Myelodysplastic Syndromes 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 website 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*.

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*. 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 are myelodysplastic syndromes?

Myelodysplastic syndromes (MDS) are 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 pieces of cells. They are needed for the blood to clot. They help plug up damaged areas of blood vessels caused by cuts or bruises.

Myelodysplastic syndromes

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 abnormal blood cells die sooner than normal 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. The group depends on how the cells of the blood and bone marrow look under a microscope and the presence of certain changes in the chromosomes of those cells. Because the differences can be very small, doctors might 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 syndromes?

There are about 13,000 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.

What are the risk factors for myelodysplastic syndromes?

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 patients, the cause is unknown.

Certain factors are linked to an increased risk of MDS:

- Earlier cancer treatment, such as chemotherapy, radiation, and stem cell (bone marrow) transplants
- Certain genetic syndromes
- Family history – MDS is more common in some families

- Smoking
- Radiation (like from an atomic bomb blast or nuclear reactor accident)
- Workplace exposure to certain chemicals
- Age (MDS is more common as people age)
- Gender (MDS is more common in men than in women)

More details about these risk factors can be found in our longer document, *Myelodysplastic syndromes*.

Can myelodysplastic syndromes be prevented?

Not smoking can lower the risk of getting myelodysplastic syndromes (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 in the workplace. But most people with MDS do not have any known exposure to these substances.

Signs and symptoms of myelodysplastic syndromes

Myelodysplastic syndromes (MDS) can cause many signs and symptoms such as weight loss, fever, and loss of appetite. These problems, however, 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 fever.
- A shortage of platelets can cause easy bruising and bleeding.

How are myelodysplastic syndromes found?

Sometimes a myelodysplastic syndrome (MDS) is suspected because of abnormal results on blood tests ordered because of some other problem. At this time, though, no special tests are used to look for MDS in people without symptoms.

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

The procedures to remove samples of bone marrow samples are called *bone marrow aspiration* and *biopsy*. Most often, these 2 tests are done at the same time. The bone marrow usually is removed from the back of the hip (pelvic) bone. You lie on a table (either on your side or on your belly) and a large needle is used to suck out bone marrow (the aspiration). Then a different needle is used to remove a small cylinder of bone (the biopsy). The skin and the bone are numbed before the bone marrow is removed. Sometimes medicine to make you sleepy is given as well.

A doctor with special training will look at the bone marrow cells under a microscope to see if they look abnormal. The doctor is also looking to see how many *blasts* are in the bone marrow. 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. Some patients with MDS have more blasts than normal, but if they have more than 20% blasts in the bone marrow they actually have acute leukemia and not MDS.

The bone marrow will also be sent for tests of chromosomes or genes. This is needed to help the doctor learn what kind of MDS is present as well as the patient’s outlook.

For more information about the tests that are used to diagnose MDS, see our document *Myelodysplastic Syndromes*.

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

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

- The percentage of 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

Doctors often use survival rates 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 might not find the numbers helpful, or might even not want to know them. If you decide 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 developed since then could 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%

* 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.

General information about treatment

Myelodysplastic syndromes (MDS) are 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)
- Immunotherapy
- Growth factors
- Supportive therapy
- Stem cell transplant

Often, a combination of these is used.

It is important to discuss all of your treatment options, including their goals and possible side effects, with your doctors to help make the decision that best fits your needs. It's also very important to ask questions if there is anything you're not sure about. You can find some good questions to ask in the section, "What are some questions I could ask my doctor about myelodysplastic syndromes?"

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.

Conventional chemo

Cells that are dividing are most affected by conventional chemo drugs. This includes cancer cells (such as myelodysplastic syndrome cells) but also some normal cells.

Myelodysplastic syndrome can turn into acute myeloid leukemia, and it can be treated the same way (with the same drugs at the same doses). This treatment wipes out the bone marrow for a time, in the hope that the abnormal stem cells will die and the normal bone marrow will grow back. This 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 some of the same chemo drugs, but at lower doses. This approach is less likely to make the MDS go away, but has a lower chance of serious side effects.

Common short-term side effects of chemo can include:

- Hair loss
- 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.

Shortages of white blood cells can lead to serious infections and patients are often given antibiotics right away if they have a fever or other symptom of infection. For more information about infections and ways to protect against them, see our document *Infections in People With Cancer*.

Transfusions may be needed to treat low platelet or red blood cell counts. More information about transfusions can be found in our document *Blood Transfusion and Donation*.

More information about specific chemotherapy drugs used to treat MDS can be found in our document, *Myelodysplastic Syndrome*.

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 can have some of the same side effects as conventional chemo drugs, 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)

Because the side effects are milder, hypomethylating agents are used much more often than conventional chemo in the treatment of MDS. More information about these drugs can be found in our document *Myelodysplastic Syndromes*.

More information about specific chemotherapy drugs used to treat MDS can be found in our more detailed document, *Myelodysplastic Syndrome*. If you'd like more information on a drug used in your treatment, see our Guide to Cancer Drugs , or call us with the names of the medicines you're taking.

Our document *A Guide to Chemotherapy* has general information about chemo and its side effects.

Immunotherapy 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

myelodysplastic syndromes (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
- Serious 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. The drugs used most often are *anti-thymocyte globulin* (ATG) and *cyclosporine*. ATG must be given in the hospital because it can sometimes cause severe allergic reactions leading to low blood pressure and problems breathing.

Cyclosporine is taken by mouth. 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.

For more information about immunotherapy for MDS, see our more detailed document, *Myelodysplastic Syndromes*.

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 myelodysplastic syndromes (MDS), so giving growth factors can help some patients. Different growth factors are used, depending on the patient's situation.

Our document *Myelodysplastic Syndromes* has more detailed information about the use of growth factors in MDS.

Supportive treatment for myelodysplastic syndrome

For many patients with myelodysplastic syndromes (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. Drugs 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.

See the "To learn more about myelodysplastic syndromes" section for documents with more detailed information.

Stem cell transplant for myelodysplastic syndrome

A stem cell transplant (SCT) is the only treatment that can cure myelodysplastic syndromes (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 – the best donor is a close relative such as 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.

Wiping out the bone marrow with high doses of chemo can lead to many severe and even life threatening side effects. This can make a regular allogeneic transplant too hard to take for older patients. A special type of transplant, called a *mini-transplant* (or a *non-myeloablative allogeneic stem cell transplant*) can sometimes be used instead. It differs from the standard approach in that *low* doses of chemo or radiation are used. It relies on the donor stem cells to kill the patient's cancer cells. The lower doses of chemo make it easier on patients who are older. Side effects, though, are still a major problem with this low-dose method.

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 website or get a copy by calling 1-800-227-2345.

Clinical trials for myelodysplastic syndromes

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 website 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.

You must meet the requirements to take part in any clinical trial. If you do qualify for a clinical trial, you decide 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 website 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 websites 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. You can also check them out on the *Complementary and Alternative Medicine* section of our website.

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 syndromes?

We encourage you to have honest, open discussions with your doctor about your condition. Ask any question 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. Keep in mind, too, that doctors are not the only ones who can give you

information. Other health care professionals, such as nurses and social workers, may have the answers to your questions. You can find more information about communicating with your health care team in our document *Talking With Your Doctor*.

- What type of myelodysplastic syndrome (MDS) do I have?
- What is my prognostic score and what does that mean?
- 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?

Here is space to add your own questions below:

Moving on after treatment for a myelodysplastic syndrome

Since a 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 go to all follow-up visits. The doctor will physically exam you, 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 your 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. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. 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
- If you were treated with a drug therapy (such as chemotherapy, hypomethylating drugs, immunotherapy, or growth factors), 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.

For more information about nutrition, see our document *Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families.*

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 a 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 documents called *Hospice Care* and *Nearing the End of Life*.

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 syndromes (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®) is a newer 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.

To learn more information about myelodysplastic syndromes

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Dealing with diagnosis and treatment

Health Professionals Associated With Cancer Care

Talking With Your Doctor (also in Spanish)

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

Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families (also in Spanish)

Coping With Cancer in Everyday Life (also in Spanish)

Family and caregiver concerns

Talking With Friends and Relatives About Your Cancer (also in Spanish)

Helping Children When A Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

What It Takes to Be a Caregiver

Insurance and financial issues

In Treatment: Financial Guidance for Cancer Survivors and Their Families (also in Spanish)

Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

More on cancer treatments

Understanding Cancer Surgery: A Guide for Patients and Families (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

Clinical Trials: What You Need to Know

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

Cancer treatment side effects

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also in Spanish)

Infections in People With Cancer

Distress in People With Cancer

Anxiety, Fear, and Depression

Nausea and Vomiting

Guide to Controlling Cancer Pain (also in Spanish)

Pain Diary

Anemia in People With Cancer

Fatigue in People With Cancer

Myelodysplastic Syndromes Detailed Guide

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

Blood Donation and Transfusion

Infections in People With Cancer

Leukemia: Acute Myeloid (Myelogenous)

Second Cancers Caused by Cancer Treatment

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 webites*

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
Website: www.aamds.org

Be the Match (formerly National Marrow Donor Program)
Toll-free number: 1-800-MARROW2 (1-800-627-7692)
Website: www.bethematch.org

The Leukemia & Lymphoma Society
Toll-free number: 1-800-955-4572
Website: www.lls.org

The Myelodysplastic Syndromes Foundation, Inc.
Toll-free number: 1-800-MDS-0839 (1-800-637-0839)
Website: www.mds-foundation.org

National Cancer Institute
Toll-free number: 1-800-4-CANCER (1-800-422-6237)
Website: www.cancer.gov

**Inclusion on this list does not imply endorsement by the American Cancer Society*

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.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org