

# CONQUER™

DECEMBER 2017 | SPECIAL ISSUE

the patient voice

## Uncovering the Unmet Needs of People Living with Multiple Myeloma



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**AONN** Official patient magazine of  
Academy of Oncology  
Nurse & Patient Navigators  
— Paid for in part by AONN+ Membership Dues —

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Paid for, in part, by AONN+ membership dues.

This special issue and the Global Patient Leadership Council Multiple Myeloma Roundtable were sponsored and moderated by Takeda Oncology.

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# Uncovering the Unmet Needs of People Living with Multiple Myeloma: From Diagnosis to Relapsed or Refractory Disease



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In February 2017, 10 patient advocates from the United States, Canada, and the European Union convened in Lisbon, Portugal, to discuss the unmet needs of patients who are living with multiple myeloma. This first annual global Patient Leadership Council Multiple Myeloma Roundtable, sponsored and moderated by Takeda Oncology, focused on understanding the needs and challenges of patients with multiple myeloma, and developing strategies to address and propose a globally adoptable solution.

Overarching themes of their discussion included how to enhance patient access to information about their disease and potential treatments; how to improve communication between doctors, nurses, patients, and caregivers; the importance of patient understanding and involvement in their treatment experience; and how new resources can empower and support patients within the multiple myeloma community. The common link between these conversations was how to enhance patient engagement, which has been shown to promote higher levels of patient satisfaction as well as

improved health and overall outcomes.<sup>1</sup> This white paper presents a summary of these discussions for use by patients, by caregivers, and by the doctors and nurses who represent the global multiple myeloma community.

## OVERVIEW OF MULTIPLE MYELOMA

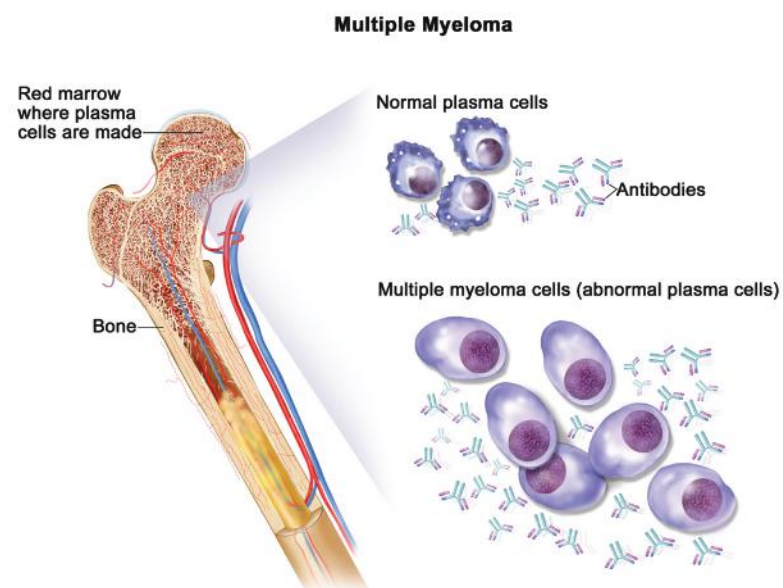
Multiple myeloma is a cancer formed when plasma cells in the bone marrow become malignant.<sup>2</sup> Plasma cells produce antibodies that combat infection, and are therefore an important part of the immune system (**Figure 1**). A malignant plasma cell is called a myeloma cell. Myeloma is identified as “multiple” because of the presence of multiple patches or areas in the bone where it grows. Multiple myeloma can appear as a tumor and/or an area of bone loss. It frequently affects areas where bone marrow is most active in adults, such as the spine, skull, rib cage, pelvis, and the areas around the shoulders and hips. Multiple myeloma is also identified by the presence of localized tumors of plasma cells called plasmacytomas. Plasmacytomas can grow in and out of bone.<sup>2</sup>

Multiple myeloma can weaken the bone structure, and can limit the bone marrow’s ability to form other blood cells. This can lead to anemia (reduction in red blood cells), thrombocytopenia (reduced levels of platelets), or leukopenia (reduction in normal white blood cells).<sup>2</sup> These side effects can lead to fractures, weakness and fatigue, increased bruising and bleeding, and difficulty fighting infections. Multiple myeloma usually produces large quantities of nonfunctional or abnormal antibodies (immunoglobulins), which can induce damage to organs, such as the kidneys and other tissues.

Multiple myeloma is considered to be a rare cancer, representing fewer than 2% of all new cancer cases in Europe, Canada, and the United States.<sup>3-5</sup> Approximately 40,000 new cases in Europe, 2800 new cases in Canada, and 30,000 new cases in the United States are diagnosed each year.<sup>3-5</sup> Although there is no cure for

**Figure 1. Multiple Myeloma**

Multiple myeloma cells are abnormal plasma cells (a type of white blood cell) that build up in the bone marrow and form tumors in many bones of the body.



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multiple myeloma, patients can have different outcomes, depending on the stage of the disease at diagnosis, the patients' age, and their overall health.<sup>6,7</sup> In Europe, survival statistics for multiple myeloma vary by country; 23% to 47% of patients will survive more than 5 years after their original diagnosis.<sup>8</sup> The statistics in the United States are similar, where it is estimated that almost half (48.5%) of the patients will survive at least 5 years after their diagnosis.<sup>9</sup>

Survival rates have more than doubled over the past decade thanks to increased understanding of the disease and the development of many new, more effective, and less toxic therapies.<sup>10</sup> In spite of these advances, availability and access to newer treatments can greatly vary among countries. These disparities are the result of an array of factors, including slow adoption for use by the physicians, low inclusion rates of these therapies on formularies, high costs of treatments, and lack of sufficient insurance coverage. Clearly, aside from the other challenges outlined below, universal access to all the currently available treatments for multiple myeloma is one of the greatest unmet needs for these patients.

## UNMET NEEDS OF PEOPLE LIVING WITH MULTIPLE MYELOMA

"One thing that we are very conscious of...is that despite all the information that we put out there online and in hospitals, and all the work that's done by other charities, we know that patients still don't always access the information that they need," said Chris West of Bloodwise ([www.bloodwise.org.uk](http://www.bloodwise.org.uk)).

Many challenges may arise over the course of the patient's treatment journey. For many patients, the initial process of receiving a diagnosis of multiple myeloma can be a substantial challenge. Because multiple myeloma is a rare disease that has a diverse nature of the symptoms, it is not uncommon for patients to have seen several doctors from different specialties (for example, their general physician, a hematologist, an orthopedist, a nephrologist) before receiving their diagnosis. In fact, a 2010 sur-



From left to right: Chris West, Alfonso Aguarón, Mira Armour, Yelak Biru.

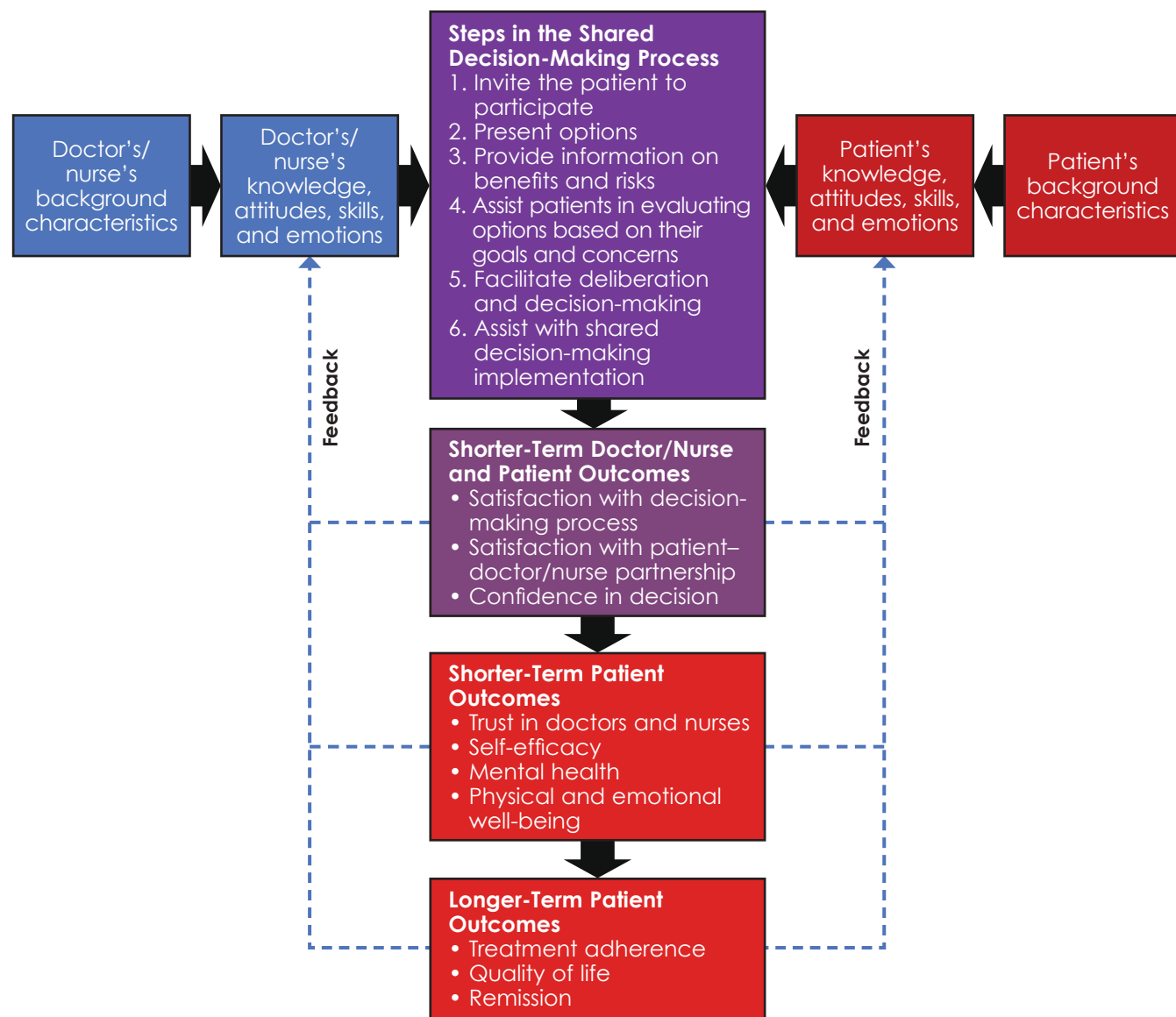
vey of patients with cancer in England showed that patients with multiple myeloma are 18 times more likely than those with breast cancer to have had 3 or more referrals to different doctors before receiving their diagnosis.<sup>11</sup>

Upon receiving the diagnosis of multiple myeloma, patients face several unknowns regarding the physical, emotional, social, and financial impact of the disease. It is important for physicians to appropriately gauge patients' stress level when the diagnosis is made, so that patients can feel as comfortable and prepared for the road ahead as possible. Patients should be encouraged to ask questions; restate, in their own words, what the doctor has told them; and bring someone to ask questions and help remember what the doctor has said. "We have tried to encourage our physicians not to ask, 'Did you understand what I told you?' because most patients and relatives would simply say 'yes,'" said Mira Armour of Mijelom Croatia and Myeloma Patients Europe ([www.mpeurope.org](http://www.mpeurope.org)). "Instead, we encourage them to ask, 'Can you tell me what I just told you?'" she added.

In recent years, it has become common practice for physicians to use a shared decision-making model for making treatment decisions, in which patients, doctors, and nurses work together to build a consensus about the overall treatment plan (**Figure 2**).<sup>12</sup> The shared decision-making model has many benefits, including increased confidence



**Figure 2. The Shared Decision-Making Communication Process**



This figure shows how patients, doctors, and nurses can bring their own background characteristics, including knowledge, attitudes, skills, and emotions, to collaborate on a treatment plan. Also shown are the outcomes of this communication strategy, and how they can influence patients, doctors, and nurses in the future.

Adapted with permission from Kane HL, et al. *CA Cancer J Clin.* 2014;64:377-388.

and satisfaction with treatment decisions; fewer decisional regrets; decreased patient-caregiver stress and anxiety; better treatment adherence; and improved treatment outcomes.<sup>12</sup> It is key, therefore, that patients receive as much information as possible about their disease and possible treatments to be adequately engaged in the decision-making process. "When I was diagnosed, I was frantic, but as soon as I went to the doctor, we had

a plan. Good. Now we know what we're going to do here. We're going into battle," stated Aldo Del Col, BScPhm, MBA, Co-founder and Chairman of Myeloma Canada. Patients can contribute to the process by considering the suggestions outlined in **Figure 3.**

Because multiple myeloma is a rare disease, patients often know very little about it or never even heard of it at diagnosis, and most patients lack

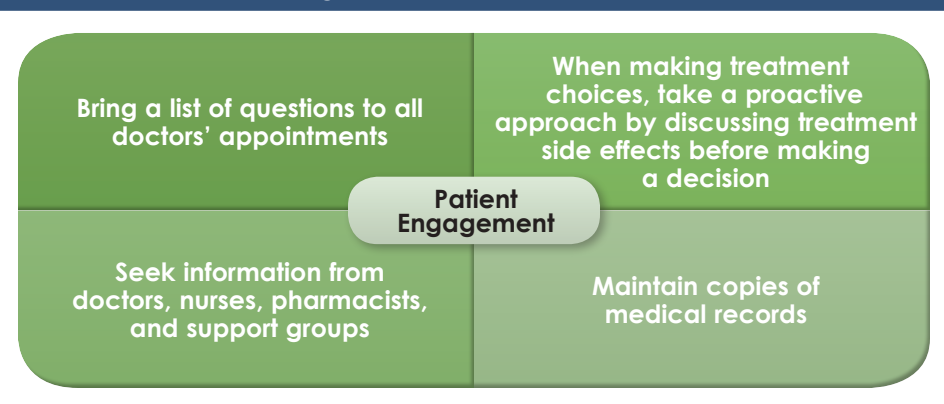
information about their illness, treatment options, and the potential impact it will continue to have on their daily lives. Details about diagnostic and subsequent tests, treatment options, and financial obligations and resources should all be a part of the initial conversation between patients and their treatment team.

Patients should be provided information to help them understand their short- and

long-term treatment plans and objectives so that they know what to expect as they continue their journey. Practical day-to-day concerns will also need to be considered, such as the ability to continue to go to work, participation in routine exercise, or changes in diet. Patients should be prepared for these conversations with their physicians. “I think [it is important] to understand what it means for your day-to-day life. Can you still work? If you can’t work, what do you have to tell your employers?” said Chris West. In addition, the impact of the disease and treatments on the family should be addressed early, because it can be a source of ongoing stress over the course of the patient journey.

The key to a patient’s day-to-day well-being is the management of side effects associated with cancer treatments. Doctors and nurses should be careful to advise patients about all the side effects that they may experience when starting a new treatment, and what they can do to monitor them, as well as emphasize that they continue to use treatment. Common side effects include fatigue, blood clots, peripheral neuropathy (nerve-related issues that present as pain, tingling, burning sensations, and numbness), constipation, nausea, diarrhea, and vomiting, some of which can be managed with over-the-counter or prescription medications.<sup>13</sup> Corticosteroids, such as dexamethasone and prednisone, are often given to patients with multiple myeloma and can have debilitating side effects, such as mood and metabolic changes, as well as blurred vision. “Once you initiate treatment, it is very important that the patient and caregiver are

**Figure 3. Suggestions for Patients to Be Better Engaged in Shared Decision-Making**



advised of the side effects,” stated Aldo Del Col. It is important that doctors and nurses educate and monitor patients regarding the impact this medication can have on their daily lives. Other therapy side effects, such as the impact on fertility, changes to libido, and the possible impact on cognitive ability, are often overlooked during these conversations, or may not be properly explained, although physi-

“I THINK [IT IS IMPORTANT] TO UNDERSTAND WHAT IT MEANS FOR YOUR DAY-TO-DAY LIFE. CAN YOU STILL WORK? IF YOU CAN’T WORK, WHAT DO YOU HAVE TO TELL YOUR EMPLOYERS?” —Chris West

cians should consider bringing them up, depending on the patient’s specific needs. Although many patients may consider side effects to be less important than prolonging their life at the initial diagnosis, the accumulation of negative effects on daily life may take a toll on the patient’s morale and overall quality of life.

Aside from the health effects of the disease and treatment, the financial impact of living with multiple myeloma is often one of the top concerns for



From left to right: Beth Faiman, PhD, CPN (Oncology Nurse Practitioner), Aldo Del Col, Nadia Elkebir, Yelak Biru, Mira Armour, Chris West, Anne Delmond-Davanture, PhD, Alfonso Aguaron, Anita Waldmann, Viorica Cursaru.

and if they achieve remission, the treatment team should discuss the next best treatment approach, which may also include maintenance therapy. The introduction of maintenance therapy is often determined based on patients' risk factors for relapse, such as the presence of genetic abnormalities known as  $t(4;14)$  and  $del(17p)$ , or the patient's ability to tolerate maintenance treatment regimens. A treatment plan for maintenance therapy should be

developed between the care team and the patient and caregiver to ensure that treatment goals are being met and maintained as well as to understand the financial impact of the new therapy on the patient, and how it will affect the patient's quality of life. During this phase of treatment, it is also important to try to attain some degree of normalcy, whether it is the patient returning to work, making dietary or nutritional changes, continuing an exercise routine, or learning how to know when a relapse may be occurring.

Because disease remission represents a strong positive milestone during the course of treatment, emotional support may often be overlooked. However, it is during this period of the patient's journey that he or she may need the most emotional support and guidance. It is also important for physicians to reassure their patients that even while the disease is in remission, the doctor is still there to provide support. "We've had patients use the phrase with us, that 'it's like falling off a conveyor belt,' because you've had constant promising clinical attention... and then suddenly it just drops off," said Chris West while discussing how physicians can better serve their patients in remission. Additional strategies, such as joining a support group, staying informed about the disease progression and treatment options, and fostering relationships with caregivers, can help patients maintain a positive attitude during remission. As noted earlier, although patients may not be

patients. The idea of potentially not being able to work, or loss of earnings, can be frightening, particularly when the patient has a family to support. Certain treatment strategies, such as high-dose therapy or stem-cell transplant, intravenous or injectable chemotherapy, and oral therapies, are associated with different recovery times and have varying impact on a patient's quality of life. Some treatments may require extensive stays in the hospital, whereas others may require routine visits to the doctor's office. Patients should be advised on how to appropriately plan for potential long absences from work or how the treatment may affect other aspects of their lives. It's important to have these discussions with your doctor to ensure the right treatment choice is made holistically, factoring in the patient's lifestyle and preserving the patient's quality of life.

For older patients who have already retired, using their pensions and retirement time can also create a psychological or financial burden, which should be addressed. Other financial aspects that all patients must consider include the costs of transportation for patients and caregivers to attend doctors' appointments, as well as the costs for accommodations associated with travel to hospitals or treatment centers far from where a patient lives; the topic of financial resources and support services should be discussed with the treatment team, a navigator, or a social worker.

Once patients have a treatment plan in place,



receiving treatment during remission, doctors and nurses still have an important role in providing psychological and emotional support to their patients during that time.

Patient questions may arise at any time during the cancer journey and may prompt further emotional support. Doctors and nurses should keep in mind an individual patient's readiness for new information, and may consider taking a stepwise approach to education and support. Regardless of where patients are along their personal journey, it is helpful for them to have a healthcare professional whom they can call to discuss their uncertainties during treatment.

Often, nurses (rather than physicians) serve as this central point of contact between the patient and the treatment team. It is therefore of great importance that nurses be adequately trained in multiple myeloma to help address patients' questions and support them throughout their journey.

Patients should also feel comfortable asking their doctors and nurses about gaining access to their medical records, which makes it easier for patients to review and discuss their illness, treatment plan, and progress with friends, family, and other healthcare professionals. Having access to medical records is part of being an engaged patient and is particularly important when seeking a second medical opinion, or when consulting with a multiple myeloma expert. "Even though the second opinion reinforces the idea of the first doctor, it may help the patient to feel sure that the decision that is made at this particular stage is correct," noted Yelak Biru, a patient and an advocate affiliated with the International Myeloma Foundation and with Global Myeloma Action Network.

Providing patients with access to their medical records may also help them and their caregivers to

**Figure 4. Selected Online and Digital Resources for Multiple Myeloma**

- Facebook groups
- #MMSM
- Af3m.org (website, Facebook, YouTube)
- Centers of Excellence [www.cancer.gov/research/nci-role/cancer-centers](http://www.cancer.gov/research/nci-role/cancer-centers)
- Blood Cancer Connect (coming in 2017)
- Clinical Trials [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Multiple Myeloma Research Foundation [www.themmr.org](http://www.themmr.org)
- International Myeloma Foundation [www.myeloma.org](http://www.myeloma.org)
- Bloodwise - Cancer Connect <https://bloodwise.org.uk/>
- Myeloma UK [www.myeloma.org.uk](http://www.myeloma.org.uk)
- Myeloma Canada [www.myeloma.ca](http://www.myeloma.ca)
- Myeloma Patients Europe [www.mpeurope.org](http://www.mpeurope.org)
- The Myeloma Beacon [www.myelomabeacon.com](http://www.myelomabeacon.com)
- EMA/FDA website [www.ema.europa.eu/ema](http://www.ema.europa.eu/ema)
- US FDA [www.fda.gov](http://www.fda.gov)
- Diseasemaps [www.Diseasemaps.org](http://www.Diseasemaps.org)
- iStopMM <http://brianduriemd.myeloma.org/?q=iStopMM>
- Smart Patients [www.SmartPatients.com](http://www.SmartPatients.com)
- Myeloma Euronet Romania <http://Myeloma.ro>
- Myelom-LHRM [www.myelom.net](http://www.myelom.net) (basic information in 13 languages)
- Mijelom.hr
- PatientsLikeMe [www.PatientsLikeMe.com](http://www.PatientsLikeMe.com)
- UpToDate [www.UpToDate.com](http://www.UpToDate.com)

prepare additional questions before their doctor visits, and ultimately help them feel more informed and comfortable with their treatment plan. However, electronic medical records can be cumbersome for nonmedical professionals to navigate, and patients should be educated on how to navigate and use their data to generate questions for their doctors and nurses.

Many organizations today provide educational resources and support for patients with multiple myeloma and for caregivers. In addition to resources available online (**Figure 4**), live support groups are available in several cities, so that patients or caregivers can find support and receive the guidance they need anywhere in the world.

Websites such as Myeloma Patients Europe ([www.mpeurope.org](http://www.mpeurope.org)), Myeloma Canada ([www.myeloma.ca](http://www.myeloma.ca)), International Myeloma Foundation ([www.myeloma.org](http://www.myeloma.org)), Bloodwise ([bloodwise.org.uk](https://bloodwise.org.uk)), Smart Patients ([www.smartpatients.com](http://www.smartpatients.com)), The Myeloma Beacon ([www.myelomabeacon.com](http://www.myelomabeacon.com)), and My Diseasemaps ([www.diseasemaps.org](http://www.diseasemaps.org)) provide scientific information, recent research, and patient experiences that may be valuable resources to patients and caregivers. Social media is another way that patients and



From left to right: Natacha Bolaños, Anita Waldmann, Anne Delmond-Davanture, Desdemona DeSouza (moderator).

## IMPROVING COMMUNICATION BETWEEN PATIENTS AND THEIR TREATMENT TEAMS

"I think what we have to bear in mind is that the basic reality is, a patient goes to the hospital, so what he wants is the best possible treatment. Treatment is more than just drugs. You have a patient, you need treatments, you need drugs and you need good doctors...with the communication between them," said Mira Armour.

caregivers can connect with each other and share experiences. Facebook has several notable community pages organized by people living with multiple myeloma. Aside from the online resources listed in Figure 4, patients should ask their care team about other virtual resources or helplines that they can access for additional support.

**"WHAT WE HAVE TO BEAR IN MIND IS THAT THE BASIC REALITY IS, A PATIENT GOES TO THE HOSPITAL, SO WHAT HE WANTS IS THE BEST POSSIBLE TREATMENT. TREATMENT IS MORE THAN JUST DRUGS."**

—Mira Armour

Despite the wealth of digital information available to patients, people must realize that just because something is on the Internet does not make it valid information. Patients should always be encouraged to talk to their care team about what resources they are using to access information.

It is important for patients to understand the severity of multiple myeloma and the available treatment options; however, when a person is first diagnosed with an illness it is often difficult to fully digest all the information that is being conveyed. It has been estimated that about 40% to 80% of medical information provided to patients by doctors and nurses is forgotten immediately.<sup>14</sup> Patients should therefore be encouraged to bring a notebook to each doctor visit or ask a friend or a family member to attend and take notes to document important information, and to ask for the medical visit report to track visit discussions.<sup>4</sup>

### **Caregivers**

Ongoing support from the treatment team should be a part of every patient's journey; this is crucial to helping guide and support the patient to make the most appropriate treatment choices. It is important to recognize that the care team is not just the doctors and nurses who provide medical expertise, but also includes the patient's friends, family members, coworkers, and patient groups who provide other forms of emotional support. Although these nonmedical caregivers can be invaluable during a patient's journey, there is no one-size-fits-all approach for patients to recruit them to their team.

Each individual patient should assess his or her specific situation and decide how to discuss multiple myeloma with friends, family, and even coworkers.

Many patients choose to tell their family and friends right away, whereas others decide to wait until they have a better understanding of the disease. Doctors and nurses, who are there after a diagnosis is made, can help patients formulate how and when they will share the news with others. By opening up and discussing their fears, uncertainties, hopes, and wishes with the people around them, patients are inviting their caregivers to be active members in their journey and in their daily life.

Many patients find it useful and even necessary to have the support of a caregiver on their care team. The level of caregiver support can range from simply providing transportation to and from healthcare visits, to being an integral part of making treatment decisions and digesting information. Regardless of their precise role, caregivers should be encouraged to ask the physician questions about what they should be doing to help the patient, what specific signs and signals they should be looking for, and how to know when it is necessary to inform the treatment team.

## ***Treatment Goals***

It is just as important for patients to discuss their goals with the doctors and nurses on the treatment team. Each patient living with multiple myeloma has different goals in mind that they want to achieve, and their individual goals are important factors in determining their choice of treatment (if options are available in their country). For example, one patient may feel strongly about continuing to go to work every day; no matter what the patient's goal is, the important part is to talk about it with the full care team. A patient's goals may also change over time. Quality of life may become a more important concern after a patient has experienced a few months of treatment, and patients should be encouraged to discuss their goals at multiple times throughout their journey.

When the patient and treatment team are discussing treatment options, it is essential for the patient to understand the expectations of each treatment from the start. Patients should feel comfortable asking about the possible impact of the treatment on their quality of life, and side effects associated with each treatment. Mira Armour stress-

es to doctors and nurses to "encourage and give them the feeling of hope always again and again, because sometimes they get tired of frequent hospital visits and all of the treatment and want to stop because of the side effects. So [you] have to make them feel assured that we know that this is a hard time [that] they have to go through, and we never can promise a cure, but we hope that there will be. That is something important to believe."

**"WE ARE REALLY TRYING TO CONVINCING OUR PATIENTS THAT ADHERENCE TO TREATMENT, AS DIRECTED BY THEIR PHYSICIAN, IS SO IMPORTANT TO ACHIEVING THE DESIRED OUTCOMES."**

—Anita Waldmann

It is important for doctors and nurses to discuss the emotional and behavioral changes that patients may experience during their treatment journey. Depression and guilt may be things that patients begin to experience but may not be readily recognized. Patients and their caregivers should be advised to communicate all physical and emotional changes to their treatment team.

## **IMPROVING ADHERENCE TO MULTIPLE MYELOMA THERAPIES**

For any treatment to be effective, it is important that patients adhere to the prescribed dosing and administration guidelines. "We are really trying to convince our patients that adherence to treatment, as directed by their physician, is so important to achieving the desired outcomes," said Anita Waldmann, a caregiver and co-founder of many patient organizations in Germany. Treatment options for multiple myeloma are continuously evolving, and many patients now have the option



**Table 1. Suggested Questions Patients Should Ask Their Doctors**

What is multiple myeloma?
What are my treatment options now?
What are my treatment options upon release from the hospital?
Do the treatment options change for a relapsed disease versus an initial diagnosis?
Are there any clinical trials available for me?
What are the details of my treatment plan?
After starting treatment, on average, how long can it take to see a positive response?
On average, how long does the treatment last?
What is the long-term outlook of my treatment plan?
What affects treatment success?
What are the potential side effects associated with this treatment?
What tips are available for managing potential side effects?
Should I avoid any activities or supplements during treatment?
Should I make any changes to my diet or nutrition?
Whom should I contact if I have any questions or concerns?

**Table 2. Suggested Questions for Caregivers to Ask the Patient's Doctor**

How often will appointments be scheduled?
On average, how long will each appointment take?
How much time from work should we expect to miss?
What else can I do to be an effective and supportive caregiver?
What are the next and long-term steps?
Whom should I call if the patient is experiencing side effects?
How can I best help the patient?

of taking their medication at home instead of in the hospital or in the physician's office. Compared with other forms of drug administration, oral medications may be less disruptive to daily life for many patients, although they also come with the additional patient responsibility of adherence to treatment.

Treatment teams should be encouraged to talk to their patients about the importance of taking their multiple myeloma medications as prescribed, in addition to the potential dangers of missing doses. Educating patients on how to take their medicine at home, what side effects to look for, and when to call the doctor should be a part of the initial treatment dis-

cussion, and readdressed at multiple times throughout the patient's journey. Doctors and patient advocates emphasize that even if patients are starting to feel better, they need to continue to take their medications as prescribed to have their best chance to achieve the best outcomes.

Modifying patient adherence to treatment can be approached in many ways, and it is often necessary to explore a range of techniques to determine which works best for a particular patient. In consultation with their doctors, some patients may find weekly organizers or calendars useful for staying on track with a treatment plan. As a more high-tech solution, smartphone applications are available that can be preset to remind patients to take their medications as well, but always check with your doctor before using these.

Among the many reasons that patients do not adhere to their medications are emotional and financial barriers. These can lead to intentional nonadherence beyond simply forgetting to take the medicine. Examples of intentional nonadherence include patients purposely skipping days to prolong having to refill their prescriptions, taking "drug holidays," or deliberately "forgetting" to bring their medication on vacation.

"Cost is an issue that needs to be talked about," said Yelak Biru. "People want to extend their medication that they're given for one month, and they want to use it for two months. They take half of it, or they take it every other day," he added.

Regardless of whether nonadherence is intentional or nonintentional, it is important for doctors, nurses, caregivers, and patient advocates to discuss why a patient may not be taking the medication, so that the root cause can be determined and adequate support can be provided. Yelak Biru also stated, "We must identify the cause of noncompliance, and help them [patients] mitigate that, if it is because

they can't afford the cost or [because of] the side effects. Somebody needs to be there to mitigate the reason why they are not able to adhere to those drugs." Support groups or mentor programs can also be valuable tools for encouraging adherence. Through these programs, patients can agree to call each other to check in on how they are managing their treatment, ask if they have been able to follow their treatment plan, and discuss whether any additional support is needed.

Staying organized can be a challenge for everyone, and particularly for patients learning to live with the complications of a new disease. Patients should be encouraged to keep a notebook or diary to record healthcare visits, listing upcoming appointments, treatment plans, and any adjustments to their treatment regimen. Patients should use their notebooks to record when they took their medications, what side effects they have experienced, and how those were managed. Patients may also find it helpful to have a binder and virtual storage place to keep educational materials, questions for their healthcare professionals, resources, and other records.

## STRATEGIES TO OVERCOME CHALLENGES DURING THE PATIENT JOURNEY

Patients and caregivers should aim to be as informed as possible; one of the best ways to accomplish this is by improving the communication between patients and the healthcare team by asking the physician or the nurse questions about multiple myeloma and the available treatment options. Suggestions for questions that patients should ask their physician are listed in **Table 1**. Caregivers should also feel comfortable asking physicians or nurses about their role in the treatment plan. Potential caregiver questions are listed in **Table 2**. In addition to the questions listed here, many of the resources shown in Figure 4 list questions for patients and caregivers to consider asking their healthcare team.

After the doctor or the nurse has reviewed all the information, and the questions have been answered, the treatment team should summarize and review the information again to ensure that the patient and caregiver understand everything that was discussed.

Patients with relapsed disease generally have a sense of what the disease is and what the treatment options are, and have already established a relationship with their doctors and nurses. "[Patients] can say, 'I understand all that happened to me before, so is that happening to me again? How does this affect all the things that I was told previously?' You can now start a more educated discussion about it," said Chris West. Although patients with relapsed disease may be more educated than they were at diagnosis, their questions for the next phase of their treatment journey may be similar to those provided in Table 1.

"WE MUST IDENTIFY THE CAUSE OF NONCOMPLIANCE, AND HELP THEM [PATIENTS] MITIGATE THAT, IF IT IS BECAUSE THEY CAN'T AFFORD THE COST OR [BECAUSE OF] THE SIDE EFFECTS. SOMEBODY NEEDS TO BE THERE TO MITIGATE THE REASON WHY THEY ARE NOT ABLE TO ADHERE TO THOSE DRUGS." —Yelak Biru

Whether a patient has just been diagnosed with multiple myeloma or has disease relapse, it should be made clear that it is fine to seek a second opinion. Living with multiple myeloma can be a frightening and complicated process, and getting a second opinion from another expert can bring a level of comfort to patients, as well as provide them with additional perspectives and educational information.

Because multiple myeloma is a rare type of cancer, some hospitals or physicians may have more experience with this illness than others. Patient

advocates and others suggest the creation of a database summarizing the leading centers and physicians for the treatment of patients with multiple myeloma in each region of the world. Such a website would provide a much-needed resource to the global multiple myeloma community, and particularly for patients who are unfamiliar with their local healthcare systems.

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## CONCLUSION

Although multiple myeloma remains incurable, patients with this disease have more therapeutic options and better overall outcomes than ever before. As more information is acquired about the disease, and as new treatments continue to be developed, providing people living with multiple myeloma the education necessary to navigate their cancer journey is essential for this community. This white paper highlights some of the unmet edu-

cational needs faced by these patients, and the potential strategies for overcoming them. Through the digitally connected, globally integrated coordination of care, patients with multiple myeloma will be better served in the future.

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