



Caregiver Quality of Life and Self-Care

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Being a caregiver has benefits. You might be feeling closer to the patient, appreciate the time you get to spend together, and know you're helping someone you care about.

Being a caregiver is also very difficult. You must take care of the patient's health **and** your own health.

It's easy to forget about your own health when you take care of someone else. Think about traveling on an airplane. Flight attendants tell you to put on your own oxygen mask before helping another person. It is the same for a caregiver, you must take care of yourself to take care of your patient.



Caregiver Stress

Symptoms of Caregiver Stress

As a caregiver, you will have stress. You might feel some or many of these symptoms.

Signs of Stress

| You might feel: | | You might have: | You might: |
|-----------------|---------------|-------------------------------|---------------------------------------|
| Irritable | Disgusted | Stomachaches | Make more mistakes |
| Angry | Ambivalent | Headaches | Not enjoy your hobbies anymore |
| Sad | Unmotivated | Difficulty sleeping | Withdraw from your friends and family |
| Guilty | Unappreciated | Extra anxiety | |
| Resentful | Nervous | Feeling withdrawn from others | |
| Impatient | Tired | | |
| Worried | Jealous | | |

If you feel stress, you are not alone. Try the strategies in Caregiver Self-Care, below.

Caregiver Burnout

You might have caregiver burnout if you:

- are physically, emotionally, or mentally exhausted from caring for a patient.
- start to feel negative and uncaring, instead of positive and caring.
- try to do too much physically, emotionally, or financially.
- don't have enough help.

You can take an [online self-assessment¹](#) if you think you have caregiver burnout.

Ask your transplant team for help if you have caregiver burnout.

Caregiver Depression

As a caregiver, you might feel sad, unhappy, or moody. You might also have symptoms of depression. Depression is more than feeling sad, unhappy, or moody sometimes.

If you have depression:

- you feel so sad, angry, or frustrated that it's hard to get through the day.
- these feelings last more than a few weeks.
- talk to a mental health professional who can help (insert links to mental health resources for support).
- know that you are not alone.
- ask your transplant team or doctor for help.

¹ <https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-interactive>

You can take an [online self-assessment²](#) if you think you have depression.

Caregiver Anxiety

It is normal to feel anxious sometimes. Sometimes, though, caregivers have an anxiety disorder.

If you have an anxiety disorder:

- you have intense, constant worry or fear about everyday situations.
- you might have panic attacks (sudden, intense anxiety that causes physical feelings of fear).
- you are not alone.
- ask your transplant team or doctor for help.

You can take an [online self-assessment³](#) if you think you have an anxiety disorder.

Relationship Stress during Caregiving

You might feel stress in your relationships with the patient and with others.

Having good relationships is important for your mental health. Try to:

- spend positive and relaxing time with family and friends.
- ask friends and family to visit you if you cannot leave to visit them.
- remember the patient is also your loved one.
- think about the relationship you and the patient had before the transplant process.
- do positive and relaxing activities with the patient when you can (not just caregiving activities).

Online Self-Assessments

- [Caregiver burnout⁴](#)
- [Depression²](#)
- [Anxiety³](#)

Caregiver Self-Care

Being a caregiver is hard work and requires changes in lifestyles, roles, plans, and goals. You must prioritize self-care. Self-care is caring for your health and giving yourself time to cope with stressors in your life.

Self-care is different for everyone. It can be:

- mindfulness
- meditation
- rigorous exercise
- walking
- reading a book

² <https://screening.mhanational.org/screening-tools/depression/?ref=CAN>

³ <https://screening.mhanational.org/screening-tools/anxiety/?ref>

⁴ <https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-interactive>

- any healthy activity that works for you

Dealing with Caregiver Stress

You might feel guilty for taking care of yourself. Remember, you must take care of yourself to be able to take care of someone else.

The “Caregiver Bill of Rights” can help you remember that it is ok to take care of yourself while you are a caregiver.

I have the right to:

- Take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of the person I am caring for.
- Seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- Maintain parts of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- Get angry, have bad moods, and express other difficult feelings occasionally.
- Reject any attempt by the one I care for (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- Receive consideration, affection, forgiveness, and acceptance for what I do for the person I care for as long as I offer these qualities in return.
- Take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of the person I care for.
- Protect my individuality and my right to make a life for myself that will sustain me in the time when the person I care for no longer needs my full-time help.
- Expect and demand that as new strides are made in finding resources to aid transplant recipients in our country, similar strides will be made toward aiding and supporting caregivers.

Adapted from [“Caregiver Bill of Rights”](#)⁵ by Jo Horne, author of *Caregiving: Helping an Aging Loved One*.

⁵ <https://www.caregiver.org/resource/caregivers-bill-rights/>

Common Emotions and Coping Strategies for Caregivers

You might feel some or many of the following emotions. Try the coping strategies to see if they help.

| Emotion | Definition | Coping Strategy |
|------------|---|---|
| | | • |
| Ambivalent | You might want to be a caregiver, and not want to be a caregiver, at the same time. | <ul style="list-style-type: none"> • Let yourself feel both feelings. • Don't be upset with yourself. • Remember that these feelings are common and they will not last forever. |
| Angry | Have you "lost it" while caring for someone? Anger is normal when you care for a patient who needs constant help. | <ul style="list-style-type: none"> • Say "I'm sorry." • Forgive yourself. • Find positive ways to express yourself. • Learn to walk away. Give yourself a "time out." • Talk about how you feel with people you trust. |
| Bored | You might have to limit activities you liked doing before you were a caregiver. | <ul style="list-style-type: none"> • Take a break. Taking time for yourself will help you be more patient. • Take a walk or read. Do something that makes you happy. • Ask friends or family to stay with the patient, so you can do a social activity you enjoy. |
| Irritable | When you are tired and stressed, you might get upset about little things or say things you regret | <ul style="list-style-type: none"> • Take a break (again!) and breathe. We have less control of our emotions when we are tired. • Don't use alcohol or junk food to feel better. • Do something healthy, like take a walk or write in a journal. |
| Sad | It's normal to be sad when someone you love is sick. | <ul style="list-style-type: none"> • Monitor your feelings. Make sure you still enjoy activities you used to enjoy. • Watch a funny movie, do a hobby you enjoy, or call a friend. • Talk to your doctor if, for several weeks, you are not motivated to do (or do not enjoy) any activities. This is a symptom of depression. • If you think you have depression, take it seriously. Depression can be treated. • Ask for help. Remember you are not alone. |
| Disgusted | Helping the patient shower, eat, or use the bathroom might be uncomfortable. It might be hard to see or smell blood, vomit, or other bodily fluids. | <ul style="list-style-type: none"> • Sometimes, you might think the patient is doing something disgusting on purpose, or you might feel guilty for being disgusted. These feelings are normal. • Try to remember that the patient is probably not in control of the things that disgust you. • Ask for help doing the activities that are most difficult for you. |

| Emotion | Definition | Coping Strategy |
|-----------------|--|--|
| Scared | You might worry that something bad will happen, and that you will be responsible. Worrying about “what ifs” can make it difficult for you to enjoy the moment. | <ul style="list-style-type: none"> • Have backup caregivers in case something happens to you. • Plan how you will manage predictable medical emergencies. • If you get scared, talk to the transplant team. • Worry is very normal when caring for someone who is sick. If the worry becomes overwhelming or out of control, ask your doctor for help. |
| Frustrated | You might feel like you can’t do anything right or nothing goes well, even when you try. When you’re tired, you can feel frustrated more easily. Sometimes, being frustrated leads to stress eating, substance abuse, or losing your temper. | <ul style="list-style-type: none"> • Remind yourself that caregiving is frustrating. • Join a support group for caregivers. • Take breaks, exercise, and sleep. Give yourself time to recharge. |
| Grieving | It’s sad to see the patient struggle with things they could easily do before. You might miss how the patient was or the way things were before the transplant. | <ul style="list-style-type: none"> • Do something special to help yourself move on. For example, make a list of the things the patient can’t do anymore or the things you’ve had to say goodbye to. Throw the list in the ocean or a lake. • Let yourself feel sad instead of avoiding the feeling. |
| Guilty | Sometimes you might not want to be a caregiver, or you might not like the patient. You might feel badly you couldn’t keep the patient healthy or that you can’t help more. You might feel guilty when you think about what you need or want, especially if the patient cannot participate. | <ul style="list-style-type: none"> • Forgive yourself. No one is perfect. • Try to change “should” thoughts. Instead of, “I should not be frustrated.” Think “Everyone gets frustrated sometimes, and I am doing the best I can.” |
| Impatient | It’s normal to feel impatient, especially if the patient can’t do things quickly. | <ul style="list-style-type: none"> • Forgive yourself. It is normal to want things to go quickly. • Try to slow down and give the patient and yourself more time to do things. • Create a list of the things you can and cannot control. |
| Jealous | It might feel unfair that non-caregivers (including family and friends) can do things you can’t do because you are a caregiver. | <ul style="list-style-type: none"> • Remind yourself that it’s okay to feel jealous. Things are not fair and at times we compare ourselves to others. • Focus on what you have and reasons to be grateful, not on what others have. |
| Not appreciated | It might be hard for the patient to accept help or depend on someone, and they might not always show appreciation. | <ul style="list-style-type: none"> • Praise yourself for the work you do. Remind yourself you are doing something important. • Journal about caregiving. • Have a support group or friends and family to motivate you and cheer you on. |
| Lonely | You might lose contact with friends and family or feel isolated. | <ul style="list-style-type: none"> • Find ways to get out of the house. • Do activities other than caregiving. • Ask friends and family for help. |

| Emotion | Definition | Coping Strategy |
|----------------|---|---|
| Loss of power | As a caregiver, you might lose independence, control, income, time, and relationships. | <ul style="list-style-type: none"> • Identify losses. What do you miss? • Look at your losses. How can you deal with each one? |
| Resentful | Over time, you might resent being a caregiver. You might resent the patient or family and friends who don't help. You might feel unsupported, trapped, or unacknowledged. You might feel guilty for thinking this way. (see # 10) | <ul style="list-style-type: none"> • Caregiving is hard. The more help you accept, the less resentful you will feel. • If family and friends are not helping you, find other people who can support you. • Participate in online or in-person support groups. |
| Tired | If the patient needs help at night, you might not sleep well. Caregiving can be a lot of work, physically. | <ul style="list-style-type: none"> • Prioritize sleep. Not getting enough sleep can lead to obesity, illness, impatience, inefficiency, and feeling mentally foggy. • Consider your sleep hygiene (your sleep routine and atmosphere). • Avoid caffeine 4 to 6 hours before bedtime. • Follow a daily sleep routine. • Talk to the transplant team and your doctor if you can't fall asleep or stay asleep. • Don't try to "just deal" with being tired. This can lead to burn out. |

There are many apps that can help you track and manage mood and stress. Try a couple apps to see if one is helpful for you.

Strategies for Caregiver Self-Care

Find the self-care activities that work for you and fit them into your daily life. Remember that you must take care of yourself to be able to take care of the patient.

Take Care of Your Health

- Don't cancel your medical appointments.
- Continue check-ups, screenings (mammogram, colonoscopy, etc.), and vaccines (flu shot).
- Don't ignore possible health problems.
- Take vitamins and all prescription medications.
- Get enough sleep.
- Monitor your mood and mental health. Learn more in *Dealing with Caregiver Stress*, above.
- Make a list of small health goals and how you will fit them in. For example: take a 10 minute walk every morning, eat fast food only once a week, or read a relaxing book for 10 minutes before bed.
- Practice meditation, mindfulness, relaxation exercises, yoga, or tai chi. Try an app like Headspace, Calm, Breathe2Relax, or Breathe.

Choose a Nutritious Diet

- Eat fruits and vegetables every day.

- Limit fast food, junk food, and late-night snacks.
- Buy healthy snacks and keep them handy.
- Look up healthy, quick recipes for meals and snacks.
- When people ask how they can help, ask them to share healthy, quick recipes. Even better, ask them to make healthy food for you.
- Choose healthy food in the hospital cafeteria, or take healthy food to the hospital.
- Drink 6-8 glass of water every day.
- Limit soda, caffeine, and sugary drinks.
- Try an app that reminds you to drink enough water and tracks your eating and drinking habits. [Learn more at the Academy of Nutrition and Dietetics website](https://www.eatright.org/)⁶

Exercise: Exercise improves sleep and mood, reduces stress, and increases energy and concentration.

- Be active at least 30 minutes a day, and get creative!
- Take a walk every day. Invite the patient, if possible.
- Exercise with the patient or when the patient does therapy.
- Use an app or video to do yoga at home.
- Do sit-ups or squats when you watch TV.
- Park farther away in the parking lot.
- Choose the stairs.
- Walk your dog or join your neighbor when they walk their dog.
- Dance to your favorite music.
- Stretch before you go to sleep and when you wake up.
- Do active chores, like vacuuming and dusting.

Connect with Other People

- Take care of your relationships.
- Spend positive and relaxing time with family and friends.
- Ask friends and family to visit you if you can't leave the patient.
- Remember that the patient is also your loved one. Think about the relationship you had before the transplant. Do positive activities together, not healthcare activities
- Connect with other caregivers or join a support group.

Set Realistic Goals and Expectations

- Remember that the transplant process can be long and difficult.
- Set realistic goals for yourself and the transplant process.

⁶ <https://www.eatright.org/>

- Ask other caregivers about their experiences.
- Ask the transplant team (doctors, nurses, social workers) what they will expect of you.
- Learn about the transplant process.
 - www.UNOS.org
 - www.TransplantLiving.org
 - [“What is it like to be a transplant caregiver?” video](#)⁷
 - [“Preparing for the Transplant Journey: A Guide for Patients and their Caregivers” video](#)⁸

Accept Help

- Let others give you a break.
- Ask for help before you feel overwhelmed.
- Make a list of ways people can help you.
- If someone asks, “Can I do anything for you?” give them a specific answer:
 - Make a healthy meal.
 - Pick up your mail.
 - Mow your lawn.
 - Take your kids to school or afterschool activities.
- Use apps to help people help you.
 - [“Lotsa Helping Hands”](#)⁹ – With an interactive calendar and message board, you can invite people to help with errands, medical appointments, etc. Use the app or website.
 - [“CareZone”](#)¹⁰ – Write about your loved one and invite others to help with their care. It has a task list, medication log, notes, photos, etc. Use the app or website.
 - [Meal Train](#)¹¹
- Find help with communication, so you don’t have to call everyone with updates.
 - Choose a person who will share updates with friends and family.
 - Create an email chain, private social media account, or group text to share updates.
 - Use a communication app for caregivers:
 - [“Caring Bridge”](#)¹² – Share updates, care arrangements, pictures, and messages with family and friends. Use the free app or website.
 - [“Caring Village”](#)¹³ – Create a “village” of family and friends to coordinate care. It includes a calendar, document storage, medication list, and wellness journal. Use the app or website.

Don’t Use Alcohol or Drugs

⁷ <https://www.youtube.com/watch?v=cj2hTAWqh9E>

⁸ <https://www.youtube.com/watch?v=GjD00PXbYgY>

⁹ <https://lotsahelpinghands.com/>

¹⁰ <https://carezone.com/home>

¹¹ <https://www.mealtrain.com/>

¹² <https://www.caringbridge.org/>

¹³ <https://caringvillage.com/>

Alcohol and drugs might give short-term relief. Over time, though, alcohol and drugs cause stress, moodiness, exhaustion, and health problems.

- Ask your transplant center if they require patients **and** caregivers to be free of alcohol, tobacco, and illegal drugs before and after transplant.
- [Talk to your doctor if alcohol causes trouble in your relationships, at work or school, in social activities, or in how you think and feel.](#)¹⁴
- Don't use illegal drugs.
- Use prescription medication **exactly** as prescribed, especially stimulants (Adderall, Concerta, etc.) and benzodiazepines (Xanax, Valium, etc.)
- Stop or limit tobacco, including e-cigarettes. For help quitting:
 - <https://smokefree.gov/>
 - 1-800-QUITNOW
 - [How to Quit Smoking](#)¹⁵
- Ask for help with drug or alcohol use if you:
 - start taking the patient's or other family member's medications.
 - fill prescriptions for the patient or other family members too early or too often.
 - don't enjoy activities you used to enjoy.
 - withdraw from (spend less time with) friends and family.
 - hide pill bottles or take other people's medications home "for safekeeping".
 - feel overly protective or secretive about medications.
 - notice a lot pill bottles or alcohol containers in your home or the patient's home.
 - have physical changes like red or glassy eyes, runny nose, or constant sniffing.
 - have bad personal hygiene.

Ask for Help

- **Ask for help.** Being a caregiver is hard. You do not have to do it alone.
- Feeling depressed, anxious, or frustrated is normal. You are not a "bad" caregiver.
- Talk to your doctor or a mental health professional if you:
 - have intense mood changes, anxiety, or panic and it's hard to get through the day.
 - avoid people or situations that cause feelings of depression or anxiety.
 - think about hurting yourself or do not want to live.
- If you want to hurt yourself, go to the Emergency Department, call 911, or call a suicide hotline.
- Find a mental health provider:
 - Ask your doctor, health insurance, or transplant team for a referral.
 - Use the Psychology Today "[Find a Therapist](#)"¹⁶ website to search by location, insurance, therapy type, gender, etc.

¹⁴ <https://www.cdc.gov/alcohol/>

¹⁵ <https://www.cdc.gov/tobacco/campaign/tips/quit-smoking/index.html>

¹⁶ <https://www.psychologytoday.com/us/therapists>

- [Learn strategies to talk](#)¹⁷ about your mental health.
- General mental health resources:
 - <https://www.mentalhealth.gov/>
 - [National Institute of Mental Health](#)¹⁸
 - National Alliance on Mental Illness (NAMI) [resource list](#)¹⁹
 - USA Mental Health First Aid [resource list](#)²⁰
 - US Department of Veteran Affairs [mental health website](#)²¹
 - CDC mental health [tools and resources](#)²²
 - [Mental Health America](#)²³
 - [National Suicide Prevention Hotline](#)²⁴

Support Groups and Connecting with Others

- Talk to family, friends, church, or other spiritual supports.
- Ask your job about resources like an Employee Assistance Program.
- Ask your transplant team for help connecting with resources or other caregivers.
- Ask if the transplant center has a caregiver support group.
- During hospital admissions, ask about social workers, psychology, chaplain services, psychiatry, music therapy, art therapy, pet therapy, etc.
- Find support through caregiving organizations:
 - UNOS [Transplant Living Community](#)²⁵
 - [Today's Caregiver](#)²⁶: The community page has (non-transplant-specific) articles, podcasts, book clubs, and ways to connect with other caregivers.
 - [Caregiver Action Network](#)²⁷: Post messages and connect to other caregivers on the Care Community page.
 - American Psychological Association ["State and National Resource Locators and Tools to Coordinate Caregiver Support"](#)²⁸
 - Caring 4 the Caregiver [resources](#)²⁹
 - [National Alliance for Caregiving](#)³⁰

¹⁷ <https://www.nimh.nih.gov/health/publications/tips-for-talking-with-your-health-care-provider>

¹⁸ <https://www.nimh.nih.gov/health/find-help>

¹⁹ <https://www.nami.org/NAMI/media/NAMI-Media/Images/FactSheets/HelpLine-Resource-Directory.pdf>

²⁰ <https://www.mentalhealthfirstaid.org/mental-health-resources/>

²¹ <https://www.mentalhealth.va.gov/>

²² <https://www.cdc.gov/mentalhealth/tools-resources/index.htm>

²³ <https://www.mhanational.org/>

²⁴ <https://988lifeline.org/>

²⁵ <https://transplantliving.org/community/>

²⁶ <https://caregiver.com/cg-community>

²⁷ <https://www.caregiveraction.org/forum>

²⁸ <https://www.apa.org/pi/about/publications/caregivers/resources/locators>

²⁹ <https://care4thecaregivers.org/resources/>

³⁰ <https://www.caregiving.org/>

- Find a [Transplant Recipients International Organization \(TRIO\) group](#)³¹: – TRIO is a nonprofit organization that helps transplant candidates, recipients, families, and the families of organ and tissue donors.
- Join an in-person or online support group:
 - [UNOS Transplant Living support groups](#)³² for patients and families (could include caregivers)
 - [Well Spouse Association](#)³³ support groups, online chat forum, peer mentors, etc.
 - [Caregiver Space](#)³⁴: a support website for caregivers of all types
 - The Transplant Caregivers - Partners for Life [Facebook group](#)³⁵

Questions for Your Transplant Center

- Do you offer mental health services to caregivers?
- Do you have a caregiving support group?
- What are the requirements for alcohol, tobacco, and illegal drug use for patients and caregivers?
- Who offers support when the patient is in the hospital?
- Do you offer a social worker, chaplain, pet therapy, art therapy, or music therapy when the patient is in the hospital?

³¹ <https://www.trioweb.org/chapters/active-chapters.html>

³² <https://transplantliving.org/community/support-groups/>

³³ <https://wellspouse.org/>

³⁴ <https://thecaregiverspace.org/>

³⁵ <https://www.facebook.com/groups/PartnersForLife/>

Resources

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: <https://www.mentalhealth.gov/>
- National Institute of Mental Health: <https://www.nimh.nih.gov/health/find-help/index.shtml>
- National Alliance on Mental Illness (NAMI) Resource List: <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: <https://www.samhsa.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=GjD00PXbYgY>

More Resources

- [Improving Caregiver Self-Care](#)³⁶
- [Transplant Caregiver Bill of Rights](#)³⁷
- Sleep Health: <https://www.nhlbi.nih.gov/resources/your-guide-healthy-sleep>

References

1. Self-care in the context of primary health care: Report of the Regional Consultation, Bangkok, Thailand, 7–9 January 2009. New Delhi: World Health Organization, Regional Office for South-East Asia; 2009. <https://iris.who.int/handle/10665/206352>
2. Caregiver Bill of Rights, <https://www.caregiver.org/caregiver%E2%80%99s-bill-rights>
3. Seattle Cancer Center Alliance- Patient and Family Education Brochures
<https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>
<https://www.caregiver.org/emotional-side-caregiving>
<https://www.mayoclinic.org/diseases-conditions/anxiety/symptoms-causes/syc-20350961>

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³⁶ https://www.myast.org/sites/default/files/03S._Improving_Caregiver_Self-Care.pdf

³⁷ <https://www.caregiver.org/resource/caregivers-bill-rights/>



Transplant Caregiver Bill of Rights

The “Caregiver Bill of Rights” can help you remember that it is okay to take care of yourself while you are a caregiver.

I have the right to:

- Take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of the person I am caring for.
- Seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- Maintain parts of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- Get angry, have bad moods, and express other difficult feelings occasionally.
- Reject any attempt by the one I care for (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- Receive consideration, affection, forgiveness, and acceptance for what I do for the person I care for as long as I offer these qualities in return.
- Take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of the person I care for.
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- Expect and demand that as new strides are made in finding resources to aid transplant recipients in our country, similar strides will be made toward aiding and supporting caregivers.

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Improving Caregiver Self-Care

Nutrition

- Eat fruit and vegetables
- Limit junk food
- No fast food
- Choose healthy options
- Make food early
- Drink water

Regular Exercise

- Take a 10-minute walk
- Get outside for fresh air
- Reduce stress with yoga and stretching

Stay Connected to Others

- Connect with friends and family
- Join a caregiver support group
- Volunteer
- Participate in social (community, church) activities

Stay Healthy

- Get 7-9 hours of sleep
- Continue your medication
- Go to doctor appointments
- Do all regular screenings

Avoid Unhealthy Activities

- Alcohol
- Illegal drugs
- Tobacco
- Emotional eating
- Too much screen time

Do Things You Enjoy

- Read
- Listen to music
- Watch a favorite movie
- Take a warm bath
- Garden
- Cook
- Color

Take Care of Your Mental Health

- Journal
- Practice daily gratitude
- Meditate
- Do breathing exercises
- Take breaks
- Set boundaries
- Prioritize tasks
- Ask for help
- Monitor your self-talk

Ask for and Accept Help

- Have backup caregivers
- Tell people you trust how you feel
- Join a support group
- Find a mental health provider

More Ways I Can Care for Myself

- 1.
- 2.
- 3.
- 4.

Reduce Temporary Distractions Incompatible with Self-Care

- Alcohol
- Drugs
- Tobacco
- Emotional eating
- Binge watching
- Excessive social media use
- Watching the news non-stop



SELF-care

*Each of these can help
to take control over what
you can and buffer
against stress!*

• **S** = Sleep

- Give your mind time to relax before bed (e.g., meditation)
- Avoid exposure to news or social media right before bedtime
- If your mind feels active, try to refocus by writing down three things that you are grateful for from the day

• **E** = Exercise – Move your body every day

- Movement and exercise release endorphins, your brain's natural painkillers, bringing around a sense of general well-being, in addition to being good for your lungs
- Try to get exercise each day, such as getting out in the sunshine and walking (while of course, remaining socially distant)

• **L** = Leisure (something fun or social) & new routines

- Build fun, creative, or leisure activities into your daily routine
- Connect with friend and family virtually
- Create your "now normal" routine
- Give yourself a break – "bend" where you need to, even if it's different than normal routines

• **F** = Food and Fluids

- Good nutrition and hydration are essential for adequate function of the immune system and can counterbalance the impact of stress – make sure you are eating and drinking regularly

Adapted from kidshealth.org and Dr. Lillian Christon