

Communicating With Your Blood or Marrow Transplant (BMT) Donor

Blood and marrow transplant (BMT) donors and recipients have many emotions after donation and transplant. Some may want to connect after transplant, and others won't. Whether you or your donor wants to connect is a personal decision. There is no right or wrong choice.

This fact sheet tells you:

- The types of communication donors and recipients may have
- How to request communication with your donor
- Rules for communicating with your donor
- Who to contact for help

Types of communication

- Anonymous communication
 You can't share any personal information that could identify you.
- Direct communication
 You and your donor can share names
 and contact information but only if you
 both agree.

General communication rules

- No communication can happen before the transplant day.
- Anonymous communication may start as early as transplant day in most cases but will depend on the rules of your donor's country/registry.
- Cord blood donors and their recipients are never able to have contact.

Anonymous communication

- Tell your transplant center coordinator that you want to send anonymous communication to your donor. If you lost contact with your coordinator, contact our NMDPSM Patient Support Center.
- 2. Ask your coordinator what the rules are for you and your donor. Each country and registry has their own set of rules.
- Give your anonymous communication item to your coordinator (or designated person). They will make sure it is sent.
- 4. Anything you send will be reviewed so that it doesn't include identifying information. If you send something that may be a clue, your item will be edited to remove that information. It may even be sent back to you.
- The review and mailing takes time, it can take several weeks or longer for your donor to receive your communication, especially if you're in different countries.

U.S. anonymous communication rules

If your donor lives in the U.S. you can send emails, cards or letters. You may not send gifts.

Emails, cards and letters cannot include:

 Personal names. This includes nicknames or initials for you, your family members, friends, pets or doctors. You can use general words like mom, dad, brother, or sister.

- 2. Organizational names. This includes names of hospitals, employer, sports teams, your registry or military branch.
- 3. Your location. This includes city, state, country, landmarks or regions.
- 4. References to organizations, causes, associations or local community groups.
- 5. Photographs.
- Personal dates, such as birthdays or anniversaries.

Please note: If you or your donor is from a different country, international registries have their own rules to follow.

Direct communication

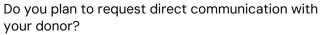
- 1. Tell your transplant center coordinator that you want to share contact information with your donor directly.
- 2. They will tell you if it's possible to have direct communication and what the rules are for your donor's country and registry.
- 3. Then, your coordinator will make the request for you.

In many cases, direct contact is possible after a waiting period of at least 1 year after transplant, but each case is unique. Some countries and registries have laws that say donors and recipients can never have direct contact. The confidentiality rules protect your privacy and your donor's privacy.

Things to consider

Do you wonder what to say to your donor?

Keep in mind, you don't have to write a
lot. Often donors appreciate short, simple notes. A note of thanks or appreciation for their donation can be very meaningful.





Consider starting with anonymous communication first. Then you can decide if you feel comfortable with direct communication.

Who to contact for help

If you have lost contact with your coordinator or have questions, contact the Be The Match Patient Support Center:

- Call: 1 (888) 999-6743
- Email: patientinfo@nmdp.org
- Visit: <u>BeTheMatch.org/ContactYourDonor</u>



At every step, we're here to help

NMDPSM has a team dedicated to providing information and support to you before, during, and after transplant. You can contact our Patient Support Center to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

Call: 1 (888) 999-6743 | Email: patientinfo@nmdp.org | Web: BeTheMatch.org/one-on-one



Every individual's medical situation: transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.