TREATMENT UPDATE:

# Myelodysplastic Syndromes (MDS)

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# Treatment Update: Myelodysplastic Syndromes (MDS)

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*Myelodysplastic Syndromes (MDS) are a group of disorders in which the bone marrow does not produce enough healthy blood cells. Most people diagnosed with MDS are over the age of 65, but MDS can also occur in younger patients.*

Bone marrow is the spongy tissue inside bones where blood cells are made. Blood cells include white blood cells that fight infection, red blood cells that carry oxygen and platelets that help with blood clotting.

## Symptoms

Most early-stage cases of MDS do not cause signs or symptoms. Over time, symptoms may include:

- Fatigue
- Shortness of breath
- Pinpoint-sized red spots just beneath the skin
- Pallor (paleness) caused by a low red blood cell count (anemia)
- Frequent infections caused by a low white blood cell count (leukopenia)
- Unusual bruising or bleeding caused by a low blood platelet count (thrombocytopenia)

# Diagnosis

If MDS is suspected, doctors will take a medical history and perform a physical examination. Blood tests will be conducted to determine the levels of red blood cells, white blood cells and platelets and to look for irregularities in their size, shape and appearance.

A bone marrow biopsy is typically performed during the diagnosis process. A small piece of bone, along with the marrow inside the bone, is removed and tested for abnormalities. Additionally, a small amount of liquid bone marrow is withdrawn using a thin needle and then examined.

Genetic testing (also called molecular testing) may also be conducted, examining for chromosome abnormalities and gene mutations occurring in MDS cells.

These tests can help identify the subtype of MDS and the risk of progression, which are factors in determining the best treatment approach.

# Treatment Options

People with MDS who are not exhibiting symptoms or whose blood counts are not low often don't receive treatment. Instead, their condition is monitored by their health care team through blood tests and physical exam, as well as a review of any symptoms that may be related to MDS. This monitoring is often referred to as "active surveillance" or "watch and wait."

If treatment is recommended, you and your doctor will discuss the approach that is right for you, based on your individual circumstances. A combination of treatments may be used to bring blood counts back to healthy levels.

## Medications

- **Growth-stimulating factors** are medications that increase the number of blood cells the body makes. Epoetin alfa (Epogen, Procrit) and darbepoetin alfa (Aranesp) are erythropoiesis-stimulating agents, a type of growth-stimulating factor that reduces the need for blood transfusions by increasing red blood cells. Filgrastim (Neupogen, Zarxio) increases white blood cells in people with certain types of MDS, helping to prevent infections.
- **Immunomodulatory drugs** are a type of immunotherapy used to treat certain types of cancer. The immunomodulatory drug lenalidomide (Revlimid) reduces the need for blood transfusions for people with MDS that is associated with the genetic abnormality del(5q).

- **Hypomethylating agents** are types of chemotherapy that affect certain genes within cells. Azacitidine (Vidaza) and decitabine (Dacogen) are hypomethylating agents used for the treatment of MDS, most often for people whose MDS has a higher International Prognostic Scoring System (IPSS-R) score. IPSS-R is a tool that assesses the risk of the MDS progressing.
- **Conventional chemotherapy** is the use of drugs to destroy cancer cells by stopping the ability of the cells to grow and divide. In July 2020, the U.S. Food and Drug Administration (FDA) approved Inqovi (the combination of decitabine and cedazuridine) for treatment of people with MDS. Other conventional chemotherapy drugs used to treat MDS are cytarabine (Cytosar-U), daunorubicin (Cerubidine) and darubicin (Idamycin).
- **Erythroid maturation agents** work by increasing the number and quality of red blood cells. In April 2020, the FDA approved uspatercept-aamt (Reblozyl) for the treatment of anemia in certain sub-groups of people with low to intermediate risk MDS.

## Blood Transfusions

Blood transfusions may be given to increase the levels of red blood cells or platelets. Transfusions may also be given if medications are being taken that have temporarily reduced the level of red blood cells or platelets.

A transfusion is typically a safe procedure. However, repeated transfusions of red blood cells can cause high iron levels in the body, which can damage the liver, heart or pancreas. Medications called chelating agents (taken in pill form) can help rid the body of excess iron through urine or stool.

## The Importance of Clinical Trials

**Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of individuals as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.**

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

# Treatment Side Effects

All cancer treatments can cause side effects. It’s important that you report any side effects that you experience to your health care team so they can help you manage them. Report them right away—don’t wait for your next appointment. Doing so will improve your quality of life and allow you to stick with your treatment plan. It’s important to remember that not all patients experience all side effects, and patients may experience side effects not listed here.

Some side effects may occur across treatment approaches. This section provides tips and guidance on how to manage these side effects should they occur.

## Managing Digestive Tract Symptoms

### *Nausea and vomiting*

- Avoid food with strong odors, as well as overly sweet, greasy, fried or highly seasoned food.
- Eat meals that are chilled, which often makes food more easily tolerated.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.

### *Constipation*

- As hydration is important to avoid constipation, make sure to drink plenty of fluids. Also, limit your intake of caffeine and alcoholic beverages, as they can cause dehydration.
- Include foods high in fiber in your daily diet, such as fruit (especially pears and prunes), vegetables and cereals. If your health care team approves, you may want to add synthetic fiber to your diet, such as Metamucil, Citrucel or FiberCon.
- Be as physically active as you can, after checking with your health care team on the level of physical activity that is right for you.
- If your doctor has prescribed a "bowel regimen," make sure to follow it exactly.

### *Diarrhea*

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose fiber-dense foods such as whole grains, fruits and vegetables, all of which help form stools.
- Avoid food high in refined sugar and those sweetened with sugar alcohols such as sorbitol and mannitol.

## Managing Loss of Appetite

- Eating small meals throughout the day is an easy way to take in more protein and calories, which will help maintain your weight. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna or trail mix.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

## Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. Here are a few tips that may help reduce fatigue:

- Take several short naps or breaks during the day.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.
- Save your energy for things you find most important.

There are also prescription medications that may help. Your health care team can provide guidance on whether medication is the right approach for your individual circumstances.

Fatigue can be a symptom of other illnesses, such as anemia, diabetes, thyroid problems, heart disease, rheumatoid arthritis or depression. Be sure to ask your doctor if they think any of these conditions may be contributing to your fatigue.

It can also be beneficial to speak with an oncology social worker or oncology nurse to help manage your fatigue. These professionals can work with you to manage any emotional or practical concerns that may be causing symptoms and help you find ways to cope.

## Managing Flu-Like Symptoms

The fever and aches that may occur with treatment can be managed with a combination of rest and medication. Acetaminophen (such as Tylenol) is often a doctor's first choice to treat these symptoms. Nonsteroidal anti-inflammatory drugs (NSAIDs) can also help, but should be taken only if recommended by your doctor, as they can cause other side effects. NSAIDs include aspirin, ibuprofen (Motrin and others) and naproxen (Naprelan, Midol, Aleve and others). Report a fever to your doctor immediately, as it could be sign of infection and require emergency treatment.

# Communicating With Your Health Care Team

As you manage your MDS, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

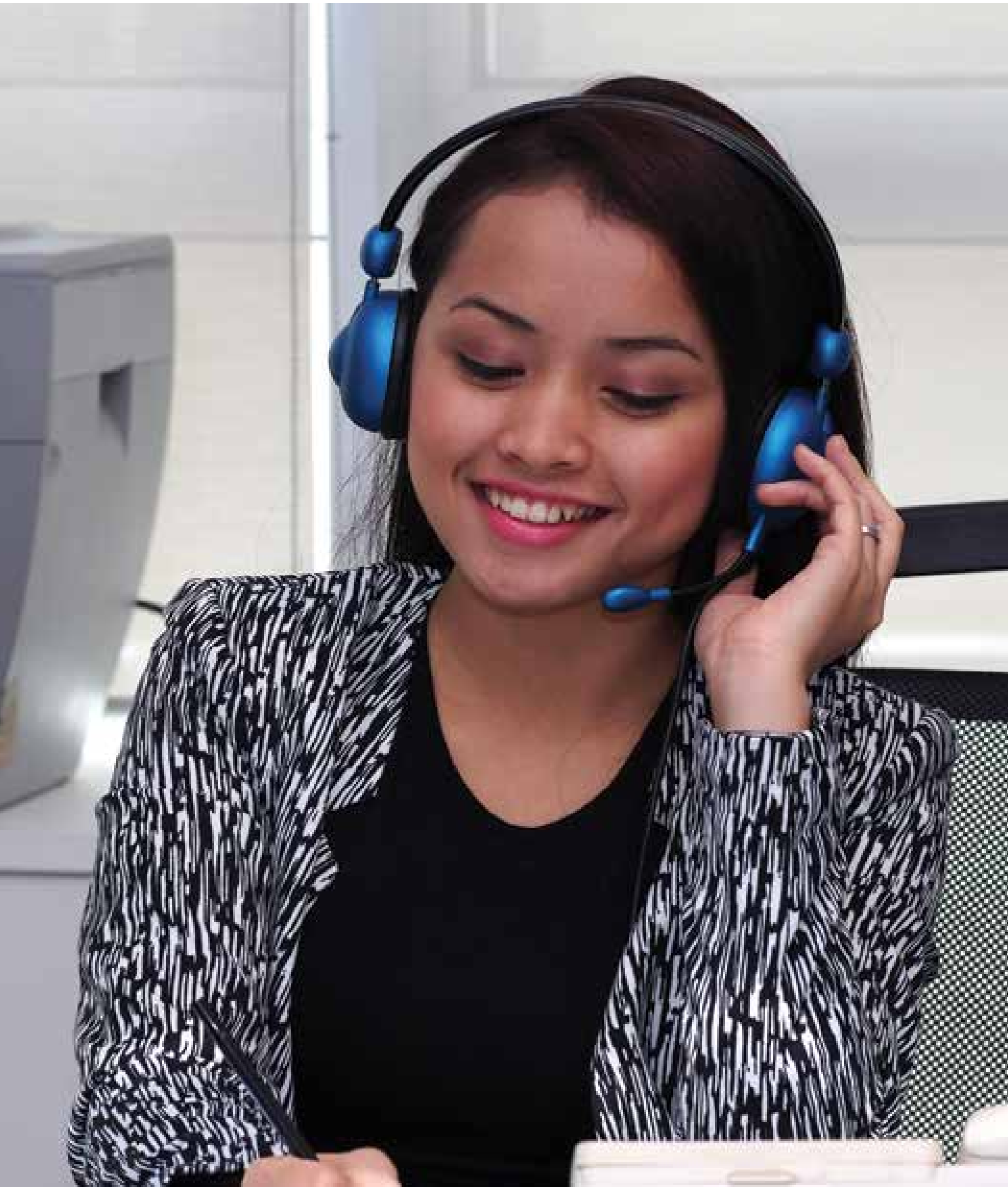
**Start a health care journal.** Having a health care journal or notebook (either on paper or in a digital format) will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor.

**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, ask your most important questions first and be as specific as possible.

**Bring someone with you to your appointments or have them be present during telemedicine sessions.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person you bring may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. You can also ask the person who accompanies you to take notes for you. If you have a mobile device, ask if you can use it to take notes. Keeping notes will help you review the information later.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends.



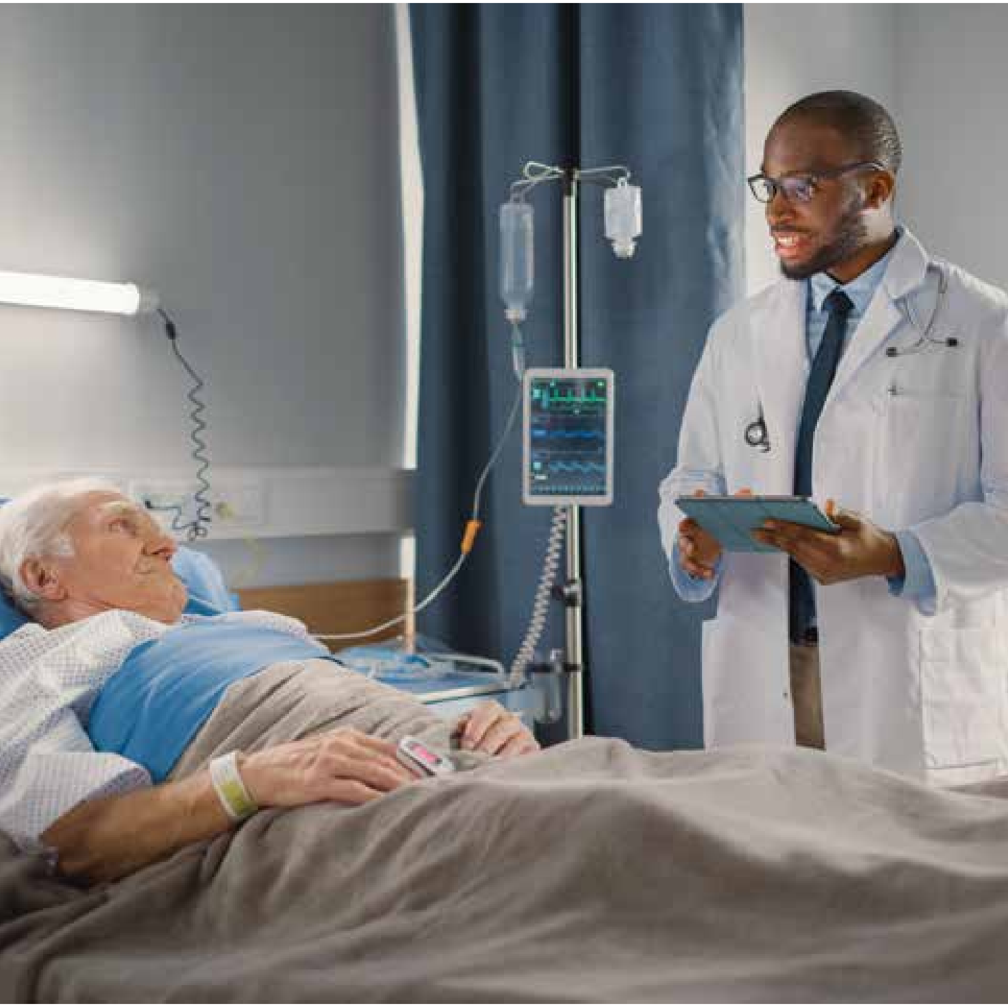
# Cancer*Care*'s Free Support Services and Programs

It can be very difficult to receive a diagnosis of MDS, and adjusting to the necessary changes in your life can be challenging.

Cancer*Care*® can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system and offer information on support groups and other resources.

To learn more about how Cancer*Care* helps, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

You will likely also build your own personal support network composed of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store, or ask a friend who's a good listener to come over for a chat.



MORE ABOUT MYELODYSPLASTIC SYNDROMES (MDS)

# Frequently Asked Questions

**Q: Is a bone marrow transplant a treatment option for MDS?**

A: A bone marrow transplant is a procedure in which diseased bone marrow is replaced with healthy bone marrow.

While bone marrow transplant may be an option for some people with MDS, it is a complex procedure with significant risks. It is typically only considered as a treatment option for higher risk MDS and for patients in relatively good health.

In the procedure, stem cells are harvested (collected) from the patient or from a donor and then stored. The patient is given high doses of chemotherapy to destroy as many unhealthy cells as possible. The stem cells are then "infused" (transplanted) into the body, where they travel to the bones and begin rebuilding bone marrow.

When a person with MDS receives their own stem cells, the procedure is called an "autologous" stem cell transplant. The procedure is known as an "allogeneic" stem cell transplant if the stem cells are from a donor (either a close relative, such as a brother or sister, or a donor from a registry).

Immunosuppressive therapy may be used to lower the risk of the bone marrow transplant being rejected by the body. This regimen consists of a combination of anti-thymocyte globulin (ATG) and cyclosporine.

### Q: What other health care professionals should I incorporate into my care team?

A: Your medical oncologist is an essential member of your health care team, but there are other health care professionals who can help you manage your diagnosis and treatment:

- Your primary care physician should be kept updated about your MDS treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking. Have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncologist knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care physician or your specialist if needed.
- Ask your oncologist to send a summary of your visits to your primary care physician and all doctors involved in your care.

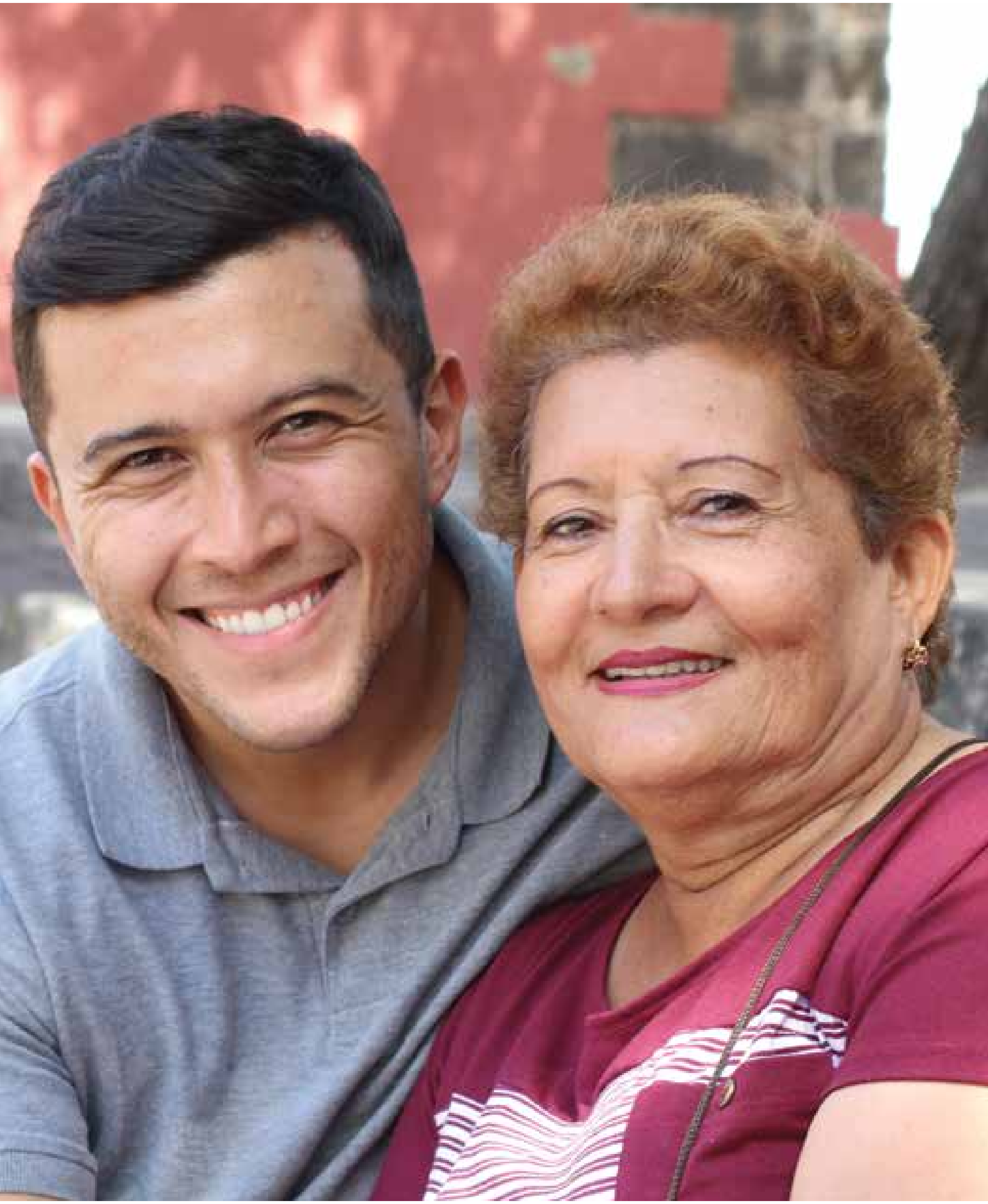
Remember, there is no such thing as over-communication.

### Q: What is a treatment summary and why is important?

A: Keeping your own records up-to-date in the form of a treatment summary can be helpful, as it allows you and your family members to have instant access to the specifics of your MDS diagnosis and treatment. A treatment summary should include:

- Your name and date of birth
- Date of diagnosis
- Prescribed therapy/therapies, including dates started and stopped and dosages when appropriate
- Dates and types of baseline and post-diagnosis testing and the results of these tests
- Other medications and supplements you are taking
- Blood transfusion dates and results
- Names, affiliations and contact information of all members of your health care team

Ask the members of your health care team what they suggest be included. Take your personal record with you when you visit any doctor, not just your oncologist.



# Resources

**Cancer*Care*®**
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www.cancercare.org

**American Cancer Society**
800-227-2345
www.cancer.org

**Cancer.Net**
Patient information from the American Society of Clinical Oncology
888-651-3038
www.cancer.net

**The Leukemia & Lymphoma Society (LLS)**
888-557-7177
www.lls.org

**MDS Foundation**
800-637-0839
www.mds-foundation.org

**Medicine Assistance Tool**
www.medicineassistancetool.org

## CLINICAL TRIALS WEBSITES

**ClinicalTrials.gov**
www.clinicaltrials.gov

**EmergingMed**
www.emergingmed.com

**National Cancer Institute**
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