

# **Shared Decision-Making Discussion Guide For Patients**

Shared decision making is a process in which the healthcare team and patients work together to make healthcare decisions. It involves sharing information back and forth. Patients are supported by their healthcare team to consider all treatment options, be well-informed about their diagnosis, understand what testing needs to be done and develop the best care plan to move forward. Shared decision making considers the patient's own preferences and values.

## CONCERNS TO DISCUSS WITH YOUR HEALTHCARE TEAM

Check the concerns below that you want to discuss with your healthcare team. This will help make sure you don't forget to talk about anything important during your appointment. This will also assist in creating a treatment plan that takes into consideration your preferences and values.

- \_\_\_\_ Treatment effectiveness
- \_\_\_\_ Addressing side effects
- \_\_\_\_ Getting to appointments/treatment
- \_\_\_\_ Ability to participate in daily activities
- \_\_\_\_ Financial concerns
- Difficulty adhering (staying on a set plan or regimen) to a medication schedule at home
- \_\_\_\_ Fear of relapse
- \_\_\_\_ Other:

## PATIENT COMMUNICATION TIPS

- Prepare for your appointment by writing down a list of questions and concerns. Consider bringing a family member or close friend with you to your appointment to help take notes.
- Tell your treatment team if you would prefer to have your medical information be explained to your caregiver. If so, then ask the healthcare team about how you can sign paperwork to give them permission to communicate with your caregiver. Then, talk to your caregiver about how to best communicate that information back to you.

- Ask the healthcare team open ended questions to get more information. For instance, if you ask about whether you can participate in a specific exercise, like riding a bicycle, your healthcare team may say yes or no. It may be more helpful to ask for a list of approved exercises and activities, which will provide you with more options.
- Try using the P.A.C.E.S. approach to improve communication with your healthcare team regarding your healthcare needs. P.A.C.E.S. stands for:
  - P: Present information
  - A: Ask questions
  - C: Check understanding
  - E: Express concerns
  - State preferences
- If you do not understand what the healthcare team is telling you, ask them to explain it again in another way. Then repeat the information back to the team. This will help you absorb the information, and it will also let the healthcare team know whether you understood.
- If you need more time with your healthcare team, make another appointment (either an in-person or tele-health visit). You can also ask if another way of communicating works to get your answers, such as a phone consult or email.

## QUESTIONS TO ASK YOUR HEALTHCARE TEAM

What is the goal of the treatment?

What are my treatment options right now? Ask your healthcare team about which treatment may be the best for you at this time:

#### CML treatment options:

- Tyrosine kinase inhibitor (TKIs)
- Chemotherapy
- Protein synthesis inhibitor
- Immunotherapy
- Allogeneic stem cell transplantation
- Clinical trial

#### CLL treatment options:

- Watch and Wait/ Active Surveillance
- Single or combination drug therapy
- Chemoimmunotherapy (chemotherapy combined
- with immunotherapy)
- Targeted therapy
- Monoclonal antibody therapy
- Clinical trial
- Radiation therapy (rarely used)
- Splenectomy (rarely used)
- Allogeneic stem cell transplantation

Please discuss side effects and possible long-term effects of treatment.

How do I find out if my insurance will cover the costs of my treatment?

What is the best way to get my questions/concerns answered between visits? (By using phone, email, text messages, etc.)

How will my daily activities be affected by my treatment?

How will I know if the treatment is working?

Can my caregiver take part in my medical visits?

NOTES

Support for this publication provided by:

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