

# Talking About Myelodysplastic Syndrome (MDS)



## A Guide for Discussions with Your Care Team



This guide can help you take control and have better discussions with your care team after a myelodysplastic syndrome (MDS) diagnosis. You will find an overview of MDS, important questions to ask your doctors and nurse, a worksheet to help you set your goals, and where to find more help and support.

Myelodysplastic Syndrome (MDS) is a group of rare blood cancers caused by the bone marrow making abnormal blood cells. Normally, blood cells develop from immature cells in the bone marrow into mature cells that enter the bloodstream. These mature cells then carry out their jobs throughout the body. With MDS, this process is disrupted causing blood cells to not mature or function properly. This leads to a shortage of healthy red blood cells, white blood cells, and platelets in the bloodstream.



For more information on MDS and additional resources, visit [www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS](http://www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS)

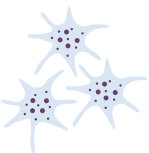


## There are some words that you may hear when talking about MDS. Some important ones to know are:

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**Red blood cell:** A type of blood cell made in the bone marrow and found in your blood. Its job is to carry oxygen to your lungs and the rest of your body.



**Platelet:** A smaller part of your cells that is made in your bone marrow. Platelets act as a bandage by stopping any bleeding. This allows your body to properly heal.



**Blasts:** Immature blood cells, ones that are not yet fully developed. In some subtypes of MDS, blasts collect in the bone marrow. This results in less room for healthy blood cells.



**Primary MDS:** MDS with no clear cause or not arising from previously completed therapies.



**White blood cell:** A type of blood cell that helps your body fight infections.



**Bone marrow:** The soft, spongy material in the middle of many large bones. Blood cells are made in the bone marrow.



**Anemia:** A low amount of red blood cells



**Secondary MDS:** When MDS is caused by cancer or other medical treatment.

## CAUSES AND RISK FACTORS

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Some kinds of MDS are linked to certain risk factors, but for most people, the exact cause is unknown. A “risk factor” simply means something that can raise your chances of getting a condition. **Having a risk factor does not mean you will get MDS.** People can still get MDS even without any of these factors.

MDS can happen to anyone, regardless of things like your lifestyle, age, or family history. Some of the known factors that can increase the chance of developing MDS include:

- Getting older: The risk goes up as you age
- Past cancer treatments: Some chemotherapy or radiation treatments can slightly raise your risk
- Smoking: Tobacco used has been linked to higher risk
- Exposure to certain environmental factors
- Specific genetic syndromes: Certain inherited conditions can increase risk
- Family history of MDS

Remember, most people with these risk factors never develop MDS. For most patients, there is no clear reason why the condition develops. If you have questions or concerns about your risk, talk to your care team. They can help you understand your personal situation and if there are any steps you can take.



## DIAGNOSIS OF MDS

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MDS is commonly found during a routine blood test. It is not typically found through signs or symptoms as with other cancers. When symptoms are present, they may be associated with low blood counts which may include:

- Fatigue, weakness, dizziness
- Fever
- Shortness of breath
- Chest pain
- Easy bruising or bleeding
- Bone pain

Sometimes, the symptoms of MDS can look a lot like those of other health conditions. This can make MDS hard to spot early on. It is important to talk with your care team if you experience any of these symptoms that prolong or worsen over time.



As part of a diagnosis, your care team may need to do a few different tests, both to rule out other causes and to figure out exactly what's going on. These tests will also help determine the subtype of MDS.

In addition to reviewing your current health status and history, your care team may have you complete the following tests:

### **COMPLETE BLOOD COUNT (CBC)**

This common blood test checks the levels of your red blood cells, white blood cells, and platelets. MDS sometimes shows up as low counts in one or more of these cell types. This CBC test can be done during a routine appointment or if you are experiencing fatigue, easy bruising, or infections.

### **BLOOD SMEAR**

This test looks at the blood cells up close under a microscope. The care team can examine the size and shape of your blood cells.

### **BONE MARROW TEST**

This test takes samples of bone marrow through a biopsy and aspiration. These tests may cause some brief pain.

- During a bone marrow aspiration, a thin needle is inserted into a bone. A common bone to use for this is the back part of your hip bone. A syringe is on the end that will pull out a sample of liquid bone marrow.
- A bone marrow biopsy is done after the aspiration. A small piece of bone and additional marrow are removed.

The samples taken from these tests are sent to a lab for additional testing. Your care team will perform other tests to help determine the specific MDS subtype. These tests look at details of your blood, genes, and any gene mutations. Since MDS can be more challenging to diagnose than other cancer types, consider asking for a specialist to review your test results.



## TYPES OF MDS

There are different types of MDS and figuring out your exact subtype is an important step in planning the best treatment for you. There are several subtypes of MDS. With frequent advances in MDS research and care, the subtypes of MDS may continue to change. Speak with your care team to understand the exact subtype of MDS you have. The subtype is very important for determining treatment options. MDS subtypes are separated into two categories:



### 1 How the MDS (abnormal) cells look under a microscope. The subtypes for this category are:

- a. MDS with low blasts (MDS-LB): This means the number of immature blood cells (called blasts) in your bone marrow is low.
- b. MDS, hypoplastic (MDS-h): “Hypoplastic” means the bone marrow has fewer cells than normal, making it less active.
- c. MDS with increased blasts (MDS-IB): Here, there are more immature cells (“blasts”) than normal, which may carry a higher risk of becoming leukemia. This is broken down into two specific categories: IB1 and IB2.
- d. MDS with fibrosis (MDS-f): This is when scar-like tissue is found around the bone marrow that hinders its ability to function properly.

### 2 The abnormal genetic changes in the MDS cells. These subtypes are each linked to specific gene mutations. This is indicated by the letters and numbers listed below. The subtypes for this category are:

- a. MDS with low blasts and isolated 5q deletion (MDS-5q)
- b. MDS with low blasts and SF3B1 mutation (MDS-SF3B1)
- c. MDS with biallelic TP53 inactivation (MDS-biTP53)

**Gene Mutation:** A change in the instructions inside your body that tell it how to function. These instructions are called genes. Sometimes, a gene can change by accident. This is called a mutation.

**Gene Deletion:** When a small part of the instructions (genes) inside your body is missing. In this situation, the body might not get the full message it needs.

**Gene Inactivation:** When a gene in your body stops working or gets turned off. If a gene is inactivated, it means the body can't use those instructions anymore.





In addition to your subtype, it is also important to know your risk score. Knowing both your subtype and risk score helps your care team find the best treatment for you. MDS does not have the typical “stages” that you see with other cancer types. Since MDS is in the blood, it is generally found throughout the body and cannot be linked to the size or spread of the tumor.

MDS has risk scores that are important for your treatment and overall decisions for your care. This risk score is called the IPSS. IPSS is the International Prognostic Scoring System. You may see this as IPSS-R or IPSS-M where R stands for Revised and M for Molecular. Both of these describe how advanced MDS is using test results. The range is from very low risk to very high risk. The lower the score, the better the outlook, or prognosis. A higher score means that MDS is more advanced and may be more difficult to treat. A higher score also means that there is a higher risk for MDS leading to acute myeloid leukemia. If you are exploring your treatment options, make sure you know your MDS subtype and risk score.

### Getting a Second Opinion

At any point in your care, you can ask for a second opinion. Many people may seek out a third opinion to confirm their diagnosis and review all available treatment options. Another hospital or doctor may offer different treatment, including clinical trials, or more useful support services. They may be a better fit for you in other ways, such as being closer to your home. **Do not worry about hurting feelings.** You can always return to the first doctor if you want. Remember, timely cancer treatment is key. You are entitled to decide what is best for you and your goals.

Read more about seeking a second opinion at [www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion](http://www.CancerSupportCommunity.org/Blog/Should-I-Get-Second-Opinion).

## TREATMENT FOR MDS

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There are several treatment options for MDS. The right one depends on your individual diagnosis, risk score, and personal preferences. **The five types are:**

### 1 Active Surveillance

If your MDS is considered low risk, your care team may suggest active surveillance as your first step. This means:

- You will have regular check-ups and blood tests to keep an eye on your blood cell counts.
- No immediate treatment is started unless your symptoms change or your condition progresses.

### 2 Supportive Therapy

Supportive therapy does not treat MDS directly. It helps manage side effects and improves your comfort and quality of life. Supportive therapy can be used alone or with other treatments. The goal is to improve quality of life through palliative care or other symptom management methods. This type of care can help manage common side effects of MDS like:

**A. Anemia (low red blood cells):** You may feel tired or weak.

**B. Low platelet counts:** This can increase your risk of bruising or bleeding.

**C. Neutropenia (low white blood cells):** This can make you more prone to infections.

Supportive therapy can look different for each patient based on the side effects that are present. The options include:

- **Palliative care:** A Palliative Care Specialist can provide ways to reduce any pain and improve your quality of life.
- **Blood transfusions:** These can help boost blood counts and reduce symptoms. People with MDS sometimes get transfusions as often as every week or 2 weeks. A transfusion can take up to several hours. You may feel better soon after a transfusion.
- **Antibiotics to treat infections:** To prevent or treat infections if your immune system is low.
- **Growth factors and Erythroid Maturing Agents (EMAs):** These are used to increase the number of mature blood cells or help improve anemia. Different drugs boost different types of blood cells.
- **Chelating agents:** Drugs to lower iron levels in your body, as blood transfusions over time can raise these levels.



### 3 Disease Modifying Therapies

Immunotherapy, targeted therapy, and chemotherapy are types of treatment that use drugs or medicines to treat MDS.

- In MDS, immunotherapy may be called immunosuppressive therapy. These drugs suppress your immune system and block its effect on your bone marrow. This allows your bone marrow to create more blood cells.
- Targeted Therapy can be an option if your MDS type has a specific gene mutation. These drugs target the specific type of mutation to attack the cancer cells.
- Chemotherapy uses drugs to kill cancer cells throughout the body. One specific type of drug used in MDS is called hypomethylating agents.

### 4 Stem Cell Transplant

A stem cell transplant (SCT) is an infusion of blood-forming cells (stem cells). It is not surgery. Stem cell transplant can also be referred to as bone marrow transplant (BMT). The procedure has two parts:

1. You will receive preparative chemotherapy and immunosuppression. This destroys blood cells and suppresses the immune system to allow it to accept the donor cells.
2. Stem cells are introduced into the bloodstream to replace blood cells. This is called an allogenic stem cell transplant. You will receive stem cells from someone else who has been determined as a donor by your care team.

Stem cell transplants are currently the only possible cure for MDS. However, it is not always effective. To learn more about SCT, please visit

**[www.CancerSupportCommunity.org/Stem-Cell-Transplant](http://www.CancerSupportCommunity.org/Stem-Cell-Transplant)**

### 5 Clinical Trials

Depending on your subtype and other factors of your MDS diagnosis, a clinical trial may be the right fit for you and your goals. Speak with your care team about the clinical trial options that are available to you.

Clinical trials are research studies to test new treatments or learn how to use current treatments better. They find new and better ways to prevent or treat cancer. A clinical trial may be the only way to gain access to a promising new treatment option. Today, the U.S. Food and Drug Administration (FDA) oversees clinical trials to keep all patients safe. For more information on clinical trials and how to find them, visit **[www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials)**.

## KEY POINTS TO REMEMBER:

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- Treatment options depend on the type and risk level of your MDS, your age, overall health, and your preferences.
- Make sure you understand which treatment your team recommends and why.
- Do not hesitate to ask questions or request more information—your care team is there to help you make the best decisions for your situation.

Every MDS patient experience is unique. Talk with your care team about the best treatment options for you. This may include looking into available clinical trials in your area. Your care team can help determine if there are any for your specific MDS diagnosis. Read more about treatment options at [www.CancerSupportCommunity.org/Treatment-Options-Cancer](http://www.CancerSupportCommunity.org/Treatment-Options-Cancer).

## THINK ABOUT YOUR TREATMENT AND PERSONAL GOALS

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After receiving an MDS diagnosis, it is important to make sure that you feel supported by your care team. It is also important to keep in mind the goals that you have for treatment. Ask your care team about how each treatment option may impact your personal goals. Tell your care team your personal and treatment goals. An example of a personal goal may be to live as long and as well as possible or reach a special milestone or event in life. It is OK if these goals change over time.

<b>Physical Health and Mental Health and Well-being</b>	What is most important for you to be able to do and feel?
<b>Family and Social Relationships</b>	What is going on in the lives of others that is important to you?
<b>Work/School</b>	Do you want or need to continue working? Can you adjust your schedule or responsibilities?
<b>Social Support/ Community Involvement</b>	Are you getting the support you need from your loved ones and community? Are you able to stay active/involved in your community?
<b>Other</b>	What else is important to you? What do you hope to achieve?



## MDS Side Effects

Below are some of the treatment side effects people with MDS may experience. Think about how often you experience each one. Share this with your care team during your next visit. They can talk with you about how to best manage them.

For more information about how to manage treatment side effects, visit [www.CancerSupportCommunity.org/Managing-Side-Effects](http://www.CancerSupportCommunity.org/Managing-Side-Effects)

PHYSICAL SIDE EFFECTS	Rarely	Sometimes	Often
Fatigue			
Bleeding			
Pain or Discomfort			
Brusing			
Shortness of Breath			
Racing Heartbeat			
Infections			
Other:			

EMOTIONAL SIDE EFFECTS	Rarely	Sometimes	Often
Fear of disease progression or upcoming appointments			
Feeling sad or depressed			
Feeling nervous, anxious, or afraid			
Other:			



For more information and ways to support for your mental health, visit [www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns](http://www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns)

## CAREGIVING FOR MDS

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Caring for someone with MDS can be both rewarding and challenging. Every caregiver experience is different. It is normal to feel overwhelmed, stressed, or even frustrated as you balance your own life with your loved one's needs. **You are not alone in feeling these emotions.** It is completely natural to feel overwhelmed, frustrated, and tired.



### As a caregiver, you might:

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Help with making decisions about treatment and finances.

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Drive your loved one to appointments.

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Assist with everyday activities like managing medications, preparing meals, or keeping track of symptoms.

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During this time, you may want to do all you can to support your loved one. **Taking care of yourself is not selfish; it is essential.** Seek out the support that is helpful for you. This could be through a family member, friend or a professional such as a licensed therapist or social worker. If you are looking for peer support, consider joining a support group for MDS caregivers. Talk with your care team about the support options available for you. For more information on caregiving, visit [www.CancerSupportCommunity.org/Caregivers](http://www.CancerSupportCommunity.org/Caregivers).



## YOUR MDS CARE TEAM

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Supportive care and treatment for MDS can be difficult to manage and require frequent visits. Your care team should include a group of healthcare professionals and specialists that you trust. Since MDS can be difficult to diagnose, consider visiting with your care team early and often. Your care team may include:

**Medical Oncologist or Hematologist** - A Medical Oncologist or Hematologist specializes in the treatment of cancer. They will offer cancer treatment options and referrals to specialists. This includes chemotherapy, immunotherapy, and targeted therapy.

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**Nurse Practitioner, Nurse, Physician Assistant** - Nurse Practitioners (NPs), Physician Assistants (PAs), and Nurses (RNs) may work with the oncologist and help answer questions about your MDS diagnosis. A nurse may perform your blood transfusions and administer treatments. These healthcare professionals are also a great resource to speak with about your mental health. They can connect you with social workers, counselors, psychiatrists, and others.

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**Nurse Navigator or Patient Navigator** - Navigators help you manage your care. They help schedule appointments, get answers to your questions, recommend educational resources, and support you during your treatment.

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**Financial Navigator** - A Financial Navigator helps you and your loved ones understand the cost of different treatments and how your insurance plan may help cover costs. They may also help find financial assistance programs or payment plans to help ease the burden of receiving treatment.

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**Oncology Social Worker and Therapist/Counselor** - A Social Worker, Therapist, and Counselor help you and your caregiver find resources to cope with cancer and its treatment side effects. Social Workers can help navigate costs and help with practical concerns. Social Workers and Therapists are trained mental health professionals who can help you address your emotions through individual or group therapy.

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**Oncology Pharmacist** - An Oncology Pharmacist is an expert on medicines used to treat cancer. They can educate you on any associated side effects and how to manage them. They can also help you understand how to best take different medications if you have multiple at once.

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**Palliative Care Doctor** - This person focuses on improving a patient's quality of life. They can be helpful if you are having difficult symptoms, pain, or side effects. Palliative care is different from end-of-life care or hospice. You can see a palliative care doctor at any point during your treatment.

## QUESTIONS TO ASK YOUR CARE TEAM

### Diagnosis Clarification

What evidence made you confident that I have MDS?

What type (or subtype) of MDS do I have?

What “stage” or risk group am I in?

Do I have any mutations? If so, can they be targeted with treatment?



### Treatment Options

What type of treatment do you recommend for me?

When will I need another bone marrow biopsy?

Am I a candidate for a stem cell transplant?

How often will my treatment take place, and where will it happen?

Will I need to stay overnight in the hospital for any part of the treatment?

What are the goals of my treatment? What are the potential benefits and risks?

Are there any new treatments or clinical trials that might be appropriate for me?

What are the possible side effects? Will I need help from a caregiver during my treatment?

When should I start treatment? What might happen if I choose to wait?

Is my MDS curable?

What is my risk of developing acute myeloid leukemia (AML)?



## Support and Safety

Who should I call if I notice a side effect or have questions? Could I have their contact information?

Who do I contact after office hours, and what is their contact information?

What steps can I take to avoid infections during treatment?

What resources are available for my caregiver, especially if I experience side effects?

## Financial and Practical Concerns

How can I manage the costs of treatment?

Is there a financial navigator or social worker I can talk with about expenses or insurance questions?



### **OPEN TO OPTIONS®**

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options® program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.





Receiving an MDS diagnosis can feel challenging at times. It may be difficult to cope with the diagnosis for a prolonged period of time. You are not alone! Stay connected with your support system and focus on things within your control. Share your concerns and questions with your care team. Know that there are many resources available to you as you navigate your cancer experience.

#### **CANCER SUPPORT HELPLINE®**

If you need help finding resources or want help getting information about cancer, call Cancer Support Community's toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by licensed community navigators and resource specialists who can assist you Monday - Thursday 11:00 a.m. - 8:00 p.m. ET and Friday 11:00 a.m. 6:00 p.m. ET.



## FINANCIAL SUPPORT RESOURCES

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### **Cancer Support Community**

888-793-9355

[www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment](http://www.CancerSupportCommunity.org/Managing-Cost-Cancer-Treatment)

### **Triage Cancer**

[www.TriageCancer.org](http://www.TriageCancer.org)

### **Cancer Financial Assistance Coalition**

[www.CancerFAC.org](http://www.CancerFAC.org)

### **Patient Advocate Foundation**

800-532-5274 | [www.PatientAdvocate.org](http://www.PatientAdvocate.org)

### **OncoLink**

[www.OncoLink.org](http://www.OncoLink.org)

## MDS RESOURCES

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### **MDS - Cancer Support Community**

[www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS](http://www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS)

### **MDS Foundation**

[www.MDS-Foundation.org](http://www.MDS-Foundation.org)

### **National Cancer Institute (NCI) MDS**

[www.Cancer.gov/Types/Myeloproliferative/Patient/Myelodysplastic-Treatment-PDQ](http://www.Cancer.gov/Types/Myeloproliferative/Patient/Myelodysplastic-Treatment-PDQ)

### **NCI Clinical Trial Registry**

[www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)

### **American Cancer Society (ACS)**

[www.Cancer.org/Cancer/Types/Myelodysplastic-Syndrome.html](http://www.Cancer.org/Cancer/Types/Myelodysplastic-Syndrome.html)

## Cancer Support Community Resources

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**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-Thurs 11am-8pm ET and Fri 11am-6pm 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.

**Services at Local CSCs and Gilda's Clubs** — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more  
**[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 secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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 publication is available to download and print yourself at **[www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS](http://www.CancerSupportCommunity.org/Myelodysplastic-Syndromes-MDS)**.

For print copies of this publication or other information about coping with cancer, visit **[Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org)**.

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