



Caregiver Resources

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This is a list of resources that might be helpful to transplant caregivers. There might be other resources not on this list. The authors of this document do not represent or endorse the websites on the list.

Transplant Caregiver Role and Responsibilities

The United Network for Organ Sharing (UNOS) is a private, non-profit organization that works with the federal government to make sure access to donated organs is fair. For more information about the organ transplant process, policies, and matching:

- [United Network for Organ Sharing¹](https://unos.org/)
- [How Organs are Matched with a Recipient²](https://unos.org/transplant/how-we-match-organs/)

These non-profit organizations offer free education, peer support, and resources to family caregivers:

- [Caregiver Action Network³](https://caregiveraction.org/)
- [Share the Care⁴](https://www.sharethecare.org/)

The Transplant Recipients International Organization (TRIO) is a non-profit organization that offers transplant specific education and resources:

- [Transplant Recipients International Organization \(TRIO\)⁵](https://www.trioweb.org/)
- [TRIO Caregiver Resources page⁶](https://www.trioweb.org/links/item/professional-organizations-2.html)

¹ <https://unos.org/>

² <https://unos.org/transplant/how-we-match-organs/>

³ <https://caregiveraction.org/>

⁴ <https://www.sharethecare.org/>

⁵ <https://www.trioweb.org/>

⁶ <https://www.trioweb.org/links/item/professional-organizations-2.html>

The United Hospital Fund created “Next Step in Care: Family Caregivers and Health Care Professionals Working Together” to help patients transition from the hospital to home. Download practical advice and easy-to-use guides:

- [Next Step in Care, Caregivers Guides and Checklists⁷](#)

The National Institute of Health offers videos and written tips on how to communicate effectively with your physicians and other healthcare providers:

- [Communications with Providers⁸](#)

EduMed offers a comprehensive guide with tools, resources, and practical solutions for caregivers:

- [The Caregiver's Handbook⁹](#)

The US Department of Agriculture offers a guide for how to handle food safely when you take care of a transplant patient:

[Food Safety for Transplant Patients¹⁰](#)

Legal and Financial Considerations for Caregivers

Family Medical Leave Act (FMLA)

- <https://www.dol.gov/agencies/whd/fmla/faq>
- US Department of Labor: Need Time? The Employee's Guide to the Family and Medical Leave Act: <https://www.dol.gov/agencies/whd/fmla/employee-guide>
- FMLA Breakdown by State: <http://www.employmentlawhq.com/state-by-state-map.html>

Family Responsibilities Discrimination

- File Complaints Through the Equal Employment Opportunity Commission: www.eeoc.gov
- File Complaints Through Your State: <https://www.workplacefairness.org/filing-discrimination-complaint>

Power of Attorney for Healthcare

- American Bar Association Healthcare Advance Planning Toolkit: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2020-tool-kit-hcap.pdf
- State Specific Advance Planning Forms: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-Inks-to-st-spcifc-advnc-drctv-frms.pdf
- Universal Power of Attorney for Health Care Form (not valid for use in New Hampshire, Ohio, Texas, Wisconsin, and Indiana): https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/power_atty_guide_and_form_2011/
- State specific statutes for legal next of kin: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-sept-default-surrogate-consent-statutes.pdf

⁷ https://www.nextstepincare.org/Caregiver_Home/

⁸ <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor>

⁹ [https://urldefense.com/v3/!PhZIOogwbDdv1oIEkziwbBbS_QU0WDXJZJHRBoeq-1JUntVyx7w6ZNGRS7gRzHP-WWfeZBJAHO4anWWjpIDR6jS\\$](https://urldefense.com/v3/!PhZIOogwbDdv1oIEkziwbBbS_QU0WDXJZJHRBoeq-1JUntVyx7w6ZNGRS7gRzHP-WWfeZBJAHO4anWWjpIDR6jS$)

¹⁰ https://www.fsis.usda.gov/sites/default/files/media_file/2021-04/at-risk-booklet.pdf

Managing Social Security/Veterans Benefits

- Social Security Administration: www.ssa.gov
- Veteran's Administration: www.va.gov

Guardianship

- American Bar Association Adult Guardian Handbook by State: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-gshp-adult-gship-hdbks-state.pdf

Paid Leave Programs by State:

<https://www.nationalpartnership.org/our-work/economic-justice/state-paid-leave-laws.html>

Fundraising

- Help Hope Live: <https://helphopelive.org/>
- National Foundation for Transplants: <https://transplants.org/>

Caregiver Quality of Life and Self-Care

Self-Assessment for Caregiver Burnout, Depression, and Anxiety:

- Caregiver burnout: <https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-interactive>
- Depression: <https://screening.mhanational.org/screening-tools/depression?ref=CAN>
- Anxiety: <https://www.mayoclinic.org/diseases-conditions/anxiety/symptoms-causes/syc-20350961>

Mental Health Assistance:

- How to Talk to Health Care Providers About Mental Health: <https://www.nimh.nih.gov/health/publications/tips-for-talking-with-your-health-care-provider/index.shtml>
- Psychology Today "Find a Therapist" Website: <https://www.psychologytoday.com/us/therapists>
- National Suicide Prevention Hotline: <https://suicidepreventionlifeline.org/>
- General Mental Health Resource, including what to look for if you worry about someone's mental health: <https://www.mentalhealth.gov/>
- Many national groups have hotlines and help to find providers and resources
 - National Institute of Mental Health: <https://www.nimh.nih.gov/health/find-help/index.shtml>
 - National Alliance on Mental Illness (NAMI): <https://www.nami.org/Find-Support/NAMI-HelpLine/Top-HelpLine-Resources>
 - USA Mental Health First Aid Resource List: <https://www.mentalhealthfirstaid.org/mental-health-resources/>
 - US Department of Veteran Affairs Mental Health website: <https://www.mentalhealth.va.gov/>
 - CDC Mental Health Tools and Resources: <https://www.cdc.gov/mentalhealth/tools-resources/index.htm>
 - Mental Health America: <https://www.mhanational.org/>
- Substance Abuse and Mental Health Administration offers help finding substance abuse and mental health treatment: <https://www.samhsa.gov/>
 - Substance abuse treatment: <https://findtreatment.gov>

Transplant Specific Caregiver Support Group Resources:

- UNOS Transplant Living Community support groups: <https://transplantliving.org/community/support-groups/>
- Transplant Recipients International Organization (TRIO): <https://www.trioweb.org/chapters/active-chapters.html>

- The Transplant Caregivers - Partners for Life Facebook Group: <https://www.facebook.com/groups/PartnersForLife/>
- Gift of Life Family House - Online Transplant Caregiver Support Group: <https://www.facebook.com/groups/caregiverlifeline>

Transplant Caregiver Videos:

- “Preparing for the Transplant Journey: A Guide for Patients and Their Caregivers” video: <https://www.youtube.com/watch?v=GjD00PXbYqY>

Printable handouts (on next page)

- [Improving Caregiver Self-Care Handout](#)¹¹
- [Caregiver Bill of Rights](#)¹²

Special Considerations with Caregiving

Advanced Care Planning

- National Institute on Aging, “Advanced Care Planning: Health Care Directives”: <https://www.nia.nih.gov/health/advance-care-planning-health-care-directives>

Palliative Care

- National Hospice and Palliative Care Organization (NHPCO): <https://www.nhpco.org/patients-and-caregivers/>
- <https://www.choosingwisely.org/wp-content/uploads/2018/02/Palliative-Care-AAHPM.pdf>
- NIH National Institute on Aging, “What are Palliative Care and Hospice Care?": <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>
- NIH National Institute of Nursing Research Palliative Care Resources: <https://www.ninr.nih.gov/newsandinformation/publications/palliative-care-resources>
- National Hospice and Palliative Care Organization “Experiencing Grief”: https://www.nhpco.org/wp-content/uploads/2019/04/There_is_no_Wrong_or_Right_Way_to_Grieve_After_a_Loss.pdf

Emergency Preparedness Resources (See also, Heart Transplant Resources)

- Federal Emergency Management Agency (FEMA): 1-800-621-FEMA (3662) or 1-800-462-7585, <https://www.fema.gov/>
- Transitional sheltering assistance: <https://femaevachotels.com/>
- Resources for individuals, businesses, and communities:
 - <https://www.disasterassistance.gov/>
 - Ready.Gov: <https://www.ready.gov/be-informed>
- Disaster Relief information: <https://www.benefits.gov/categories/Disaster%20Relief>
- The American Red Cross: <https://www.redcross.org/get-help.html>
- American Thoracic Society Disaster Related Resources: <https://www.thoracic.org/professionals/clinical-resources/disaster-related-resources/>

¹¹ https://www.myast.org/sites/default/files/03S._Improving_Caregiver_Self-Care.pdf

¹² <https://www.caregiver.org/resource/caregivers-bill-rights/>

Relationship Dynamics between Patients and Caregivers

When a patient does not accept care:

- <https://giftoflifehowieshouse.org/bridge-caregiver-support/bridge-post-transplant/patient-compliance-for-transplant-caregivers/>

Preserving relationships while being a caregiver:

- <https://www.caringvillage.com/2019/02/08/keeping-marriage-strong-caregiving/>

Kidney Transplant

- National Kidney Foundation: <https://www.kidney.org/>
- American Kidney Fund: <https://www.kidneyfund.org/>
- National Institute of Diabetes and Digestive and Kidney Disease: <https://www.niddk.nih.gov/>
- US Department of Health & Human Services Organ Procurement and Transplantation Network: <https://optn.transplant.hrsa.gov/learn/professional-education/kidney-allocation-system>
- American Association of Kidney Patients: <https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/>
- Transplant Strong: <https://transplantstrong.com/>

Heart Transplant/LVAD

- American Heart Association: <https://www.heart.org/>
- International Society of Heart and Lung Transplantation (ISHLT): <https://www.isHLT.org/about/patient-resources>
- Dilated Cardiomyopathy Foundation: <https://dcmfoundation.org/>
- My LVAD: <https://www.mylvad.com/>
- I Decide LVAD: <https://patientdecisionaid.org/lvad/>
- LVAD Gear: <https://lvadgear.com/>
- HeartMate LVAD: <https://www.heartmate.com/patient>
- MedTronic (HeartWAre LVAD): <https://www.medtronic.com/us-en/patients.html>

Lung Transplant

- UNOS “Lung” Information Page: <https://transplantliving.org/organ-facts/lung/>
- American Lung Association: <https://www.lung.org/>
- Lung Transplant Foundation: <https://lungtransplantfoundation.org/>
- International Guidelines for the Selection of Lung Transplant Candidates: <https://www.atsjournals.org/doi/full/10.1164/ajrccm.158.1.15812>
- Pulmonary Fibrosis Foundation: <https://www.pulmonaryfibrosis.org/>
- Cystic Fibrosis Foundation: <https://www.cff.org/>
- COPD Foundation: <https://www.copdfoundation.org/>
- International Society for Heart and Lung Transplantation (ISHLT): <https://www.isHLT.org/about/patient-resources>

Liver Transplant

- American Liver Foundation <https://liverfoundation.org/>
- <https://liverfoundation.org/caregivers/the-role-of-a-caregiver/>
- Substance Abuse Resources:
 - Findtreatment.gov
 - <https://unityrecovery.org/digital-recovery-meetings>
 - 12-Step Groups
 - AA Online Meeting Directory: <https://aa-intergroup.org/directory.php>
 - AA – Online: http://12stepforums.net/alcoholics_anonymous_online_meeting.html
 - AA COVID-19 Informational Page: https://www.aa.org/assets/en_US/en_updatesoncoronavirus.pdf
 - Al-Anon – Online: http://12stepforums.net/alanon_family_group_online_meeting.html
 - IDAA: <https://www.idaa.org/>
 - NA Online Meetings “Addicts helping Addicts Recover”: <http://na-recovery.org/>
 - NA – Online: http://12stepforums.net/narcotics_anonymous_online_meeting.html
 - NA COVID-19 Informational Page: https://www.na.org/admin/include/spaw2/uploads/pdf/Coronavirus_web_message_12Mar.pdf
 - Online Recovery Group (ORG): <https://onlinerecoverygroup.org/schedule>
 - Buddhism-Based Recovery: <https://recoverydharma.online/>
 - Refuge Recovery: <https://refugerecovery.org/meetings?tsml-day=any&tsml-region=online-english>
 - SMART Recovery: <https://www.smartrecovery.org/community/>
 - LifeRing: <https://www.lifering.org/online-meetings>
 - All Pathways: <https://unityrecovery.org/digital-recovery-meetings>

Living Donor

- United Network for Organ Sharing: <https://unos.org/transplant/living-donation/>
- American Liver Foundation: <https://liverfoundation.org/for-patients/resources/brochures/>
- UNOS Transplant Living: <https://transplantliving.org/living-donation/>
- National Living Donor Assistance Center: <https://www.livingdonorassistance.org/How-to-Apply/Eligibility-Guidelines>)
- American Society of Transplantation Living Donor Toolkit: <https://www.livingdonortoolkit.com/>
 - Included within the Living Donor Toolkit:
 - *Living Donor Financial Toolkit* - <https://www.livingdonortoolkit.com/financial-toolkit>
 - *Living Kidney Donor Medical Toolkit* - <https://www.livingdonortoolkit.com/medical-toolkit>
 - *Living Liver Donor Medical Toolkit* - <https://www.livingdonortoolkit.com/living-liver-medical-toolkit>

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