



BE YOUR OWN BEST ADVOCATE A Fact Sheet for Donor Families



After the death of someone we love, our world is changed forever. You may want support from other families who have “been there” or you may need time alone. If your loved one was an organ or tissue donor, you may have questions about donation and transplantation. Other donor families have provided the following ideas for how to “be your own best advocate” to care for your needs during your grief journey.

The National Kidney Foundation (NKF) formed the National Donor Family Council (NDFC), “The Home for Donor Families” in 1992 to serve families who gave the gift of life through organ or tissue donation. The NKF’s “People Like Us” movement brings together thousands of people, including donor families, living donors, people with chronic kidney disease, and transplant recipients who are empowered, educated and encouraged to be their own best advocate. To help yourself and others, you can:

Share your personal story, support and connect with other donor families. At www.donorfamily.org, you can talk with other families on our *Message Board*, share a poem in the *Comfort Café*, write a tribute, add a photo and story to the *Butterfly Garden*, and learn more about resources that can help. You’ll find a safe place to talk about your loved one. You can join the National Kidney Foundation’s Facebook page at www.facebook.com to read about and share your story with others. You can also find support through a counselor, clergy member, close friend, or support group.

Create a Quilt square in honor of your loved one. *Patches of Love*, the National Donor Family Quilt, is made up of thousands of quilt squares honoring special individuals. Making a quilt square can be a testament to your loved one’s life and legacy.

Ask questions about what happened and your loved one’s gift. If you have unanswered questions about the death or hospitalization, you might find answers from the hospital, police, clergy, family or friends. If you need more information about the donation, please contact the National Donor Family Council and we’ll try to help. We can help answer your questions about brain death and what that means, organ or tissue donation or communicating with recipients.

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Care for your physical and emotional health. Basic self-care such as eating right, getting some light physical activity, avoiding drugs or alcohol, trying to rest, and slowing down can help tremendously. If you feel like you need help coping, contact a counselor in your area or ask other donor families for support.

Find creative ways to express everything that you're feeling. Some people find that writing helps—stories, poems, articles. Others paint pictures, plant a garden, create a memorial or website, cook a special meal, help someone else in need, or make a quilt square.

Take time to feel the loss of your loved one. Grief changes over time and everyone grieves differently. Feelings of anger, guilt, sadness and loneliness are common. Grief can also affect us physically, leading to headaches, muscle aches, stomach pains, or exhaustion. Don't be too hard on yourself—be patient. The death of someone you love isn't something you get over; instead, you learn to live without him or her in the best way that you can.

Allow yourself the space to grieve. This might mean saying "no" to invitations or obligations that you can skip, getting away for a few hours or days, reading about grief to learn that what you're feeling is normal, and protecting yourself from people who don't fully support you.

Learn about special events, publications and other resources that might help, when and if you are ready. Visit www.donorfamily.org for more information about the Transplant Games, Donor Recognition Ceremonies, free publications, and more.

Read everything you can about donation, grief and loss, and coping. The NDFC has many free resources for you, including the quarterly *For Those Who Give and Grieve* newsletter, written by and for donor families. Just ask us to send materials to you.

Get Involved to help other grieving individuals or raise awareness about organ and tissue donation. The NDFC can give you suggestions and ideas.

Join the "People Like Us Take Action Network" if you want to get involved on kidney disease, organ donation and transplantation-related public policy issues. Visit www.kidney.org/takeaction to learn about important issues and use your voice to affect change. When you join, you will receive email alerts and guidance for contacting elected officials.

Need more information? Contact us at:

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