

## NATIONAL HOLIDAY

# On Labor Day, fight continues for paid time to care

BY **CAROL JOYNER**

*Family Values@Work.*



**W**hen I was just turning 40, with two young children and a full-time job, my mother was diagnosed with Alzheimer's. I had never seen her sick a day in my life. She was my rock and the center of our large, rowdy and loving family.

I had no idea what the future would hold for her, or us. But I learned quickly about the human cost of policies that do not protect and support workers when it became clear I had to step up as the primary caregiver.

My four siblings did not have reliable paid-leave benefits. Doctor visits, stage transitions, a multitude of crises — all of it required my attention. My siblings supported me as much as they could, but nothing takes the place of having time dedicated for caregiving.

The thing about Alzheimer's and other terminal diseases is that you're not likely to take off for the entire period of the illness — my mom was sick for 11 years — but these are also chronic conditions requiring intermittent periods of leave.

Devastating crises like involuntary hospitalizations, injuries due to falls and the periodic shift in levels of care all require full attention from caregivers.

My mother's anxiety level was calmed by familiar faces, family memories and constant reassurance that she was safe and loved.

And then there's the intense coordination with various paid caregivers — indispensable to her health and well-being — and ours.

Six years into my mother's illness, my dad was diagnosed with cancer and required a year of intense chemotherapy, radiation and recovery.

By then they had moved closer to me and my husband, and I managed their care in two different facilities. I often felt I would break in half! Imagine if you don't have a big family, a partner and friends to help out. Imagine if you don't have paid leave.

Tragically, too many can imagine the worst.

It's reprehensible that people still have to make the impossible choice between caring for their loved ones and putting food on the table.

These are the consequences when our nation lacks the right to fundamental paid family and medical leave for all. COVID-19 has exacerbated a horrible reality.

We cannot "build back better" without investing in care.

Right now in the United States, paid leave and quality childcare are not accessible to most workers and families.

Only 21% of workers have access to paid family leave through their employers. Only 40% have access to employer-provided medical leave. Child-care funding only reaches one in seven eligible children.

To make real change, members of Congress must make real investments in our communities.

If we don't get it right this time, we will not fully recover

and make the proper reset that our country needs. The amount allocated in budget reconciliation needs to be sufficient to ensure that:

- No family spends more than 7% of their income on childcare and that many families can access care at no cost.

- Childcare providers are paid a living wage.

- Comprehensive paid family and medical leave that includes 12 weeks of affordable leave is readily available and covers the main reasons for care.

- The paid leave program that gets enacted has a progressive wage replacement so workers earning lower wages can take the leave and still pay their bills. It must recognize and value all families and it must have a right to return to your job (otherwise it's not really paid leave).

I would need to write a book to demonstrate all the ways my life has been touched by caregiving.

I worked for a union-sponsored childcare fund while my children were themselves in childcare centers.

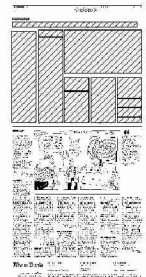
I witnessed the devotion of home healthcare workers, nursing home and hospital staff during my parents' care, and my job wrapped its arms around me with paid time off.

It has been one continuous care journey.

My parents lived long, full lives until they got sick. I cherish my days as their caregiver, and the memories make me smile, cry and sometimes cringe.

I am a better person for having cared for them, but here's the rub: I had paid leave and lots of support.

When lawmakers in Congress



vote on the reconciliation package, I hope they, too, are thinking about those they've cared for or those who have cared for them.

Those are the moments that define our humanity, and the care policies Congress passes must honor that.

*Carol Joyner is director of Labor Project for Working families at Family Values@Work.*



AP Darron Cummings

The burden of caring for elderly parents with Alzheimer's usually falls on loved ones, who are also trying to hold down full-time jobs.