

# 10 Tips for Living Well with Myelodysplastic Syndromes



Life with myelodysplastic syndromes (MDS) is different for everyone. It often begins with questions to which there is not one answer or one path. Whether you are

a patient or a caregiver, we hope that these tips will help make tomorrow and the days to follow easier.

# 10 Tips for Living Well

If you or a loved one has myelodysplastic syndromes (MDS), consider some of these 10 Tips to help you feel more in control and more proactive about this cancer journey:

- 1. Take one step at a time and make one decision at a time.** Life with MDS can feel overwhelming. Yet, with small steps you can find your best path. Learn about MDS by talking with doctors and patient navigators. Reach out to MDS organizations. Don't trust everything you read online. Ask all your questions. In time, you can collect the information and support you need to make good financial, medical, and personal decisions.
- 2. Find a treatment team you trust.** MDS is a group of rare diseases that are not well understood. It is important to find a knowledgeable treatment team. Your team might include a hematologist, medical oncologist, palliative care specialists, nurses, social workers, and patient advocates. Trust comes from being able to talk openly with your team and believing they can help. Try to get a second opinion from a doctor at an academic medical center or National Cancer Institute-approved cancer center. Ask about clinical trials that might be right for you. Treat this like an interview to find the best experts for the job. Your team should help you care for your mind, body, and spirit.
- 3. Use a notebook to keep track of your diagnosis, symptoms, answers to questions, and next steps.** Be sure to write down the subtype and IPSS-R risk score of the MDS you have. When you talk with your doctor, take notes or ask someone to help you take notes. You may hear new words. Ask your doctor to spell them out and define them. Write down this information and go back to it as needed.
- 4. Accept help when it is offered.** Day-to-day life and tasks can become harder. Ask others for the help you want and need. Often, your friends and family will feel good offering assistance. An online scheduler can help you and your loved ones stay organized and informed. **MyLifeLine.org** is a tool that can connect your friends and family to the help you may need.
- 5. Reach out to other people with MDS.** It's comforting to talk with others who understand what you're going through. People with MDS can also be a good source of knowledge. You and your loved ones don't have to feel lonely, helpless, confused, or hopeless. You can connect with others through the internet or a local support group. To find an in-person location near you for support, go to **CancerSupportCommunity.org/FindLocation**.
- 6. Seek support from a patient advocate.** A trained advocate can help you navigate through many parts of the cancer journey. They can help manage insurance issues, find resources, and help with legal documents such as your will, medical directives, and estate plans. Many cancer centers offer, or can refer you to, a skilled advocate or patient navigator.
- 7. Learn to relax and find a new perspective.** An MDS diagnosis is life changing. Be aware of your feelings and how you handle them. You can calm yourself with deep breathing, journaling, exercise, or creative activities.

If you feel worried or depressed, consider talking with a social worker or therapist. You can learn to manage your feelings and find a sense of calm. Take time to think about your life goals and self- image. Explore what's important to you and what makes you feel happy. Focus your energy on things that improve your well-being.

**8. Find ways to feel in charge of your life.**

At times you may feel frustrated by changes to your work, school, and family life. Take action. Work with your medical team to come up with a plan that gives you as much control as possible over your treatment and care.

**9. Focus on nutrition and exercise.** Every small step you take to eat better, get more

exercise, and find more humor in life can make you feel better. Eating well will give you more energy and nutrients to help your body. You may feel tired but try to find times when you have energy to be active. Physical activity can lift your spirits, boost your energy, and reduce stress. Even when you feel tired, you can set reachable goals for healthy eating and physical activity (example: a 10-minute walk).

**10. Remember that hope is possible.** It may help to focus on family connections, cultural customs, and spiritual beliefs. If a cure is unlikely, hope can still make each new day better in some way. Plan to do something that makes you smile. Accept that some days will be better than others, but you can continue to enjoy the small, special moments.



# General Cancer Information, Survivorship, and Support

**Cancer Support Community** • 888-793-9355 • [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**American Cancer Society** • 800-227-2345 • [www.cancer.org](http://www.cancer.org)

**CancerCare** • 800-813-4673 • [www.cancercares.org](http://www.cancercares.org)

**Cancer.net** • 888-651-3038 • [www.cancer.net](http://www.cancer.net)

**National Cancer Institute (NCI)** • 800-422-6237 • [www.cancer.gov](http://www.cancer.gov)

**NCI Clinical Trial Information** • 800-422-6237 • [www.cancer.gov/ClinicalTrials](http://www.cancer.gov/ClinicalTrials)

**Patient Advocate Foundation** • 800-532-5274 • [www.patientadvocate.org](http://www.patientadvocate.org)

## Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below call 888-793-9355 or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).

**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, 9 am–9 pm ET.

**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.

**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/FranklySpeakingAboutCancer](http://www.CancerSupportCommunity.org/FranklySpeakingAboutCancer).

**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](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry**® — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**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. Connect with other Multiple Myeloma patients by joining the Managing Multiple Myeloma online discussion board. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.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/become-advocate](http://www.CancerSupportCommunity.org/become-advocate).

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The Cancer Support Community and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

This booklet is available to download and print yourself at [www.CancerSupportCommunity.org/MDS](http://www.CancerSupportCommunity.org/MDS). For print copies of this booklet or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org).

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