



## **Podcast Transcript: Support for Myeloma Patients and Caregivers**

### **HOST:**

Many patients face emotional challenges when they are diagnosed with myeloma and also during and after treatment. Jennifer Mijangos is a licensed clinical social worker for the myeloma program at Huntsman Cancer Institute and works with patients and their families to help them cope with difficult emotions and life changes related to having multiple myeloma.

Jennifer, thank you for joining us to discuss supportive care.

### **JENNIFER MIJANGOS:**

Hi. It's good to be here.

### **HOST:**

Can you tell us a little bit about your background and what you do here at Huntsman Cancer Institute?

### **JENNIFER MIJANGOS:**

My professional background is fairly diverse. I've worked on multi-disciplinary teams in hospital settings as well as mental health clinics and hospice agencies. I decided to join Huntsman's myeloma team because of the passion I have for helping patients and their loved ones deal with difficulties that are surrounding adjustment to their illness and treatment.

A lot of the time that I spend is working with patients and their families in finding ways to best cope with treatment and face their diagnosis.

### **HOST:**

And what can you do for patients with myeloma who are expressing anxiety and perhaps even depression?

### **JENNIFER MIJANGOS:**

That's a great question. Strong emotional reactions can be a normal part of dealing with diagnosis and treatment of myeloma. Even if you've never experienced feelings like that before. So it's very important to find out the reason or the cause behind some of the emotions that people are experiencing. Sometimes it might be related to medications that patients are taking.

Whenever I meet with patients or their families, we talk about what kind of coping techniques they are already utilizing and often times I suggest additional coping techniques to help them in managing their moods.



**HOST:**

And what kinds of things do you discuss with patients when you meet with them?

**JENNIFER MIJANGOS:**

That's entirely up to the patient and their caregivers. Social workers often counsel patients and their loved ones on the transplant process and life after treatment. We focus on supporting their practical, emotional, and spiritual needs.

Our conversations aren't always serious or problem-focused, though. Often times meeting with a social worker can be a welcome distraction to part of their ongoing clinic routines and testing. It's an opportunity to speak with an objective and supportive person that really cares about you.

**HOST:**

What are some of the common feelings and worries that myeloma patients may experience?

**JENNIFER MIJANGOS:**

Often times patients are worried about the unknown, which is very normal and completely understandable.

So, there's a lot of adjusting to: What will this mean for my life on a daily basis? What is treatment going to look like? How am I going to feel during the process? How am I going to make day-to-day decisions and plan for the process of treatment in general? How am I going to talk to my friends and family about things?

So, again, these are all very common concerns and they are things that we can really work through together.

**HOST:**

Do all of the myeloma patients who come to Huntsman Cancer Institute automatically meet with you?

**JENNIFER MIJANGOS:**

Ideally, all patients do meet with me when they first arrive. Often times that's in the context of the preliminary testing that they are doing, and they meet with me for what's called a psycho-social assessment. It's not a really formal or structured interview, though. It's just an opportunity to meet me and for us to establish a relationship. I can explain to patients about the clinical social work services that we have to offer.

I also get a chance to find out what are the strengths and the resources that they are bringing to the treatment process and also what are their stressors, their fears, their concerns that may really make this a challenging experience for them. By



talking about those things upfront, we can look together for solutions and we can kind of problem solve and cope ahead of time so that patients feel really comfortable as they approach the treatment process.

**HOST:**

And you meet with the family members as well, is that right?

**JENNIFER MIJANGOS:**

Absolutely. We're here to support patients and anyone who cares about them. Being a caregiver for a myeloma patient is a big job. Primary caregivers are partners with the patient. They spend a lot of time and energy making sure that their wishes and concerns are properly addressed.

So, providing emotional support for the patient and being an advocate for them can be a very taxing role. Sometimes caregivers experience their own stressors and they have a hard time sharing that with the patient because they want to protect the patient and they want the patient to spend all their time and energy on getting well.

So, often times caregivers find it really nice to be able to speak with a social worker, vent some of their concerns, talk about their worries, and get answers to their questions.

**HOST:**

Is there any general advice that you would give to myeloma patients or their loved ones and caregivers?

**JENNIFER MIJANGOS:**

Many people with a life-threatening illness spend a lot of time worrying about the worst case scenario, but they are afraid to discuss these worries and concerns with their loved ones. By avoiding the subject, people often end up suffering in silence and losing sleep.

By talking with clinical social workers here at Huntsman, patients can get support in dealing with these difficult issues, so I always recommend that people take some time to think about those things. Then they can spend all of their energy for the rest of treatment focusing on getting well.

**HOST:**

Do any of the patients feel stigmatized by even asking for help?

**JENNIFER MIJANGOS:**

I think you're bringing up a really good point. Often times patients when they are coming here may not anticipate meeting with a social worker and they may wonder if



we are assuming that there are some kinds of problems or concerns that need to be addressed.

But, typically, within the first five minutes of meeting each other, patients get a pretty good idea that really the main reason behind meeting with me is so that we can make sure that they have good comprehensive care; so that they get a chance to really believe that we care about the whole person and not just the treatment process.

Even though some patients do talk about being a little bit apprehensive in terms of meeting with a social worker at first, they find that it is a really nice way to make a personal connection and they feel much more at ease in the treatment process.

**HOST:**

How can patient get in touch with you?

**JENNIFER MIJANGOS:**

Patients and their loved ones can reach me by phone at: 801-587-4695.

They can also reach me at our website, which is [www.fightmyeloma.org](http://www.fightmyeloma.org)

**HOST:**

Alright, thank you again for your time.

**JENNIFER MIJANGOS:**

Thank you.

**HOST:**

Also joining us is Debbie Coleman. She's the new patient coordinator for the myeloma program and she also coordinates a myeloma support group.

Debbie, thank you for being here.

**DEBBIE COLEMAN:**

My pleasure.

**HOST:**

Can you tell us a little bit about your background and what you do here at Huntsman Cancer Institute?



**DEBBIE COLEMAN:**

Yes. I have been working at Huntsman Cancer Hospital since October of 2007. I come from a social services, non-profit background so most recently was working with domestic violence survivors and their children. I've also worked with children dealing with trauma and people managing addictions. I have a license in professional counseling, so I was drawn to work in this program because of the unique opportunity to create a certain kind of patient experience.

For new patients, I am the first point of contact so I give them a lot of information about what the program is about, the methods of treatment that are done here, as well as listen to their concerns and fears.

I am also developing patient education for patients and their caregivers which will provide hopefully comprehensive information that assists them in understanding what they'll be going through and how they might be impacted.

I am also running the support group with Jen Mijangos and this is a different format from the patient education group. It is also for patients and caregivers.

**HOST:**

Can you give us some more details about the support group—what the goal is?

**DEBBIE COLEMAN:**

The National Institute of Health along with the Institute of Medicine studied the psycho-social needs of patients with cancer and how these needs are met. The evidence suggests that the psychological and social problems that are created or exacerbated by cancer can be effectively addressed through certain interventions. One of these is a support group.

Being a participant in a group connects you to others who can identify with your current circumstances. They may not be feeling the same sort of things that you are feeling, however they can offer an understanding that others might not be able to.

Listening to others can provide hope about getting through a difficult time. It can give ideas and perspective that you had not considered. And, overall, the experience is designed to provide support, information, and to ensure that your emotional and psychological needs are being met at a very critical time.

**HOST:**

What can patients expect when they attend a meeting?

**DEBBIE COLEMAN:**

We meet in the chapel, so the environment is very quiet. There are large windows that have a view of the front of Huntsman Cancer Hospital. We'll have patients and caregivers sign in. There are light refreshments that are available.



It's designed to be fairly unstructured with the intent of inviting people to bring up issues and subjects that have been on their mind. The goal is to encourage conversation so that group members can openly share their concerns, their questions, thoughts and feelings, and receive support and understanding from each other.

**HOST:**

And how often does the group meet?

**DEBBIE COLEMAN:**

We will meet weekly. We will meet on Wednesdays from noon to one. The chapel is located on the first floor of the Huntsman Cancer Hospital to the left of the front entrance. It's tucked behind the gift shop.

The group is open to both patients and their caregivers who are thinking about, in the process of, or post transplant.

**HOST:**

Are there any other opportunities here in the Salt Lake area for patients for get support?

**DEBBIE COLEMAN:**

There are. There's a variety of ways and if you go to the [fightmyeloma.org](http://fightmyeloma.org) website that we have, under the supportive care section, there's a list of websites that offer support. That support ranges from getting connected to those with a similar disease as what you have, as well as the staging, and so connecting to those people to get information and to share stories.

**HOST:**

I understand that as part of being a new patient coordinator as well, you offer assistance to new patients. What kinds of things do you help them with and what are some of the common concerns of patients with multiple myeloma?

**DEBBIE COLEMAN:**

When new patients call, they're often just diagnosed and so there are a lot of questions and concern about what they are facing and so in the new patient process it's a lot of information giving. Giving information about Huntsman Cancer Hospital if they are not from the local area, giving information on the clinic and on the doctors that are in the clinic, on the treatment methods that are done, specifically the tandem autologous stem cell transplant.

Some of the concerns that I hear are related to the cost of the transplant. If people are coming from out of state, the cost of temporarily relocating for the time that treatment would be going on.



There's questions about: is this done outpatient or inpatient? What sort of facilities do you have there at Huntsman?

There are a lot of questions about the tandem autologous transplant. What does that involve? What's the time frame? What are the needs of the patient?

I often talk to caregivers as well as patients, and so the questions are similar and they are very different based on whose perspective it is. Many questions are about how to manage the whole process in general. How to manage the diagnosis if it's recent. How to deal with, if they've already had a previous transplant, is it possible for another transplant to be done?

Overall, there's an incredible need for information about what they are facing and where they may be facing it at if they come to Huntsman.

One of the common questions from both patients and caregivers is the initial process that they go through to come into the program and that involves pretty extensive testing. So, for people who have been diagnosed—or people who have not been diagnosed but there is a suspicion—they go through the same testing process.

The tests include about two to two and a half days of exams. Some of the tests are a bone marrow biopsy, an MRI, a PET scan. A lot of blood is drawn and labs are run on that. And, two heart function tests and a lung function test are done. So these typically take up two to two and a half days and then a consultation with the doctor is scheduled after that.

The reason that it's so extensive on the front end is really to give the doctor a comprehensive view of the disease, the stage, and to really inform the doctor and the patient about treatment options that are available.

**HOST:**

Is there any advice you'd give to new patients or to those seeking a support group?

**DEBBIE COLEMAN:**

To think carefully about what they need. To be very clear about what is really going to support them in this process. And to do research on what place is really going to provide what they need. I think at Huntsman, the benefit if you're being treated here is that we really have such great wrap-around services right on site. So it's convenient. It's affordable in that there's not a charge. And it's a connection with people that are experiencing a very similar circumstance.

**HOST:**

How can patients get in touch with you?



**DEBBIE COLEMAN:**

By phone they can call: 801-587-4652.

And through the website, [fightmyelom.org](http://fightmyelom.org), they can contact me through the contact form on the web.

**HOST:**

Ok, well thank you for that information.

**DEBBIE COLEMAN:**

You're welcome. My pleasure.

*To find out more about multiple myeloma and the Myeloma Program at Huntsman Cancer Institute, visit <http://www.fightmyeloma.org>.*