

## Tailoring care plans for life long after transplant

Blood or marrow transplant (BMT) may cure blood cancers and blood disorders, but it may also cause health issues months or years later, such as graft-versus-host disease (GVHD). Many primary care and other healthcare providers are not familiar with the care people need after BMT.

Patients, caregivers, healthcare providers and researchers worked together to create a survivorship care plan (SCP) tailored for life after transplant.

An SCP is a paper or electronic tool that includes:

- Possible health issues that can happen months and years after BMT
- Recommended ways to watch for and prevent them



The researchers invited people from around the U.S. to discuss SCPs in groups over the phone. The groups included 19 patients, 3 caregivers and 55 healthcare providers.

Patients and caregivers said they wanted the care plans to be personalized and to include information on fertility, sexual health, emotional health and risk of a new cancer. They asked for guidelines on when their immune systems would be strong enough for them to resume normal activities. Patients saw as many as 12 specialists after BMT, so they wanted SCPs to be detailed and to provide a section for taking notes.

Providers wanted SCPs that explained exactly what care is needed for their patients, such as when to give vaccines, what lab tests are needed and how to identify GVHD. Transplant providers said SCPs saved time because they used information already collected from patients and their primary care providers.

Researchers took all of this feedback and revised the SCP to make it more useful. Then, they tested it in [another study](#) to see if patients benefited from it.

### Keep in mind

This study included mostly white patients who had allogeneic (using someone else's stem cells) BMTs, so it might not apply to everyone.

### Ask your transplant doctor

After BMT, how will you communicate with my primary care provider? What should I be aware of?

### Learn more about

- [This research](#) and [related research](#)
- [After Transplant Care Guide](#)
- [Life after transplant](#)

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#### **Source**

Denzen EM, Preussler JM, Murphy EA, et al. Tailoring a survivorship care plan: patient and provider preferences for recipients of hematopoietic cell transplantation. *Biology of Blood and Marrow Transplantation*. 2018 Oct 10. pii: S1083-8791(18)30614-1. doi:10.1016/j.bbmt.2018.10.005. Epub 2018 Oct 10.

#### **About this research summary**

This information is provided on behalf of the Consumer Advocacy Committee of the CIBMTR<sup>®</sup> (Center for International Blood and Marrow Transplant Research<sup>®</sup>). The CIBMTR is a research collaboration between the National Marrow Donor Program<sup>®</sup>/Be The Match<sup>®</sup> and the Medical College of Wisconsin.