

The following are direct quotes (unattributed for anonymity) from interviews about caregivers' Lifespan Respite experience and its benefits:

This was something we didn't plan on or ask for and it changed our lives overnight. We cancelled dreams. Respite has helped me to be able to have resources to make sure that we are caring for our children without any of us needing to be institutionalized. It's so helpful to get a four-hour break and not worry if the kids needs are being met. We are hyper-focused and "on" all of the time. Being able to take a step back and concentrate on each other instead of the situation is essential. A stable household comes from having a caring relationship and relieving stress is critical to that. Caring for grandkids is hard on our marriage.

When our son was injured, it was devastating and life changing. The whole family, even our dogs, was affected by the change that happened to our lives and our son. Unless someone has been through something similar, it's so hard to explain to people...people avoid us like the plague. I have lost friends. People don't know how to handle it...We all go through periods in our lives - high school graduation, college graduation, having kids - where we've lost friends because we move in different directions, but we have things we gain in those times too. The difference here is that with this change, we just lost. Getting respite has allowed us to gain something we've lost. Even if it's as seemingly trivial as a bit of time between husband and wife, it gave us back one small thing. It's huge in our lives. We can't just do what we want whenever we want and respite has allowed us to gain back one small thing. That is life changing to us.

I can't say enough good things about the [Lifespan Respite] program. It has been so well run and is a huge help to my family. And I've seen how important it was to others. When I worked as a case manager, the focus of my work was helping biological children stay with their families. The number one success factor for those families was respite. It is a simple, practical, helpful thing...It's a matter of Maslow's Hierarchy of Needs. If basic needs of the parents aren't being met, they aren't going to be able to rise in the level of care they can give others. If they can get enough sleep, get a break, have time to talk to a friend or get other emotional support, they will come back stronger and healthier.

This saves the government dollars because it keeps us providing care. If these kids had stayed with parents, they would have been like their parents. Someone would end up in jail or dead.

Respite is particularly helpful for those of us dealing with dementia. We can be caregiving for decades. After some period, you have to give up. Respite can give a break that allows you to keep going.

My children are all still alive. None of us have a drug or drinking problem which is a small miracle. The mental ability to breathe and get a night's sleep without completely worrying is a godsend.

Having access to that money outside of our budget has allowed us to think in terms of “what do we need to keep going.” We’re looking at two, possibly three children that require care for the rest of our lives. We’re in our 50s and look forward to our own space and time to do things we like and if we didn’t have that money to take respite time, we’d be run down, tired, overwhelmed.

Our kids are all I think about. I need to make sure they’re taken care of, safe, have what they need for health and happiness. All of our energy and resources go into that. To be able to step back from that and really rest your mind and body is crucial to being able to interact with kids in a healthy way.

The Lifespan Respite program helps in more ways than just giving respite to the caregiver. I particularly like it when the person you get to take your place is better than you and you learn new things or you can create a relationship for your loved one.

As a caregiver, I feel that it has given us an opportunity to do some of the things we were not able to before. It gives my daughter freedom from me to have someone else take her. It’s such a blessing and resource to have. Caregivers need to take care of themselves too. If the caregivers go down, it has a lot of effects. Every circumstance is different but you do what you’ve got to do. It’s given us some time to breathe and takes pressure off my shoulders to be able to have respite.

Respite takes the pressure off. I needed to go somewhere for work and having a good caregiver, gave me peace of mind. You can’t enjoy yourself and get a real break if you’re worried about the person you’re leaving behind. You can relax when you’re not worried and that has mental and physical health benefits.

Being without responsibility for two hours improves emotional and mental health. Even if it’s mindless, I’m a better person and parent when I’ve had an hour. You get to think of you. You don’t get that as a parent and really lose yourself when you have a special needs child. When I first had an hour for respite, I didn’t even know what to do. Leaving felt weird and staying didn’t make sense. But getting away helped me reconnect with who I am as a whole person. I’m me again. Without you guys, I wouldn’t do the things I’m doing. I would be in an even more overwhelmed, exhausted state. So grateful.

Getting that break allows you to keep doing the work. Most Americans work 9-5 and as a caregiver that’s not the case – it’s 24/7 365 days a year. For mental and emotional well-being, the break is essential.