

Welcome to the season of turkey, crunching leaves, and gratitude. November welcomes **National Family Caregiver's Month**, which feels fitting because who gives more freely of their time, hearts, and strength than a caregiver? AARP's 2020 study reports there are 53 million caregivers in the U.S. alone. Caregivers shine their lights bright on the outside for all the world to see. Yet on the inside they huddle with darker feelings of perceived grief and worry. The pendulum of emotions swings high and wide, and it can feel confusing, overwhelming, and lonely. This month (this season, this year, this lifetime), I invite you to pause and give thanks to the caregivers in your world. The gestures don't need to be grand. An hour of respite. A meal. A simple note, "I'm thinking of you," goes a long way. Because, as humans, what we all crave is to be seen. Acknowledged. And loved. Because it's all about love.

Erin Copelan, author
Welcome to Caregiving: The Things Caregivers Never Talk About

Erin's Story

February 2009—I sat in a sterile office with my husband as the specialist chattered on about tests and transplants. With both of us feeling confused, Jerry interrupted her, "What are you talking about?" he asked, frustrated. The specialist stopped. Surprised, she said, "Didn't they tell you? You have cancer." (No, they hadn't)

That was the moment I became the sole caregiver to my husband for the next fifteen years (and counting). Together, we have survived a major liver resection surgery, a liver transplant, and graft vs host disease. Post-transplant, my husband's cancer has recurred three times. He (we) just keep fighting. Fighting and loving.

For many years I believed my sacrifice would save him. That somehow my restless sleep, weight loss, and anxiety would be the cure to his disease. I believed that if I pretended to be okay, I would be. These false (and sometimes irrational) beliefs led me down a path to depression, PTSD, and recovery periods that have been double and triple those of my husband's. My healing journey has been long and hard, yet fruitful. I gained insight on the importance of self-awareness, about my feelings and their connection to my body, and I reframed the concept of "self-care" to something that feels manageable and healthy. Our feelings aren't determined by the seasons, or dates on the calendar. My wish for you is that amongst all the changes you are experiencing that joy, hope, and love find a way to flicker their light for you. Because it's all about love.

Resources

- Welcome to Caregiving: The Things Caregivers Never Talk About as well as free tools, resources, downloads and a weekly newsletter: <https://www.ErinCopelan.com>
- The Caregiver Action Network spearheads National Family Caregiving Month every year (also has a hotline): www.caregiveraction.org/nfc-month
- VA Caregiver Support Program (also has a hotline): www.caregiver.va.gov
- Gift of Life: Howie's House (caregiver support for transplant families): <https://giftoflifehowieshouse.org/bridge-caregiver-support>

ADDITIONAL INFORMATION

This section of our monthly newsletter will focus on support and resources offered both by the Organ Transplant Center and throughout the nation. Please utilize these as you need them and reach out with any questions.

Kidney and pancreas line: 319-356-1136

Heart line: 319-356-1028

Liver line: 319-356-1137

Lung line: 319-356-2016

Medicare and Transplant

Medicare eligibility is based on age, disability, having end-stage kidney failure, or receiving a kidney transplant. No other organ transplant or need for organ transplant qualifies one for Medicare. There is a 1-year enrollment window for Medicare from date of kidney transplant. Delaying enrollment can increase chances of higher out-of-pocket expenses for anti-rejection medication. Medicare Advantage plans cover anti-rejection medications, and out-of-pocket expenses are subject to plan.

* For further questions or coverage changes, please contact the Organ Transplant Center financial counselors.

Video Resources

The Organ Transplant Center has put together videos to better explain the transplant evaluation process and provide additional patient education. Please click the links below to access these videos.

- [Kidney Transplant – Patient Education Videos](#)
- [Liver Transplant – Patient Education Videos](#)
- [Pancreas Transplant – Patient Education Videos](#)

Organ Transplant Support Group

Starting in February 2024, the Organ Transplant Center will begin having our support group every other month. The support group will also be a hybrid version—both in-person and by Zoom. Each group will be focused on a specific topic, with speakers followed by time for discussion. If you have any questions, please contact 319-467-8385.

Location:

Iowa Donor Network
550 Madison Avenue
North Liberty, IA 52317

Date:

December 12, 2024

Speaker: UI Health Care
infectious disease
physician

Zoom Information:

Meeting ID: 964 3943 5181
Passcode: 107198

Additional Resources

Social Security Disability

- [Adult Disability Starter Kit](#)
- [SSI Child Disability Starter Kit](#)

National Living Donor Assistance Center (NLDAC):
[How to Apply](#)

Iowa Anatomical Gift Fund: [Application](#)

Iowa Donor Network / Writing Your Donor Family:
<https://www.iowadonornetwork.org/transplant-recipients/writing-your-donor-family>

University of Iowa Telepsychology Training Clinic offers free, short-term counseling to Iowans with limited access to mental health care.

- [Click here](#) to see if you qualify