

Individuals with chronic leukemias, including chronic lymphocytic leukemia (CLL) and chronic myeloid leukemia (CML), may advocate for their own health and take part in decisions regarding their treatment. Using shared decision making (SDM) can help achieve these goals. This video is brought to you by The Leukemia & Lymphoma Society with grant support provided by AbbVie Inc.; Genentech, A Member of the Roche Group and Pfizer Inc. It is designed to help patients:

- Understand shared decision making and how it may aid patients throughout their cancer journey,
- Communicate effectively with members of the healthcare team to ensure that patients understand all the treatment options available to them,
- Share their goals, values, and preferences with their healthcare team to ensure they are considered when decisions are made, and
- Identify and use appropriate resources to support a shared decision-making approach

What Shared Decision Making Is

Shared decision making is a process in which healthcare providers and patients share information. Using SDM ensures that patients are well-informed about their diagnosis and treatment and that they can consider all options available to them. SDM includes what testing to do and what the treatment plan should be. SDM involves understanding that patients are independent and free to make their own decisions based on their goals, preferences, and values.

There are three components of SDM: choice talk, option talk, and decision talk.

- *Choice talk* refers to making sure patients know about the different options that are available to them. This can occur face-to-face, as well as during a tele-medicine visit or by email, letter, or phone call.
- *Option talk* refers to providing detailed information about the different options, including their risks and benefits. It can be very helpful for patients to summarize key points of the information provided by their healthcare team to confirm that they understood correctly.
- *Decision talk* refers to supporting patients as they decide what is best for them. In this step, it is important to remember what matters most to you and allow enough time to make your decision.

During busy, stressful, and even emotional medical appointments it can be difficult for both doctors and patients to keep shared decision-making top of mind. The acronym PACES can help clinicians and patients remember the steps of SDM. PACES stands for:

- **P**rovide information; in this step patients should present the issues or topics they are thinking about.
- **A**sk questions; once patients have provided the information, they should ask specific questions about that topic to get the clarity they need to make informed decisions.
- **C**heck understanding; patients should repeat things back to their provider or ask additional questions to make sure they are understanding. Medical jargon is often complicated, so this ensures they have interpreted the information correctly.
- **E**xpress concern; it is essential that patients tell their doctor of any concerns they have with a treatment or test.
- **S**tate preferences; patients should tell their doctors and nurses their preferences for treatments and care so that together they can decide what's best.

The Role of the Patient in Shared Decision Making

The most important thing patients can do is have an open and honest conversation with their care providers about their priorities and expectations. It is essential for patients to present information to their healthcare team, ask questions, check their understanding of any information given to them, express concerns they have with any tests or treatments, and state their preferences.

Patients should be sure to discuss quality of life with their care team because it is an important part of shared decision making. “Quality of life” refers to a person’s general wellbeing, including physical, emotional, and social wellbeing. It can include things like how easily a person can handle daily tasks or whether a person is living without pain or discomfort. Quality of life is an important factor for both patients and their healthcare team to consider.

Patients should think about which of their caregivers can be consulted or included in conversations with the health care team to avoid any issues with privacy or disclosing sensitive information. Priorities of patients and their caregivers sometimes differ. Balancing everyone’s priorities can be difficult, but it’s important to come to the best decision possible. To do this, patients can ask their doctors and other members of their healthcare team specific questions.

The Role of the Healthcare Team in Shared Decision Making

Patients are the expert on themselves, and their opinions are important. For shared decision making to work, the healthcare team needs to get to know the patient and understand his or her values, goals, preferences, and concerns at every stage of their medical journey.

The healthcare team should also be open with patients to determine how involved they want to be in decisions—some patients may rely more heavily on the opinion of their doctor, whereas other patients may wish to be at the center of the decision-making process.

Finding Common Ground

Sometimes the priorities of patients and doctors can be different. For example, patients sometimes don’t report their symptoms honestly, but doctors need to know the symptoms patients are having in order to recommend and adjust treatment correctly. Even if the patient’s priorities don’t directly align with those of the healthcare team, it’s necessary discuss opinions and preferences.

Patients and their clinicians should come to an agreement on how they’re going to evaluate treatment goals—will the patient consider the treatment a success if he or she has few or no side effects, or if the cancer is not progressing? Agreeing on the goal of treatment is essential. Patients will find that they and their healthcare team often have the same common goal, despite having different opinions on the path to get there.

Doctors and patients often evaluate how well a treatment is working differently. A doctor may prioritize how well a drug is working, whereas a patient may care more about how he or she feels day-to-day. If the side effects of a medication are too bothersome, patients may not continue to take the prescribed dose of the drug. By openly and honestly discussing what your priorities are and what your doctor’s priorities are, a good match between the two can be found. This will allow everyone to establish shared treatment objectives and determine what the desired goal is.

There are many doctors and nurses who use shared decision making with their patients every day. But some care providers don’t use SDM as much or as well as they should. One common reason why they hesitate to use SDM is time pressure—they have a limited amount of time with each patient and their schedules are often overloaded. Other reasons why SDM is not properly used is the belief that patients lack the ability to make important medical decisions and that patients don’t *want* to be involved in these decisions. If patients find themselves in a situation in which their provider is skipping or limiting the use of SDM, they should try to change the situation by asking questions and talking with the healthcare team, making it clear that they want to be a part of the decision making process.

Themes Discussed in the Video

The primary goal of this video is to promote shared decision making. It does this through a series of scenarios that many patients with CLL commonly face. For example, evaluating the role and conduct of clinical trials is a focus of one of the scenarios, and the role of “watch and wait” is discussed in another scene.

For more information on Chronic Leukemia’s please visit www.LLS.org/Leukemia.

Additional Resources

The Leukemia & Lymphoma Society (LLS) has created this video and a variety of other resources to support individuals with blood cancers throughout their journey. Numerous resources for patients and their caregivers can be found at LLS.org; these include educational materials such as booklets, podcasts, and webcasts, as well as information about support groups, clinical trials, and financial support.