44 million Americans age 18 and older provide unpaid assistance and support to adults. Because of the multi-faceted role that family and caregivers play, they need a range of support services to remain healthy, improve their caregiving skills, and remain in their caregiving role.

Caregivers typically assist with:

- Transportation
- Housework
- Grocery shopping
- Preparing meals
- Managing finances
- Helping with medication (e.g., preparing pills, giving injections)
- Arranging or supervising paid services
- Personal care/hygiene



Evidence shows that in some cases caregivers are unprepared for their role and provide care with little or no support, yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves. Emotional, mental, and physical health problems could arise from complex caregiving situations and the strains of caring for loved ones. These health risks can hinder the caregivers' ability to provide care, lead to higher healthcare costs, and affect the quality of life of both the caregiver and care receivers.

- ➔ Thousands of men in the United States are caregivers
- ➔ Most men have grown up in a household – and a culture – in which women have been perceived as the primary family nurturers. Yet, often by necessity, more men than ever are rolling up their sleeves and helping a loved one with day-to-day tasks and health related issues
- ➔ Men sometimes experience anxiety in handling the multiple demands of care, while also learning new skills
- ➔ Male caregivers should be aware of the many social, health, and human services available in the community. Men's Health Network (MHN) and other organizations listed in this toolkit are able to assist caregivers with this.

# Fibromyalgia Fact Sheet

For people living with fibromyalgia, the chronic, widespread pain and tenderness is persistent and debilitating. Some fibromyalgia patients may also experience other symptoms, which can prevent them from sleeping well, performing everyday tasks, and enjoying life to its fullest.

- ➔ Between 80 and 90 percent of people diagnosed with fibromyalgia are women, but men can be affected also.
- ➔ Fibromyalgia is a disorder that causes muscle pain and fatigue.
- ➔ People with fibromyalgia have “tender points” on the body. Tender points are specific places on the neck, shoulders, back, hips, arms, and legs. These points hurt when pressure is put on them.
- ➔ Fibromyalgia is often considered a rheumatic arthritis-related condition; it is not truly a form of arthritis (a disease of the joints) because it does not cause inflammation or damage to the joints, muscles, or other tissues. Like arthritis, however, fibromyalgia can cause significant pain and fatigue, and it can interfere with a person’s ability to carry on daily activities.

People with fibromyalgia may also have other symptoms, such as:

- Trouble sleeping
- Morning stiffness
- Headaches
- Irritable Bowel Syndrome (IBS)
- Painful menstrual periods
- Tingling or numbness in hands and feet
- Problems with thinking and memory

The causes of fibromyalgia are unknown, but there may be a number of factors involved. Fibromyalgia has been linked to:

- ➔ Repetitive injuries
- ➔ Serious illness
- ➔ Stressful or traumatic events, such as car accidents, which may have damaged the brain or spinal cord
- ➔ People with certain rheumatic diseases, such as rheumatoid arthritis, systemic lupus erythematosus (commonly called lupus), or ankylosing spondylitis (spinal arthritis)
- ➔ Having a family member with fibromyalgia are more likely to have fibromyalgia themselves, but the exact reason for this—whether it be heredity, shared environmental factors, or both—is unknown.



# Live a Healthy Lifestyle with Fibromyalgia

Your loved one's self-management is integral to a meaningful improvement in symptoms and daily function. As they better manage their symptoms with treatment, help them to begin increasing their activity levels and functions. Begin to do things that you had originally stopped doing because of the pain and other symptoms. You can assist them to:

- ➔ **Schedule time to relax each day.** Deep-breathing exercises and meditation will help reduce the stress that can bring on symptoms.
- ➔ **Establish a regular pattern for going to bed and waking up.** Getting enough sleep allows the body to repair itself, physically and psychologically. Also, avoid daytime napping and limit caffeine intake that can disrupt sleep. Nicotine is a stimulant, so those with sleep problems should stop smoking.
- ➔ **Exercise regularly.** This is a particularly important part of fibromyalgia treatment. While difficult at first, regular exercise often reduces pain symptoms and fatigue. Patients should follow the adage, "Start low, and go slow." Begin with physical activity that fits into your lifestyle. For instance, take the stairs instead of the elevator, or park further away from the store, slowly adding daily fitness into your routine. Then push harder. Add in some walking, swimming, water aerobics and/or stretching exercises. Remember, it takes time to establish a comfortable routine, so just get moving, stay active and don't give up!



- ➔ **Educate yourself.** Nationally recognized organizations like the Arthritis Foundation, National Fibromyalgia Association, and Men's Health Network are excellent resources for information you can share with family, friends and co-workers.
- ➔ **Look forward, not backward.** Focus on what is necessary to get better.

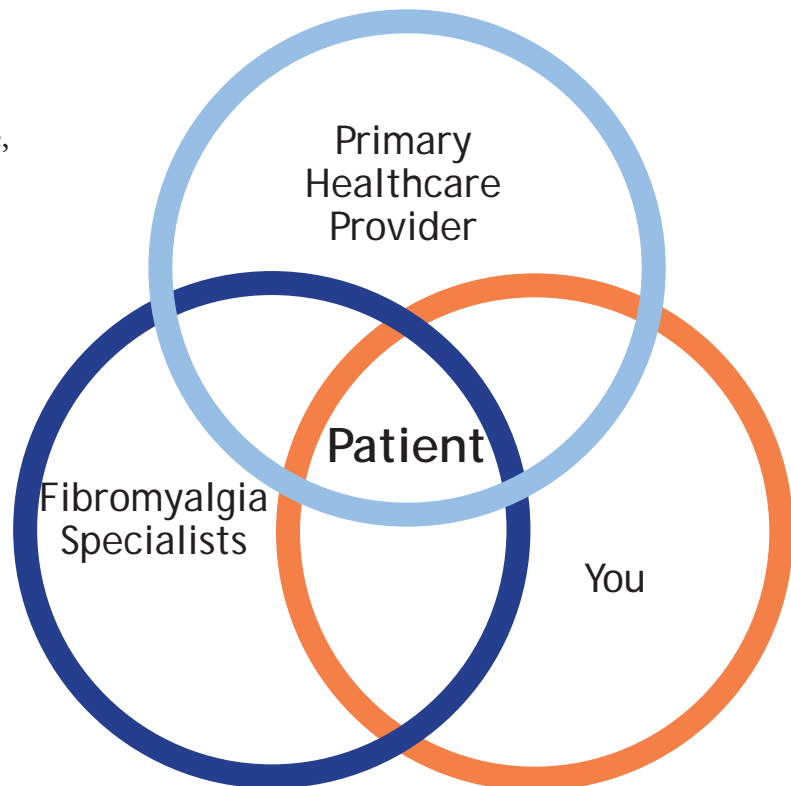
# Strategies for Seeking & Optimizing Care

Your loved one's primary healthcare provider will help you find the right specialists to provide the necessary care. They may include:

- Rheumatologists
- Neurologists
- Pain Management Specialists
- Psychiatrists (rehabilitation specialist)
- Physical Therapists

The key in all this is keeping your loved one comfortable. You, as the caregiver, need to be up to date on all things related to fibromyalgia and healthcare provider recommendations. You should ask questions that your loved one may have forgotten about.

In most cases, you will be taking them to their healthcare provider, providing services at home, and being their consoler during the difficult times. You will be involved in all aspects of care and are an integral part of their well being.



# Caregiver Communication Strategies, Tips, and Family Plans

➔ **Maintain a safe environment.** Because a person suffering from fibromyalgia has tender points in joints, muscles, and tendons, it is vital to avoid items/locations in the home which might aggravate those parts of the body. If pain is severe, limit the amount of steps/stairs your loved one must take to get to various places of the home.

➔ **Get trained.** Some local hospitals provide information on caregiving, or they may be able to refer you to a support group which can offer encouragement and education in a trusted environment. You can also check out some of the additional resources listed in this toolkit for more information and support group listings.



➔ **Learn about the disease.** Sit down with your loved one and discuss how they are feeling and go over any information you have collected from doctors' visits or from your own research.

➔ **Keep a journal.** For both your loved one's symptoms and any questions that may arise in between medical visits.

➔ **Keep updated & informed.** Keep all of your loved one's medical records, medications, and symptom notes, current and in one location. That way you know exactly where to go when you need to provide their healthcare professional with information.

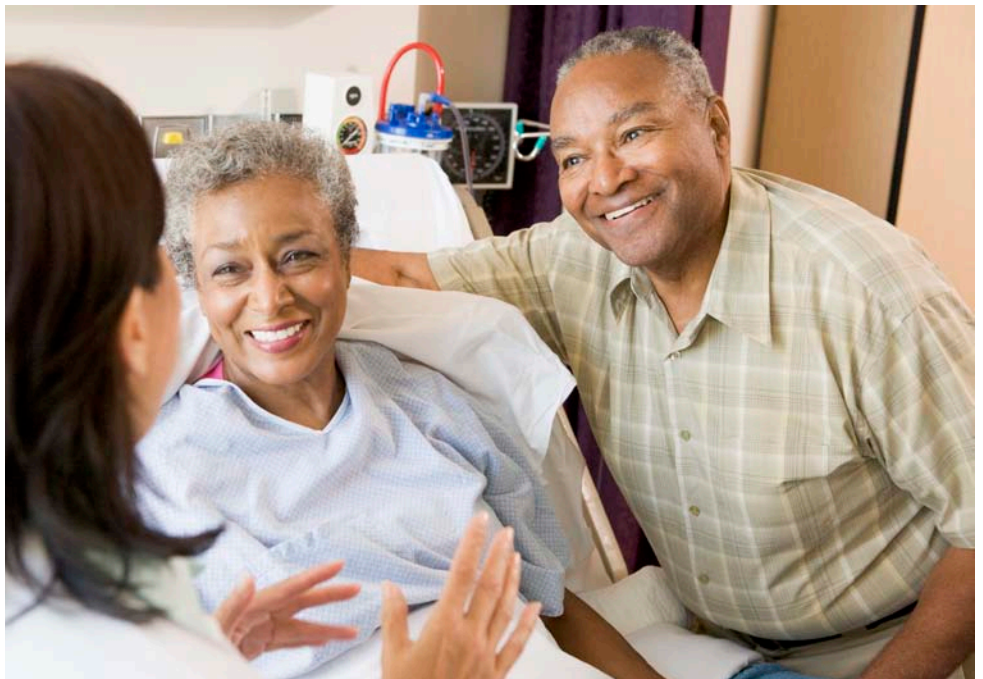
➔ **Update family members.** Let the rest of the family know how your loved one is doing and see if they would like to be involved in caregiving as well, when appropriate.

➔ **Don't be afraid to ask for help.** There are many options available, from family and friends, to professional services.

# Tips for Talking to Your Loved One's Healthcare Provider

Here are some basic things to keep in mind as you and your loved one are meeting with healthcare providers:

- ➔ Understand what your loved one wants to get out of a consultation with their healthcare provider.
- ➔ Come prepared! Do some research on fibromyalgia and any symptoms your loved one may be experiencing.
- ➔ Bring along your symptom journal with up to date recordings to give the healthcare provider the most accurate responses.
- ➔ Have a list of key questions ready to ask the healthcare provider.
- ➔ Be a beacon of support for your loved one. Allow them to speak freely and you can fill in as needed.
- ➔ Don't expect the healthcare provider to know all the answers. Like any other disease, there are seldom definitive answers a healthcare provider can give you about fibromyalgia.
- ➔ Take notes during the visit, highlighting anything specific you may want to research about at a later time.





# Frequently Asked Questions

**Q.** Is there a cure for fibromyalgia?

**A.** Unfortunately, there is no cure for fibromyalgia, but there are FDA approved medications which may reduce pain and improve daily function in some patients.

**Q.** What can I do to better assist my loved one?

**A.** Lifestyle modifications may help conserve energy and minimize pain. Learn what factors aggravate your loved one's symptoms and avoid them when possible. Many patients find being in warm water to be soothing. Hot wraps for particularly painful areas are also beneficial. Maintain a rigid sleep schedule ensuring that they receive at least eight hours of sleep per night. Gentle movement and stretching exercises will help maintain function, which is essential when the body is tired and the muscles hurt. Most importantly, stay informed!

**Q.** What can I do to ensure I provide the best care I can to my loved one?

**A.** Take care of yourself! Make sure that you are well rested, eat right, and exercise. That is the only way to ensure that you will be at your full capacity to assist your loved one. Neglecting your own health is not beneficial to anyone involved. Assess your living situation and create an environment that is conducive to providing the best care for your loved one and yourself.

**Q.** Where can I find information on fibromyalgia and caregiving in general?

**A.** Additional resources are provided in this packet, which include web addresses for various organizations. You may also contact Men's Health Network for more information.

**Q.** What if I am unsure about the treatment options the healthcare provider is offering?

**A.** It may be helpful to get a second or even third opinion. There is no right or wrong way to go about seeking help. Keeping your options open allows for a better decision making process.

**Q.** How do we find the right healthcare provider?

**A.** Your primary care provider will decide whether you will need a specialist, the professional may be a Rheumatologist, Neurologist, Pain Management Specialist, Psychiatrist, or Physical Therapist.

**Q.** What if my loved one develops a lack of sexual interest?

**A.** Muscle cramping and side effects of pain medications can have negative effects on patients, making this a common concern for couples. The key thing to remember is that there are various ways to be intimate which will not cause discomfort to a fibromyalgia patient. Open and honest communication is vital so that both of you are comfortable, so be creative and adapt!

# Other Caregiver Resources & Tools

Our toolkit is focused toward male caregivers caring for their loved one's suffering with fibromyalgia, but there is a variety of information available for fibromyalgia patients themselves and for caregivers. Below are a few of those resources:

## For general caregiving reading...

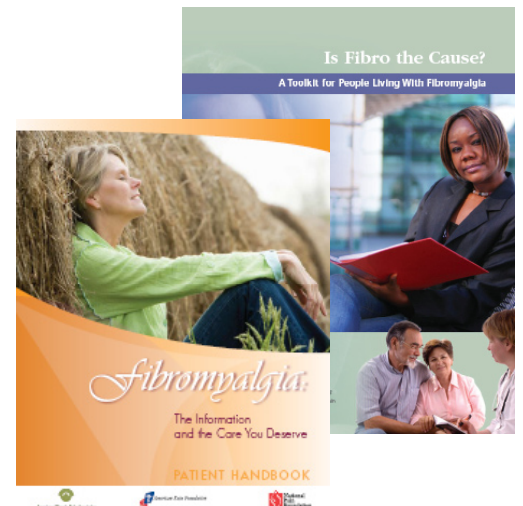
*National Alliance for Caregiving: Care for the Family Caregiver*  
[www.caregiving.org/data/Emblem\\_CfC10\\_Final2.pdf](http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf)



## Reading for patients suffering from fibromyalgia...

*Is Fibro the Cause? A Toolkit for People Living with Fibromyalgia.*  
[www.painfoundation.org/learn/publications/files/is-fibro-the-cause.pdf](http://www.painfoundation.org/learn/publications/files/is-fibro-the-cause.pdf)

*Fibromyalgia: the Information and the Care you Deserve, Patient Handbook*  
[www.painfoundation.org/learn/publications/files/fibrohandbook.pdf](http://www.painfoundation.org/learn/publications/files/fibrohandbook.pdf)



## Online Resources:

*National Fibromyalgia Association*  
[www.fmaware.org](http://www.fmaware.org)

*American Pain Foundation*  
[www.painfoundation.org](http://www.painfoundation.org)

*Fibromyalgia Network*  
[www.fmnetnews.com](http://www.fmnetnews.com)

*National Alliance for Caregiving*  
[www.caregiving.org](http://www.caregiving.org)

*Centers for Disease Control and Prevention*  
[www.cdc.gov/arthritis/basics/fibromyalgia.htm](http://www.cdc.gov/arthritis/basics/fibromyalgia.htm)

*Mayo Clinic*  
[www.mayoclinic.com/health/fibromyalgia/DS00079](http://www.mayoclinic.com/health/fibromyalgia/DS00079)

*MedLine Plus*  
[www.nlm.nih.gov/medlineplus/fibromyalgia.html](http://www.nlm.nih.gov/medlineplus/fibromyalgia.html)

*Arthritis Foundation*  
[www.arthritis.org](http://www.arthritis.org)



# A Caregiver's Voice

Sharing your story can provide hope, encouragement and understanding to others. It can also be helpful for your own process to share you struggles, emotions and hopes for the future. We would love for you to share your story with us so that we can feature in on our website and inspire other caregivers.

You can write your story on the lines below and mail in or you can email it to us at [info@menshealthnetwork.org](mailto:info@menshealthnetwork.org).

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

City, State: \_\_\_\_\_ Age: \_\_\_\_\_

Your Story:

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- Yes, please share my story on Men's Health Network's website
- Yes, please share my story, but I would like to remain anonymous (only location will be listed)
- No, please do not share my story on the website

From: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please affix  
postage here

Men's Health Network  
c/o Fibro Story  
PO Box 75972  
Washington, DC 20013

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**Men's Health Network (MHN)** is a national nonprofit organization whose mission is to reach men and their families where they live, work, play, and pray with health prevention messages and tools, screening programs, educational materials, advocacy opportunities, and patient navigation.

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