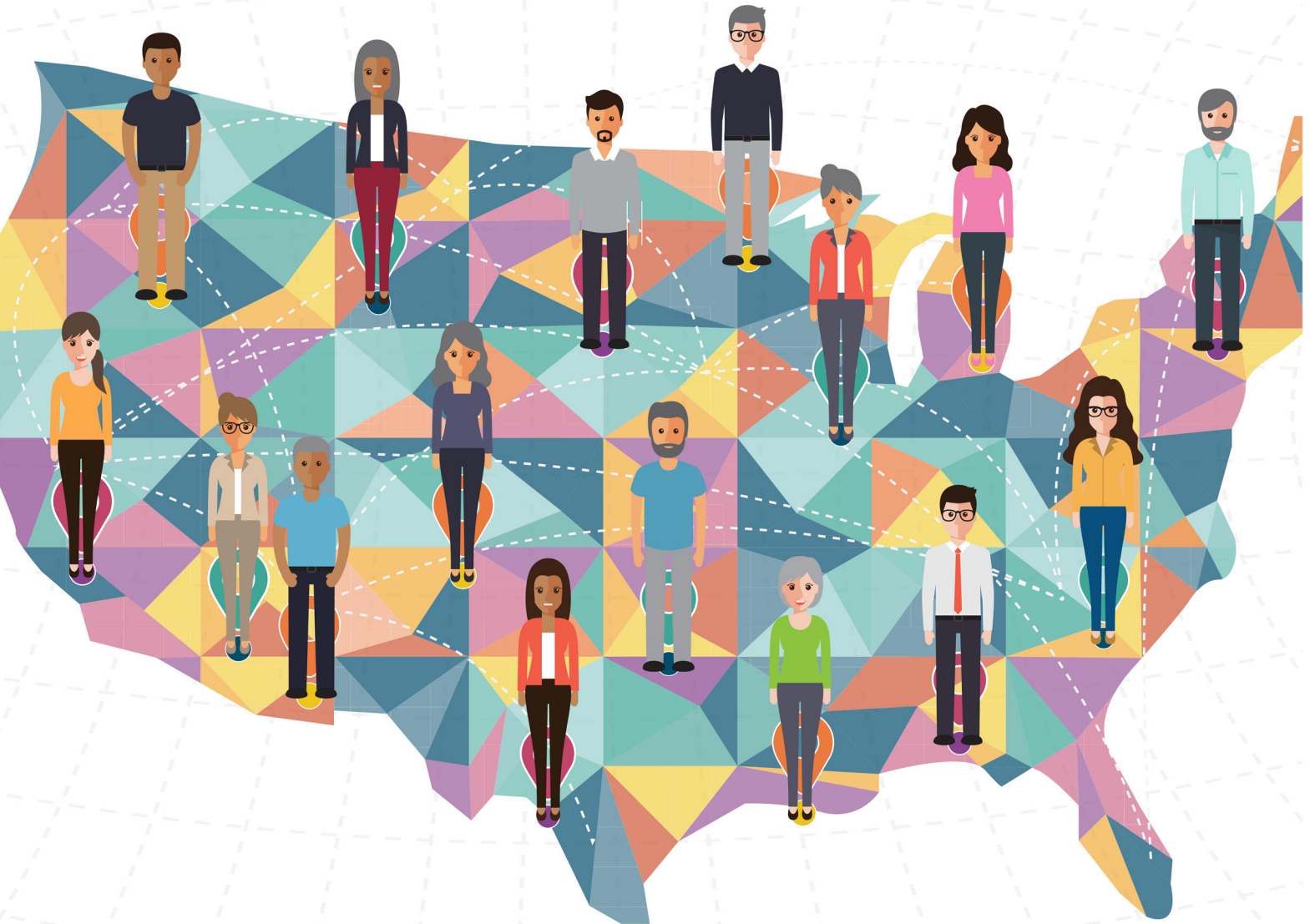


SPECIAL FEATURE

CONQUER[®]

the patient voice



CONQUERing Myeloma™

NAVIGATING YOUR JOURNEY



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CONQUERING Myeloma™

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Senior Vice President/Group Publisher
Russell Hennessy
rhennessy@the-lynx-group.com

Vice President/Director, Sales & Marketing
Joe Chanley
jchanley@the-lynx-group.com

Senior Editorial Director
Dalia Buffery
dbuffery@the-lynx-group.com

Associate Editor
Lara Lorton

Copy Editor
Adam Buffery

Production Manager
Cara Nicolini



President/CEO
Brian Tyburski

Senior Vice President/Group Publisher
Nicholas Englezos
nenglezos@the-lynx-group.com

Senior Vice President/Group Publisher
John W. Hennessy
jhennessy2@the-lynx-group.com

Senior Vice President, Sales & Marketing
Philip Pawelko
ppawelko@the-lynx-group.com

Vice President, Finance
Andrea Kelly

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Account Group Supervisor
Pamela Intile

In August 2017, Takeda Oncology assembled a roundtable meeting that included a distinguished panel of patients with multiple myeloma, caregivers, patient advocates, and nursing professionals. The roundtable meeting was convened to discuss the informational, logistical, and financial challenges faced by people with multiple myeloma and their caregivers, and to collaboratively identify actionable solutions that serve to improve the overall patient experience.

During the roundtable, panelists recommended development of a series of articles to support patients and caregivers, and enable better interpersonal dialogue with healthcare providers. The series, titled *CONQUERing Myeloma: Navigating Your Journey*, represents the culmination of those efforts.

The compendium features 5 key topics:

- I've Been Diagnosed with Multiple Myeloma—Now What?
- Choosing an Oncologist to Lead Your Treatment Team: Who Treats Multiple Myeloma?
- Taking an Active Role in Multiple Myeloma Treatment Decisions
- Making Sure Your Treatment Team Stays Connected
- Financial Planning Considerations for Patients with Multiple Myeloma

We hope you find *CONQUERing Myeloma: Navigating Your Journey* a valuable and useful resource in your efforts to learn about multiple myeloma and collaborate with your treatment team to decide on the course of care that best meets your individual needs.

I've Been Diagnosed with Multiple Myeloma—Now What?



JACK AIELLO
Patient Advocate
San Jose, CA



DEBORAH CHRISTENSEN, MSN, APRN-BC, AOCNS, HNB-BC
Oncology Nurse Navigator,
Intermountain Southwest
Cancer Center,
Dixie Regional Medical Center,
St George, UT



LORI PUENTE
Patient Advocate
Elk Grove, CA

No one is ready for the initial shock that comes with a diagnosis of cancer. The feelings that accompany a cancer diagnosis may be difficult to imagine beforehand, challenging to process as you hear and attempt to accept the news, and impossible to appreciate fully if you are not the individual who has just been diagnosed.

A diagnosis of multiple myeloma can be particularly tough to accept, in part because most people have never heard of this disease. Many questions may arise, such as: What is multiple myeloma? How did I get it? Can it be treated? What treatment options are available? How long do I have to live?

Multiple myeloma, which is sometimes shortened to “myeloma,” is a relatively rare type of

cancer, in which abnormal plasma cells (myeloma cells) in the bone marrow alter the development and functioning of other blood cells, including red blood cells, white blood cells, and platelets. Unlike breast cancer or lung cancer—2 types of solid tumors that are routinely mentioned in the news—multiple myeloma is a cancer of the blood. Physicians can feel a cancerous lump in a patient’s breast or see a lung tumor on an x-ray. However, multiple myeloma and other blood cancers typically cannot be seen or felt, and they cannot be removed by surgery.

Although multiple myeloma is not curable, researchers have made great strides in developing new treatments for this type of cancer in the past decade. Before the availability of new treatments, the average life ex-

pectancy of patients with multiple myeloma was 3 to 5 years. Today, based on the availability of novel treatments, and the increasing use of combination therapies, many patients with multiple myeloma are living longer.

LEARNING ABOUT MULTIPLE MYELOMA: KNOWLEDGE IS POWER

A wealth of information is now available at our fingertips, and patients who have been diagnosed with cancers such as multiple myeloma are tempted to jump on the Internet and find fast answers to their questions. However, they can quickly feel overwhelmed by the large amount of information available online and through social media, as well as from friends and family, healthcare providers, and advocacy groups.

The learning process can be daunting. Which sources are the most reliable, trustworthy, and up to date? How much information do you really need? Does knowledge about multiple myeloma really translate into power? The following organizations may offer up-to-date information about multiple myeloma:

- International Myeloma Foundation (www.myeloma.org)
- Multiple Myeloma Research Foundation (www.themmr.org)
- Leukemia & Lymphoma Society (www.lls.org)
- Myeloma Crowd (www.myelomacrowd.org).

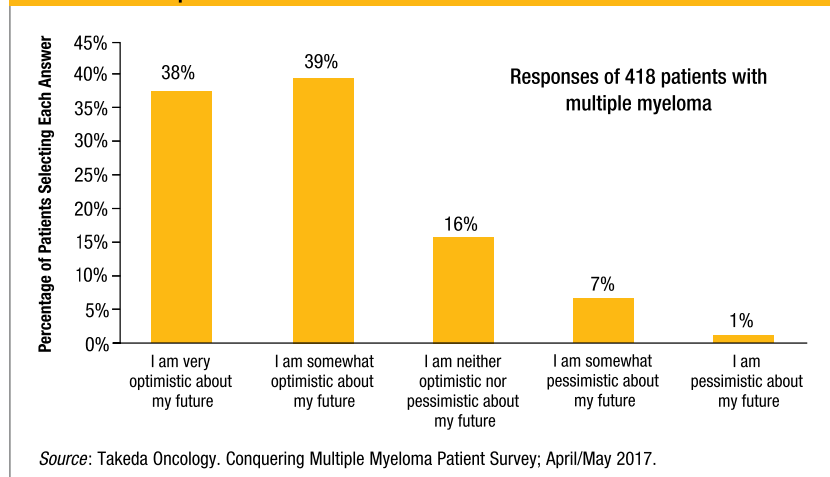
KNOWLEDGE LEADS TO OPTIMISM

“Don’t let the disease control you. You control the disease. It’s overwhelming at first, but gaining knowledge and speaking with other people can help you move forward,” wrote John W. Killip, DDS, a multiple myeloma survivor, in his article in *CONQUER* magazine (in August 2017).

An online survey conducted by Takeda Oncology and The Lynx Group in April/May 2017 showed that among more than 400 people with multiple myeloma, most (77%) are optimistic about their future, as can be seen in the **Figure**. People living with multiple myeloma who proactively seek information are more likely to feel optimistic about their future than those who do not seek information. In this survey, being optimistic about the future was also associated with:

- Having a caregiver
- Spending less time in the cancer clinic

FIGURE. How Optimistic Are You About Your Future?



- Having direct communication with the healthcare team about quality-of-life issues and personal goals.

WHAT’S NEXT AFTER A DIAGNOSIS OF MULTIPLE MYELOMA?

People who are diagnosed with cancer, such as multiple myeloma, need to learn enough information without being overwhelmed, and should actively participate in decisions about their care, while benefiting from the expertise of their treatment team. What is the best way to achieve this balance?

In August 2017, a roundtable meeting, which included individuals with multiple myeloma, caregivers, advocacy group leaders, nurse practitioners, and nurse navigators, convened to provide insight and advice related to multiple myeloma. Participants outlined the important next steps for patients with multiple myeloma through the difficult period associated with the shock of a cancer diagnosis, as outlined below.

1. Select Your Multiple Myeloma Treatment Team

Start with choosing a physician who specializes in your type of cancer. This physician will likely have a support team that may include oncology nurse and patient navigators, nurse navigators, nurses, physician assistants, pharmacists, and social workers. It is important for you to get to know these team members, because each represents a potential resource and may play an important role in your care. If you have other medical conditions, remember that your primary care physician will continue to be an important member of the extended care team.

Support groups can often help you to identify physicians in your area who specialize in the treatment of multiple myeloma. Online referral sources include the International Myeloma Foundation (www.myeloma.org/support-groups), the Multiple Myeloma Research Foundation (www.themmr.org/living-with-multiple-myeloma/), and the Myeloma Crowd (www.myelomacrowd.org/myeloma-directory/).

Tips for Working with Your Treatment Team

- ▶ Do your best to be informed when you and your loved ones speak with your treatment team. Having knowledge about your disease and available treatments will help to be prepared to participate directly in the decisions that will affect your care
- ▶ Ask questions. No one begins their journey as a cancer expert. Seek the expertise of your treatment team
- ▶ Although members of your treatment team are busy, they should never be too busy to talk with you, answer your questions, and help you navigate through the healthcare process. Come prepared with five questions, and don't be shy or intimidated.
- ▶ Obtain second and even third opinions, at diagnosis and at later points in your care, because the decisions that you make directly affect so many aspects of your life.

2. Think About Your Personal Support Network

In addition to family and close friends, members of your support network can include acquaintances from work, your place of worship, or your community, as well as other patients with multiple myeloma.

Reach out to other patients with multiple myeloma through social media, local support groups, and advocacy organizations, such as the International Myeloma

Foundation (www.myeloma.org), MyMentor Connections (www.Mymentorconnections.com), Multiple Myeloma Research Foundation (www.themmr.org), and The Myeloma Beacon (www.myeloma.beacon.com).

Tips for Working with Your Support Team

- ▶ Ask for and accept help. Your needs will vary throughout treatment. It is okay if you need more help at certain points during your journey. There may be times when you will not feel well enough to drive, run errands, or complete household tasks. Let your support network know when you need help
- ▶ Members of your support team have unique skills and talents that they want to use to help you. Divide key tasks among them, and don't forget to say "thank you"
- ▶ Remember that your caregivers and support team need time to care for themselves, too. Allow them time and space to rest and recharge. Caregiver resources can be found at Caregiver Action Network (www.caregiveraction.org) and MyLifeLine (www.mylifeline.org).

3. Understand Your Insurance Plan and Costs

Do you have health insurance coverage? If so, contact your insurance company to ensure that you have adequate coverage for multiple myeloma treatment.

Insurance benefits vary from one health plan to another. You may be able to switch to a plan that offers better coverage options for the specific tests, medications, and other healthcare treatments and services that you may need. If you get insurance through your employer, you may also contact the Human Resources department for information about your health insurance coverage.

Ask members of your treatment team to help you manage this often-complex process. Many cancer centers have financial counselors on staff who work with insurance companies and other support organizations. These counselors can help you to determine your health insurance benefits, including any copays and direct costs to you. They can also ensure that you will be able to get the medications you need.

If you have a trusted financial planner, consult with that person about how to manage the costs associated with your treatment. Additional financial resources are available at the Family Reach Foundation (<http://familyreach.org>) and Triage Cancer (<http://triagecancer.org>).

Although these tasks can feel overwhelming, they can be accomplished in small doses as you prepare for your initial treatment. Remember to ask your family, friends, and other members of your support network for help when you need it. ♦

Choosing an Oncologist to Lead Your Treatment Team: Who Treats Multiple Myeloma?

When you are first diagnosed with cancer, including multiple myeloma, you probably have many questions. You may ask: Do I have a multiple myeloma specialist close to my home? If not, am I able to travel? Should I consider participating in a clinical trial if I am eligible and my doctor recommends it?

Doctors who are trained to treat cancer are called oncologists. Oncologists specialize in caring for patients with cancer from the time of diagnosis throughout the disease journey. As the leaders of the treatment team, their role includes:

- ▶ Explaining the cancer diagnosis and disease stage to patients and their caregivers
- ▶ Discussing available treatment options and providing their recommendations
- ▶ Helping patients manage cancer-related symptoms and side effects of treatment
- ▶ Delivering high-quality and compassionate care.

There are several types of oncologists, including medical, surgical, and radiation oncologists. Medical oncologists manage the care and treatment of patients with cancer. They administer chemotherapy and other



JOHN W. KILLIP
Patient Advocate
Kansas City, MO

types of medication, including targeted therapies and immunotherapies. Targeted therapies act on specific molecular targets that are associated with cancer. Immunotherapy is a treatment that uses your body's own immune system to help fight cancer.

Surgical oncologists perform surgery to remove tumors. Radiation oncologists attack tumors with high-energy radiation. All of these types of physicians are first trained in internal medicine and then complete several years of additional training to learn how to diagnose and treat cancer.

Some oncologists, known as hematologists, specialize in the diagnosis, evaluation, and treatment of diseases of the blood and lymph (the fluid that circulates throughout the lymphatic



BARBARA ROGERS, CRNP, MN, AOCN, ANP-BC
Nurse Navigator, Fox Chase Cancer Center, Philadelphia, PA

system), including cancers such as multiple myeloma.

WHO SPECIALIZES IN MULTIPLE MYELOMA?

The confirmation of your diagnosis may take place at a hospital or an oncologist's office that is close to your home. After confirmation of your diagnosis, you may want to speak with a doctor who specializes in treating patients with multiple myeloma.

Some medical oncologists are "generalists" who treat different types of cancer, including solid tumors, like breast, lung, or colon cancer, as well as blood or lymph cancers, such as leukemia, lymphoma, and multiple myeloma. Although general medical oncologists usually have some experience in managing multiple myeloma,

they are typically not considered multiple myeloma experts.

Hematologists, some of whom are affiliated with universities, may subspecialize in a particular type of blood or lymph cancer and may be experts in the treatment of multiple myeloma. Oncologists who focus on the management of patients with multiple myeloma are known as multiple myeloma specialists.

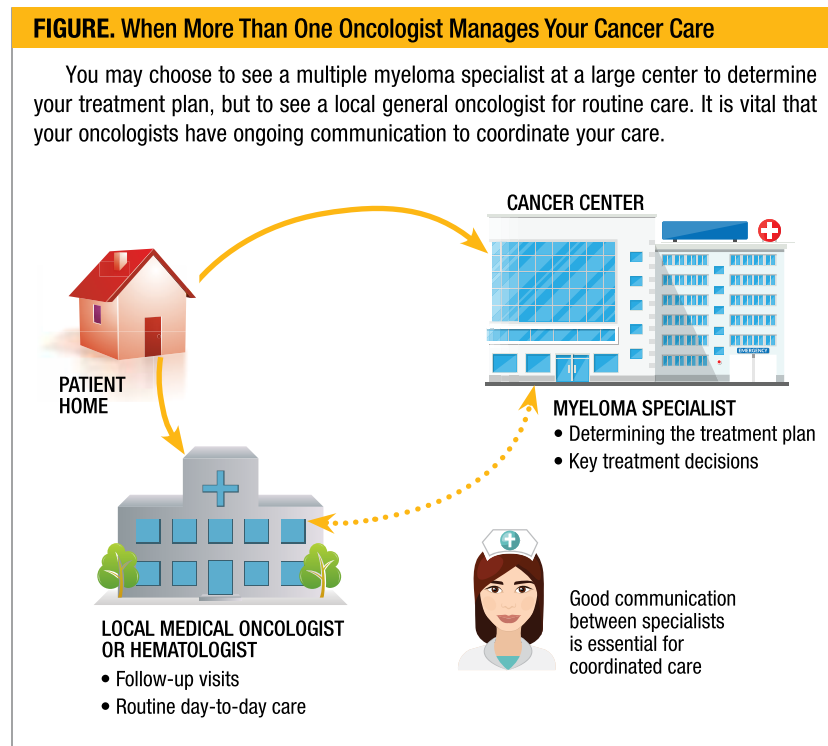
These physicians may be more familiar with the newer treatments for multiple myeloma, and their cancer centers may be more likely to offer stem-cell transplantation or encourage patients to participate in clinical trials of treatments being studied for this disease.

They often also conduct cancer research, and work with other multiple myeloma specialists from around the world. Medical oncologists and hematologists often work with multiple myeloma specialists to ask for their advice for a particular patient.

In a recent survey conducted by Takeda Oncology and The Lynx Group of more than 400 patients with multiple myeloma,

How you approach your care is up to you. The key is to communicate your needs and preferences to the oncologist.

most (94%) reported that they see a multiple myeloma specialist. However, the term “specialist” can be interpreted in different ways. As a follow-up to the survey, a group of patients with multiple myeloma, caregivers, advocacy group leaders, nurse practitioners, and nurse naviga-



tors gathered at a roundtable meeting to discuss the survey results and provide their insights on several topics, including how to choose the right doctor to treat multiple myeloma. Survey responders might have had a different understanding of what a “specialist” in multiple myeloma means.

FINDING THE RIGHT DOCTOR TO TREAT MULTIPLE MYELOMA

The roundtable participants suggested several important factors to consider when choosing the primary oncologist to manage multiple myeloma treatment, including:

- Distance from your home and your ability and desire to travel
- Your insurance plan’s limitations on out-of-network and out-of-state physician consultations
- The doctor’s level of specialization in multiple myeloma
- Your comfort level with the doctor’s treatment approach and “bedside manner”
- How you feel about the other members of the treatment team (nurses, pharmacists, navigators, social workers, office staff), and the overall “vibe” that you feel in the office, cancer center, or clinic.

You may choose more than one oncologist to manage your cancer care (see **Figure** on page 39). For example, you may choose to see a myeloma specialist at a large cancer center when determining your treatment plan, or when key treatment decisions need to be made, such as stem-cell transplant may be a treatment option.

You may also decide to see a local general oncologist for routine day-to-day care, chemotherapy administration (in some cases), and follow-up. In this case, it is very important that the two oncologists communicate with each other to ensure that you receive coordinated care.

Before making a final decision about your oncologist and treatment team, do some research.

ADVOCACY ORGANIZATIONS

These organizations can help you learn more about your disease and find a multiple myeloma specialist:

International Myeloma Foundation
www.myeloma.org

Multiple Myeloma Research Foundation
www.themmf.org

Leukemia & Lymphoma Society
www.lls.org

The Myeloma Beacon
www.myelomabeacon.com

Myeloma Crowd
www.myelomacrowd.org

Several advocacy and patient education organizations offer online resources to help you schedule appointments with oncologists, including experts in the treatment of multiple myeloma. Most health plans also offer profiles and “report cards” for oncologists who are affiliated with the insurance network. Read them to learn how other patients grade the care provided by these physicians.

INTERVIEWING ONCOLOGISTS

As you and your loved ones speak with oncologists to determine the best course of action, consider the following advice:

1. Prepare a list of questions to ask the oncologist in advance of your meeting

2. Decide ahead of time how you feel about your needs and treatment goals, and then explain this to the oncologist that you interview. How aggressive do you want the treatment to be?

What about your tolerance level for treatment-related side effects?

Or do you want to prioritize your quality of life and physical comfort?

3. Ensure that all these questions are answered completely during the meeting; do not let yourself be intimidated or rushed by the doctor

4. Bring someone you trust to the meeting. That person can provide a second set of ears

and make sure that you ask all your questions.

SELECTING YOUR DOCTOR

After talking with several oncologists, sit down and compare them before making your decision. Consider completing a checklist that includes questions such as:

- What level of experience does the oncologist have in multiple myeloma? How many patients with multiple myeloma has that oncologist treated in the past year?
- Is the oncologist affiliated with a cancer center or university? How easy is it for the oncologist to communicate with colleagues who have a lot of experience with treating multiple myeloma?
- Did the oncologist listen to your questions and concerns? Was he or she genuinely interested in getting to know you and learning about what is important to you?
- How do you feel about the other team members that you met?
- How do you feel about the atmosphere of the office or clinic, the overall “vibe”?

COMMUNICATE YOUR NEEDS

How you approach your care is up to you. The key is to communicate your needs and preferences to the oncologist as clearly as you can.

Your oncologist must understand the “big picture,” so he or she can tailor the best treatment plan for you ♦

Taking an Active Role in Multiple Myeloma Treatment Decisions

Since you were diagnosed with multiple myeloma, you have undoubtedly heard and read all kinds of advice about how you should be treated. Your friends, loved ones, and work colleagues—your support team—as well as your treatment team, which includes your doctors, nurses, social workers, navigators, and other professionals, have so much information and advice to share. They all want to help you choose the course of action that is right for you.

But what is the best treatment approach for you? Who decides what “best” really means? Although you are not a multiple myeloma expert, your opinion counts. What role should you play in your treatment decisions? Is taking an active role in cancer treatment decisions important?

SHARED DECISION-MAKING IN CANCER CARE

In 2001, the Institute of Medicine, a nonprofit organization that provides health policy advice, suggested that the quality of cancer care improves when people who have been diagnosed with cancer share in decisions related to their treatment.¹ Since that time, surveys of patients with cancer have shown that most patients prefer to play



PATRICIA MANGAN, CRNP
Nurse Practitioner
Philadelphia, PA

an active role in their treatment choices.^{2,3} Patients with cancer are less satisfied with the quality of their care when physicians determine their treatment without their input.³

So, patients with cancer are happier with their care when they participate in decisions about their treatment. But how



JAN SEALOVER
Patient Advocate
Rockville, MD

your care team? This may seem daunting at first, but resources are available to help you take an active role in your multiple myeloma care.

An Internet-based survey that was conducted by Takeda Oncology and The Lynx Group in April and May 2017 showed that among more than 400 Ameri-

Be kind to yourself as you absorb and sift through all the new information you receive. Take breaks. Ask your support team for help, and don't forget that you know yourself best.

do you do this? Who should you talk with to make sure that your voice is heard as treatment choices are being made? Where can you find the information that you need to communicate with

cans with multiple myeloma, the majority (86%) had spoken with their treatment team about their treatment goals and how treatment may impact the quality of their lives (**Figure 1**).

When asked to list the treatment team members they speak with the most about these issues, patients listed their hematologist oncologists most often (78%), followed by primary care physicians (52%) and nurses or physician assistants (PAs; 41%).

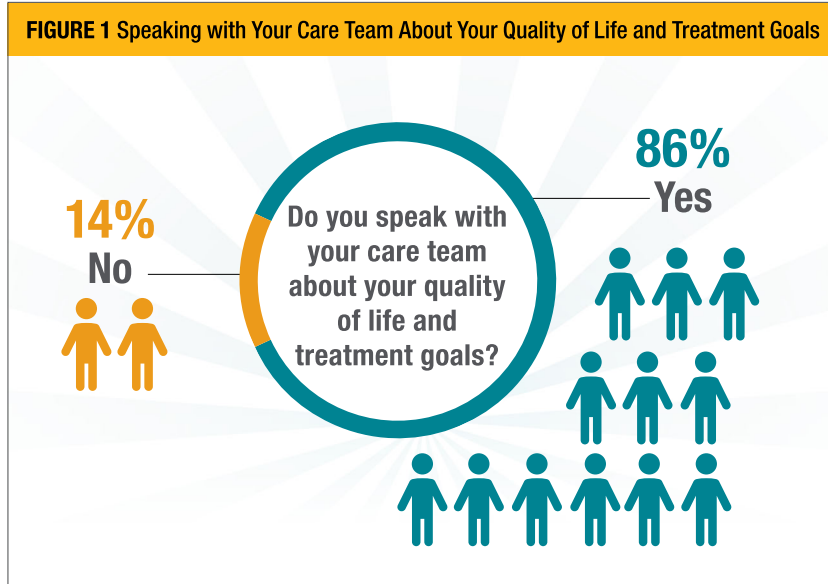
A group of patient advocates, caregivers, nurse practitioners (NPs), and nurse navigators participated in a roundtable meeting. They discussed the survey results and provided personal insights on important topics, including shared decision-making in cancer treatment.

The study confirmed that patients are speaking to their care team, but the roundtable participants also question whether patients could comprehend the complex medical information provided.

One roundtable nurse participant commented, “We give patients a lot of information to digest. How do we know the level of information is right? How do we know that patients really understand it? We need to give patients time to digest the information, and then to ask questions. In our practice, we like the idea of someone in the treatment team contacting the patient before starting their first treatment. This gives the patient time to talk about the treatment plan, and helps us to know that the patient really understands how it may impact them.”

SHARED DECISION-MAKING TIPS

To help you and other patients with multiple myeloma, roundtable participants provided



their perspective on shared decision making.

Treatment team members involved in shared decision-making

In addition to you, your caregiver, and your hematologist oncologist, pharmacist, NP, PA, clinic nurse, nurse or patient navigator, social worker, and financial advocate, may all provide valuable input into treatment decisions based on their knowledge and experience in working with patients. In addition, a hematologist oncologist who specializes in multiple myeloma may consult on your case.

Important medical information to consider

The hematologist oncologist typically outlines and explains your treatment options and other care team members, like the NP, PA, nurse, and navigator, will then follow up with you

to help clarify this complex information.

The information you receive from your multiple myeloma team is likely to include the following:

► **Understanding your type of multiple myeloma.** Your treatment team may recommend testing to determine your specific type of multiple myeloma. The most common diagnostic tests use blood or bone marrow to evaluate the biological aggressiveness.

Bone marrow testing can be used to identify damage to chromosomes in myeloma cells.⁴ These tests may be used to determine whether your multiple myeloma is a high-risk type. This may help determine the type of treatment that is appropriate for you.

► **Evaluating your overall health status and comorbidities.** Your age and other non-cancer health conditions, such as diabetes or heart disease, may play a

FIGURE 2 What Specific Questions Should You Ask Your Oncologist and Treatment Team?



role in determining which treatment option is best suited for you.

► **Treatment options.** Your treatment team should discuss the treatment options with you and with your caregiver. They should review the benefits and risks of each option, which may include combination therapy and/or stem-cell transplant. It's important to understand your treatment plan, including how often you'll have office appointments, how the therapy will be administered, and how long you will need to receive treatment.

► **Clinical trials are also an important treatment option.** Clinical trials are designed to study

new drugs and help to advance our understanding of multiple myeloma. Ask your doctor if you have questions.

IMPORTANT NON-MEDICAL INFORMATION TO CONSIDER

There are also important non-medical issues to consider when making treatment decisions. In the survey mentioned earlier, nearly 60% of survey respondents indicated that multiple myeloma interferes with their daily lives considerably. Here are some things to think about:

• **Are you working?** More than one-third of survey respondents

said that they retired or took long-term disability because of multiple myeloma, so it's important to consider your finances and employment options as you begin your treatment. A nurse navigator or a social worker may help you to prepare to discuss your multiple myeloma diagnosis with your employer.

• **Do you have one or more caregivers?** You may need assistance with transportation to and from appointments, so it's important to communicate your needs to your personal support team.

• **What other things are important to you?** You may have hobbies or other pursuits that are very important to you. When speaking to your treatment team, tell them about the activities that matter most to you, so they can recommend a treatment plan that is best for you.

YOUR NEEDS AND PREFERENCES

The roundtable participants noted that your hematologist oncologist should offer specific treatment recommendations for you to consider after listening to your needs and preferences.

The group also recommended thinking over the treatment options presented to you; discussing with family members, fellow patients, and caregivers; repeating back what you learned from your healthcare team, and asking follow-up questions. One way to do this is to keep a diary to help you prepare for each appointment.

Figure 2 lists some important questions that you should consider asking your hematologist

oncologist and other members of your treatment team.

WHAT COULD HINDER SHARED DECISION-MAKING IN CANCER CARE?

Language barriers, healthcare complexities, and individual differences in patient and physician personalities can affect how much patients can participate in their own decision-making.

One roundtable participant suggested, "Individual personalities affect the chances of shared decision-making. Some patients are very proactive and have a ton of questions listed in their diary when they come into the office. They are ready for

that dialogue with their doctors and nurses, and feel very comfortable with it.

Other patients come in and wait for the doctor to tell them what to do next. These patients seem less comfortable with the idea of participating in treatment decisions. Maybe they don't feel comfortable to chime in, but they really are. They know themselves best."

The roundtable participants highlighted the importance of a positive outlook throughout your multiple myeloma treatment journey. Remember that both parties—you (the patient) and your treatment team—need time to learn how to interact best with each other.

Be kind to yourself as you learn and sift through all the new information you receive. Take breaks. Ask your support team for help, and don't be afraid to ask questions. ♦

References

1. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
2. Keating NL, Guadagnoli E, Landrum MB, et al. Treatment decision making in early-stage breast cancer: should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology*. 2002;20(6):1473-1479.
3. Kehl KL, Landrum MB, Arora NK, et al. Association of actual and preferred decision roles with patient-reported quality of care: share decision making in cancer care. *JAMA Oncology*. 2015;1(1):50-58.
4. Multiple Myeloma Research Foundation. Multiple myeloma diagnosis. www.themmr.org/multiple-myeloma/diagnosis/. Accessed April 2, 2018.

☞ In Memoriam: Jan Sealoover ☞

Jan's story of living with multiple myeloma outshines her recent passing and will continue to encourage others living with the disease.

We are grateful to Jan for her contributions to this article and know that her passion for helping others will continue to touch all who read it.

Making Sure Your Treatment Team Stays Connected

One of the many things that you probably did after receiving a diagnosis of multiple myeloma was to select a doctor and care team. They helped you to learn about multiple myeloma and how to navigate the complexities of treatment decision-making.

As you have continued with your multiple myeloma journey, your relationships with members of the treatment team have grown. New team members may have come into the mix as your medical needs have changed. For example, if you underwent a stem-cell transplant procedure, a transplant doctor and specialized team of nurses and care coordinators cared for you.

Surveys and studies of patients with cancer show that clear, timely communication among all team members—including your treatment team, other specialists, and caregivers—is critical. This communication is especially important during certain milestones in your multiple myeloma journey, such as:

- When you are first diagnosed
- Once treatment decisions need to be made, for example, deciding whether stem-cell transplant is the right decision for you
- Upon relapse, if you're experiencing side effects, or any time



JACK AIELLO
Patient Advocate
San Jose, CA

things change, and new treatment decisions need to be made

- After a period of treatment, when discussing the results
- When you need a referral to another specialist, such as a cardiologist or a pain specialist
- When the goals of your care change and you need to make decisions about things such as advance directives, living will, and end-of-life care.

As the treatment team has evolved and new members have come in, are you sure that they are actively communicating with each other about your care? If you have had a stem-cell transplant, is your transplant doctor communicating with your oncologist after your follow-up visits to the transplant hospital? What about your visit to a multiple myeloma expert at a large cancer center? Is he or she communicating with your



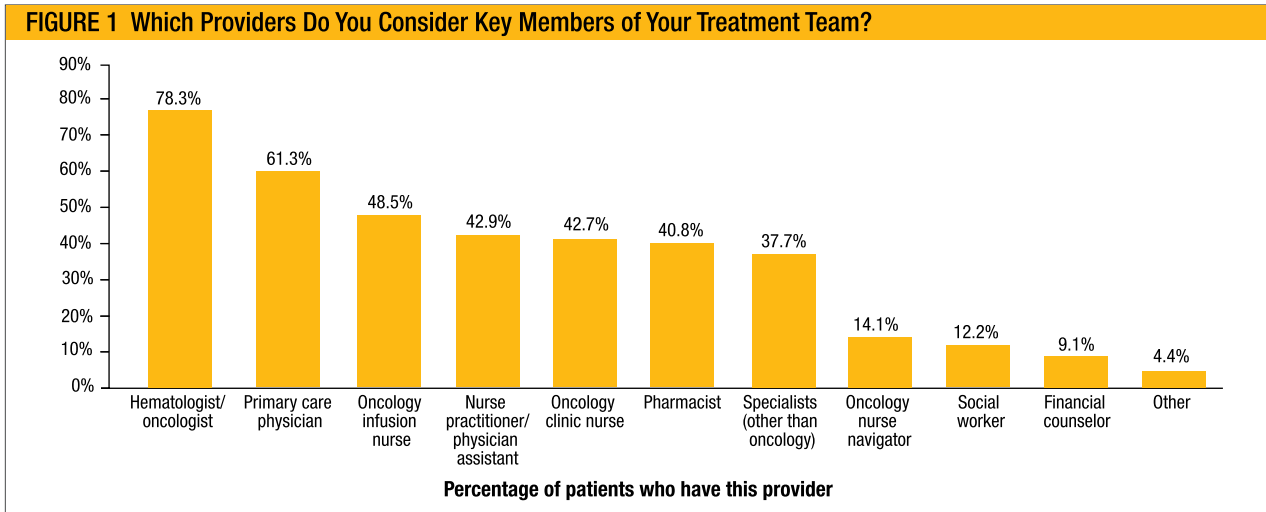
NANCY KAUFMAN
Patient Advocate
Columbus, OH

local oncologist after seeing you? Is your primary care physician aware of the details of your multiple myeloma journey?

COMMUNICATING WITH YOUR TREATMENT TEAM IS CRITICAL

A survey conducted by Takeda Oncology and The Lynx Group in April and May 2017 showed that more than 400 people with multiple myeloma identify their hematologist/oncologist (78%) and primary care physician (61%) as key members of their treatment team (see **Figure 1**).

As a follow-up to this survey, a group of patients, caregivers, advocacy group leaders, nurse practitioners, and nurse navigators were brought together at a roundtable meeting. They discussed the survey results and provided personal insights on



key topics, including treatment team communications.

The roundtable participants agreed that survey responders showed they were interacting with key team members, but they were particularly surprised to see that only 61% of the patients listed primary care physician as part of their treatment team. The participating healthcare professionals discussed the challenges that they face when patients with cancer want their oncology office to serve a double role as their primary care office.

One participant stated, “The fact that only 61% said their primary care physician was part of their team is concerning. In my mind, 100% of people should say that a primary care physician is involved in their cancer care.”

Another participant said, “This is a problem for us, too. Many of our patients will say, ‘But, you are my primary care doctor.’ I explain to them that we are not their primary care physician, but I realize the problem; it means yet another doctor’s appointment. When you start adding

up all the doctor visits, it is a lot for people and their caregivers to manage.”

Another question in the survey asked patients with multiple

myeloma about other medical conditions, and whether they are regularly seeing a physician to manage them. Although approximately 30% of the survey

MULTIPLE MYELOMA TREATMENT TEAM MEMBERS

All cancers, including multiple myeloma, are treated using a multidisciplinary approach, in which many types of healthcare providers work as a team to care for the patient. These providers include:

- Hematologist/oncologists, including stem-cell transplant specialists and multiple myeloma experts
- Other specialty doctors (nephrologists, cardiologists)
- Primary care physicians
- Nurse practitioners
- Physician assistants
- Oncology nurses
- Nurse and patient navigators
- Caregiver(s)
- Pharmacists
- Social workers
- Psychologists and psychiatrists
- Pain specialists (anesthesiologists, neurologists)
- Rehabilitation specialists (physical therapists, speech therapists)
- Home health aides

One doctor, usually the oncologist, coordinates your care and communicates important information to the other team members. For details about the role of each team member, see [www.cancer.org/publications/59-your health care team your doctor is only the beginning](http://www.cancer.org/publications/59-your-health-care-team-your-doctor-is-only-the-beginning).

responders reported having high blood pressure, and approximately 34% reported having high cholesterol, most patients with these conditions do not regularly see a physician to manage them (see **Figure 2**).

Several roundtable participants were also troubled about patients with cancer who do not go to dentists and optometrists, or do not get regular annual physical exams by their primary care physician.

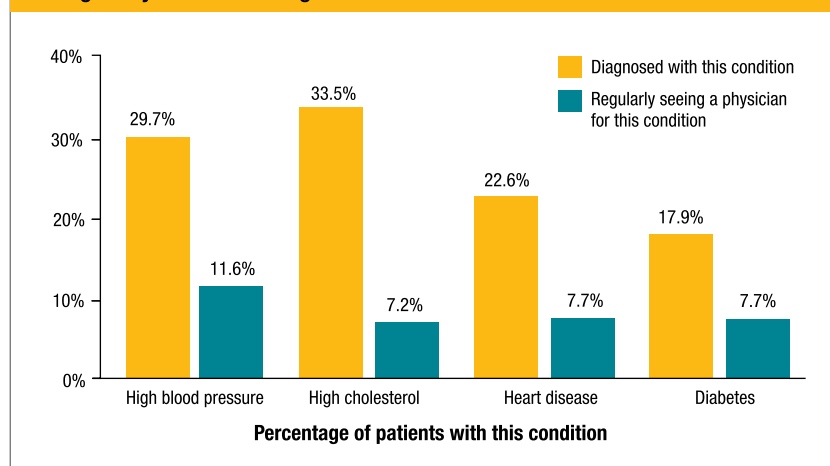
The healthcare professionals participating in the roundtable emphasized the importance of patients with multiple myeloma continuing to see other physicians for medical conditions that are not related to their multiple myeloma.

One participant pointed out, “Your oncologist and treatment team are not thinking about testing your PSA [prostate-specific antigen] if you’re a man; we do not check it. If you’re a woman, we do not ask if you’ve had your mammogram. We are not experts in managing high blood pressure, high cholesterol, or diabetes, but patients with multiple myeloma still have these problems. These conditions don’t go away just because you’ve been diagnosed with cancer.”

HOW THE TEAM MEMBERS COMMUNICATE

In addition to talking with each other in person and via telephone, members of your treatment team have sophisticated tools that they use to keep each other up to date.

FIGURE 2 Which of the Following Conditions Do You Have? Are You Regularly Seeing a Physician to Manage This Condition?



One of the most important tools is their electronic medical record, or EMR, systems. You can think of your EMR as a computerized version of your medical chart. The EMR contains all the medical and clinical information that has been gathered in your doctor’s office.

In addition to being more secure and durable, an EMR allows your treatment team to:

- Monitor changes in your health status over time
- Identify if you are due for a specific visit, such as lab work, scans, or other studies
- Improve overall quality of care.

Your provider’s office can give you full access to your medical record. By accessing your EMR, you can see your medical details, including lab results, and learn follow-up information after an office visit or a hospital stay, including self-care instructions, reminders about follow-up care, and links to Internet resources. For more information about EMRs visit www.healthit.gov/providers-

[professionals/electronic-medical-records-emr.](#)

COMMUNICATION TIPS FOR YOUR TREATMENT TEAM

The roundtable participants recommended several steps to help your treatment team communicate well.

1. Be Your Own Advocate

▶ Share important medical information with your treatment team at each visit. Bring a diary or notebook with your updates, questions, and concerns.

▶ Learn the names of your medications and their dosages (the number of times to take each day, and the amount), and keep track of your lab results (including the date of the test). There are numerous mobile apps that can help you manage your medications and provide reminders.

▶ Do not allow yourself to be rushed if your doctor or nurse seems busy.

▶ Ask questions to make sure team members are communicating with each other:

“Doctor, did you see my latest test results? The nurse said my blood counts were low.”

“Did the infusion nurse tell you that I had a reaction to my medication?”

▶ Tell each doctor about other doctors who care for you, and all the medications you are taking.

If you have a cardiologist for your heart disease or an endocrinologist for your diabetes care, tell your oncology team. Tell your cardiologist that you

have cancer and are being treated by an oncologist.

Make sure your doctors are communicating with each other about your care.

2. Enlist Your Caregiver(s) to Use Available Communications Tools

▶ Your caregiver can update your nurse or patient navigator, pharmacist, financial advocate, and social worker as treatments change and as new decisions are made.

▶ You and your caregiver can e-mail your treatment team members through electronic

patient portals. Although there are times when an urgent phone call is necessary, many nonurgent questions and needs can be handled electronically.

Fully informed team members are a key element of well-coordinated care for patients with multiple myeloma. Your doctors, nurses, and pharmacists must be updated on your medical history and status as they make treatment recommendations and monitor your health. As your treatments and care plan change, it is critical for everyone to stay informed. ♦

Financial Planning Considerations for Patients with Multiple Myeloma

After the shock of being diagnosed with multiple myeloma wore off, you have learned a new “language” related to cancer and multiple myeloma care, you have likely read and talked about treatment options, and you may have already started treatment. You may have also joined a support group. Ideally, your loved ones, friends, support group members, and work colleagues—your support team—as well as your oncologists, nurses, social workers, navigators, and other professionals—your treatment team—are guiding and supporting you through this process. Now you may be thinking about financial considerations related to your care.

If you are currently working, you may be unsure how to discuss your multiple myeloma diagnosis with your employer. You may have concerns about your ability to take time off, cut back your working hours, or even apply for disability insurance benefits. Learn about your insurance benefits and find out what resources are available to you.

HEALTH INSURANCE

Understanding how your insurance coverage works is especially important at a time when you are likely to face sub-



DEBORAH CHRISTENSEN, MSN, APRN-BC, AOCNS, HNB-BC
Oncology Nurse Navigator,
Intermountain Southwest
Cancer Center,
Dixie Regional Medical Center,
St George, UT

stantial expenses. It is important to know what your health insurance plan covers (see the **Health Insurance 101 Infographic**).

Comprehensive health insurance usually covers hospital stays, medical care, diagnostic tests, and prescription drugs. It may also cover additional services, such as durable medical equipment (eg, walkers, wheelchairs, shower chairs) and complementary medicine (eg, acupuncture, biofeedback, massage), but this may vary depending on your health plan.

A recent survey conducted by Takeda Oncology and The Lynx Group in April and May 2017 showed that among more than 400 people in the United States with multiple myeloma, health insurance premiums and



JOHN W. KILLIP, DDS
Patient Advocate
Kansas City, MO

annual deductibles were ranked as the most burdensome cost categories, so it's important to understand your benefits.

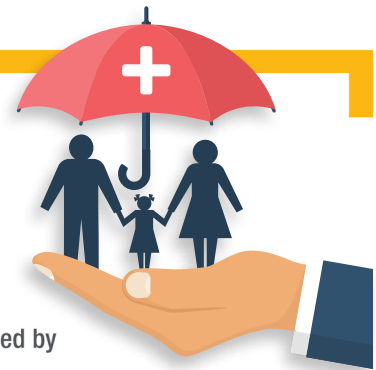
Remember, every health plan is different, so be sure to review your summary of benefits and speak with an agent or a care coordinator to understand the details of your health insurance coverage. Your care team or physician's office and other patients with multiple myeloma may also be a great resource.

MEDICARE COVERAGE

Many people with multiple myeloma are eligible for Medicare coverage. If you are 65 or older or are disabled, you may qualify. Medicare coverage includes 4 categories—Part A,

HEALTH INSURANCE 101

Health insurance is an arrangement with an insurance company that can help protect you from the high costs of healthcare. The term “benefits” refers to the services that are covered by health insurance. Private companies that offer health insurance are often called health plans.



Types of health insurance



Group health insurance is offered by your employer or union



Individual health insurance is purchased directly from the insurance company or health plan



Government-sponsored health insurance is obtained through a government agency or program such as Medicaid or Medicare (see Medicare 101)

Different healthcare services are covered under different benefits



Medical Benefits usually pay for doctor’s office visits and medications that are given in the office

Pharmacy Benefits usually pay for medications taken by mouth (oral medications) or injected at home



Hospital Benefits pay for inpatient stays in the hospital

Although most health insurance covers these three types of benefits, there may be differences in the details of what they pay for. An example is a medication that is covered by one health plan may not be covered by another.



Out-of-pocket costs

Your out-of-pocket costs may also vary from plan to plan. There are several types of out-of-pocket expenses that may be your responsibility:

The premium is the amount of money charged by an insurance company for coverage. If you have group health insurance, your employer or union decides how much of the premium employees must pay for coverage.

The deductible is the amount you owe for healthcare services each year before the insurance company begins to pay.

The copayment, or copay, is a fixed amount you pay for each covered healthcare service. For example, you may have a \$50 copay each time you visit your doctor.

Coinsurance refers to your share of the costs of a covered healthcare service calculated as a percent of the allowed amount for the service. For example, you may be responsible for 20% of the cost of the medication while your insurance company pays for the remaining 80%. Typically, you either pay a copay or coinsurance, but not both for a single service.



For people in need

Several types of patient assistance programs are available to help you pay for cancer medications. Each program has different eligibility requirements and amounts of support that they offer.

Manufacturer copay programs (sometimes called **copay cards**) are offered by pharmaceutical (drug) companies to help patients afford the cost of specialty medications, such as drugs that treat cancer. Each “manufacturer program” is limited to the medications they make and sell. By law, these programs are only available to patients with private insurance, not government-sponsored insurance.

Most pharmaceutical companies also have Patient Assistance Programs to help uninsured or underinsured patients afford the costs of their specialty cancer medications.

Independent foundations, such as **CancerCare**, the **Patient Advocate Foundation**, and **HealthWell Foundation** (to name a few), also provide support to patients in need. Unlike manufacturer copay programs, independent foundations may be permitted to provide assistance to patients with government-sponsored insurance as well as those with private insurance.

MEDICARE 101

Step 1. How are you covered?

MEDICARE



Medicare Part A

Covers hospital-related services and emergency care



Medicare Part B

Covers doctor's office visits (including drugs given during visit)

MEDICARE ADVANTAGE PLAN

Medicare Part C (an HMO or PPO)

Covers Part A and Part B
Many plans also provide prescription drug coverage and additional benefits, such as wellness, dental, and eye care



Medicare Part A



Medicare Part B



If plan doesn't cover prescription drugs



If you elect Medicare Advantage (Part C), you can't buy or use a Medigap policy

Step 2. Decide if you need to add drug coverage



Medicare Part D

Covers prescription drugs taken at home

Step 3. Decide if you need to add supplemental coverage



Medicare Supplement Insurance (Medigap policy)

Covers most of your out-of-pocket costs for medical services not usually covered by Medicare Parts A & B

- If you qualify for Medicare, most people receive Part A at no cost.
- Medicare Parts B, C, D, & Medigap require you to pay a monthly fee (premium) for coverage.
- Medicare Parts A, B, C, & D do not cover out-of-pocket costs (e.g., copayments, coinsurance, or deductibles).
- For more information, please go to www.medicare.gov.

Part B, Part C, and Part D (see the **Medicare 101 Infographic**).

When you become eligible for Medicare, you are covered under Medicare Part A, which covers most hospital costs. All other parts of Medicare (and Medigap) are optional pro-

grams, which require you to pay a monthly fee for each.¹

FINANCIAL CONSIDERATIONS

Although health insurance may cover a good chunk of the costs of your cancer care, you

will probably still have some out-of-pocket costs. However, there may be resources that can help you to pay for some of these expenses.

There are programs that can help you with the cost of your cancer medications. For pa-

tients with private insurance, some drug companies offer discount cards to offset the cost of your copay. Drug companies may also offer patient assistance programs to help eligible patients who are uninsured or underinsured. After your doctor has prescribed a cancer medication or medications for you, ask your care team to explain any available programs and help you enroll.

Most medications also have websites and toll-free numbers that you can visit or call to obtain information. If you are taking more than one prescription drug, each medication may have its own program, so be sure to ask about all of them, and how they may differ.

In addition, independent and nonprofit organizations and foundations are available that help patients who cannot afford their medications. Ask your care team about available resources.

Organizations such as Triage Cancer have information that may answer many of your questions related to employment, health insurance, and finances, and may be able to guide you through some of the challenges you may face.

These may be especially important for patients with Medicare, Medicaid, or other government insurance who may not be eligible for programs provided by the drug companies.

FINDING INFORMATION

How do patients with multiple myeloma find out about the resources available to them? Who helps them get through all the steps and paperwork required?

As a follow-up to the multiple myeloma patient survey, a group of patients, caregivers, advocacy group leaders, nurse practitioners, and nurse navigators were brought together at a roundtable meeting. Their goals were to discuss the survey results and provide personal insights on key topics, including how patients can navigate financial challenges. Roundtable participants agreed that giving patients with multiple myeloma information about their insurance coverage and available resources is critical, in part because oncologists focus primarily on treatment and not on financial discussions.

One roundtable participant said, "Clinicians are often uncomfortable talking about treatment costs, because there are so many variables involved. Each patient has a unique set of circumstances: their financial status, insurance company, and specific health plan may affect what they are responsible to pay....We have financial advocates at our cancer center, and

PATIENT ADVOCACY ORGANIZATIONS

American Cancer Society
www.cancer.org

CancerCare
www.cancercare.org

Cancer Support Community
www.cancersupportcommunity.org

International Myeloma Foundation
www.myeloma.org

Leukemia & Lymphoma Society
www.lls.org

Multiple Myeloma Research Foundation
www.themmr.org/tips-to-help-myeloma-patients-get-help

Myeloma Crowd
www.myelomacrowd.org

My Mentor Connections
www.mymentorconnections.com

Triage Cancer
www.triagecancer.org

Takeda Oncology is not affiliated with these organizations. By listing these resources, Takeda Oncology is not endorsing any particular service or group and we are not responsible for the content of these sites or services. They are provided here for informational purposes and are not meant to replace your healthcare provider's medical advice.

nurses who work with patients before the start of any treatment, intravenous (given by a needle or tube inserted into a vein) or oral. Their job is to help patients understand their out-of-pocket costs. If a patient cannot afford those costs, the financial advocate finds resources for assistance. They also might talk with the oncologist to learn

if an alternative treatment option is available."

If you have financial or insurance-related concerns and questions, the best places to start are with your treatment team and your insurance plan's customer support phone line. In many cases, your treatment team will include a nurse navigator, a financial advocate, and/or a so-

cial worker who can help you.

In addition, patient advocacy organizations should be considered as a resource to answer questions. Several organizations are listed on the previous page, and more patient advocacy organizations are available. ♦

Reference

1. Medicare.gov. www.medicare.gov. Accessed August 29, 2018.



