

# **Myelodysplastic Syndrome Overview**

The information that follows is an overview of this type of cancer. It is based on the more detailed information in our document, *Myelodysplastic Syndrome*. This document and other information can be obtained by calling 1-800-227-2345 or visiting our Web site at www.cancer.org.

## What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide into new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out, damaged, or dying cells.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of this out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells keep on growing and form new cancer cells. These cancer cells can grow into (invade) other tissues, something that normal cells cannot do. Being able to grow out of control and invade other tissues is what makes a cell a cancer cell.

In most cases the cancer cells form a tumor. But some cancers, like leukemia, rarely form tumors. Instead, these cancer cells are in the blood and bone marrow.

When cancer cells get into the bloodstream or lymph vessels, they can travel to other parts of the body. There they begin to grow and form new tumors that replace normal tissue. This process is called *metastasis* (muh-tas-tuh-sis).

No matter where a cancer may spread, it is always named for the place where it started. For instance, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is called metastatic prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and breast cancer are very different diseases. They grow at different rates and respond to

different treatments. That is why people with cancer need treatment that is aimed at their own kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign* (be-nine). Benign tumors can cause problems-- they can grow very large and press on healthy organs and tissues. But they cannot grow into other tissues. Because of this, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

# What is myelodysplastic syndrome?

Myelodysplastic syndrome (MDS) is the name of a group of conditions that occur when the blood-forming cells in the bone marrow are damaged. This damage leads to low numbers of one or more types of blood cells.

### Normal bone marrow

Bone marrow is the soft, inner part of some bones, such as those of the skull, shoulder blades, ribs, pelvis, and backbones. Bone marrow contains stem cells that divide to form new cells. When a stem cell divides it makes 2 cells: one cell that stays a stem cell, and another cell that can make other kinds of blood cells. There are 3 kinds of blood cells: red blood cells, white blood cells, and platelets.

- Red blood cells carry oxygen from the lungs to the rest of the body and carry away carbon dioxide.
- White blood cells help the body fight infection. There are many types of white blood cells.
- Platelets are really pieces of cells. They are needed for the blood to clot. They help to plug up damaged areas of blood vessels caused by cuts or bruises.

### Myelodysplastic syndrome

In MDS, some of the cells in the bone marrow are damaged and have problems making new blood cells. Many of the blood cells that are made by these damaged cells are not normal. The body destroys many of these abnormal blood cells, leaving the person without enough normal blood cells and with low blood counts.

MDS can turn into a fast-growing cancer of bone marrow cells called *acute myeloid leukemia*. This happens in about 1 out of 3 people with MDS. In the past, MDS was called pre-leukemia or smoldering leukemia. Since most MDS patients do not get leukemia, these terms are no longer used. Now that doctors have learned more about MDS, it is thought to be a form of cancer.

The American Cancer Society document, *Leukemia: Acute Myeloid (Myelogenous)* has more information about the leukemia that develops in some MDS patients.

# Types of MDS

The system used to classify MDS is known as the WHO (World Health Organization) system. This system divides MDS into 7 groups. Most of the time, the group depends on how the cells of the blood and bone marrow look under a microscope. Because the differences can be very small, doctors may not agree about which group a patient's disease belongs in. Your doctor can explain to you the exact kind of MDS you have.

Cases of MDS can also be grouped based on the cause of the disease. (This is called *clinical classification*.) If no cause can be found, it is called *primary MDS*. It is called *secondary MDS* when the cause of the disease is known. Secondary MDS is often called treatment-related, because the most common cause is earlier treatment for cancer. Secondary MDS is much less likely to respond to treatment.

# How many people get myelodysplastic syndrome?

There are about 12,000 new cases of myelodysplastic syndrome (MDS) each year in the United States. The number of new cases seems to be going up as the average age of the population has increased.

About 80% to 90% of all patients with MDS are older than 60 years. It is rare in young adults.

# What are the risk factors for myelodysplastic syndrome?

A risk factor is anything that changes your chance of getting a disease such as cancer. Different cancers have different risk factors. For instance, smoking is a risk factor for cancer of the lung and many other cancers. But risk factors don't tell us everything. People without any risk factors can still get the disease. And having a risk factor, or even several, does not mean that you will get the disease.

Although some cases of myelodysplastic syndrome (MDS) are linked to known risk factors, in most cases, the cause is unknown.

#### Risk factors for MDS

#### Earlier cancer treatment

Having had treatment with chemotherapy ("chemo") is the most important risk factor for MDS. Patients who have been treated with certain chemo drugs for cancer are more likely to get MDS. Getting these drugs along with radiation treatment increases the risk even more. MDS is also seen in patients who have had stem cell transplants (bone

marrow transplants) because these patients get very high doses of chemo. Still, only a small percentage of people who are treated with these drugs will go on to get MDS.

#### **Genetic syndromes**

Some bone marrow problems are caused by changed (mutated) genes that have been passed on from one or both parents. People with these problems (called *syndromes*) are more likely to develop MDS.

#### Family history

In some families, MDS has been found to happen more often than would be expected.

#### **Smoking**

Smoking increases the risk for MDS. Many people know that smoking causes cancers of the lungs and other organs, but few also know that it can affect cells that do not come into direct contact with smoke. Substances in tobacco smoke that cause cancer get into the bloodstream and can affect many parts of the body.

#### Radiation and certain chemicals

Radiation and certain chemicals have been linked to MDS. Being exposed to a lot of radiation (such as from an atomic bomb blast or nuclear reactor accident) increases the risk of developing MDS. Long-term workplace exposure to benzene and certain chemicals used in the oil and rubber industries can also increase the risk of getting MDS.

### Age and sex

Age is a risk factor for MDS. This disease is rare in people younger than 40. Most cases are found in those older than 60. MDS is also more common in men than in women.

# Can myelodysplastic syndrome be prevented?

Not smoking can lower the risk of getting myelodysplastic syndrome (MDS) as well as the risk for many other cancers, heart disease, stroke, and other diseases.

Doctors are looking at ways to lower the risk of MDS in patients who need to have chemotherapy (chemo) and radiation. In some cancers, doctors may try to avoid using the drugs that are more likely to lead to MDS. But the clear benefits of treating serious cancers with chemo and radiation must be balanced against the small chance of getting MDS years later.

People should avoid dangerous chemicals like benzene in the workplace. But most people with MDS do not have any known exposure to these substances.

# How is myelodysplastic syndrome found?

Follow-up exams and blood tests may help find some cases of MDS in people who were treated with certain chemotherapy drugs in the past. But at this time, no special tests are used to look for myelodysplastic syndromes (MDS) in people without symptoms.

# Signs and symptoms of MDS

MDS can cause many signs and symptoms such as weight loss, fever, and loss of appetite. Of course, these problems are most often caused by something other than cancer.

Shortages of one or more types of blood cells cause many of the symptoms of MDS.

- A shortage of red blood cells can cause tiredness, shortness of breath, and pale skin.
- A shortage of normal white blood cells can lead to infections and high fevers.
- A shortage of platelets can cause easy bruising and bleeding.

# Tests used to find and classify MDS

If there is any reason to suspect MDS, the doctor will look at cells from your blood and bone marrow to find out if the disease is really there.

#### Blood cell counts and blood cell exams

The complete blood count (CBC) is a test that measures the different cells in the blood, like red blood cells, white blood cells, and platelets. Patients with MDS will often have changes in the numbers of different blood cell types. Under the microscope the cells may also look different in shape and size. Blood tests can suggest MDS, but the doctor will need to look at a sample of bone marrow cells to be sure.

#### **Bone marrow tests**

Bone marrow samples are taken by a bone marrow aspiration and biopsy. These 2 tests are most often done at the same time. For these tests, you lie on a table (either on your side or on your belly). The sample is taken from the back of the hip (pelvic) bone. After cleaning the area, the skin is numbed and then a needle is used to suck out a small amount of liquid bone marrow. Even with the numbing medicine, most patients have some brief pain when the marrow is removed.

A bone marrow *biopsy* is usually done just after the aspiration. A small piece of bone and marrow is removed with a different needle that is twisted as it is pushed down into the bone. The biopsy may also cause some brief pain. Once the biopsy is done, pressure will be applied to help prevent bleeding.

A doctor with special training (a pathologist) will look at the sample of cells under a microscope to see if cancer is present and if so, what kind it is. The percentage of marrow cells that are *blasts* is very important. Blasts are very early cells that are made by bone marrow stem cells. Over time, blasts should change (mature) into normal blood cells. In MDS, the blasts do not mature, so there may be too many blasts and not enough mature cells. A patient with less than 20% blasts in the bone marrow has MDS. A patient who has more than 20% blasts in the bone marrow is considered to have acute leukemia.

#### Other tests

There are a number of other ways to study the cells from blood or bone marrow. These tests use chemicals or other methods to help the doctor pinpoint the exact type of cells that are present. You can ask your doctor to explain what types of tests were done and what they showed.

# Staging for myelodysplastic syndrome

Doctors often group cancer into stages based on the size of the tumor and how far the cancer has spread. This helps them decide on the best treatment for the patient and predict the person's outlook (prognosis).

But myelodysplastic syndrome (MDS) is a disease of the bone marrow. It cannot be staged by looking at the size of a tumor like some other cancers. In MDS, other factors are used instead. These factors include the patient's blood counts, the patient's age, how the bone marrow looks, and certain gene changes in the bone marrow cells.

# International Prognostic Scoring System

One system used for staging MDS is called the IPSS system (International Prognostic Scoring System). The system uses 3 factors to stage the cancer:

- The percentage blasts in the bone marrow
- Abnormal chromosomes (genes)
- The patient's blood counts

On the basis of these factors, the IPSS groups people with MDS into these 4 groups. The higher the risk group, the more serious the disease.

- Low risk
- Intermediate 1 risk (Int-1)
- Intermediate 2 risk (Int-2)
- High risk

# WHO Prognostic Scoring System (WPSS)

This newer scoring system is based on 3 factors:

- The type of MDS based on the WHO classification
- Abnormal chromosomes
- Whether or not the patient needs blood transfusions

This system puts patients with MDS into 5 groups

- Very low risk
- Low risk
- Intermediate
- High risk
- Very high risk

These risk groups can also be used to predict outlook (see the next section)

# Survival rates for myelodysplastic syndrome

Survival rates are often used by doctors as a standard way of talking about a person's prognosis (outlook). Some patients with cancer may want to know the survival rates for their type of cancer, while others may not find the numbers helpful, or may even not want to know them. If you decide that you do not want to know them, stop reading here and skip to the next section.

Median survival is one way to look at outcomes and measures the amount of time for half the patients in a certain group to die. This is a middle value – half the patients live longer than this, and half do not live this long. These numbers are based on patients whose cancer was found some time ago. Better treatments since then may mean a better outlook for people with myelodysplastic syndrome (MDS) found now.

The following survival statistics are based on the International Prognostic Scoring System (IPSS) risk groups. These were published in 1997 and do not include patients treated with intensive chemotherapy.

IPSS risk group	Median survival
Low	5.7 years
Int-1	3.5 years

Int-2	1.2 years
High	5 months

The WHO Prognostic Scoring System (WPSS) risk groups can also be used to predict outcome. These statistics were published in 2007 based on patients whose MDS was found between 1982 and 2004.

WPSS Risk Group	Median Survival	Risk of Leukemia (within 5 years)+
Very low	12 years	3%
Low	5.5 years	14%
Intermediate	4 years	33%
High	2 years	54%
Very high	9 months	84%

<sup>+</sup> The percentage of people who will develop leukemia within 5 years of being put into this risk group.

While these numbers give an overall picture, keep in mind that every person is unique and the statistics can't predict exactly what will happen in your case. Talk with your cancer care team if you have questions about your own chances of a cure, or how long you might survive your cancer. They know your situation best.

# How is myelodysplastic syndrome treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

### About treatment

Myelodysplastic syndrome (MDS) isn't just one disease; it is a group of diseases. The different types of MDS vary in their outlook and response to treatment. Treatment is

based on the type of MDS, as well as the patient's age and health. Treatment is given by a specialist like a cancer doctor (oncologist) or a doctor who treats blood diseases (hematologist).

The main types of treatment for MDS are:

- Chemotherapy (including hypomethylating drugs)
- Growth factors
- Supportive therapy
- Stem cell transplant

Often, a combination of these is used.

# Chemotherapy for myelodysplastic syndrome

Chemotherapy (chemo) is the use of drugs, taken by mouth or put into a vein, to treat cancer. The drugs enter the bloodstream and reach most places in the body. The purpose of the chemo is to kill the abnormal stem cells and allow normal ones to grow back.

Because MDS can progress to acute leukemia, patients with MDS may get the same treatment as leukemia patients. This type of treatment can help some patients, but it has many severe side effects. Problems from this kind of chemo may hasten death, particularly in the elderly. Still, this treatment may be an option for some patients with advanced MDS.

Another option is to use lower doses of chemo drugs. This approach can lower the chance of serious side effects.

While chemo drugs kill cancer cells, they can also damage normal cells, causing side effects. These side effects depend on the type of drugs given, the dose, and how long they are given.

Short-term side effects can include:

- Hair loss (the hair grows back once treatment ends)
- Mouth sores
- Loss of appetite
- Nausea
- Vomiting
- Greater chance of infection (from a shortage of white blood cells)
- Easy bruising and bleeding (from low platelet counts)
- Tiredness, called fatigue (from a shortage of red blood cells)

The doctor will watch carefully for all side effects and adjust treatment as needed. Your health care team often can suggest ways to lessen side effects. For example, other drugs can be given along with the chemo to prevent or reduce nausea and vomiting.

If a patient's white blood cell counts are very low during treatment, the risk of infection can be reduced by doing certain things. Patients should be very careful about washing their hands and not eating fresh, uncooked fruit and other foods that might carry germs. They might also wear a surgical mask around crowds. The doctor might also give strong antibiotics even before an infection has started.

If platelet counts are low, patients might have platelet transfusions or red blood cell transfusions if their red cell counts are low. They might receive growth factors to raise red blood cell counts.

#### **Hypomethylating agents**

These drugs are a form of chemo that affects the way genes are controlled. They help in MDS by slowing down genes that promote cell growth. They also kill cells that are dividing rapidly. In some MDS patients, these drugs improve blood counts, lower the chance of getting leukemia, and even prolong life. Red blood cell counts may improve enough to stop transfusions.

These drugs have some of the same side effects as regular chemotherapy, but these side effects are usually mild. They include:

- Nausea/vomiting
- Diarrhea or constipation
- Fatigue and weakness
- Low blood counts (most often the white blood cells or platelets)

## Immune treatments for myelodysplastic syndrome

## Immune modulating drugs

The drugs *thalidomide* and *lenalidomide* (Revlimid®) belong to the group of drugs known as immunomodulating drugs (or IMiDs). Thalidomide was used first in treating MDS. It helped some patients, but many people stopped taking the drug because of side effects. Lenalidomide is a newer drug that has fewer side effects.

Side effects include:

- Decreased blood counts (most often the white cell count and platelet count)
- Diarrhea or constipation
- Feeling tired and weak

• Pain in the hands and feet from nerve damage

Lenalidomide can also increase the risk of serious blood clots that start in the veins in the legs. Part of a clot can break off and travel to the lungs where it can cause problems with breathing or even death. Many experts feel that patients getting this drug should also get some kind of treatment to prevent blood clots.

Because of concern that these drugs could cause birth defects, these drugs are only available through programs run by the companies that make them.

#### **Immunosuppression**

Drugs that suppress or weaken the immune system can help some patients with MDS. A drug called *anti-thymocyte globulin* (ATG) has helped some people, usually younger ones, with MDS. It must be given in the hospital because it can sometimes cause severe allergic reactions leading to low blood pressure and problems breathing.

Another drug that works by suppressing the immune system is called *cyclosporine*. It was first used to block immune responses in people who have had organ or bone marrow transplants, but it has helped some patients with MDS. Side effects of cyclosporine include loss of appetite and kidney damage.

### Growth factors for myelodysplastic syndrome

Growth factors are substances that speed up the process of making blood cells in the bone marrow. The body itself makes growth factors, but they can also be made in the lab. They can then be given to patients in large doses to help their bodies make more blood cells. Patients usually get the growth factors as shots (injections) under the skin.

A shortage of blood cells causes most of the symptoms in people with MDS, so giving growth factors can help some patients. There are different growth factors that might be used, depending on the patient's situation.

# Supportive treatment for myelodysplastic syndrome

For many patients with myelodysplastic syndrome (MDS), the main goal of treatment is to prevent problems from low blood counts. These patients might be very tired because of low red blood cell counts and may need to get many blood transfusions. One problem from a lot of blood transfusions is the build-up of iron in the blood. Too much iron can cause liver and heart damage. There are drugs that can be given to help prevent this.

MDS patients with bleeding problems caused by a shortage of platelets may be helped by platelet transfusions. Patients with low white blood cell counts might get infections which could be very serious. These infections are treated with antibiotics. A white blood cell growth factor may also be used to help raise the white blood cell count so that the body can fight the infection.

# Stem cell transplant for myelodysplastic syndrome

A stem cell transplant (SCT) is the only treatment that can cure myelodysplastic syndrome (MDS). In this treatment, the patient gets very strong chemotherapy (chemo) and perhaps radiation to kill cells in the bone marrow. Once the bone marrow cells are destroyed, the patient gets new, healthy, blood-forming stem cells. For patients with MDS, these new stem cells come from a donor -- often a brother or sister. This is called an *allogeneic* stem cell transplant. If there is no matching family member to be a donor, sometimes a matched, unrelated donor may be used. Using stem cells from an unrelated donor has more risks than using stem cells from a relative.

#### How the process works

Most often, stem cells are taken from the donor's blood in a process called *apheresis*. The stem cells are frozen and stored. The patient then gets high-dose chemo and, often, radiation treatment. This destroys the MDS cells, but it also kills the normal cells in the bone marrow.

The donor's stem cells are then given to the patient as a transfusion. These cells travel through the blood to the bone marrow where they settle and start to grow. Over time they start making white blood cells, then platelets and, finally, red blood cells.

There is a newer type of transplant, called a *mini-transplant* (or a *non-myeloablative allogeneic stem cell transplant*) that can be used. It differs from the standard approach in that *low* doses of chemo or radiation are used. This makes it easier on patients who are older. Side effects, though, are still a major problem with this low-dose method.

#### **Side effects**

Transplant can have serious, even fatal, side effects and is rarely used in older patients. Because of the side effects, many doctors only use SCT in people younger than a certain age.

The side effects of SCT can be divided into early and long-term effects. Early on, the side effects are much the same as those caused by high-dose chemo. The side effects that occur later can last for a long time. They include:

- Radiation damage to the lungs (this is rare)
- Damage to the ovaries that can result in infertility, sudden change of life (menopause), and hot flashes
- Damage to the thyroid gland
- Cataracts (clouding of the eye that can cause vision problems)

The most serious side effect from allogeneic transplant is called *graft-versus-host disease* (or GVHD). This happens when the new immune cells (from the donor) see the patient's tissues as foreign and so attack them. GVHD can happen early on or it can start later.

Symptoms include weakness, tiredness, dry mouth, rashes, infection, diarrhea (which can be severe), and muscle aches. Severe GVHD can even be fatal. Drugs to suppress the immune system are given as part of the transplant to prevent or treat GVHD.

Right now allogeneic SCT is the only treatment that can cure some patients with MDS, but not all patients who get a transplant are cured. Also, patients may die from complications of this treatment. Your chance for cure is higher if you are young and your MDS hasn't begun to change into leukemia. Still, doctors recommend waiting until the MDS is in a more advanced stage before thinking about a transplant.

If you would like more detailed information on SCT, please see our document *Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants)*. You can read it on our Web site or get a copy by calling 1-800-227-2345.

# Clinical trials for myelodysplastic syndrome

You may have had to make a lot of decisions since you've been told you have cancer. One of the most important decisions you will make is deciding which treatment is best for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your medical needs. You can reach this service at 1-800-303-5691 or on our Web site at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials Web site at www.cancer.gov/clinicaltrials.

There are requirements you must meet to take part in any clinical trial. If you do qualify for a clinical trial, it is up to you whether or not to enter (enroll in) it.

Clinical trials are one way to get state-of-the art cancer treatment. They are the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

You can get a lot more information on clinical trials, in our document called *Clinical Trials: What You Need to Know*. You can read it on our Web site or call our toll-free number and have it sent to you.

# Complementary and alternative therapies for myelodysplastic syndrome

When you have cancer you are likely to hear about ways to treat your cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to

Internet groups and Web sites may offer ideas for what might help you. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

#### What are complementary and alternative therapies?

It can be confusing because not everyone uses these terms the same way, and they are used to refer to many different methods. We use *complementary* to refer to treatments that are used *along with* your regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help you feel better. Some examples of methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been proven not to be helpful, and a few are even harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be harmful, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to be helped by standard medical treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

#### Finding out more

It is easy to see why people with cancer think about alternative methods. You want to do all you can to fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemotherapy can be hard to take, or they may no longer be working. But the truth is that most of these alternative methods have not been tested and proven to work in treating cancer.

As you think about your options, here are 3 important steps you can take:

- Look for "red flags" that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a "secret" that requires you to visit certain providers or travel to another country?
- Talk to your doctor or nurse about any method you are thinking of using.
- Contact us at 1-800-227-2345 to learn more about complementary and alternative methods in general and to find out about the specific methods you are looking at.

### The choice is yours

Decisions about how to treat or manage your cancer are always yours to make. If you want to use a non-standard treatment, learn all you can about the method and talk to your

doctor about it. With good information and the support of your health care team, you may be able to safely use the methods that can help you while avoiding those that could be harmful.

# What are some questions I can ask my doctor about myelodysplastic syndrome?

We encourage you to have honest, open discussions with your doctor about your condition. Feel free to ask any question that's on your mind, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them. Nurses, social workers, and other members of the treatment team may also be able to answer many of your questions.

- What type of myelodysplastic syndrome (MDS) do I have?
- What is my prognostic score and what does that mean for me?
- What treatment choices do I have?
- Which treatment (if any) do you recommend and why?
- Should I get a second opinion, and whom do you recommend as an expert in this field?
- What are the side effects of the treatment you recommend?
- How can I help reduce these side effects?
- What is the outlook for my survival?

Add your own questions below:

# Moving on after treatment for myelodysplastic syndrome

Since myelodysplastic syndrome (MDS) is rarely cured, most patients never really complete treatment. Patients may go through a series of treatments with rests in between. Some people stop active treatment in favor of supportive care. Learning to live with cancer that does not go away can be hard and very stressful. Our document, *When Cancer Doesn't Go Away*, talks more about this.

## Follow up care

Even if you have stopped your treatment for MDS, it is still very important to keep all follow-up visits. The doctor will do physical exams, order blood tests, and watch for signs of infection, progression to leukemia, and short-term or long-term side effects of treatment. You should report any new symptoms to you doctor right away.

Almost any cancer treatment can have side effects. Some may last for a few weeks or months, but others can be permanent. It is also important to keep health insurance. With a chronic disease like MDS, your treatment may never really be over. You don't want to have to worry about paying for tests and treatment.

# Seeing a new doctor

At some point after your cancer is found and treated, you may find yourself in the office of a new doctor who does not know about your cancer. It is important that you be able to give your new doctor the exact details of your diagnosis and treatment. Make sure you have this information handy and always keep copies for yourself:

- A copy of your pathology report from any biopsy or surgery
- If you had surgery, a copy of your operative report
- If you were in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home from the hospital
- If you had radiation treatment, a summary of the type and dose of radiation and when and where it was given
- A list of your drugs, drug doses, and when you took them

The doctor may want copies of this information for his records, but always keep copies for yourself.

# Lifestyle changes after having myelodysplastic syndrome

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

### Making healthier choices

For many people, finding out they have cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on the alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes

that can have good effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345. This service can help increase your chances of quitting for good.

#### **Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

#### Rest, fatigue, and exercise

Extreme tiredness, called *fatigue*, is very common in people treated for cancer. This is not a normal tiredness, but a "bone-weary" exhaustion that doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness to decline. Any plan for exercise should fit you. An older person who has never exercised will not be able to take on the same amount of exercise as a 20-year-old who plays tennis twice a week. If you haven't exercised in a few years, you will have to start slowly — maybe just by taking short walks.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn't there.

If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (To find out more about dealing with fatigue, please see our documents *Fatigue in People With Cancer* and *Anemia in People With Cancer*.)

Keep in mind that exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- It makes your muscles stronger.
- It reduces fatigue.
- It lowers anxiety and depression.
- It can make you feel generally happier.
- It helps you feel better about yourself.

Long term, we know getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

# How does having myelodysplastic syndrome affect your emotional health?

At some point, you may find yourself overcome with many different emotions. This happens to a lot of people. You may have been going through so much at first that you could only focus on getting through each day. Now it may feel like a lot of other issues are catching up with you.

You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, if you start feeling better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your own preferences. Some people feel safe in peer-support groups or education groups. Others would rather talk in a setting such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It is not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren't sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

# If treatment for myelodysplastic syndrome stops working

If your myelodysplastic syndrome (MDS) does not improve with one treatment, it is often possible to try another treatment plan to help you live longer and feel better. But if you have tried many different treatments without improvement, your disease may be resistant to treatment. If this happens, it's important to weigh the possible benefits of a new treatment against the downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with MDS – when you have been through many treatments and nothing is working anymore. Your doctor may offer you new options, but at some point you may need to think about whether that treatment is likely to improve your health or change your outcome or survival.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called *palliative care*.

Palliative care helps relieve symptoms, but is not meant to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose; the main purpose of palliative care is to improve the quality of your life or help you feel as good as you can for as long as you can.

Sometimes the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemotherapy might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer.

At some point, you may want to think about hospice care. This is treatment that focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice is concerned with your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health problems. You can learn more about hospice in our document called *Hospice Care*.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends – times that are filled with joy and meaning. Pausing at this time in your cancer treatment gives you a chance to focus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

# What's new in myelodysplastic syndrome research?

# Genes and biology of MDS

Research on the causes and treatment of myelodysplastic syndrome (MDS) is being done at many cancer research centers. Scientists are making progress in learning how changes in a person's DNA can cause normal bone marrow cells to become cancer.

Scientists are also learning how cells called *stromal cells* affect MDS cells. Stromal cells are found in the bone marrow, but they do not develop into blood cells. Instead, they help support, nourish, and control the blood-forming cells. Recent studies suggest that although the stromal cells in MDS patients are not cancer, they are not normal either, and they seem to have a role in causing MDS.

As more information unfolds, it might be possible in the future to use gene therapy. In this approach, the abnormal DNA of cancer cells is replaced with normal DNA to restore normal control of cell growth.

# Chemotherapy

New drugs that have fewer side effects (chemo drugs as well as other kinds of drugs) are being studied. Research is also going on to see if there is a group of patients that may benefit from more intense chemo.

# Immune suppression

For some patients, blocking the patient's immune system seems to help. The drug alemtuzumab (Campath), which suppresses the immune system, was helpful in a recent study in MDS. .

# Targeted therapy

Targeted therapy is a newer type of cancer treatment that uses drugs or other substances to find and attack cancer cells while doing little damage to normal cells. Each type of targeted therapy works differently, but all alter the way a cancer cell grows, divides, repairs itself, or interacts with other cells.

# Stem cell transplant

Scientists continue to refine stem cell transplants. They hope to improve how well transplant works, reduce side effects, and learn which patients are most likely to be helped by this treatment.

# Drugs to help blood counts

Romiplostim (Nplate<sup>®</sup>) is a new drug that raises platelet counts. It is approved to treat patients who have a disease in which their immune system attacks and destroys their platelets, but in more recent studies it has helped raise platelet counts in people with MDS.

# More information about myelodysplastic syndrome

# From your American Cancer Society

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345.

Myelodysplastic Syndrome Detailed Guide

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

**Blood Donation and Transfusion** 

Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants) (also available in Spanish)

Caring for the Patient With Cancer at Home (also available in Spanish)

Infections in People With Cancer

Leukemia: Acute Myeloid (Myelogenous)

Second Cancers Caused by Cancer Treatment

Understanding Chemotherapy: A Guide for Patients and Families (also available in Spanish)

When Cancer Doesn't Go Away

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at cancer.org/cancer/bookstore to find out about costs or to place an order.

# National organizations and Web sites\*

Along with the American Cancer Society, other sources of information and support include:

#### Aplastic Anemia & MDS International Foundation, Inc.

Toll-free number: 1-800-747-2820

Web site: www.aamds.org

#### **Be the Match (formerly National Marrow Donor Program)**

Toll-free number: 1-800-MARROW2 (1-800-627-7692)

Web site: www.bethematch.org

#### The Leukemia & Lymphoma Society

Toll-free number: 1-800-955-4572

Web site: www.lls.org

#### The Myelodysplastic Syndromes Foundation, Inc.

Toll-free number: 1-800-MDS-0839 (1-800-637-0839)

Web site: www.mds-foundation.org

#### **National Cancer Institute**

Toll-free number: 1-800-4-CANCER (1-800-422-6237)

Web site: www.cancer.gov

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

Last Medical Review: 11/12/2012

Last Revised: 11/12/2012

2012 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society 1-800-227-2345 or <a href="www.cancer.org">www.cancer.org</a>

<sup>\*</sup>Inclusion on this list does not imply endorsement by the American Cancer Society