

‘Look for joy and happiness in little things’

Actor and writer Steve Guttenberg shares how he cared for his father at the end of his life



Steve Guttenberg has made audiences laugh and smile with his starring roles in hit comedies such as *Police Academy* and *Three Men and a Baby*. In 2019, he took on a new and unexpected role as caregiver to his aging father, Stanley. He would drive hundreds of miles back and forth every week to help Stanley, who died of [kidney failure](#) in 2022. Guttenberg recently wrote a book, *Time to Thank: Caregiving for My Hero*, about the experience, and he spoke with NIH MedlinePlus Magazine about his caregiving journey. He hopes to bring attention to caregiving and share empathy with the millions of others facing similar challenges.

You basically dropped everything to help with caregiving for your father. Can you share how your caregiving journey started?

My dad had signs of declining kidney function for years, but we largely ignored them. He felt fine, and we thought he would get better. But things eventually got worse, and his [internist](#) (a doctor of internal medicine) said he needed to see a [nephrologist](#) (a kidney specialist). The nephrologist said Dad’s kidneys were failing and could no longer filter the toxins from his blood. She said he needed to receive kidney [dialysis](#) three days a week.

Our family knew it was going to change his life and ours. We were going to have to build our lives around his schedule, change the food he ate, and carefully monitor his fluid intake. It was a shock for all



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of us. That’s when I started my ritual: Every week I drove 400 miles from Los Angeles to Phoenix to take my dad to four-hour dialysis sessions to clean his blood. I did this drive four days a week—the number four literally became my rhythm of life.

How did all of this impact your family?

The change in lifestyle and decline in my dad’s health were really tough on him and all of us. He had always been the strength of our family and a strong man. He was a real specimen—190 pounds of muscle. He was a U.S. Army Ranger and a New York City police officer who exercised his whole life.

But when a loved one is facing a serious illness and needs your help, you stand up, you get to work, and you do what you have to do. You look for joy and happiness in little things every day so you can carry on. My sister Susan was really the captain of everything we did. She was amazing and selfless. She gave up her job in teaching to take care of our parents. Our mother lives with her.

How did you and your family educate yourselves about your father’s condition and how to help him as caregivers?

We did as much research as we could about kidney failure and dialysis and how it affects the body. We read a lot to learn how to help my dad stay strong and comfortable through everything.

We also asked a lot of questions of his doctors, and we talked to the technicians who managed the dialysis sessions. We got all kinds of tips from them, practical things you need to know, like how to keep his skin safe as he sat in a chair for four hours at a time. We also learned when and what he could eat during dialysis. And because the dialysis technicians had four or five patients at a time, we learned my dad needed an advocate with him at all times during the treatment so we could get help quickly if something went wrong and he needed medical attention.

Is there anything from your caregiving experience that you especially cherish?

Yes. Every time I would walk into the room in the morning and see him, his eyes would light up with the most authentic emotion I have ever encountered. His eyes would go wide, and his smile was so bright. And he would reach out his hands. I would grab his hands, kiss them, and hold them tight.

“We read a lot to learn how to help my dad stay strong and comfortable through everything. We also asked a lot of questions of his doctors, and we talked to the technicians who managed the dialysis sessions.”



Steve Guttenberg drove from Los Angeles to Phoenix every week to take care of his father, who died of kidney failure. Guttenberg said his father had always been a strong person, so his illness was hard for the family to process.

How did your caregiving experience impact your relationship with your father and your other family members?

It brought us much closer and made our relationship much deeper. But I would have much preferred to deepen our relationship through a happy experience!

What is your message to other caregivers or those who may be caregivers in the future?

When someone you love needs you, how can you not help them? When they open *their* eyes in the morning, make sure they see two loving eyes looking back at them. Make sure they see a loving atmosphere that makes them warm and gives them hope. Make sure they are surrounded in their daily lives with love and care.

You can always make a difference in someone’s life. Think about who you can help, whether it is a friend or a loved one. Give them a call, send a card, or bring flowers. Visit them and come in with a smile, a joke. Touch them physically and emotionally—people need to be touched and cared about.

What does the future hold for you? Are there any professional projects you are working on that you’d like to share with readers?

I’m excited that we have released the audio version of my book about caregiving, *Time to Thank: Caregiving for My Hero*. I wrote and acted in a wonderful play last year called *Tales of the Guttenberg Bible*, and I’m in a TV series, *High Potential*, out this fall on ABC. I’m also starting to film two new movies! ■

Caregiving 101

Worksheets, resources, and suggestions from the National Institute on Aging

Being a caregiver or care partner is a big undertaking. Caregivers don't just manage someone else's health care, daily tasks, financial decisions, and other logistics. They also have their own schedules and responsibilities to balance. It can be hard to know where to begin!

Whether you're new to caregiving or have been doing it for a while, the National Institute on Aging's (NIA) [website](#) has expert-backed advice to help make things more manageable. Here is just a sample of what you'll find.

New to caregiving? Start here

As someone's caregiver, it's important to [learn as much as possible](#) about their medical condition. This way you can better anticipate their needs and how to manage their health care over time, including in an emergency. Ask the person about what treatments they are getting or medications they take. Get their health care providers' contact information.

If someone is hesitant to talk about their health with you, explain that knowing this information will help you care for them. They may prefer that you talk to their health care provider directly. Remember that, by law, you need written permission from them to receive their medical information unless they can give consent to the provider in person.

The Caregiver's Handbook

The Caregiver's Handbook is available [to download online or order for free](#). It outlines basic information on topics such as:

- Finding care needed at home
- Long-term care facilities
- The costs of caregiving
- How to coordinate medical care
- Planning ahead
- Caring for yourself, too

This guide is for anyone who provides care for family members or friends who need help with daily living.



Get caregiver training

Hospitals, state and local governments, and nonprofit organizations sometimes offer free or low-cost training for caregivers. Check whether [Medicare](#) or [Medicaid](#) will cover some of the cost, too!

Helping someone with exercise

Many caregivers help older adults and people with chronic health conditions with mobility challenges. Physical activity is important for just about everyone, including caregivers. Talk with the person's health care provider about what's best and see whether there are any exercises you two can do together.

Check out NIA's exercise ideas for someone with a [chronic condition](#) such as:

- Alzheimer's disease and other dementias
- Arthritis
- Chronic obstructive pulmonary disease (COPD)
- Type 2 diabetes
- Heart health issues
- Osteoporosis
- Chronic pain

Tracking and sharing caregiver duties

Caregiving involves keeping track of a lot of responsibilities and needs. NIA has [worksheets](#) to help you remember everything and delegate responsibilities to other family or friends when you need extra hands. These worksheets include checklists about:

- Caregiver responsibilities
- Medications and supplements
- Important documents and paperwork

If you need to [share caregiving responsibilities](#) with others, think about everyone's personal limits and who will be the best person for each task.

Making someone's home safer

If someone is still living in their home while in your care, look for potential falling hazards or areas where they may need extra help to move around the house. NIA has a [home safety checklist](#) with suggested precautions. You can also follow this [room-by-room guide](#).

Other resources include:

- Advice for helping older adults [avoid falls and fractures](#)
- Information on [aging in place](#) and knowing [when it's time to move](#) somewhere more suitable

Your state or local government may have home modification programs to help older people prevent falls. Ask your local health department or [Area Agency on Aging](#), or search the [Eldercare Locator](#).

Finding services and community resources

Some nonprofit organizations and government agencies offer services for older adults to help reduce some of the caregiving workload. If an older adult needs help with daily needs, from chores to grocery shopping to getting dressed, there may be a local service to help with that.



As someone's caregiver, learn as much as possible about their medical condition so you can best help them.

These services may be free or low-cost. In some cases, they may be covered by health insurance, Medicare, or Medicaid. Eldercare Locator is a good place to start your search.

NIA also has [ideas for finding services](#), including:

- Home health services
- Transportation, including for patients with dementias
- Money management for older adults
- Nutrition and meal services and their eligibility
- Personal emergency medical alert systems for patients who may live alone
- Adult day care

Caregiving for someone with Alzheimer's disease

[Alzheimer's disease](#) and related dementias can present unique challenges for caregivers. Daily life, social gatherings, and other medical conditions need special attention. NIA has a variety of resources for caregivers of people with Alzheimer's and ideas for [getting help with caregiving](#). Explore more information on topics such as:

- Adapting activities for people with Alzheimer's
- Tips for helping someone with bathing, grooming, dressing, and eating
- Taking someone with Alzheimer's to the hospital
- [Legal and financial planning](#)

Still have questions about caregiving?

The [NIA Information Center](#) is here to help. Staff answer telephone, email, and written requests and make referrals to local and national resources. Support is available Monday through Friday, 8:30 a.m. to 5 p.m. ET.

National Institute on Aging Information Center

Call 800-222-2225 (toll-free) or email niaic@nia.nih.gov for more information about health and aging.

National Institute on Aging Alzheimer's Disease Education and Referral (ADEAR) Center

Call 800-438-4380 (toll-free) or email adear@nia.nih.gov for more information about Alzheimer's and related dementias. ■

Home safety tips for older adults

A few changes could make your home easier and safer to live in and help you continue to live independently.

For more information, visit www.nia.nih.gov/aging-in-place.

SOURCE: [NATIONAL INSTITUTE ON AGING](#)

Helping from miles away: Strategies for long-distance caregiving

Do you support a friend, parent, or relative who lives far away?



Video calls can help you stay connected with family, friends, and medical providers.

Millions of people act as long-distance [caregivers](#), supporting loved ones who are aging or coping with an illness or disability. This role can include managing a loved one's finances, organizing their medical appointments and care, coordinating with their other caregivers, and offering emotional support.

Whether you are already a caregiver or may become one in the future, these tips can help you navigate [long-distance caregiving](#) effectively.

Understanding their health and care

Learn about your loved one's health, treatments, and living situation. Research their health condition and available resources, including Medicare and Medicaid benefits, and have open conversations with them about their situation and what support they need.

Ask your loved one for written permission to speak with their medical team. This allows you to stay informed about their health and care, even from a distance. Doctors and other health care providers need this consent to share medical information with you.

Keeping track of important documents

[Collect and organize](#) important legal, financial, and medical documents. Make sure they are up to date and located somewhere secure and easy to find. Create lists of medications they take and

when they take them. Gather contact information for their doctors, health care providers, and other important contacts, and update this information regularly.

Planning meaningful visits

Schedule in-person visits with your loved one when you can. Before you arrive, ask what your loved one would like to do during your visit, whether it's grocery shopping, visiting friends, or household tasks. If possible, schedule doctor's appointments during your visit (with permission) and meet with your loved one's other caregivers if they live close by.

Don't forget to carve out quality time together *not* related to caregiving. Whether it's a shared hobby or simply relaxing and catching up, enjoyable activities make visits less stressful. This ensures your time together is about more than just tasks and responsibilities.

Creating a local care network

You can't do it all alone, especially from far away. Identify local family members, friends, neighbors, and others who can lend a hand or help in emergencies. Let them know what's going on and how to contact you.

Build relationships with your loved one's health care providers and other caregivers. Consider hiring local caregivers or care managers to help coordinate care.



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Helping the primary caregiver

Even if you're not the primary caregiver, you can still support that person by staying in regular contact, asking what you can do to help, and offering to take on tasks or responsibilities. Before you visit, check in with that person about what support they might need and how you can help. If possible, plan your visits so the primary caregiver can take a break, and arrange for [respite care](#) if necessary.

Staying connected and informed

Regular communication is key. Schedule regular check-ins with your loved one and with their other caregivers to stay up to date on their condition.

Technologies such as video calls, group chats, and shared calendars can be useful tools for staying connected. Join your loved one's telehealth visits (with their permission) and set up calls with other providers and caregivers to discuss their health and well-being.

This [short video](#) from the National Institute on Aging has essential tips to help long-distance caregivers stay informed and effective.

Adapting as their needs evolve

Be prepared to adjust if your loved one's situation or needs change. Have a conversation about different options (such as assisted living or in-home care services) and consult with their health care providers about which ones might be useful and when. ■

Long-Distance Caregiving: How Can I Help if I'm Far Away?

You can still provide support as a caregiver, even if you don't live close by.

From a distance, you may be able to:



Arrange for in-home care, such as a home health aide



Research long-term care options, such as assisted living or a nursing home



Plan occasional in-person visits to help out the day-to-day caregivers



Order medical equipment, medicines, and other supplies



Assist with paying bills and managing insurance claims



To learn more, visit www.nia.nih.gov/long-distance-caregiving.



SOURCE: [NATIONAL INSTITUTE ON AGING](#)

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Home sweet home: Supporting a loved one aging in place

With planning and support, older adults can often continue living independently



Aging in place is possible with the right support.

Many older adults prefer to stay in their own homes as they age. This is called “aging in place.” Here are some things to consider so you can help your loved one stay safe, healthy, and comfortable at home.

What your loved one might need support with

- **Personal care.** Friends, relatives, or a professional aide can support your loved one with daily activities like bathing, dressing, and getting around, even if just for a few hours a day.
- **Household tasks.** Residential cleaning services and other local services can help with chores like cleaning, shopping, and laundry. Many stores offer delivery services for groceries and prescriptions.
- **Meals.** These can include community dining programs, meal delivery services, or shared meals with friends.



- **Money management.** Trusted relatives or financial counselors can help manage bills.
- **Health care.** In-home services can support various aspects of health care, including medication management, physical therapy, and in-home nursing.
- **Getting around.** If driving is difficult, there may be local transportation programs and public transit options for seniors.

What you can do

Talk with your loved one about their needs and preferences and what assistance they might need, and work together to create a [personalized plan](#) to help your loved one stay safe, comfortable, and independent.

- Learn about [services for older adults living at home](#), and research what programs and resources are available in your loved one’s local community.
- [Assess their home](#) for any potential hazards. Making changes such as installing grab bars or improving lighting throughout the house can help make the home safer and more accessible.
- Involve friends and family in planning and encourage your loved one to reach out to them for support.
- Learn from others’ experiences of caring for loved ones who are aging in place.

Finding services

To locate services in your loved one’s local area, contact their local [Area Agency on Aging](#) or use the [Eldercare Locator](#). This free, nationwide program connects older adults and their families with local, trustworthy support resources for housing, transportation, home care, and more. [Get in touch](#) by email, chat, or calling 800-677-1116.

What about the cost?

You may be able to get help paying for repairs and safety updates to an older adult’s home. Check with your state housing finance agency, social services department, community development groups, or the federal government for financial aid programs and discounts. You can also contact the [Eldercare Locator](#) for assistance finding resources to help with these changes. ■

Many older adults prefer to stay in their own homes as they age. This is called “aging in place.”

End-of-life care: What to expect and how to plan

The National Institute on Aging has helpful tips and resources

When older adults and people with terminal illnesses are dying, they may need a lot of care. This care can last from days to months, and it will look different for everyone depending on their needs.

End-of-life care can be medical and physical, but it can also look like emotional or spiritual support. It often involves making treatment or legal decisions with or on behalf of the dying person. Family and friends of the person who is dying may need support, too.

This can be a lot to manage. The National Institute on Aging (NIA) has information to help you plan end-of-life care for yourself or a loved one.

What does end-of-life care involve?

End-of-life care may involve a team of doctors, nurses, palliative or hospice staff, counselors, and religious community members. People who are dying generally need care in [several areas](#):

- **Physical comfort.** The person may experience pain, breathing problems, skin irritation, digestive issues, fatigue, or temperature sensitivities. These symptoms can be hard to manage, so ask their health care provider how best to relieve them.
- **Mental and emotional needs.** Be present with the person. Try to set a comforting mood by playing music, reading, or holding hands if they wish. A counselor with experience in end-of-life emotional issues can give you advice.
- **Spiritual needs.** Many people find solace in their faith at the end of life, while others may struggle with spiritual beliefs. Talking, praying together, or listening to religious music can help.
- **Practical tasks.** Both the dying person and their caregivers may need help with practical tasks to ensure peace of mind for everyone. This might include big things like personal affairs or small things such as laundry.

End-of-life care can happen anywhere, but common settings are [at home, in a hospital, or in a care facility](#). Each of these options comes with unique costs and equipment needs depending on the type of care.

Not everyone has the chance to decide where they will die, but people who know the end of their life is approaching may be able to prepare. An [advance care plan](#) can help loved ones and the patient's doctor know what care they want at the end of their life.

Getting your affairs in order: Advance care planning

Making health care decisions for yourself or someone who is no longer able to do so can be overwhelming. That's why it's important to get a clear idea about preferences and arrangements while you can make decisions and participate in legal and financial planning together.

Use this checklist to ensure health care and financial arrangements are in place before serious illness or a health care crisis.



Start discussions early with your loved one while everyone can still help make decisions.



Create documents that communicate **health care, financial management,** and **end of life** wishes for yourself and the people you care for, with legal advice as needed.



Review plans regularly, and update documents as circumstances change.



Put important papers in one place. Make sure a trusted family member or friend knows the location and any instructions.



Make copies of health care directives to be placed in all medical files, including information on every doctor seen.



Give permission in advance for a doctor or lawyer to talk directly with a caregiver as needed.



Reduce anxiety about funeral and burial arrangements by planning ahead.



SOURCE: [NATIONAL INSTITUTE ON AGING](#)

What if someone doesn't have an advance care plan or can no longer make decisions for themselves?

If someone is dying but can no longer communicate, a relative or caregiver will [need to make decisions](#) about their care and comfort. This can be overwhelming, especially if the dying person's wishes aren't known or if multiple family members are involved and do not agree.

Ask yourself these questions:

- Did the person ever talk about what they would want at the end of their life?
- Did they ever express an opinion about someone else's end-of-life treatment?
- What were their values and what gave meaning to their life? For example, if being close to family or spending time outdoors was important to them, is further treatment likely to help them do these things again?

Talk to their health care provider about treatment options and potential risks and benefits. It's hard to predict exactly how much longer someone will live or how their condition will progress, with or without treatment. If the person is in a hospital, there may be an on-site palliative care professional or counselor who can help.

Talk with their doctor about [hospice care](#) if they predict your loved one has six months or less to live. Doctors and hospice providers can also tell you what to expect over the coming hours, days, or weeks.

If hospice care is considered, find out how hospice staff will coordinate care. Check whether health insurance, Medicare, or Medicaid covers it. Although hospice staff provide a lot of support for someone who is dying, family or caregivers often provide some day-to-day care.

What to know about end-of-life care for someone with dementia

End-of-life care for someone with Alzheimer's disease or a related dementia can be [uniquely challenging](#). Dementia is terminal (ends in death), and its progression is often unpredictable.

The signs of the final stages of dementia may include:

- Being unable to move around on one's own
- Being unable to speak or be understood
- Eating problems, such as difficulty swallowing

If someone with dementia can no longer make decisions about their health care, their family or caregivers may need to decide on their behalf. Decision-makers should weigh the benefits, risks, and side effects of any treatment. In some cases, these decisions may be based on the person's comfort rather than trying to extend their life or maintain their abilities for longer. It can be hard to give someone emotional support in this stage of their illness, but it's good to maintain whatever connections you can.

[Alzheimers.gov](#) has more information about making end-of-life care, financial, and other crucial decisions for someone with dementia. ■

Advance care plan: A checklist for the future

Do you and your loved ones have an advance care plan? An advance care plan spells out decisions you'd like to make if you can't communicate because of an illness or accident.

You can base this plan on your personal values, preferences, and discussions with family and other loved ones. It can include advance directives, which are legal documents used in the event you are unable to communicate.

Making an advance care plan is valuable for people at any age but especially for older adults or those facing a terminal illness. The National Institute on Aging (NIA) encourages people to create an advance care plan when they are healthy and able. When making your plan:

- Consider who should be your **health care proxy**—a person who can make your health care decisions if you can't. This is usually a trusted family member, friend, or advisor.
- Think about what kind of **end-of-life care** you are comfortable with. Would you prefer dying at home, in a hospital, in a care facility, or somewhere else?
- Write a **living will** that includes all your decisions on care and treatment, and have it notarized.

- Tell **key family members or trusted individuals** where they can find your advance care planning documents.

To get you started, [Advance Care Planning: A Conversation Guide](#) is a free publication from NIA with clear guidance and worksheets.

The guide is also [a good resource for caregivers](#) who need help starting the conversation about advance care planning with a loved one. Caregivers can explain to their loved one why an advance care plan is important for both of them. By documenting someone's wishes ahead of time, that person is more likely to get the care they want at the end of their life. ■



SOURCE: NATIONAL INSTITUTE ON AGING

Caring for yourself while caring for others

If you're a caregiver, you also need to take care of yourself

Are you helping a loved one with daily tasks, medical care, or emotional support? If so, you're a [caregiver](#)...and you're not alone. According to the [Centers for Disease Control and Prevention](#), nearly 1 in 5 adults in the United States are now caregivers, and the number is growing as the population ages.

Caregiving can be an extremely rewarding experience, but it can also be physically and emotionally draining. Whether you're supporting an aging parent, a spouse with a chronic illness, or a friend recovering from surgery, it's easy to be so focused on their needs that [you forget about your own](#).

But here's the thing: if you're exhausted, easily agitated, feeling disconnected from others, or unable to take care of your own needs—if you don't "[fill your own cup](#)"—you can't give your loved one your best care.

Your health matters

Caregivers often put their own health on the back burner. Research shows that caregivers are at a [greater risk for chronic health conditions](#) such as high blood pressure, heart disease, and depression. That's why it's so important to pay attention to your own health needs.

It's not always easy to recognize when you're pushing yourself too hard, so keep an eye out for these signs:

- Do you feel constantly tired or overwhelmed?
- Are you getting irritated easily?
- Are you having trouble sleeping?
- Have you lost interest in activities you used to enjoy?
- Are you experiencing frequent headaches or other physical problems?

If any of this sounds familiar, it might be time to focus on self-care.

Preventing and managing caregiver stress

Many caregivers struggle with guilt around taking time for themselves. But remember, taking care of yourself isn't selfish; it's necessary for your health and well-being, which directly benefits the person you're caring for.

Here are some tips from the [National Institute on Aging](#) and the [National Cancer Institute](#) to help you take care of your own physical and mental health while being there for someone else:

Let others lend a hand

As a caregiver, you might feel like you have to do it all. But you're not in this alone. Reach out to friends and family for help, and don't be afraid to say yes when someone offers support. Be specific about what you need. Maybe a friend could pick up groceries or a family member could sit with your loved one for an hour while you take a break. Many people want to help—they just might not know how.

Take time to recharge

Try to do something for yourself every day. You could read a chapter of a book you enjoy, practice deep breathing or meditation, or meet up with a friend. Even if it's just a short walk or a few minutes of quiet time, stepping away from caregiving responsibilities can help recharge your batteries.



Prioritize your own health

One of the most important parts of self-care is taking care of your own health. This includes being active, eating a balanced diet, staying hydrated, and getting enough sleep. It's also important to keep up with your own medical appointments and screenings. Make sure your doctor knows about your caregiving role and tell them how you've been feeling (both physically and mentally).

Be gentle with yourself

It's common to experience a wide range of emotions as a caregiver. You might feel frustrated, sad, resentful, joyful—all in the same day or even in the same hour! These feelings are a normal part of the caregiving experience, and it's okay to express them.

Recognize when it's time for a break

If you're feeling overwhelmed, consider speaking with a counselor or your doctor. They can offer resources and support to help you manage these feelings. [Respite care](#), which offers short-term relief for primary caregivers, may also be an option. Services can range from a few hours of in-home help to a short stay with your loved one at their care facility. Respite care gives caregivers time to rest, travel, or spend time with other family and friends.

Connect with other caregivers

Caregiver support groups can be a great way to talk about your experience with people who understand what you're going through. Your health care provider or local senior center may be able to recommend a group in your area.

Self-care might seem overwhelming right now, and that's okay. You don't have to tackle everything at once. Even small steps can make an enormous difference in your well-being...and your ability to care for others. ■

‘Nothing important went unsaid’

Rebecca’s journey of love, loss, and caring for her partner through his final days

Over the course of their relationship, Rebecca Rose Vassy supported her long-term partner Sean in managing multiple chronic health conditions. Then a cascade of medical complications caused Sean’s health to decline rapidly, and Rebecca’s role shifted dramatically. She became a full-time caregiver, providing 24/7 support at home and later at the hospital, until Sean’s passing in July 2023.

Caring for Sean brought with it sleepless nights, physical demands, the overwhelming task of coordinating Sean’s care, and the emotional toll of witnessing his pain as his health declined. But through it all, Rebecca found strength in the love she shared with Sean and the support of an extended network of friends, chosen family, and partners, as well as Sean’s dedicated clinical team.

By sharing her story, Rebecca hopes to bring awareness to the challenges of caregiving, help others navigate caring for a loved one in a health crisis, and inspire greater understanding and support for those in caregiving roles.

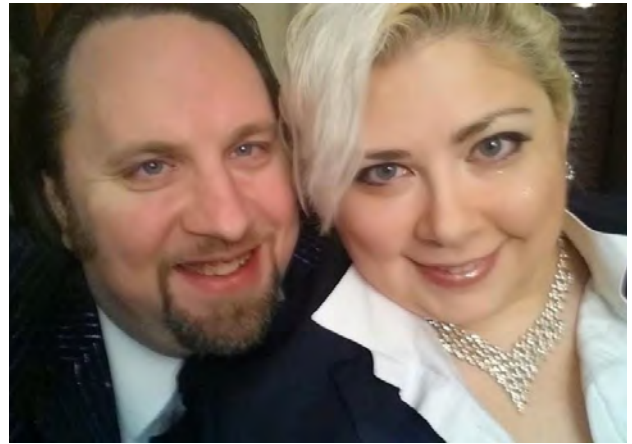
Tell us about your caregiving journey and how you became a caregiver for your partner.

Sean and I lived together for 29 years. He had some health issues, like hypertension and diabetes, but everything was fairly well managed for a long time.

Then, two weeks into the pandemic, Sean got pneumonia, and we took him to the hospital. While there, doctors noticed his kidney function was declining. By August of 2020, he was experiencing severe edema (swelling caused by fluid in the body’s tissues), tiredness, pain, and difficulty getting around. His doctor sent him to the ER, where they put him on [dialysis](#). He eventually transitioned to [peritoneal dialysis](#), which was much easier and more comfortable for him. We were even navigating the process of getting him a kidney transplant.

Things took a turn for the worse in March 2023. Sean’s doctors put him on steroids because they thought he might have [giant cell arteritis](#) (inflammation of the arteries), but we needed a biopsy to confirm the diagnosis. But due to a breakdown in communication between his medical teams, he was on unnecessary steroids for about a month, which led to him developing a series of serious bacterial infections. From that point, it was just one thing after another, and his body couldn’t keep up.

Before this decline, Sean was on disability and sometimes needed a little more support with daily things, but it was very light caretaking. In March 2023, he became essentially bedridden, and I took care of him 24/7. He was hospitalized again in early May and was there until he died on July 11, 2023.



Rebecca Rose Vassy (right) with her partner Sean (left).

How did you stay informed about Sean’s health condition and treatment options?

Before Sean started dialysis, I often went with him to medical appointments. Sean and I were each other’s life partners in our polyamorous relationship. His other partner, Christine, was also very involved in his care. Christine is a pharmacist, so she could understand his medical chart, ask questions I wouldn’t have known to ask, and explain things to me that would otherwise have been overwhelming. That was unique to our situation and incredibly valuable. I tell people that’s what polyamory is really about: all these things we’ve supported each other through.

Once he began treatment, either Christine or I attended every appointment. Sean had a fear of needles, so sometimes we’d just sit there and hold his hand. It also meant there was always someone there to ask questions and keep track of information.

We had an amazing clinic staff. When Sean was on peritoneal dialysis, he had to go in frequently for appointments. I would call it the “clinic party” because we’d see everyone there. Nurses, nutritionists, social workers would all come in and discuss all aspects of Sean’s life, ask about his mental health, and give their recommendations.

Sean and I also did our own research. He was a curious guy and liked to dig into the medical information himself.

Can you describe what a typical day or week looked like for you as a caregiver?

It was easier before Sean’s kidney disease. Once he went on dialysis, he wasn’t allowed to lift more than 25 pounds, and he would get tired easily. There was a lot less he could do day-to-day. He loved to cook, though, and sometimes the one thing he could do that day was make me dinner. I know he wanted to do more, but we had to manage his energy carefully.

Sean couldn't work, so I worked at least full-time, often doing side hustles to make sure we were supported financially. Things had to get done, so I did them, but there was always so much to do. Many of my days were nonstop from when I got up until I went to bed after midnight.

How did your role change over time?

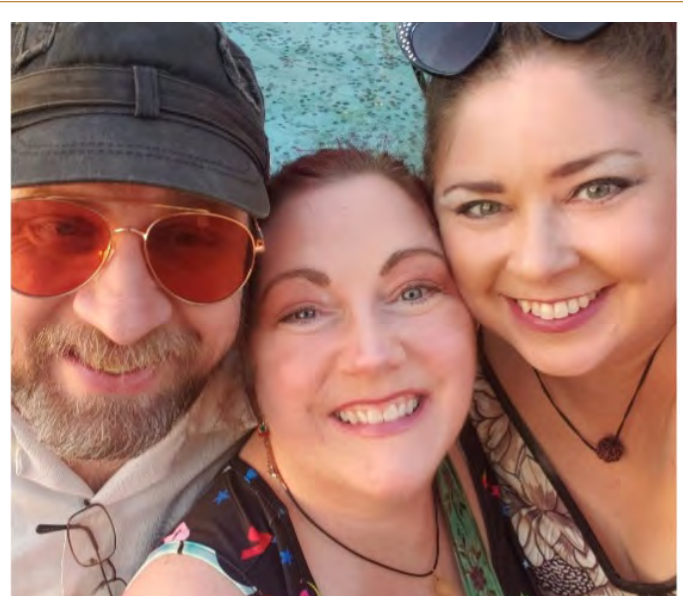
After he started to get really sick, he could barely walk and couldn't get upstairs to our bedroom. He lived on our living room couch, and I slept on the other couch because he needed someone to help him to the bathroom, soothe him when he was in pain, and be available for anything that came up. He only ate if I stayed on top of him to do so. My entire existence was devoted to him, often at the expense of work, social life, everything else. For several weeks we had a home health care aid for a few hours a day. She mostly helped fetch him things, pushed him in his wheelchair, and came to medical appointments. But I still had to be on call because there were things she couldn't do, like lift him to his feet.

Once he went into the hospital, Christine and I would alternate visiting him and resting ourselves. Most days I'd get up, go to the hospital, and spend as much time there as I could. As his condition worsened and he was in more pain, we were often moving nonstop. It was so hard to make him comfortable or to get him to eat, drink, and take his meds.

As his cognition started declining, it became harder to just communicate with him. A lot of that time he felt frustrated and guilty. He had trouble expressing himself—sometimes hallucinating, saying weird things, losing words or using the wrong ones—and I was trying to interpret what he needed.

What resources or support systems did you find most helpful in your caregiving journey?

I had some help. My housemate stepped in and took over the household chores. My other partner Ben (not his real name) stayed with us until after Sean died and provided additional household support. Christine and Ben also managed Sean's visitation schedule. There was a group chat to coordinate that, so I didn't need to think about it.



Sean (left), Christine (center), and Rebecca (right).

I shared a lot about what was going on with my personal network on social media. I always made it clear I wasn't looking for advice, but it created opportunities for people with similar experiences or conditions to be like, "Hey, do you mind if I tell you something that was really helpful for me?"

How did you take care of your own health and well-being during that time?

In a lot of ways, I didn't. I put off my own medical appointments. Sometimes eating was just grabbing a hot dog or whatever. There were days I didn't eat anything until late in the evening.

Therapy was very helpful, as was having friends who had lived through similar types of intense experiences. I could post things like, "I managed to get away for half an hour to scream and cry in the shower." People would tell me, "You need to take more time off. You need to let other people shoulder things." Even my therapist told me Sean didn't need me at the hospital all the time. Looking back now, though, I don't regret a single minute I spent there.

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