Background and Process

An Institute of Medicine (2004) report defined health literacy as “the degree to which individuals can obtain, process, and understand basic health information and services they need to make appropriate health decisions” (p. 1). Readers of easy-to-read materials are not limited to those with little education, those who speak English as a second language, and children. Most adults with low health literacy are white, native-born Americans (Parker, Ratzan, & Lurie, 2003). Individuals who need easy-to-read materials are in every race, ethnic, age, and income group.

Patients with cancer may have an increased risk of cognitive dysfunction compared with those who have never had the disease (Heflin et al., 2005). Cognitive dysfunction is a frequent finding in people with cancer, but it may go unnoticed. Cognitive problems result from many causes, including the direct effects of cancer on the central nervous system, indirect effects of certain cancers, and effects of cancer treatment on the brain. Mental and emotional aspects of dealing with a cancer diagnosis (e.g., information overload, stress of living with a lack of predictive information and making treatment decisions, changes in schedule, anxiety, fear, financial pressure) also play a role.

People with limited health literacy generally have lower medication compliance rates, higher hospitalization rates, and worse health outcomes (Williams, Davis, Parker, & Weiss, 2002); therefore, the society’s easy-to-read materials are written to encourage and enable communication between patients and providers, as well as between patients and families, to motivate patients to follow health advice and reduce anxiety by helping them gain a sense of control. Approximately 153,000 easy-to-read English- and Spanish-language booklets have been distributed to date through the society’s Information Resource Center, its 68 chapters, and community health and cancer treatment facilities.

The initial draft of the myeloma booklet was based on the content of the society’s existing comprehensive myeloma booklet, which is updated regularly with the most recent diagnostic, treatment, and research information, for example Williams Hematology’s myeloma chapter (Barlogie, Shaughnessy, & Epstein, 2006). Many patients find the comprehensive booklet to be a valuable source of accurate and detailed information. However, for a considerable number of patients, especially the newly diagnosed, it is not the ideal resource because of its length and detail. The easy-to-read version presents the information over 32 pages, emphasizing key points about myeloma and its treatment in plain language, including brief explanations of medical terms, and incorporating graphics to convey ideas. The society’s patient services staff and medical director reviewed the draft for medical accuracy.
The patient handout that follows this article is based on text from the easy-read booklet *Myeloma: A Guide for Patients and Caregivers*. It provides an example of content and word choice; however, layout and fonts are as important to easy-read material as content and word choices and are not reflected in the example. See the easy-to-read booklet for that information.

### Lessons Learned

Fortunately, the number of easy-to-read patient-centered health materials is growing. Several resources are excellent guides for creating easy-to-read health materials (see Figure 1). In addition, the list that follows is practical information for creating easy-to-read materials that the society has learned so far. The suggestions are geared toward healthcare professionals in primary patient care.

- Have one specific main objective or focus to easily identify needed and unnecessary information. (For example, identify the information most readers need to communicate with their providers about treatment. Then, determine how, where, and when to direct subsets of readers who will want more detail on specific topics.)
- Organize the information like a conversation. (Is the piece organized like a text for nursing students or does it mirror the flow of a discussion with patients and family?)
- Step back and think about each page’s organization and how each page flows into the next. (Keep mutually supporting concepts on the same page or “spread” [two facing pages].)
- Avoid using words with more than one meaning. (For example, use the phrase “friends and family” instead of “close friends and family.”)
- Educate the organization. (Creating health-literate material is usually a culture change. Make others in the organization aware of the goals of easy-to-read information and methods to generate feedback in keeping with the goals and to minimize comments that are not appropriate for an easy-to-read piece [e.g., “stated in a previous section” when your intention was to repeat the information to make it clearer for readers].)
- Listen to patient-reviewer feedback. If readers cannot easily find the content they want, consider it not included. (Avoid such situations by incorporating resources such as definitions and organizational contact information into the text rather than in appendices.)

In the final analysis, when feedback is received such as, “I never understood this before and now I do” and “I could use this information to talk to my doctor,” the society knows it is on the right track. However, comments such as, “Aren’t you smart? There’s so much to know about this, isn’t there?” are cues to the patient education team that the content needs revision.

### Conclusion

Many patients and caregivers do not remember much information given when they first learn of a cancer diagnosis. Yet they are expected to make treatment decisions when they may be least able to cope. The challenges of helping them grasp complex information are likely to keep transforming with changes in healthcare delivery, treatments, and technologies for monitoring treatment responses. The quality of patient decisions can affect treatment adherence, quality of life, and even health outcomes (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). Therefore, frequent updates of patient education materials are critical, not only to provide current medical information but also to incorporate better ways to foster health literacy. Ongoing research is needed to identify the most effective ways to help patients to become health literate. Many of the answers will come from the experiences of newly diagnosed patients, survivors, and their caregivers, combined with the vision and skills of healthcare providers and health educators.

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### References

Myeloma: What Patients and Caregivers Need to Know

This is a hopeful time for patients with myeloma. There is no cure for the disease, but more treatments are available today and new treatments are being studied.

Myeloma is a cancer of plasma cells. Plasma cells are part of the body’s immune system (cells and proteins that defend the body against infection). Myeloma starts with a change to a single cell called a B lymphocyte (a type of white blood cell).

Some patients feel well in the early stage of myeloma; they may find out they have the disease after a healthcare checkup. Other people have bone pain, bone fractures with no known cause, or low red blood cell counts.

Here is some information to help you understand your disease and treatment.

Bone Marrow, Blood, and Blood Cells

Bone marrow is the spongy center inside bones.

Blood cells are made in the marrow. Blood cells begin as stem cells and become red cells, white blood cells, and platelets in the marrow. The red cells, white cells, and platelets then enter the blood.

The bone is also made up of plasma. Plasma is mostly water. It also has some vitamins, minerals, proteins, hormones, and other natural chemicals.

Platelets prevent bleeding and form plugs that help stop bleeding after an injury.

Red cells carry oxygen around the body. When the number of red cells is below normal, it is called anemia. Anemia can make you tired, pale, or short of breath.

White cells fight infection in the body. Lymphocytes are a type of white cell and can be B lymphocytes, T lymphocytes, or natural killer cells. All of these cell types help fight infection.

Plasma cells are part of the body’s immune system. Plasma cells make antibodies to help fight infection.

B lymphocytes usually become normal plasma cells. In myeloma, the change to a B lymphocyte causes a normal plasma cell to become a myeloma cell. Myeloma cells cannot help the body fight infection like normal plasma cells. As the myeloma cells grow in the marrow, they crowd out the normal plasma cells. They also crowd out other normal blood cells.

Facts About Myeloma

Doctors do not know the causes of most cases of myeloma, and there is no way to prevent it. You cannot catch myeloma from someone who has it. Most people with myeloma are age 50 and older. Americans of African descent get myeloma about as often as Americans of European descent. People of Asian and Hispanic descent have low rates of myeloma.

Types

There are different types of myeloma, but multiple myeloma is the most common type. With multiple myeloma, the disease is in many areas of the body. Rarely, people have solitary myeloma (myeloma in one area). Some people have a single clump of myeloma cells outside the marrow, which is called an extramedullary plasmacytoma. Extramedullary means that the mass of myeloma cells is outside the bone marrow. Plasmacytomas can form in the skin, muscle, lungs, or almost any other part of the body.

Some cases of myeloma take a long time to grow. These cases are described as smoldering or indolent myeloma. Sometimes doctors decide not to treat patients with smoldering or indolent myeloma right away; but, in most cases, treatment is needed at some point during the disease.

Physical Exams and Lab Tests

Medical Tests to Look for Signs of Myeloma
- Bone marrow biopsy
- Blood and urine tests
- Imaging tests: x-rays (skeletal surveys), computed tomography (CT) scans, magnetic resonance imaging (MRI), positron emission tomography (PET) scans

A bone marrow biopsy shows if myeloma cells are in the patient’s marrow. This test may be done in a doctor’s office or a hospital. First, the patient gets an injection to numb the skin. Once the skin is numb, a needle is used to remove a small amount of marrow from the hip bone or breast bone. The marrow is looked at under a microscope to see if there are myeloma cells.

Lab tests are done to see if M protein or M spike is in the patient’s plasma and urine. M protein (M is for monoclonal) is an abnormal protein made by myeloma cells. The amount of M protein is one of the ways to estimate the stage (the extent) of myeloma. Another protein called light chains can be found in the patient’s urine. This protein is also called Bence-Jones protein.

Other tests to find myeloma are called imaging tests. X-rays of areas of bone pain; x-rays of the skull, spine, and ribs (skeletal surveys); MRIs; and CT and PET scans are types of imaging tests. X-rays and CT scans are used to see if there are any holes, breaks, or thinning of the bones. MRIs and PET scans look for changes to the bone marrow and pockets of myeloma cells.

Infections and Other Problems

Patients with myeloma may have problems from their disease.

Infections: Patients with myeloma may have more infections because myeloma cells do not make antibodies to fight infection. Patients should follow the advice of their healthcare provider about how to reduce their risk. Antibiotics may be given to treat infections.

Bone pain: Myeloma may cause bone pain. Drugs called bisphosphonates (pamidronate or zoledronic acid) may help.

Kidney problems: Patients with myeloma have a protein called light chains or Bence-Jones protein. The patient may also have high levels of calcium in the blood. Each of these can damage the kidneys. The doctor will check the patient’s kidneys.
Acute myelogenous leukemia (AML): A small number of patients develop another disease called AML.

Treatment Goals
There are more treatments for myeloma available today. The goals of treatment are:
- To slow the growth of the myeloma cells
- To help patients who have bone pain, fatigue, or other problems from their disease to feel better.

Treatments
The best treatment for a patient depends on the type and stage of myeloma, the patient’s age, and the patient’s overall health.

Many doctors use a staging system (stage I, II, or III) to help plan myeloma treatment.

How Is a Treatment Plan Made?

Lab and imaging tests are done to stage (measure the extent of) myeloma.

The amount of M protein in the blood and urine is measured. This protein is made by the myeloma cells. Doctors check how many parts of the bones are affected by the myeloma. In addition, doctors check:
- Blood counts of red or white cells may be lower than normal with myeloma.
- Blood calcium levels may be higher than normal with myeloma.
- Blood beta 2-microglobulin levels may be higher than normal with myeloma. Beta 2-microglobulin is a protein found on the surface of plasma cells and some other cells.
- Albumin (a protein in the blood) may be lower than normal.

Doctors also use lab tests such as a fluorescence in-situ hybridization test to see if there are changes to chromosomes of the myeloma cells. Every cell in the body has chromosomes that carry genes. Genes give instructions that tell each cell what to do.

Treatments for myeloma include:
- Drugs that kill or damage cancer cells: Some chemotherapy or other drugs are given by mouth. Other drugs are given through a vein. A small needle is placed in the arm (called an IV). Chemotherapy can result in a good period of remission for some patients.
- A combination of treatments: Most patients get two or more drugs that are often used together. Some combinations are melphalan and prednisone with thalidomide, lenalidomide, or bortezomib. Patients may be treated with other combinations such as thalidomide and dexamethasone. Several other drug combinations are also used.
- Certain drugs that can increase red cells: Erythropoietin (epoetin alfa) and darbepoetin alfa are drugs that may help certain patients with anemia.
- Radiation therapy (treatment with x-rays or other high-energy rays): It may be used to treat patients with solitary myeloma.

Radiation therapy may also be used to treat a clump of myeloma cells (a plasmacytoma) outside the marrow.

Doctors are testing new drugs and new combinations of drugs to treat myeloma. Doctors are also testing new ways to use drugs that are already approved. For example, changing the amount of the drug or giving it with another type of treatment might be better.

Some Drugs Used to Treat Myeloma
Bortezomib is given by injection. It is used in patients who have tried at least one other treatment that has not helped. Bortezomib is also being used in clinical trials (research studies) as a first-line treatment alone or in combination with other drugs such as thalidomide.

Thalidomide is given by mouth. Thalidomide is used with dexamethasone to treat newly diagnosed patients with myeloma. It is also being studied together with other drugs.

Lenalidomide is a drug like thalidomide. It may be safer and work better for patients with myeloma. The drug is used with dexamethasone to treat patients who have already had at least one other type of treatment.

Arsenic trioxide is given by injection. It is being tested in clinical trials for patients who have relapsed or who have not responded to other treatment. It also is being tested with vitamin C and melphalan, which is called MAC therapy.

Other Treatments
New treatments are studied in clinical trials: The goals of new drug studies are to add years of good health to patients and to find a cure. To learn more about clinical trials, ask your doctor if a clinical trial might help you.

Radiation therapy and stem cell transplantation may also be used to treat myeloma.

The goal of high-dose drug therapy or radiation is to kill all myeloma cells. The treatments can also kill normal cells in the bone marrow. A stem cell transplantation is a treatment to help the patient’s bone marrow make new blood cells after high-dose drug or radiation therapy. Stem cell transplantation is a choice for some patients. This treatment is done in the hospital.

Having a stem cell transplantation depends on a number of things, such as:
- Other good treatment choices that are available for a particular patient
- The patient’s physical ability to handle a stem cell transplantation.

There are two main types of transplantation. When a patient’s own stem cells are used, it is called an autologous stem cell transplantation. This is the most common type for patients with myeloma. With a stem cell transplantation, stem cells are collected before drug therapy and are injected into the patient’s blood after drug therapy. The transplanted stem cells go to the marrow and help start a new supply of blood cells.

High-dose chemotherapy plus autologous stem cell transplantation is not a cure. It does give patients longer disease-free periods than standard-dose chemotherapy without a stem cell transplantation.

Another type of stem cell transplantation is called an allogeneic stem cell transplantation. With this type, stem cells from a donor are used. The donor can be a brother, sister, or another person with stem cells that “match” the patient’s.
Allogeneic stem cell transplantations are used less often to treat myeloma than autologous stem cell transplantations. Allogeneic stem cell transplantations are being studied in patients with myeloma younger than age 55 and in patients who are not doing well with other treatments.

**An allogeneic stem cell transplantation is a high-risk procedure.** For this reason, it is not a good treatment for all patients with myeloma. An allogeneic stem cell transplantation may be a good treatment for patients who are not doing well with other treatments if the expected benefits of a stem cell transplantation exceed the risks. For patients with myeloma, allogeneic transplantations are usually done as part of a clinical trial (research study).

Doctors are working to make stem cell transplantations safer. In the future, more patients with myeloma may be able to have stem cell transplantations.

Some types of stem cell transplantations under study are

- **A mini-transplantation:** A mini-transplantation uses lower doses of chemotherapy in combination with an allogeneic stem cell transplantation. This treatment is also called a nonmyeloablative transplantation. Older and sicker patients may be helped by this treatment.

- **Cord blood stem cell transplantation:** Stem cells are obtained from umbilical cord blood. One cord blood unit provides enough stem cells for a child or small adult. Clinical trials are ongoing using multiple cord blood units from more than one donor to make this stem cell resource available for average-sized adults.

- **Tandem transplantation:** A tandem stem cell transplantation is a treatment with two transplantations. A patient who has a tandem stem cell transplantation has one autologous transplantation and then a second autologous transplantation within six months. The goal of tandem transplantations is to eliminate the disease completely. **Another type of tandem transplantation** is under study. The first transplantation is an autologous stem cell transplantation. The second one is a mini-allogeneic stem cell transplantation.

**Treatment Side Effects**

Patients with myeloma should talk with their treatment team about side effects before they begin any type of treatment. The main effect of treatment for myeloma is to kill myeloma cells. The phrase side effect is used to describe how treatments affect healthy cells.

**Patients react to treatments in different ways:** Sometimes there are very mild side effects. Other side effects may be serious and last a long time. Some side effects of treatments are

- Upset stomach and vomiting
- Mouth sores
- Constipation
- Extreme tiredness
- Infections
- Low red cell count (anemia)
- Low white cell count
- Low platelet count
- Achy feeling
- Numb feeling in arms, hands, legs, or feet.

**Your doctor does tests to see if the treatment is working.** Tests are done throughout treatment. The test results help the doctor to decide if changes to treatment are needed. **Blood and urine tests** are done to check blood cell counts, kidney function, and growth of myeloma cells. **A bone marrow biopsy** is used to look at the amount and pattern of myeloma cells in the marrow. A bone marrow biopsy is also used to do a **cytogenetic analysis.** A cytogenetic analysis looks to see if there are changes to chromosomes of the myeloma cells. There may be too many, too few, or broken chromosomes.

**Imaging tests** (x-rays, CT scans, MRIs, and PET scans) are used to see if there are any holes, breaks, or thinning of the bones. MRIs and PET scans look for changes to marrow and pockets of myeloma cells.

**Response to Treatment**

The treatment team may use the following terms to talk about a patient’s response to treatment.

- **Remission** (response): no sign of disease
- **Complete remission** (response): no sign of M protein in the blood and urine; normal percent of plasma cells or no sign of myeloma cells in marrow
- **Partial remission** (response): more than a 50% decrease in M protein in the blood
- **Complete molecular remission** (response): no sign of myeloma cells in the marrow using very sensitive tests
- **Minimal response:** less than a 50% decrease in M protein in the blood
- **Progressive disease:** more than a 25% increase in M protein in the blood, new areas of bone damage, or a new clump of myeloma cells (plasmacytoma)

**Choosing a Doctor**

Choose a doctor who specializes in treating myeloma or have your local cancer specialist work with a myeloma specialist. Talk with the doctor about myeloma and how the doctor plans to treat the disease. This will help you to know more about the disease and treatment. It will help you to be involved and make decisions.

**Write down the answers to your questions and review them later.** You may want to bring a caregiver, family member, or friend with you to the doctor to listen, take notes, and give support. Some patients tape-record information from the doctor and listen to the tape at home.

**Take Care of Yourself**

Patients with myeloma can take care of themselves by doing the following.

- Patients with myeloma should talk with their caregivers, family, and friends about how they feel. They can share what they know about the disease.
- Keep all appointments with the doctor. Follow the doctor’s advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals.
- Contact your doctor if you have pain or other side effects, even if they occur between visits.
- Do not smoke. If you do, get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.

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