

### HOW TO ENCOURAGE PATIENTS TO BE MORE ACTIVE IN THEIR CARE

- Tell patients you welcome questions and honest, detailed conversation
  - They can even have a list of questions/topics they'd like to address during the appointment
  - They can also reach out via the patient portal or call your office after the appointment for any follow-up questions
- Remind them they can bring family members or friends to appointments so they feel supported
- Allow patients to take notes or record, if appropriate
- Be open to talking about financial assistance options they may be eligible for



### MPN PROGRESSION INFORMATION AND TIPS

- Both essential thrombocythemia (ET) and polycythemia vera (PV) may progress to myelofibrosis (MF); you may see progressive anemia and splenomegaly along with increased LDH (lactate dehydrogenase)
  - Make sure you have a baseline symptom burden, baseline spleen size, and baseline bone marrow biopsy with mutation analysis so you can see where a patient started and if things change, you can go back and compare
  - Use risk stratification tools
- MPNs may progress to acute myeloid leukemia (AML). Factors to look for include higher number of platelets or white blood cells, blasts in the bone marrow, or chromosomal alterations and epigenetic modifiers EZH2, ASXL1, IDH1, and IDH2, the mRNA splicing regulator SRSF2, and the tumor suppressor p53

[Source | Source]

### HOW TO HAVE CULTURAL HUMILITY

- Listen to your patients with interest and curiosity
- Have awareness of your own possible biases
- Attempt a non-judgmental stance about what you hear
- Recognize your inherent status of privilege as a provider
- Possess a willingness to be taught by your patients
- Educate yourself on health-related beliefs, practices, and cultural values of the populations you serve
- Know the illnesses and diagnostic prevalence among diverse populations
- Keep up to date on treatment efficacy data of diverse populations

### FROM A CARE PROVIDER

"It's important to educate patients on disease progression, but I remind them this is an infrequent event. I also say we can't necessarily change that at this moment, there are tools that we can use in the future. But try to put that information in a box in your brain, put the key, put it away, try not to think about that every day when you're outside of here. Definitely okay to open that back up when you're with me in the room." - **Gabriela Hobbs, MD**

### EPEP PORTAL

The Empowering Providers to Empower Patients Portal uses PEN's robust resource library and that of numerous trusted advocacy partners to collate a vetted list of patient education resources, all in one place. Select resources within the form and receive an emailed PDF within minutes to share with your patients - try it today.

[LEARN MORE](#) 

### FROM A CARE PROVIDER

"Assess your patient by listening and get to know them. Then, educate them, not to put fear in them, but so they are well-empowered on their disease & how we're gonna move forward. Lastly, provide them with resources regarding treatments and ways to alleviate symptoms to further their knowledge. By doing these 3 things, we aim to improve their quality of life & overall survival."

- **Natasha Johnson, MS, APRN, AOCNP**

### FOR YOUR PATIENTS

- [ACCC](#)
- [CancerCare](#)
- [Cancer Grace](#)
- [Family Reach](#)
- [MPN Research Foundation](#)
- [MPN Cancer Connection](#)
- [MPN Info](#)
- [MPN Advocacy and Education International](#)
- [Cancer Support Community](#)
- [LLS](#)
- [Triage Cancer](#)

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