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KNOWING

SYMPTOMS. HEALTH CONCERNS. CHALLENGES.

Your experience with myelofibrosis (MF) is unique to you. Identifying your symptoms, monitoring possible related health issues, and pinpointing your challenges can all help you define where you are on your journey.

In this brochure, you'll learn why it's important to monitor your symptoms and regularly evaluate your MF. You'll also find helpful tips for living with MF, from focusing on your health and wellness to coping with stress. With this knowledge, you can better share what you see and feel with your Healthcare Professional to stay active in your care.

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REGULARLY EVALUATING

It's important to take an ongoing role in managing your health and be aware of what's going on with your MF. Regularly monitoring your symptoms is key to understanding your MF—and can help you see how your condition may be changing over time.

As you continue to evaluate your MF, be sure to tell your Healthcare Professional about any new symptoms you may be experiencing—even those you don't think are related to your MF.

By sharing what you're seeing and feeling, you can effectively partner with your Healthcare Professional and make an important contribution in managing your condition.

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THE ROLE OF THE SPLEEN IN MYELOFIBROSIS

An enlarged spleen is a common finding in MF. **In fact, at least 85% of people living with MF have an enlarged spleen at diagnosis.**

When the bone marrow cannot make enough normal blood cells, the spleen begins to make them. This causes the spleen to grow larger. The medical term for an enlarged spleen is splenomegaly (splee-nuh-MEG-uh-lee).

- An enlarged spleen can cause pain or discomfort in your abdomen or below your left ribs
- You may also feel full, even when you've eaten very little

IDENTIFYING THE COMMON

OF MYELOFIBROSIS

Which of these common MF symptoms are you experiencing?

- ☐ Itching
- ☐ Night sweats
- ☐ Fever
- ☐ Unexplained weight loss
- ☐ Fatigue
- ☐ Bruising or bleeding easily
- ☐ Bone pain
- ☐ Pain or discomfort in the abdomen or under the left ribs—possibly resulting from an enlarged spleen

It's important to tell your Healthcare Professional about any new or worsening symptoms you experience. These symptoms may be signs that your disease is changing.

HEALTH AND WELLNESS

Some of the symptoms of myelofibrosis can have an impact on your appetite or energy level. The stress of living with a chronic condition like MF may also affect your mood. Focusing on your overall health and well-being is an important way you can help manage your MF, including eating right and staying active.

These are some health challenges that may be affecting you:

EXPERIENCING **WEIGHT LOSS**	**HAVING** LESS ENERGY	COPING WITH **STRESS**

Get tips on how to address these challenges on the following pages.

EXPERIENCING WEIGHT LOSS

With MF, it's not uncommon to experience changes in your appetite and level of physical activity that may make it more challenging to maintain your weight. Fatigue from MF may affect your appetite and can decrease your level of physical activity. When you're less active, you may have less of an appetite. Also, if your spleen is enlarged, you may feel full even if you haven't eaten much. These may be just some of the reasons why you may experience weight loss.

CAN TAKE ACTION

- Ask your Healthcare Professional to refer you to a dietitian or nutritionist who can help you plan a healthy diet and get the nutrition you need
- Eat healthy foods and a balanced diet whenever you can, including foods from all food groups
- Try eating healthy snacks every few hours throughout the day
- Activities like walking or other moderate exercise may help build your appetite. Ask your Healthcare Professional what activities would be right for you

This brochure is not intended to replace the advice of your Healthcare Professional. Always check with your Healthcare Professional before changing your diet.

Notes & Questions to Share with Your Healthcare Professional

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HAVING **LESS ENERGY**

With MF, your condition can make you feel very tired for a variety of reasons. You may be experiencing weight loss or fever that could make you feel fatigued. Fatigue could also lead to a cycle of being less active. If you're less active, you may lose some lean muscle which could lead to having less energy.

Other factors can also affect your energy level. Being anemic can make you feel weak, due to the decreased number of red blood cells that carry oxygen from your lungs throughout your body. An enlarged spleen may also make you feel fatigued.

CAN TAKE ACTION

- Tell your Healthcare Professional if you are feeling weak and tired, even if you are not sure it is related to your MF
- Try to get plenty of rest, including naps, when needed
  - Stick to a regular bedtime
  - Avoid drinks with caffeine late in the evening
- Talk to your Healthcare Professional early on about starting an exercise program to help improve your energy, flexibility, and mood
  - Plan daily time for walking or other appropriate exercise, when you have the most energy

You'll find more nutrition and exercise tips, including workshops, podcasts, and brochures at **cancercare.org**.

Notes & Questions to Share with Your Healthcare Professional

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COPING WITH STRESS

When you're living with a chronic condition like myelofibrosis, stress can build up and your mood can be affected, making you feel anxious, sad, or depressed. Knowing how stress is affecting you and communicating that to your Healthcare Professional is important.

CAN TAKE ACTION

Make time for activities you enjoy

- Try to maintain a manageable daily routine that includes time for visits, activities, hobbies
- Plan time to spend with friends and family
- Take a walk or do some light gardening
- Read a book or listen to music
- Watch a movie that makes you laugh and lifts your spirits
- Consider meditation, yoga, or other activities that help you relax
- Consider spiritual outlets

Connect, share, and communicate

- Talk to your Healthcare Professional team regularly about your mood and how it is affecting you
- Don't be shy about asking for help
- Let a friend know how you are feeling
- Join a support group to connect with others living with MF
  - The MPN Education Foundation, MPN Research Foundation, and other associations offer access to online and local support groups

Build your knowledge and share it

- Gain a solid understanding of MF to discuss with your Healthcare Professional
- Share what you've learned with your family and friends
- Contact organizations that support people like you who are living with MF

Be sure to consult with your Healthcare Professional about your health and wellness concerns.

Get more tips on coping with stress at these web sites:

cancercare.org

cancersupportcommunity.org

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ON YOUR MF JOURNEY

With the knowledge you've gained, you'll have greater insight into where you are on your journey with MF.

Regularly share what you've observed about new or changing symptoms with your Healthcare Professional. Be open about how MF is affecting your daily life. Together, you and your Healthcare Professional can work to manage your condition in a way that's right for you.

Notes & Questions to Share with Your Healthcare Professional

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