

Preparing for Your Doctor's Visit



A WORKSHEET FOR PEOPLE WITH MULTIPLE MYELOMA

If you have **multiple myeloma**, this worksheet can help you talk with your health care team about symptoms, treatment options, side effects, and getting the emotional and practical support you need.

ASK YOUR HEALTH CARE TEAM

- Talk with your doctor and confirm that the specialists on your health care team have experience treating multiple myeloma.
- Ask about what type and stage of multiple myeloma you have, the next steps in your treatment, tests you need, and how you'll know your disease is under control.
- Ask about symptoms and side effects and which ones you need to report to your team. Ask about side effect management.
- Ask questions until you understand what is being said. You can ask for information in a different language or a drawing if you need it.
- Ask if any clinical trials are right for you.
- Talk to your health care team about how you feel. Ask about a counselor or mental health services if you feel overwhelmed or anxious.
- Ask who to contact after hours, between visits, and in an emergency.
- Ask if specific treatments may limit your future treatment options.

TIPS FOR TAKING CONTROL

- Take someone with you to appointments for support and to take notes. If you go alone, ask to use a recorder or a cell phone to record your conversation with your doctor.
- Write down your questions before each doctor's visit. Keep a journal to take notes and track your progress over time. This can include notes on your side effects or symptoms and your test results. (For more on lab results, go to www.CancerSupportCommunity.org/multiple-myeloma#tab2).
- Learn the words that doctors use to talk about multiple myeloma. This can help you better understand your test results and treatment options.
- Bring a list of all medications and supplements you're taking to all your visits.
- Get a second opinion from a myeloma specialist. If you don't feel your health care team is addressing your concerns, consider changing care teams.
- Talk to your health care team or financial navigator about how to manage treatment costs before you start treatment.
- If your health care team has recommended active surveillance or "watch and wait," talk about what this means. Ask about next steps and treatment options.

Below are some symptoms and side effects people with multiple myeloma may experience as shared by members of our Cancer Experience Registry. Think about how often they affect you. Talk to your health care team about how to manage them.

	Rarely	Sometimes	All the Time
Fatigue, trouble breathing, or shortness of breath			
Pain in your bones, dental problems, or muscle pain or cramps			
Bleeding or bruising			
Feeling anxious, overwhelmed, or depressed			
Tingling, pain, or numbness in hands, arms, feet, or legs, problems moving			
Diarrhea, constipation, weight loss/gain, appetite, or bloating			
Fever or chills or getting sick often			
Headaches, confusion, or blurred vision			
Edema (swelling), unexplained lumps			
Others:			

How often are cancer or side effects interfering with your life?	Rarely	Sometimes	All the Time
Work/school/home (unable to go to work/school or do daily tasks)			
Unable to do activities or hobbies I normally enjoy			
Confidence/self-image			
Difficulty thinking/brain fog/chemo brain			
Social relationships, relationships with loved ones, sexuality/intimacy			
Health insurance or other financial worries			
Eating and/or exercise/being active, gastrointestinal issues			
Difficulty sleeping/insomnia			
Others:			

THINK ABOUT TREATMENT AND PERSONAL GOALS

When you talk to your doctor about your treatment options, ask about the goals of each treatment and how it may affect your personal goals. Possible goals may be to: choose the option with the fewest side effects, live as well as possible, contribute to progress by taking part in research, be healthy enough to attend a special event/milestone, or find cutting-edge treatments. When making treatment choices, it is important to talk about personal goals with your health care team. Remember your goals may change over time.

Physical Health and Well-Being	<i>What is most important for you to be able to do?</i>
Family and Social Relationships	<i>What's going on in the lives of others that is important to you? Are there important milestones in your loved ones' lives coming up?</i>
Work/School	<i>Do you want to continue working? Can you adjust your schedule or responsibilities? Do you want to explore retirement or disability?</i>
Community/Involvement	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Other	<i>What else is important to you?</i>

PREPARING FOR YOUR NEXT HEALTH CARE VISIT

If you are feeling either better or worse today than at your last appointment, let your health care team know.

Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

- What tests will be used to monitor my myeloma? How will I know if I am responding or relapsing?
- Can you explain my test results to me? Are results available online ahead of our appointments?
- When should I start treatment? What happens if I don't start treatment now?
- Are there any genetic risk factors or biomarkers that I should be aware of?
- How long will I be on this treatment? What are the common side effects? What are we hoping it will do?
- The symptoms and side effects that are affecting me the most are: [discuss your answers from page 1].
- They are interfering with my life in these ways: [discuss your answers from the top of page 2].
- What can we do to manage them? Are there complementary therapies or a diet that would help?
- My top goals for treatment are: [fill in your answers from the bottom of page 2].
- Is the treatment that I am currently on the best treatment for me to meet these goals?
- What other treatments are available to me? What are the pros and cons of each option? Are there any new treatments or clinical trials that may be right for me?
- What are my treatment options if I relapse?
- How can I manage treatment costs? Is there a financial navigator I can talk with?

GETTING SUPPORT

Think about people in your life who can help (your spouse or partner, friends, faith community, support group, or coworkers).

- Make a list of things you need (childcare, meal prep, laundry, etc.) and who can help with each task. Consider using MyLifeLine.org to help you stay organized and let friends know what you need.
- Ask your health care team about resources for social, emotional, and practical support.
- You can also ask for a mentor or to be matched with another person with multiple myeloma.
- If you search for information online, make sure that you use trusted websites. You may want to talk about this with your primary care physician.
- Turn to the back page of this publication to see a listing of trusted organizations. CSC and many other organizations have helplines, support groups, online discussion boards, and more ways to seek support from others who have multiple myeloma.

FINANCIAL RESOURCES

Even with health insurance, treatment is expensive. Keeping up with costs can be overwhelming. However, there are many resources that can help.

- Talk with your health care team and your pharmacist about the cost of your treatment.
- Ask your doctor to refer you to an oncology social worker, a financial counselor, or a nonprofit organization for help managing the financial issues and costs.
- Reach out to your health insurance company to find out what resources they have that could help you. Ask what the appeal process is if you are turned down for treatment.
- Ask about pharmaceutical assistance programs and what the qualification requirements are.
- If your treatment is far away, ask if there are assistance programs to help cover travel costs.

The more you learn, the more you can help to reduce unexpected costs. To learn more about ways to manage the cost of treatment, visit: www.CancerSupportCommunity.org/cost.

Multiple Myeloma Information & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org/multiple-myeloma

Multiple Myeloma Research Foundation • 888-841-6673 • www.themmr.org

American Society of Clinical Oncology (ASCO) • www.cancer.net/cancer-types/multiple-myeloma

International Myeloma Foundation • 800-452-2873 • www.myeloma.org

Leukemia & Lymphoma Society • 800-955-4572 • www.lls.org/myeloma

NCCN Guidelines for Patients: Multiple Myeloma • www.nccn.org/patients/guidelines/myeloma/index.html

Financial Support Resources

Cancer and Careers (CAC) • www.cancerandcareers.org

CancerCare • 800-813-4673 • www.cancercare.org/financial_assistance

Leukemia & Lymphoma Society • 800-955-4572 • www.lls.org/financial-support

Patient Access Network Foundation • 866-316-7263 • www.panfoundation.org/assistance-programs

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

PhRMA's Medicine Assistance Tool • www.medicineassistancetool.org

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FSAC

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/policy-advocacy/become-advocate.

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For more information and resources, please visit the CSC Multiple Myeloma page at www.CancerSupportCommunity.org/multiple-myeloma.

Share your experience and make your voice heard. Join the Cancer Experience Registry and participate in the special community of people facing multiple myeloma at www.CancerExperienceRegistry.org.

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