

Communication and Shared Decision Making

How to have better diagnosis conversations with people who have endometrial cancer.

Welcome to “Communication and Shared Decision Making: How to have better diagnosis conversations with people who have endometrial cancer.” This module was developed by dandelionRX in partnership with Greater Good Studio. We seek to ensure that all patients and caregivers receive the best possible communication for their needs, in order to improve patient health outcomes.

Introduction

An initial endometrial cancer diagnosis comes as a shock for most people. Those who have heavy, irregular, or post-menopausal bleeding—the visible symptom of endometrial cancer that also makes it possible to diagnose at an early stage—often believe they’re experiencing symptoms of perimenopause or menopause. Or, they associate it with a history of irregular bleeding throughout their lives. They go to the doctor seeking relief—not a cancer diagnosis. When they hear “you’ve got cancer,” patients have to adjust to a new, unanticipated reality, make decisions quickly, and prepare for their unique experience through treatment. Approximately 80% of endometrial cancer cases are diagnosed in Stage I, and the survival rate for these cases is high. However, no matter how positive a patient feels about their prognosis, a cancer diagnosis is a life-altering experience.

Shock makes communication between healthcare teams and the patients, and their caregivers, challenging. A diagnosis of recurrent endometrial cancer can be even more traumatic. But shock isn’t the only barrier to effective communication. Patients have different levels of literacy and health literacy. Depending on the stage of cancer at diagnosis and the circumstances, there is an urgency for the patient to make treatment decisions. For patients diagnosed with advanced endometrial cancer, there are difficult tradeoffs they have to

make when it comes to length and quality of life. For healthcare providers, they must navigate additional constraints such as ensuring that they are on schedule, patient records are up-to-date and other administrative needs are met.

Patients experience a range of emotions during a diagnosis of endometrial cancer: disbelief, fear, anger, even shame. Patients diagnosed with recurrent cancer report feeling higher levels of depression and anxiety than they did during their initial diagnosis. When communication breaks down between patients and healthcare teams during the diagnosis appointment—and it often does—these emotions are compounded.

Clear, direct, and empathetic communication from the oncology team is a cornerstone of shared decision making and can transform the patient experience. Shared decision making is the process by which healthcare professionals, patients, and their caregivers, make decisions together about the patient's care. Together, the patient and their care team choose treatment plans that are based on clinical evidence. As well, providers help the patient balance risks and expected outcomes with the patient's preferences and values.

Good communication can build a bond of trust with the patient, help them learn about their cancer and treatment options, and empower them to engage in their care—three of the necessary ingredients for shared decision making.

How can you as a provider create an experience that engages patients in their care? How can you support a shared decision-making process that is rooted in clinical evidence, while balancing risks and expected outcomes with patient preferences and values?

After completing this module, you will be able to:

- Identify barriers to productive communication between providers and patients during a diagnosis of endometrial cancer
- Articulate guiding principles and best practices for provider-patient communication, and
- Use communication strategies to develop and support a therapeutic relationship with your patients

These objectives apply to you communicating with both patients and their caregivers. However, to keep things simple, we will be referring solely to

patients, unless a strategy or tactic is targeted specifically to caregivers.

Over the course of this hour, we will introduce you to a set of evidence-based principles and targeted strategies you can use to communicate with your patients, and that also support shared decision making. We'll explore health communication and patient education research. You'll also meet some patients who have been diagnosed with endometrial cancer, their caregivers, and healthcare professionals whose firsthand experiences and insights helped to inform these principles and strategies.

We'll also share "Understanding Your Diagnosis of Endometrial Cancer," a set of communication tools developed with patients, their caregivers, and healthcare professionals like you. These evidence-based, interactive materials are designed to support you and your patients as you engage in shared decision making.

During initial diagnosis appointments, you can use the "Understanding Your Cancer Diagnosis" worksheets to explain to patients some of the most important facts about their diagnosis and treatment plan. You can refer them to the patient journal, which they can review in the office or at home. The journal has additional information on supportive care, side effects, and sexual health, as well as advice from other patients. Patients can also use the journal to track their treatments, side effects, and questions that come up between appointments. Also included is a booklet for caregivers, where they can write down their own questions and review advice from other caregivers. All of these materials are contained within a folder, where patients can store these and other materials they receive during their diagnosis visit.

Every provider brings their perspective, their experience, and their knowledge into their relationships with their patients. For that reason, these strategies may look very different when they're used in different care settings. Throughout this module, we'll ask you to reflect on your experience and consider how these strategies and tools might fit into your practice. We've asked these same questions to experienced healthcare professionals in gynecologic oncology, and we'll share their responses with you along the way.

We've already highlighted some of the barriers to effective communication and shared decision making. Let's explore more about what happens to patients when they hear, "You've got cancer."

It's difficult to educate patients during a moment of crisis, and to complicate matters, each patient's needs are different. Their individual personalities, lived experiences, preferences, and communication styles alter the way they react during the diagnosis conversation.

Patients and providers find that communication is even more difficult when it's not possible for a caregiver to be in the office with the patient. While there are many reasons why a patient may come alone, the COVID-19 pandemic has restricted who can be physically present at the appointment. The care team has to be even more sensitive to the patient's individual needs when their caregiver is attending the appointment virtually.

For racially and ethnically diverse patients, there are additional obstacles. Patients may harbor mistrust of the medical system, concerns about privacy, and feelings of not being respected. They may have past experience of discrimination. There may be language barriers. Racially and ethnically diverse patients report poorer communication and less relationship-building efforts made by physicians than do White patients. Additionally, these patients are more likely to be seen in settings where the contextual barriers of limited time and resources are even more pronounced.

African American women are consistently diagnosed with a higher stage and tumor grade, and have significantly higher rates of aggressive endometrial cancers than White women. As a result, while the incidence of endometrial cancer is similar for African American women and white women, African American women are 2.5 times more likely to die from the disease.

The reasons for this disparity are multifold: African American women may have varying responses to treatment, comorbidities, and genetic mutations that put them at greater risk of developing the disease. Additionally, they may have more limited access to care, more limited finances, or lack insurance, all of which can lead to delays in diagnosis and treatment.

These disparities stem from systemic issues that are larger than what you can solve in an appointment. But they should be acknowledged, because even those providers who are highly skilled at patient communication may start out

with a “negative balance” or deficit as they seek to establish trust, understanding and a shared approach to decision making.

In addition to emotional, racial, and cultural barriers to communication, patients and caregivers are grappling with another important issue. When a patient is diagnosed with endometrial cancer, they’re not just receiving life-changing news. They’re also being flooded with new, and often frightening, information. As a healthcare expert, you’re tasked with introducing all this new information to patients. Research shows that most oncologists prioritize specific details about the patient’s diagnosis and current treatment options. However, patients want different information: they want to know about testing, and timeframes for testing results. They also want to know what the possible implications of treatment decisions may be, from its near term side effects, to long term or even permanent effects on important aspects of their life, such as their fertility.

Patients frequently leave their diagnosis appointment without a working understanding of medical information, and many do not have time to reflect and consider their treatment options. And it isn’t just a lack of time or information: patients may not be aware that they have a role to play in making treatment decisions.

How can we close this knowledge gap and improve shared decision making? Oncology teams need to tackle some challenging questions. What does the patient need to know, and how can you help them to understand it? What does the patient want to know, and how can you help them find answers? How do you support the patient to engage in their care and make decisions with you?

Providers can support their patients’ health by addressing these communication barriers. As with other gynecological cancers, patients with endometrial cancer have consistently high levels of unmet needs for psychological and physical support. Clear communication reduces patients’ anxiety and depression, and it promotes overall well-being. It also has an impact on the patient’s behavior after they leave the doctor’s office: if the patient remembers what they learned during their diagnosis, they are more likely to follow their provider’s recommendations and adhere to treatment regimens. By starting to build a positive relationship with your patients—from the very first interaction—you start to overcome the common communication barriers that stand between you and them. Diagnosis is a difficult moment, but

it's also the beginning of your partnership with the patient, and with their caregivers.

You want your patients to leave the diagnosis appointment with everything they need: trust in their care team, the tools they need to understand their condition, and readiness to engage in their treatment journey.

These make up our three principles for improved provider-patient communication when presenting a diagnosis of endometrial cancer:

1. Build a foundation of trust with the patient and caregivers,
2. Support the patient in developing an initial understanding of their diagnosis and treatment, and
3. Empower the patient to engage in their care.

Let's discuss each of these principles in greater depth. We'll also explore some communication strategies that illustrate how these principles might work in practice.

Principle 1: Build a foundation of trust with the patient.

Reflect on your experience

Take a moment to reflect on your own experience. How do you build trust with your patients? Have you ever felt like you were starting from a “negative balance” of trust? What did you do to repair that trust so you could begin to build a positive relationship?

About the principle

When we asked other providers this same question, here's what one oncology nurse navigator had to say: “Sometimes our body language can be authoritative, and we don't even realize it. The first thing I do is sit down, so I'm at their level and not booming over them. Then I talk to them about something mundane. If they have on interesting earrings, I'll say, “Tell me

about your earrings.” If they came from far away, I’ll ask, “How was the traffic?” It gives us a way to connect as people, and signals that I see them as a whole person.”

Endometrial cancer is scary. To come to terms with their diagnosis, patients need to feel comfortable with their provider. As their treatment and follow-up care progresses, patients should feel like they’re able to come to you and your team with concerns, questions, and decisions. The diagnosis visit provides the foundation for a relationship that requires trust and open communication. During their first appointment, patients need to know their well-being is important, they are being heard, and they will receive the best care.

Luanne was diagnosed with Stage III endometrial cancer thirteen years after being treated for ovarian cancer. She began experiencing some of the common symptoms — missed periods, cramping, and heavy bleeding. She told her doctors about it repeatedly, but the symptoms weren’t investigated. Finally, after a sustained stretch of heavy bleeding, Luanne knew something was definitely wrong. She went in for an ultrasound, followed by an endometrial biopsy, and was diagnosed five days later.

In the diagnosis appointment, Luanne was in disbelief: cancer, again? Then, she got angry.

“I spent years going to the doctor, and nobody caught it. I felt like I wasn’t heard all those other times. The people I paid to take care of me ignored my symptoms. They would always say it was something else. Now I was sitting in the same position I was 13 years ago, only worse.”

Luanne proceeded with treatment, but her guard was up. She knew from past experience that she had to look out for herself. She vividly recalls moments when trust was absent, and the difference it made when it was present.

“I saw a radiation oncologist who suggested brachytherapy. I said ‘I don’t want that. Why do I need that?’ She wouldn’t tell me. So I got a second opinion, and that radiation oncologist actually didn’t recommend brachytherapy. It wouldn’t be harmful, but it would be overkill. The first doctor tried to push the therapy on me without explaining why, and the second one took the time to

explain the therapy and why it wouldn't be effective." For Luanne, trusting the doctor meant knowing the reason behind the recommendation.

To find a doctor she could trust, Luanne sought out a second opinion. We brought up the question of second opinions with Sean, an oncologist who maintains a private practice affiliated with a larger hospital network. He's well-known in his network for the time that he takes explaining things to patients, and for his holistic approach to patient well-being. He believes that when patients get a second opinion, it builds trust between him and his patients. Sean told us, "I don't mind if people get a second opinion. Without trust or faith between the patient and the provider, things break down."

As a provider, you're under pressure to deliver complex, vital information to patients in a limited amount of time. There's a lot that can "break down." But the reality is there will be many opportunities after the diagnosis visit to talk with patients—but only if the patient trusts you. This brings us to our first communication strategy:

Strategy 1: Focus on establishing a relationship, not simply delivering information.

Patty has 30 years of experience as a hospital-based oncology social worker. "If you give patients a lot of information and make it about you, you've failed. You have to make it about them...You have to start where they're at."

The diagnosis visit is only one conversation out of the many you will have with patients as they undergo their treatment. "Starting where they're at" takes some of the pressure off to "cover" a large amount of material in a short amount of time. And it allows you to connect with the patient at a personal level.

Janna is a gynecological oncologist who works at a community cancer center. She works with a diverse group of patients. Her patients have a wide range of responses to their diagnoses: some want all the information up front, while others shut down. She has a technique for building relationships with patients that don't immediately comprehend the information she shares at the first appointment: "Oftentimes, when I'm not comfortable that the patient understands, I'll have them come back in a few days to redo the conversation.

Or I'll set up a phone call a few days later, so that they don't have to make any decisions in the office.”

When providers establish a foundation of trust with their patients, those patients feel more confident in the quality of their care. As we discussed earlier, there are many reasons why providers may be starting with a “negative balance” of trust. One additional reason is that many patients with endometrial cancer have a complicated history with the medical system because of their body weight. A growing body of evidence shows many providers implicitly perceive patients with obesity as undisciplined or unintelligent. Obese individuals are more likely to be subject to stigma, discrimination, and poor communication in the healthcare system.

70% of patients with endometrial cancer are obese. In a study on obesity and endometrial cancer, some patients felt they were treated differently than normal weight individuals, being offered non-curative alternatives to surgery because of their body weight, or being refused certain treatments altogether without evidence to do so.

While obesity is a risk factor for endometrial cancer, a new cancer diagnosis is not the right time to focus on weight or weight management. Janna explains why: “I try to be really, really careful about not making people feel like they gave themselves cancer. Or that, if they have a recurrence, that it's their fault. I don't want them to think, ‘If I had eaten better, my cancer wouldn't have come back.’”

In a moment of crisis, the last thing she wants to do is compound the trauma with feelings of guilt and shame. Additionally, doing so risks destroying the foundation of trust you need to establish with the patient.

Janna goes on to share when she does bring it up: “I bring up weight with patients when they're done with treatment. I'll tell them, ‘This is an opportunity to reset your lifestyle, eat better, and exercise more.’”

With patients and providers, we've developed and tested “Understanding Your Diagnosis of Endometrial Cancer,” a communication tool that supports effective provider-patient conversations. We're going to use this tool as an example of how to improve communication during diagnosis.

The “Understanding Your Diagnosis of Endometrial Cancer” tool has

several worksheets designed to support you as you manage patient questions and introduce the care team. You can select specific worksheets based on the amount of information the patient wants to discuss at the first appointment: they may want to know about the way endometrial cancer is treated. If so, the “Understanding Your Care” worksheet has information to support their understanding. They may have questions about supportive care. Each of these topics has its own standalone worksheet that you can include if the patient is ready for it. But if the patient is only ready to take in a little bit of information, you can share only what they need to know right away.

Diagnosis is not the right time to talk about obesity as a risk factor for endometrial cancer. However, nutrition and physical activity are two subjects you can introduce early on. Many patients are eager to learn about how they can eat well, and they may ask questions about diet at their diagnosis visit. The “Staying Healthy After Diagnosis” worksheet includes an overview of the benefits of eating healthy and doing physical activity during treatment. On the same page, there is an activity that you can do with patients to discuss foods they like to eat, physical activities they enjoy, and new things they can incorporate into their lifestyle to take care of themselves. This activity takes a positive, patient-centered approach to these topics: Do they love to dance at church? Then try dancing a bit more often. Do they love chocolate cake? They don’t need to eliminate it from their diet entirely, but how about replacing dessert with fruit a few times a week?

Strategy 2: Leverage the full care team to ensure no concerns of the patient and their caregiver are left hanging, and no questions remain unanswered.

Providers have a limited amount of time to spend in any one appointment. For some patients, that means an appointment has to end before you have a chance to fully answer all of their questions. You can balance your patient’s needs with the constraints of a busy schedule by connecting them with the rest of the care team. A “warm handoff” to a nurse, physician’s assistant, or another staff member reassures them they won’t be left with outstanding concerns. If that’s not possible, you can share the name and direct contact information of another person on your team they can reach out to after the appointment ends.

Some topics are important to introduce at a diagnosis appointment, even if a patient is not ready to talk about them in greater depth. Patients need time and space to process critical information, and to get comfortable discussing sensitive topics. For this reason, it's important to introduce the impact of cancer and its treatment on sexual health at the initial diagnosis visit. However, it may not be appropriate to go into depth until the patient has had time to make sense of their diagnosis and to prepare for a deeper conversation.

Sexual health is a state of physical, emotional, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. A majority of patients seen for gynecological cancers report short- and long-term sexual dysfunction, but patients also report that they do not learn about the effects of cancer and treatment on their sexual health from their providers. Providers may encounter many obstacles to communicating with patients about sexual health, including time constraints, training limitations, personal biases, and the belief that patients will report their own sexual health concerns if they have any.

However, some patients don't realize they can speak with a provider about their sexual health concerns, and don't feel comfortable bringing it up. Wendi, who was treated for Stage III endometrial cancer, told us, "I would have wanted to know about the side effects that happen during treatment before I had surgery. It wasn't forefront in my mind, but that would have been good to know then. After treatment, I would have wanted to know about some of the longer term issues. If I had known more, I could have been more proactive about minimizing the side effects."

A diagnosis conversation is likely not the right time to discuss the topic in depth. Patients are grappling with a traumatic life event, and they are trying to take in a large amount of complex information. To help patients prepare for later conversations about sexual health, you might bring up the topic briefly at diagnosis or at another visit early on in a patient's treatment. It's another opportunity to introduce the idea that they may want to connect with other members of the care team.

A patient needs to know that they can have this conversation at a time, in a

place, and with a person they feel comfortable speaking to—which may or may not be you. Gloria, a nurse navigator, recalls an experience earlier in her career when she came across a gynecological cancer patient crying in her car in the parking lot outside the hospital. The woman had just found out about the sexual health implications of her upcoming surgery. “We talked for a long time. I asked if she wanted to talk with her oncologist. She responded immediately, ‘No way, he could be my grandfather!’”

There are many dynamics that shape if, when, and with whom patients are comfortable talking to about sexual health: age, race, gender, and religion are just a few. By leveraging your entire care team, you can ensure that patients can connect with someone they feel safe with.

The “Understanding Your Diagnosis of Endometrial Cancer” communication tool provides you with spaces to make a note of your patient’s questions while you are explaining the basics of their diagnosis and treatment. In addition, the “Care Team” section of the patient folder can help you to connect the patient to people who can help answer their questions after their time with you is up. It has space for names, roles, and contact information for the people who may be able to answer specific questions—or who will play a major part in the patient’s care going forward. The patient can continue to add names as their treatment progresses. By reassuring patients they have a whole team backing them up, you can start to build trust in the system that supports patients. Lastly, the supportive care worksheet can help you introduce sexual health in an unthreatening, non-invasive way by suggesting it among a list of other kinds of resources available to support patients. The patient journal, which we’ll explore in further detail later, includes more information on sexual health that patients can explore with a care team member when they are ready.

At the beginning of our discussion about trust, you reflected on the way you practice the first communication principle: Build a foundation of trust with the patient and caregivers. Now that you’ve reviewed the principle in more detail, think about what you can do to strengthen your relationship-building with your patients during diagnosis. What’s something that you can add to your practice to build a foundation of trust with patients and caregivers? How might this encourage them to be more active in participating in decisions about their treatment?

Apply the strategies

At the beginning of our discussion about trust, we shared Luanne's experience with her providers. She didn't trust the first radiation oncologist she saw, because they wouldn't share the reasoning behind her treatment recommendation. Luanne left to get a second opinion.

Imagine you're in a similar situation in your care practice: a patient is in your office. You've shared the diagnosis, and you're starting to outline next steps. The patient says, "Before we do that, I think I want to get a second opinion." How would you respond?

We spoke to Maria, a nurse practitioner who works with many cancer patients. When patients bring up second opinions, she tells them, "It's okay to get a second and third opinion. We want you to feel comfortable with all your decisions."

Reflect on the principle

At the beginning of our discussion about trust, you reflected on the way you practice the first communication principle: Build a foundation of trust with the patient and caregivers. Now that you've reviewed the principle in more detail, think about what you can do to strengthen your relationship-building with your patients during diagnosis. What's something that you can add to your practice to build a foundation of trust with patients and caregivers? How might this encourage them to be more active in participating in decisions about their treatment?

Principle 2: Support the patient as they develop an initial understanding of their diagnosis and treatment.

Reflect on your experience

Now that we've discussed the first principle, which focuses on building trust, let's turn to our second principle for provider-patient communication: Support the patient as they develop an initial understanding of their diagnosis and treatment.

You already do a lot to educate patients about their condition and their care plan. Think about some of the conversations you've had with patients who are finding out they have endometrial cancer. How do you know when patients understand their diagnosis from the information you have given them?

When we asked a gynecological oncologist, she told us, "Usually these are long, in-depth conversations. Patients may tune out everything you say after 'endometrial cancer.' I write a lot of it down and use diagrams to explain. I use patients' nonverbal cues to see if they understand, but I also ask the patient or her caregiver to repeat what I've said, or to summarize it, to be sure they understand."

About the principle

Over the course of their diagnosis and treatment, patients absorb a lot of information about cancer. They learn about their disease, seek out information on treatment, encounter and learn to manage side effects, and accumulate knowledge about how to navigate the healthcare system.

The first diagnosis appointment sets the stage for a patient's learning. In a lot of ways, it's like the first day of school—it's just the beginning of a learning pathway. On that journey, patients will have to make informed choices based on what they know.

Some patients come to the diagnosis appointment highly literate, with good insurance and a sophisticated understanding of their health, the healthcare system, and possibly even their diagnosis. They may already know a lot of the

medical terminology that providers use to talk about treatment. However, only 12% of adults have the health literacy skills needed to manage the demands of our healthcare system. Most patients will start out with lower levels of health literacy, more basic or no health insurance and superstitions about diseases. . They will need support to make sense of the medical information you are sharing with them.

Carla recalls her experience finding out about her cancer. Her gynecologist had told her that her uterine lining was a little thick. After doing an ultrasound, the doctor made an appointment for her with a gynecological oncologist for the following Monday.

“When I got home from the doctor’s, I told my daughter that she wanted me to see a gynecological oncologist. She dropped what she was doing. I said, ‘What?’ And she said, ‘Mom, they think you have cancer!’ I was like, ‘How do you know?!’”

While Carla would become very familiar with a whole host of new terms soon, at the beginning, even the word “oncologist” and its meaning were new for her. No matter what your patient knows when they arrive in your office, they’re adjusting to their new reality: they have endometrial cancer. Given the shock of a cancer diagnosis, even the best prepared patient can struggle to fully comprehend their diagnosis before they leave the appointment.

Strategy 3: Use multiple modes of communication, including visuals, to clarify concepts.

To help patients build an understanding of the most critical information, use multiple modes of communication, including visuals, to clarify concepts. Patty, the oncology social worker, reminds us that at the beginning, patients need to know the basics about their diagnosis and treatment: “It’s the what, the why, and the how.”

But keep in mind that the way you share information is just as critical as what you share. To use this tactic, be aware of all the ways you’re able to communicate with patients. You explain things out loud, connecting with patients in real time and responding to their reactions in the moment. You write down key facts so that patients can see the words in front of them and

reference them after they leave the office. And you use visuals and models to help patients visualize what's happening inside their body, as you're explaining it to them.

When it comes to oral and written communication, it's important to:

- Use simple language. Using plain language can help you to overcome any gaps in patient literacy or health literacy levels.
- Use active voice, not passive voice. If you are giving step by step instructions, it's better to say, "After you've taken your medication..." instead of "After your medication has been taken..."
- Speak in the second person. Use "you" statements whenever possible. Limit your use of jargon, and use words that a 14-year-old would understand. It's easy to overlook some of the technical language that patients hear during diagnosis. For some people, basic terms—like "cell" or "tissue"—may be long-forgotten vocabulary from high school biology class.
- Define new words and terms. There are some terms that patients will hear a lot over the course of their treatment, and it's important that they understand what they mean. For words that don't have a plain language equivalent, be sure to provide a clear explanation of their meaning.
- To build the patient's understanding over time, moderate the flow of information. Be aware of how much you are presenting at the diagnosis visit. When Katrina was first diagnosed with Stage III endometrial cancer, her doctor provided her with a lot of information. "One book was 40 pages; another was 100. Even the nutritionist gave me a stack of papers! They gave me all the details all at once. It was information overload."

By using pictures and models, you help patients build an even stronger understanding of what they learn in the diagnosis visit. When visuals are introduced into the conversation, accurate patient recall of their health information rises from 14% to as high as 85%. An effective visual depiction can increase a patient's likelihood to follow their recommended course of treatment. This is particularly true for patients with low literacy skills, or who are relying on translators—a plain-language, spoken explanation, combined with pictures, will support the patient even after they leave the office.

Before Carla’s diagnosis, she believed she had a strong understanding of her health. She was a fitness instructor, and she had a strong connection to her body. But when she found out that she had cancer, she struggled to understand what her care team was telling her—until one of them drew her a picture: “When she drew the picture, I could see it and not just imagine it. She had talked about the uterine wall, the cervix, and the ovaries, but now I could see them. It just clicked.” The drawing took abstract terms and made them concrete.

Patients understand more about their diagnosis when providers use tools that use simple language, anatomical images, and visual metaphors. You can use the illustrations on the “Understanding Your Diagnosis of Endometrial Cancer” worksheets to define technical terms, like cancer type, grade, and stage. You can also draw on the diagram of the reproductive organs to show a patient where their tumor is located, while introducing or re-familiarizing them with relevant anatomical terms.

Patients often come into the diagnosis appointment with questions about their stage. Whether or not the stage is known, you might share the “dandelion” visual metaphor with patients to show how cancer spreads from its original site. This analogy serves two purposes: first, it provides a starting place for patients who don’t have a lot of prior knowledge about cancer and/or staging. The dandelion metaphor has been evaluated with gynecological cancer professionals, as well as endometrial cancer patients and their caregivers. Providers believed that using the dandelion metaphor throughout their explanations of diagnosis and treatment could help patients understand some of the more technical aspects of their disease. Patients reported that they found the metaphor simple and easy-to-understand, and they were able to articulate the concept of staging without reading the text descriptions. The visual metaphor can be particularly helpful for visual learners and people who have difficulty reading.

Second, patients also found the visual metaphor hopeful and calming. Katrina recalls her diagnosis appointment: “It was like those Charlie Brown conversations, where it’s like blah blah blah. The feeling of fight or flight comes over you. You start thinking about your family. But had I been shown this, this would have helped me so much. Even if I couldn’t engage with it

during the visit, I would have had something I could take with me and review at a quieter time.”

This worksheet, which includes an anatomical diagram of the body, can help patients connect the metaphor to what it represents in real life. If the difference between Stage III and Stage IV is how far the cancer has spread, what does that mean in their body? You can use this diagram to show patients where the cancer started in their body. It’s also useful for explaining when the cancer has metastasized to other sites.

The organs on this diagram are color-coded. The colors provide visual clarity, and they act as a “key” for anatomical terms that might be unfamiliar or intimidating. As Carla noted, “Someone could say, ‘the hot pink one’ or ‘the orange one,’ and you know you’re both talking about the same organ.”

Strategy 4: Regularly assess for patient understanding.

Janna always begins appointments with her patients at the community cancer center in the same way. “I start out by asking the patient why they’ve been sent to see me. That’s my standard opener with patients because it gives them a chance to talk. It makes patients feel a bit less nervous, and it helps me assess where the conversation needs to start. Very rarely, the patient will be like, ‘I’ve been diagnosed with ovarian clear cell carcinoma...’ for example. Most of the time, patients are pretty confused when they come into the oncologist’s office.”

Don’t assume that your patient understands what you’re telling them, even if they appear engaged, e.g. nodding. Take frequent breaks in the conversation to check in. By asking patients, “What questions do you have?” or “What are some things you want to understand better?” and then pausing, you set the expectation that it’s normal for them to have questions, or to be uncertain about something they heard. Not only will this allow them to ask for clarification if they need it, these pauses will help to punctuate the discussion and give them time to digest. Remember that if the patient or caregiver is calling in over audio or video, you won’t see the same nonverbal cues that you would during an in-person visit.

After Sonal first found out she had cancer, her best friend Ambika accompanied her to her first appointment. They were both filled with anxiety and uncertainty. Ambika remembers that during Sonal's visit, "The doctor would pause regularly and ask, 'What do you need to understand?'" Sonal found that these regular pauses kept her engaged throughout the visit, and made her more comfortable when she did need to ask for clarification.

At the end of your visit, you could ask the patient or their caregiver about conversations they plan to have with a friend or family member: "How would you explain this to your sister? Your son?" Patients may be more comfortable asking questions about how to explain the diagnosis to someone else. By shifting the focus to a third party, you'll be able to gauge the patient's understanding in a respectful way.

When Patty encounters patients who are unable to make sense of their diagnosis, she uses familial relationships as a way to make things simple without being condescending. "I'll provide information that they could give to their grandchildren. It simplifies the information, but it doesn't make it sound like I'm talking down to them."

We mentioned the "Understanding Your Cancer Diagnosis" worksheets have spaces for you to make a note of patient questions. These spaces are distributed throughout the entire "Understanding Your Diagnosis of Endometrial Cancer" tool. These can be used as prompts to create breaks in the explanation, so that you can check for patient understanding at several different moments in the visit.

Apply the strategies

There are a lot of ways to support the patient in building an initial understanding of their diagnosis and treatment. It's important to be conscious of how you're communicating with your patient, and to be aware of what they understand. Imagine a situation in which a patient and their caregiver come to your office for their first visit. The patient has high grade papillary serous carcinoma. How might you explain this to them?

What words would you need to define? What visuals might you use to support your explanation? How will you know if they understood?

Reflect on the principle

Take another step back: what strategies might you add to your practice that will help patients to start making sense of their diagnosis? To borrow Patty's phrase, how can you "start where they're at"?

Principle 3: Empower the patient to engage in their care.

Reflect on your experience

Consider the following: Cancer diagnoses can make patients feel like they've lost any sense of control over their life. What can patients take control of as they begin their treatment journey?

As one oncologist told us, "Once a patient has been diagnosed, she feels like she's not in control, but there are things that she can control: exercise, a healthy diet, social support, peer mentoring. We highlight these things with patients. If you arm them with information and support, it makes them feel more in control. Even writing out questions in advance of appointments can help a patient feel more prepared."

About the principle

Many patients feel powerless when they find out they have cancer. They look for explanations: things they could have done, or should have done, to stop this from happening to them. The diagnosis can feel unfair and random. Being sick is a monumental disruption to life as they know it—and treatment can turn their life upside down. Some patients cope by disengaging, by turning things over to their provider or caregiver, or by focusing on unrelated parts of their life. Others want to know everything they can do on their own to improve their situation.

The first visit can be the beginning of an active partnership between

patients and providers. Before the patient leaves their first appointment, you can restore some of their sense of control, and empower them to engage in their care.

Ann learned that she had cancer in the emergency room. She and her husband Mark didn't get a lot of information about the diagnosis from the ER doctor, but they did have some time to prepare themselves before their first visit with the oncologist.

All the same, her diagnosis visit was a whirlwind. "It was so fast. You're trying to process all that information, and then you're sitting there and realizing your hair's going to fall out—and I don't own a wig. There was no information forthcoming about that." Her attention snagged on something that she could control: finding a wig.

Patients want information about the resources and supports available to them, and the steps they can take, that will help them heal. Many patients actively seek out social work services, advice about dietary changes, or information about how to manage hair loss. When patients feel like they're involved in decision-making about their treatment—including decisions about supportive care and lifestyle changes—they experience a higher quality of life and improved emotional health.

One caveat: If you share these resources with tact and care, it's reassuring and empowering. However, if this information is presented out of context, it's distressing. Patients might feel like they have more on their plate than they can handle. Patty has experienced this firsthand with patients who don't understand why their provider has connected them with a social worker. "Patients have said, 'The social worker is here to comfort me because I'm dying.' I tell them, 'No, this is about how to live well. I'm here as a social worker to make sure you establish goals for your care.'"

Strategy 5: Support the patient in articulating their goals and priorities

Sheryl is a chemo coordinator at a large hospital network and has been working in gynecological oncology for 20 years. She advises patients that while cancer is disruptive, it's not the only thing that matters. "I tell patients they still need to live their life as normally as possible. It's a big roadblock, but you

still need to live your life. You can't put your life on hold while you get treatment for 18 weeks.”

For some patients, living well with cancer may mean reevaluating—and even changing—some of their most important goals with honesty and courage. Julia and Ron were planning to have biological children when she learned that she had cancer. The diagnosis meant Julia had to reevaluate a lifelong dream of hers. “I had to make a choice: do I have more years with my husband and give up having babies?” She was able to talk openly with her provider and her family about the decision. With the advice of her doctor and the support of her family, she decided that she needed to change course.

When you ask about your patient's goals and priorities, you're providing them with the space they need to be open about challenging decisions. You're also signaling their treatment plan can incorporate the things that they want to do. Living well with cancer is also about participating in activities that bring joy and meaning. Julia says, “You can still have a life. You can still have fun. You can still be who you are. It doesn't have to consume you.”

At her diagnosis visit, her doctor wanted her to come in for surgery on a Friday—the same day that she and her husband had concert tickets for a favorite artist. “We asked, ‘If we wait a week, will it hurt anything?’” The doctor assured them that rescheduling the surgery wouldn't increase her risk. They went to the concert on Friday and came in for surgery the following week.

Donna worked with her doctor to schedule a trip to Europe with her daughter. “Because I was doing treatment, I asked my doctor if I could plan on going on a trip. She said that she recommended it, because there might be a time in the future when I wouldn't feel as good as I was feeling then.” Donna was glad that she'd taken the opportunity to take care of herself, to do something for fun, and to be with her family. Julia and Donna's doctors were able to help them see beyond their diagnosis—that they could make time to live their lives, even while they were dealing with cancer.

The “Living Well While Getting Treatment” worksheet in the “Understanding Your Diagnosis of Endometrial Cancer” tool can help patients reflect on their goals and priorities. This may be something a care team member reviews with the patient while they're at the cancer center—or the

patient may take it home so that they can respond to the questions with their friends or family.

Patients might cite big goals, like Julia’s goal of having children, that require a reevaluation. They might also bring up questions about whether or not they’ll be able to participate in activities that they enjoy, like watching their grandkids once a week or going to a class. The worksheet has been designed to elicit a range of responses and start a conversation to help patients understand how their diagnosis will affect their life.

Strategy 6. Encourage the patient to think holistically about their health.

As a provider, you can help your patients to take care of themselves as they undergo treatment. You may be able to advise them on other aspects of their health—for example, the types of exercise that are safe for them to engage in. For more in-depth issues, you can connect them with complementary care resources, including dietitians, acupuncture, fitness programs, psychotherapy, massage, and other health and wellness services.

Patients with endometrial cancer often experience feelings of isolation because of their diagnosis. Currently, this is an even greater concern, as so many areas are under social distancing restrictions because of COVID-19. As a provider, you can encourage patients to find ways to connect with friends, colleagues, and family virtually. Many support groups offer online meetings. Social connections can improve patients’ mental health.

When you encourage patients to think about their health in a more holistic way, you can help to restore that sense of control during a time of uncertainty. Jodie, an oncological dietician, says a lot of patients try to take action on their health by making nutritional changes: “Patients ask, ‘What diet should I follow? What diet should I eat to fight cancer?’” She finds that patients who make manageable changes to the way they eat respond better to their cancer treatment. They also regain, to some degree, the feeling of being in charge of their own life.

Sexual health is another component of health that you can encourage patients to think about. As we discussed earlier, it’s critical to introduce sexual health with patients before they undergo treatment, as treatment may have an

effect on it. Not all patients are comfortable bringing it up, and many do not know they can raise the topic with a healthcare provider.

How can you approach discussing sexual health with a patient?

- First, respect their level of comfort: For a variety of reasons, some people will feel comfortable speaking about this earlier than others. If they aren't ready to talk, this conversation could feel invasive or offensive.
- Normalize the topic: Sexual health is a natural and normal part of being human. It doesn't just mean having sex — it can include cuddling on the couch, having a heart-to-heart conversation, or whatever form of intimacy one desires.
- Ensure privacy: Meeting in a private space is critical. You'll also want to find out whether or not they want their partner or other caregiver in the room.
- Give them time and space to prepare thoughts: Ask them to think about their sexual health concerns, questions, or current issues between appointments, so that they can consider the topic on their own time first.
- Lastly, proceed without assumptions or judgements: Everyone's sexual preferences, behaviors, and histories are different. Don't assume that, because some is older, they're not interested in sex; or that because a woman is in her early 40s, she's not interested in having children.

For some people, a discussion about sexual health may bring up a history of sexual abuse. Gloria, the nurse navigator we heard from earlier, told us, “For some, sexual health issues go way back. You just don't know if there was any kind of harassment or abuse. You have to be aware of that.” Be ready for anything that may come up, and know that you can always bring in additional support from your care team if you need to.

Gloria also told us how she opens the door for discussing sexual health. “I will see a patient in a private area, like in an exam room. I'll tell them about me, and what I do as a nurse navigator. Then I'll say, ‘Some of the things we might want to have a conversation about are: your appetite, your energy level, any sexual issues you might have...’ And I just go down my list of things. I don't expect them to answer, but I want them to know they can talk about this whenever they're ready.”

“Understanding Your Diagnosis of Endometrial Cancer” addresses supportive care in a few different places. First, the “Understanding Your Care” worksheet explains how supportive care—like complementary care, treatment breaks, and symptom and pain management—help to improve a patient’s quality of life.

Next, providers can include the names of complementary care practitioners on the “Care Team” section of the folder, if referring a patient to a specific care practice. In the patient journal, patients can review additional information about complementary care—including a definition of the term, an explanation of how it can help, and advice from care professionals and other patients to get started. The patient journal also includes an explanation of sexual health and intimacy. Patients can review a short set of reflection questions before discussing sexual health with you or a member of your care team.

Strategy 7. Help the patient keep track of relevant experiences that occur outside the doctor’s office.

Endometrial cancer treatment is a time-intensive process. However, even with all the hours that patients spend in the healthcare setting, a lot of their experience takes place elsewhere. While they’re at home, they might have a headache that just won’t go away. They wonder if this is a symptom, a side effect, or just a normal headache. They might stumble across some information about a treatment for endometrial cancer on the internet. They’re curious about whether or not it might work for them.

During a conversation with their spouse, the patient might come up with a clarifying question about their diagnosis. They want to get a better understanding of what they learned in their last visit, but they didn’t realize it until they got home. When patients keep track of these experiences and bring them to their next appointment, they’re able to take a more active role in their care. Over time, they’ll become experts in their own experience: they’ll build their own bank of questions and answers.

Valerie works as a nurse in a community care clinic. She recommends that patients create a physical record for themselves: “When they’re at home, patients think about things to ask the doctor. I encourage them to have a little notebook to write them down. Something like, ‘I noticed my heart beating a little fast.’ I tell them, ‘Write it down and you’ll be able to bring it up later.’”

Patients and caregivers alike told us about their notebooks: they used them to make sure that they didn’t forget important questions or symptoms that came up between appointments, to keep track of treatments, and, in some cases, to support multiple caregivers in staying organized.

You can encourage patients to keep notes of things that come up between appointments using part of the “Understanding Your Diagnosis of Endometrial Cancer” tool. The patient journal has space for patients to keep track of their experience over time. The journal has space for patients to track tests, treatments, supportive care and other activities, and how they’re feeling. There is also space for them to write down questions they want to ask at their next visit.

Apply the strategies

Patients may already be asking you directly about ways to be more active partners in their health. Picture this: You’ve just finished explaining a patient’s diagnosis. They’ve started to understand what this means for them, and you’ve reviewed what will happen next. The patient asks you, “What should I be eating?”

According to many of the providers we talked to, this specific question comes up a lot in the initial diagnosis. When we asked Jodie, she had a clear recommendation: “I would not tell a patient, ‘Eat all you want; it doesn’t even matter.’ That’s old school thinking. I would say, ‘Eat a colorful plan—Mediterranean is a good food plan. If you want more, see an oncological dietician.’ That could help them a ton to start, to either look on their own, or to schedule an appointment.”

Reflect on the principle

You have your own ways to help patients engage in their care. Based on this principle and the strategies we've explored, what might you do to increase patients' feeling of empowerment?

Conclusion

Summary reflection

Over the course of the last hour, you've reflected on how you communicate with patients. Take some time to review what you've written down. You've probably recognized some of the strategies presented in this module—maybe you're already putting them into practice. How do those strategies affect your patients' well-being? What impact do they have on your relationship with your patients?

You also identified some ways you can build on your existing communication methods. If you add to your existing strategies, how will the patient experience in your office change?

These three principles—establish a foundation of trust with the patient, support the patient in building an initial understanding of their diagnosis and treatment, and empower the patient to engage in their care—will help you to communicate effectively, build strong relationships with your patients, and create more opportunities for shared decision making. As patients experience all of the emotions that come along with a cancer diagnosis, you will help them to feel safer, better informed, and more in control. When you bring trust, learning, and empowerment into your communication with patients, you're giving them, and their caregivers what they need to successfully navigate this phase of their life.