THE STATE OF CARE

Care connects us all. Each of us will need to give or receive care at some point in our lifetime. Whether it’s as disabled people or older adults who are seeking to live independently; parents or other family caregivers who are providing care for their children, grandchildren, neighbors, and loved ones; or as care workers, who are providing the essential services that make all other work possible.

But instead of recognizing care as essential, our current policies leave care workers underpaid, families struggling to afford child care, caregivers forced to choose between providing care and working, and hundreds of thousands of disabled people and older adults without the care that they need to live and age with dignity.

Giving and receiving care shouldn’t be this hard – and it doesn’t have to be. As care advocates, we can rally our communities to push for truly equitable, affordable, and accessible care that meets everyone’s needs.

We need:

- A robust, federal paid family and medical leave program that provides every worker with at least 12 weeks of job-protected paid leave for bonding with a new child, dealing with a personal or family illness, or handling needs arising from military deployment;
- A child care system that works for our kids, families, and communities, including family-sustaining wages, benefits, and the ability to join together in a union for child care workers and early educators, long term investments to expand the supply of child care, and universal access for all children and families;
- A comprehensive system for aging and disability care, with long-term investments that ensure access to care for every person who needs it in the community-based settings that enable maximum autonomy, supports unpaid family caregivers, and good union jobs with family-sustaining wages, health and other benefits, for all direct care workers; and
- Good jobs for all care workers that protect workers’ rights to organize, the freedom to join together in a union, and provide pay and benefits that allow workers and their families to thrive.

Our policymakers have the tools and power to change the care system, but it will only happen if we mobilize and work together to push them to make a difference. We are all their constituents, and we can demand a system that is truly caring and that works for every caregiver, care worker, and person who needs care. Creating these systems will make it possible for more people to be there for loved ones, to age with dignity, and to afford care when they need it.

ASK YOUR ELECTED OFFICIALS & CANDIDATES ABOUT CARE

Your representatives represent — you guessed it! – YOU! They make decisions every day that impact care. It is their duty to be responsive to their constituents’ concerns! In this guide, you’ll find sample questions to ask your representatives and candidates, whether they are running for Congress, your state
legislature, a local office, or for President. Additionally, there is guidance on locating town halls and other events your elected officials may attend, as well as guidance on how to share your story with them. **You can ask these questions to find out how your elected officials will act on care.** As you ask your questions, you can also weave in your own story and connection to care, so your representatives understand your experiences and offer real solutions.

**Aging & Disability Care:**

- Direct care workers provide life-saving, dignifying care to disabled people and older adults. Yet these workers aren’t paid enough to make ends meet or are simply burnt out and frustrated by the lack of respect for their work—and many are leaving these jobs for other positions, leading to high turnover rates and worker shortages that impact access to and quality of care. What proposals do you support to increase pay and improve job quality for direct care workers?
- The majority of people want to live and age in their own homes and communities. Still, disabled people and older adults who need care have to rely on their friends or family, and are at risk of having to move into institutions. What can you do to help older adults and disabled people stay in their homes and also make sure that family caregivers get the support they need?
- 53 million people in this country are caregivers, 11 million people care for their children and a disabled or older adult simultaneously, and half of all family caregivers get no outside help at all, often at the expense of their own well-being. What would you do to help family caregivers?
- One in 5 adults in the US say they or a loved one need new or additional paid supports, and 690,000 people in this country are on waiting lists for aging and disability care through Medicaid in their homes and communities. What is your plan to increase access to aging and disability care in homes and communities and support family caregivers?
- Far too many caregivers, disabled people, and older adults face astronomical costs in trying to pay for care and are often forced to either leave their jobs because of a lack of paid leave, spend tens of thousands out of pocket, or impoverish themselves to get the care they need. How would you make aging and disability care affordable in this country?

**Child Care:**

- The average cost of child care in the US is more than $10,000 per year and even higher for infants and toddlers. Do you support a universal child care system where all families have access to care and providers are paid family-sustaining wages and have a path to a union?
- Early educators are among the lowest paid workers in the country, making a median wage of $13.71, which has resulted in high rates of turnover and workers leaving the profession. What are you doing to support child care workers so they are paid family-sustaining wages, receive benefits, and have a path to a union?
- Like clean water, highways, and good public schools, affordable and accessible child care is a public good that our economy and communities need to thrive. Public investments are needed to fill the gap between what families can afford to pay and what educators need to make to provide high-quality care and sustain their own families. How will you prioritize funding for child care so families and providers no longer have to navigate these challenges on their own?
- In a time when millions of families are struggling to make ends meet and child care costs comprise one of the largest shares of household budgets, what would you do to help make it easier for families to access care that meets their needs?
Paid Family & Medical Leave:

- As one of the only countries in the world without any form of national paid leave, the US leaves too many people, particularly women, in the position of choosing between caring for our loved ones and keeping our jobs. In your role, would you support a national paid family and medical leave program that guarantees all working people access to paid leave to care for a new child, a seriously ill or disabled loved one, or their own serious health issue—like those that now exist in 13 states and DC?
- A record 85% of people want a national paid leave program. What will you do to ensure that when someone falls ill, or has a baby, or needs to care for a loved one, that they can do so without losing their jobs or their paycheck?

Ask About Their Experience With Care:

- What’s your connection to care?
- What supports do you wish you had for care in your own life?
- Millions of family caregivers and people who receive care feel isolated, alone, and like their struggles aren’t seen by our representatives. What can you tell the people who feel like there’s little help for them?

SHARING YOUR CARE STORY WITH YOUR ELECTED OFFICIALS

Sharing your story with your elected officials is a powerful way to move policy forward. Elected officials are moved by people’s stories, more than by statistics or facts. You can use these tips to help think about sharing your story!

Make it personal:

- Tell us about how you’re connected to care. Have you given care — to a parent, child, family member, loved one? Received it?
- Share as little or as much as you’re comfortable sharing. The more personal and specific your story, the more effective it’ll be. Don’t skip the details.
- Don’t be afraid to be emotional about how hard it is to give or receive care because of our patchwork system.

Some topics may include:

- The high cost you are paying out of pocket for care and difficulty finding care providers.
- If you’ve had to decrease your work to provide care for yourself or a loved one, or remove money from your retirement savings or increase your work to be able to pay for care.
- Experiences with lack of care – like not having child care or experiencing firsthand the difficulty of managing disability needs day to day without access to the help of a care worker.
You can end your story with a positive vision of what you’d like to see from our care systems. What are the improvements or changes that you’d like your legislator to make?

Want to share your care story online?

You can here: [https://stories.caringacross.org/question/share_your_care_story](https://stories.caringacross.org/question/share_your_care_story)

Here are some best practices when sharing your story via video:

- Try and take a video that is well-lit and make sure your audio is captured clearly.
- Act naturally! Read through the prompts above and decide what you’d like to say ahead of time. If it helps, jot down some notes. No need to be scripted, do what feels natural.

To take it a step further, you can encourage your friends and family to share their care stories, too.

Your post on Facebook, Instagram, or any other platform could include the video you’ve created, or the graphics or sample language below.

- We all have care in common. Sharing our stories helps show how powerful our care movement really is.
- Our stories are powerful. That’s why I’ve just shared my care story to help fight for a better care system for all of us. Join me: [https://stories.caringacross.org/question/share_your_care_story](https://stories.caringacross.org/question/share_your_care_story)

You can download the graphics below [at this link](#).
HOW TO FIND TOWN HALLS, SET MEETINGS, AND OTHER WAYS TO INTERACT WITH YOUR REPRESENTATIVES

Especially during an election year, representatives and candidates will be more frequently publicly available. They’ll hold town halls, come to parades, engage in debates, press conferences, and more. You can also always ask to meet with your elected officials or their staff – they have that job to serve their constituents! And town halls are explicitly for them to hear from and respond to their constituents.

How to find town halls or other events:

- First, check who your federal representatives are at Congress.gov or at your state legislature’s website for state officials.
- Most elected officials at all levels of government have a newsletter that you can sign up for, which will often include information about town halls or other public meetings. They will also post on their website and social media about upcoming events. Follow those communications to find an upcoming event and then plan to attend.

Request a meeting:

- Almost all elected officials have websites where you can typically find information to request meetings or find the numbers for their offices. You can call to ask about scheduling a meeting or ask for the contact information of the staffer who handles scheduling for constituent meetings.
Millions of families are sitting at their kitchen tables, struggling to pay for care for their children, grandchildren, parents, siblings, chosen family, other loved ones, and themselves.

- There is no federal policy that provides paid family and medical leave or paid sick days for all workers. Only 1 in 4 workers in the US receive dedicated paid family leave through their jobs, just 4 in 10 have short-term disability insurance for medical leave, and millions of workers don't even have a single paid sick day. The most underpaid workers, who are particularly likely to be women, people of color, disabled people, and/or immigrants, experience the most barriers to accessing paid leave.

- More than 1 in 5 Americans, 53 million people, are unpaid family caregivers, who provide more than $600 billion in unpaid care, which disproportionately falls on women and people of color. Family caregivers experience significant workforce and earning losses, and are often providing care without training or other support.

- While the vast majority of adults in the US would prefer to receive care at home instead of in a care facility, one in five adults report that they or a family member need new or additional paid support, demonstrating the need for investments in care. Additionally, 690,000 people are on waiting lists for Medicaid programs in their homes and communities, millions more don't qualify for any financial support that would make care affordable, and the average out of pocket cost for long-term care is approximately $50,000 per year.

- There are 11 million sandwich-generation caregivers, providing care to both their children and to an aging or disabled loved one.

- While direct care workers provide critical care and are the second-largest occupation in the US, the average income for a direct worker is less than $24,000 yearly. Most care workers do not receive benefits such as health insurance and paid time off.

- The average cost of child care is $10,000 annually. In every state, center-based child care exceeds the average cost of rent. In 31 states and the District of Columbia, the average price of child care for an infant exceeds the cost of in-state university tuition. Workers, especially women, in the US have lost $9.4 billion in wages annually because of child care issues.

- Child care workers, who provide critical early childhood support and education, earn an average of $14 per hour, making them among the lowest paid workers in the country.

- The U.S. loses $122 billion each year in economic productivity and revenue due to the lack of child care. We must create a child care system that meets the needs of children, families, communities, and child care providers.

- The lack of a comprehensive, robust care system particularly impacts women of color, who make up the majority of direct care workers, a disproportionately high percentage of child care workers, and a large percentage of family caregivers, who experience particularly high levels of stress related to caregiving without adequate support.
Care Can’t Wait is a coalition of organizations, stakeholders and advocates committed to building a comprehensive, 21st century care infrastructure — that means robust investments to expand access to childcare, paid family and medical leave (PFML), and home- and community-based services (HCBS), and ensure good jobs for the care workforce. The coalition is led by the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO); American Association of People with Disabilities (AAPD); Be A Hero; Campaign for a Family Friendly Economy; Caring Across Generations; Center for Law and Social Policy (CLASP); Child Care for Every Family Network; Coalition on Human Needs; Community Change; Family Values @ Work; Institute for Women’s Policy Research; MomsRising; National Domestic Workers Alliance; National Partnership for Women & Families; National Women’s Law Center; Paid Leave for All; Service Employees International Union (SEIU); The Arc; and ZERO TO THREE.