

Shared Decision-Making in Hemophilia

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In shared decision-making, the patient and/or their caregiver collaborates with their health care team. The patient talks about their needs and concerns while the treatment plan is created. Together, the team works to find the best fit for therapies and lifestyle changes that not only takes safety and efficacy into account but also patient preferences and goals.¹

Be a Part of the Team

Patients may find that having a treatment plan tailored to their lifestyle, priorities, and goals can be easier to follow. If the plan doesn't fit into one's lifestyle, it won't offer the best chance at managing hemophilia well. When patients work closely with their health care team and are encouraged to communicate openly about treatment goals, it could lead to an improved quality of life.²

The process of shared decision-making in treatment plans does mean that patients need to take some responsibility for their own care. However, being prepared for appointments and clearly discussing the impact of all the available treatment choices could lead to better experiences and outcomes.

Staying Plugged In

Part of being an empowered patient is being informed about research and advances in new treatments. People who live with hemophilia have choices when it comes to prophylactic, on-demand, and perioperative therapies.

Advances in care and treatments for hemophilia are being made. Maintaining a connection with your care team to ask questions and get information about what options are right for you is key to staying informed. The staff at hemophilia treatment centers and hemophilia advocacy groups are good sources of information on clinical trials, available treatments, and upcoming therapies.

Taking the Lead

The health care team will often use a patient-centered approach that takes shared decision-making into account. However, in some cases, patients and/or caregivers may need to take a more active role in advocating for themselves and ensuring that their voices are heard.

Connecting with other patients and attending support groups are ways to learn more about how to engage more effectively with the health care team. Pfizer's Patient Affairs Liaisons can also be a source of helpful information on shared decision-making; details on how to contact them can be found at the bottom of this page. Taking the time to understand hemophilia, what treatment options are available, and what one's personal goals (and even family and friends' goals) are will all be a part of preparing for the shared decision-making process.

Available Decision Tools

In the management of hemophilia, there are multiple therapies available. This is good from the aspect of patient choice, but it also means that putting together a plan takes more thought and effort.¹ There may not be a clear-cut path to developing the "best" plan. This is why patient choice and comparing how options align with lifestyle and preferences becomes important. Researchers and patient advocacy groups have developed tools that can help health care providers and patients work together to decide on a plan.¹ Some of these include:

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- National Hemophilia Foundation: Products Licensed in the US, at www.pfi.sr/hemophilia-products
- Hemophilia Federation of America Dateline Federation, at: www.pfi.sr/hemophilia-spring

References: 1. Nossair F, Thornburg CD. The role of patient and healthcare professionals in the era of new hemophilia treatments in developed and developing countries. *Ther Adv Hematol.* 2018;9(8):239-249. doi:10.1177/2040620718784830 2. Sun HL, McIntosh KA, Squire SJ, et al. Patient powered prophylaxis: a 12-month study of individualized prophylaxis in adults with severe haemophilia A. *Haemophilia.* 2017;23(6):877-883. doi:10.1111/hae.13319



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Visit www.pfizerpal.com to connect with your Patient Affairs Liaison.