



Care

COMMUNITY SCREENING KIT
Excerpts for educators

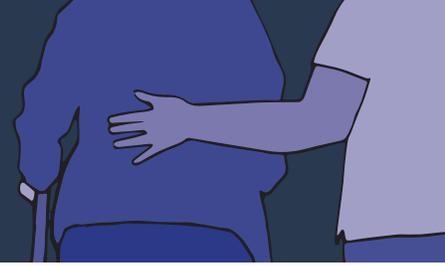
www.newday.com/film/care



WE'RE ALL AGING. And if we're lucky enough to live a long life, most of us will need help. What's more, that need is growing: The U.S. elder population will double over the next two decades.

But our current care system is unprepared. Cornerstone safety nets for families are at risk, at a time when families are already feeling intensifying pressure; they juggle work and caregiving responsibilities, and struggle to access or afford the care they require—sometimes even losing their life savings. While professional home care is one of the most affordable and desired options available, home care workers are also struggling. Whether working in rural Pennsylvania or in the bustling Bronx, the vast majority are underpaid and working under precarious conditions. The situation is untenable. The stakes are high. We need a new way forward. That's where **Care** comes in.

DISCUSSION PROMPTS



The questions below are designed to support discussions about Care that help audiences deepen their understanding of the issues, the people, and the relationships at the center of our current system of care. A valuable goal for these conversations will be to help audiences walk in the shoes of the home care workers and care recipients featured, and to make connections to their own experiences.

Conversation Starters

Allow audience members a moment to process what they just saw before diving into the issues. The following prompts can help. They are designed to let audience members speak from the heart in a way that remains grounded in the experience of the story.

- What is your immediate reaction to the film?
- Is there a scene or moment that stood out for you? If so, which one and why?
- What person(s) in the film could you most relate to and why?

General Questions

Pick and choose from the following questions to design the most useful conversation for your objectives.

1. Dee is a 93-year-old woman who never married or had children. She now needs 24-hour care. But losing her independence has been difficult for her. If you were in her shoes, what conditions and support would help you feel better about a transition like this?
2. In one scene, Vilma says: “Every elder person has the right to real attention and real care. Because you’re going to be older too and you don’t know what is going to happen.” What do “real attention” and “real care” mean to you?
3. Peter and Toni were all set to retire, but because he was diagnosed with Parkinson’s they now struggle to cover the care he needs. What role—if any—should local, state, or federal government play in situations where life savings do not cover the costs of care?
4. “Personally,” says Toni, “I think that we’re all of us imagining that it isn’t going to be us.” But, she goes on: “If we live long enough, we will be disabled.” Consider your own situation, have you thought about how you will plan for an experience like hers?
5. It worries Toni that the Medicaid workers she was assigned are paid \$140 for a 24-hour shift. “That’s less than \$6 an hour,” she says. Why do you think she’s concerned about the low pay her husband’s caregivers get?

6. With only 10% use of each lung, Larry relies on life support. “He’s really deteriorating,” says his caregiver, Laurie, “and it breaks my heart.” How do each of the home care workers appear to manage the unique, emotional strains of their work?



THE WORKFORCE

Home care workers—who provide an estimated 70% to 80% of all paid, hands-on care—make up one of our nation’s fastest-growing occupations. This is because most households today are dual-income, making paid caregiving an essential component of our daily lives. In fact, over the past 10 years, the home care workforce has doubled. Meanwhile, wages (adjusted for inflation) have stagnated. Median hourly wages are just \$10.11. These low wages combined with inconsistent hours mean that the typical home care worker brings home just over \$13,000 per year. This workforce is disproportionately made up of women (90%) and people of color.

See PHI’s *U.S. Home Care Workers - Key Facts*: phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf and *PHI’s America’s Direct-Care Workforce*: phinational.org/resource/the-direct-care-workforce-year-in-review-2018/

7. Laurie explains how part of her job is to help motivate Larry and encourage him to exercise. What other roles and responsibilities do home care workers featured in the film appear to have?
8. Neither Larry, nor Dee, nor Peter wants to be in a care facility. “It would be a death sentence to put [Peter] in an institution right now,” says Toni. Why do you think this is so important to them?
9. Edith, Peter’s caregiver, explains: “It’s hard to leave your own bed to come and stay in somebody’s place.” What do you imagine some of the challenges would be if your workplace was someone’s home?
10. Despite facing major challenges of their own, each of the home care workers demonstrates a commitment to their work. Delores, for example, continues supporting Miss Nina despite being left homeless after Hurricane Sandy. What skills/characteristics appear to help the care workers navigate the emotional terrain of their jobs?

**9 in 10
people say
they want
to stay in
their home
as they age**



HEALTH AND SAFETY

When it comes to serious workplace injuries, home health aides, personal care attendants, and certified nursing aides top the lists for workplace injuries, illness, and violence, in some cases second only to laborers/freight movers. It is likely that home care workers' injuries are severely underreported.

From NELP blog, [Health and Safety Risks Grow for Home Care Workers:](http://www.nelp.org/blog/health-and-safety-risks-grow-for-home-care-workers/)

11. Jill, Dee's niece in California, says: "I so admire these women who are helping Dee. I stayed with her one time when she had chemotherapy, and it was the most difficult thing I ever did." What do you think the most challenging aspect of being a caregiver is/would be for you?
12. Despite planning and saving, after three years of home care Dee runs out of money. So her aging sister, who will soon need help herself, loans half her life savings. In your opinion, what basic protections could help families avoid difficult choices like this?
13. Do you expect to support and cover the care expenses for yourself, your parents, or an older loved one at some point in your life? How do you think it will affect your future, financially and otherwise? What resources would you—or could you—draw upon?
14. Laurie cares for Larry in rural Pennsylvania. But she explains that living in a rural area makes carework more complicated. What might be some of the challenges of living in a rural area related to long-term care? How about in an urban area?



TRAINING

Most home care workers are not required by law to have training. For home health aides, federal regulations require a minimum of 75 hours, including at least 16 hours of supervised practical or clinical training and 12 hours of continuing education per 12-month period. This requirement hasn't changed since 1987, and only 16 states require more than the federal minimum. For personal care aides, there is no federal minimum training requirement. So training standards vary considerably from state to state, with few states requiring any rigorous training.

From PHI: phinational.org/

15. Toni says: “The [aides] who do better, they see it’s their job to make the life of the patient better.” What are some of the other qualities that you witnessed in the film that, in your opinion, make an effective home care worker?
16. Toni expresses concern that the agency-assigned aides are nervous around Peter because they have not been trained to work with him. Do you think professional home care is work that requires training? Why or why not?
17. Like many care workers, Vilma is an immigrant. She is also undocumented. Were you surprised to learn of the challenges she faced in becoming a legal resident? Should financial and logistical barriers like the ones she faced be removed for immigrants like her? Please explain.
18. In one scene, a meeting facilitator asks: “What does it mean for care in our society to be thought of as a private responsibility?” How would you respond? Please explain.
19. In another scene, the same facilitator asks, “How do we want our society to understand care and approach it?” How would you respond? Please explain.
20. We learn that by 2040, the number of older Americans will double and that the current U.S. eldercare system is unprepared. Toni asks: “How do we reinvent this?” What do you think?



THE DEMAND

Making home care jobs quality jobs is not only the right thing to do for workers; it is imperative if we are to meet the demands of an aging America. Nearly 90% of older adults want to stay in their home as they age, and there is only one paid workforce that will allow for aging in place to become a reality: home care workers. In addition to being the consumer preference, remaining at home is most often less costly than alternatives such as institutional care. With 10,000 Americans turning 65 every day, it is projected that we will need an additional 600,000 home care workers over the coming decade. We must ensure that this workforce, which provides an estimated 70% to 80% of paid, hands-on care, is supported in its critical role.

From NELP’s fact sheet “Aging in Place Will Require Investing in Home Care Workers”: www.nelp.org/content/uploads/Aging-in-Place-Investing-in-Home-Care-Workers.pdf



HOT TIP: FOR EDUCATORS

The *Care* DVD is chaptered and presents a description of useful themes covered in each section, so you can decide if you want to screen it all in a single sitting or break it up across different class sessions. Pick and choose from the discussion prompts and resources to facilitate a discussion that meets your learning objective, whether it is bolstering a geriatrics or social science curriculum or introducing social issues in our current health care system to medical learners at the resident or fellow level.



CARE SOLUTIONS THAT WORK

Caregiving is critical, compassionate, dignified work that requires skill and grace. The best solutions recognize this and create conditions that allow home care workers to do their best work. They also strengthen social safety nets for families so that those who need care can get it—and on their own terms. These solutions include the following:

- Increase investment in home care, including increasing wages, improving working conditions, and providing access to workforce training
- Create long-term social insurance programs that ensure affordable, quality, in-home care
- Secure living wages and protections for workers
- Meet demand for care with a pathway to citizenship for undocumented workers
- Advance better Medicaid and Medicare reimbursement rates

To learn more about these solutions and more, visit: www.caringacross.org.

GLOSSARY



Consumer: A consumer is a person who receives home care services. Sometimes referred to as a “patient,” “client,” or “recipient.” Dee, Peter, and Larry are all consumers of home care services.

Cooperative: A cooperative is a business or organization that is worker-owned. Delores works for a home care cooperative in the Bronx, Cooperative Home Care Associates.

Family Caregiver: A family caregiver is a family member—or a friend or neighbor who is like family—who helps to support a consumer. A family caregiver is generally not paid to provide care.

Home Care Agency: These may include Medicare-certified home health care agencies, Medicaid-funded home care agencies, personal care agencies, and other organizations or companies that employ home care workers and offer home care services to consumers.

Home Care Worker: This term describes an aide—like Vilma, Delores, and Laurie—who provides in-home supports and services that allow older adults and people with disabilities to remain in their homes. Home care workers include home health aides, personal care aides, caregivers, companions, and certified nursing assistants who are employed in private homes. They provide assistance to people with daily activities such as: bathing, grooming, feeding, etc. They may also assist with meal preparation, light housework, and getting to and from appointments or social engagements. Some home care workers assist with paramedical tasks. See: phinational.org/resource/u-s-home-care-workers-key-facts-2018/

Home Health Aide: A home health aide is a type of home care worker who assists people in their homes or in community settings under the supervision of a nurse or therapist. These aides may also perform light housekeeping tasks. There are basic federal training requirements for home health aides. States may impose additional requirements.

Labor Protections: This refers to the laws in place that govern the relationships between workers, their employers, and the government. Unlike most workers in the American economy, home care workers have continually been excluded from basic workplace and labor protections because they are typically employed in private homes and often directly by the consumer. For example, up until recently (2015), home care workers did not qualify for federal minimum wage and overtime protection under federal law. And unlike other health care workers, home care workers are not typically paid for the time they are “on-call,”—for example, when they provide 24-hour care and “sleep in” at the consumer’s home.

To learn more about the overnight “sleep-in” requirements, see: www.dol.gov/whd/homecare/sleep_time.htm and www.dol.gov/whd/FieldBulletins/fab2016_1.pdf

Long-Term Care Insurance: This insurance helps provide for the cost of long-term care beyond a predetermined period. Long-term care insurance covers care generally not covered by health insurance, Medicare, or Medicaid.

See: www.aarp.org/health/health-insurance/info-06-2012/understanding-long-term-care-insurance.html

Medicaid: This state and federal social insurance program provides critical coverage to people who need long-term services and supports. In many states that implemented Medicaid expansion, it allows people with limited assets to access home care workers and is the largest source of payment for home- and community-based services. But the program varies state by state, and limits on coverage can often be stringent. In the case of Peter and Toni in the film, in order to qualify, they had to spend down their assets until they were near poverty. Also, wage levels for home care, which are largely determined by states, are often too low to attract, retain, or cover the workforce.

Medicare: This federal social insurance program provides health coverage if you are 65 or older or have a severe disability, no matter your income. It provides only minimal home care services, limited to short-term care after a specific injury or illness.

Medicare or Medicaid Reimbursement Rates: These are the rates at which an individual or home care agency is paid to provide home- and community-based services. Medicare rates are set by a federal agency, the Centers for Medicare and Medicaid Services (CMS), whereas Medicaid rates are set by states. These rates are not necessarily based on the cost of labor—decent wages and benefits for home care workers. Consequently, home care agencies that rely on Medicaid funding are often constrained in their ability to improve home care wages. Improving Medicaid reimbursement rates and requiring that increases go directly to the lowest-paid workers is an important strategy that policymakers and advocates are proposing to improve job quality.

Personal Care Attendant/Aide: A PCA is a home care worker who provides assistance with the activities of daily living. These workers often help with housekeeping chores, meal preparation, and medication management. They provide the long-term services and supports that allow for people to remain in their home and community. Training requirements and scope of practice for PCAs are set by state law; most states have no training requirements for PCAs.

Poverty Wages: These are wages that fall below or around the federal poverty line. In 2016, this was \$11,880 for individuals and \$16,020 for a family of two. In the film we learn that \$13K per year is the median income for a homecare worker. Laurie, for example, brought home \$302 a week as a home care worker, which meant she could not afford insurance and had to rely on her partner’s support to survive.

Sandwich Generation: The nearly half (47%) of American adults (according to a 2013 report by the Pew Research Center) who are in their 40s and 50s and provide support for both a parent (age 65 or older) and a young child or financially dependent grown child (age 18 or older).

Undocumented Immigrant: This is a foreign national who resides in the United States without proper documentation. Vilma, for example, an immigrant from Costa Rica, was married to a U.S. citizen but could not afford to process her immigration paperwork. So she became undocumented, a civil (not criminal) offense.

Workforce Retention: The ability of an organization to retain its employees. Turnover in the home care industry is notoriously high. One in every two home care workers leaves her job, annually. In the film, Ai-jen Poo explains that many home care workers leave their jobs because they can't afford to stay. For example, after Larry passed away, Laurie started hauling stone for roadways in Pennsylvania, earning \$5 more an hour than she did as a home care worker, with full benefits, a 401K plan, and health insurance. Policy efforts aimed at improving workforce retention for home care workers are becoming even more important.

Learn more.

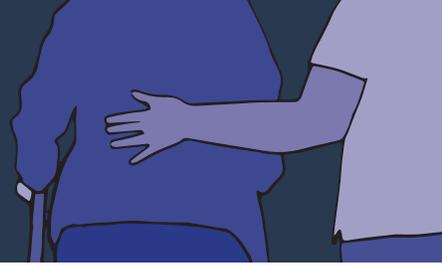
The organizations in the Resources section below are at the forefront of the movement to create a stronger, better care system. Learn more about the issues by getting to know them. The books and reports under Reading can also give you more valuable context.



STAY INFORMED

These state-by-state resources can help you track policy and services near you:

- PHI State Data Center. State-by-state data and resources relating to nursing aides, home health aides, and personal care aides:
phinational.org/policy/states
- HCBS Advocacy. A platform for the aging and disability communities to track home- and community-based services in their state, settings rules, and compliance: www.hcbsadvocacy.org
- Fair Labor Standards. Advocates can use this resource to help promote good implementation of federal protections for home care workers in their state:
s27147.pcdn.co/wp-content/uploads/2015/03/Home-Care-State-by-State.pdf



Organizations

- Consumer Voice. The leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves: www.theconsumervoice.org
- Eldercare Workforce Alliance. A group of 31 national organizations, joined together to address the immediate and future workforce crisis in caring for an aging America: www.eldercareworkforce.org
- Interfaith Worker Justice. A network of over 70 organizations working to mobilize people of faith and work advocates in support of economic justice and worker rights at the local, state, and national levels: www.iwj.org
- Jews for Racial and Economic Justice. Pursues racial and economic justice in New York City by advancing systemic changes that result in concrete improvements in people's everyday lives: www.jfrej.org
- Jobs With Justice. Promotes the right of workers to organize unions and bargain collectively: www.jwj.org
- National Domestic Workers Alliance. A vibrant network of nannies, house cleaners, and care workers organizing for respect, dignity, and protections in the U.S.: www.domesticworkers.org
- National Council on Aging. Resources for professionals, older adults, caregivers, and advocates: www.ncoa.org
- National Employment Law Project. Advocating for employment rights of lower-wage workers: www.nelp.org
- PHI. Improving the lives of people who need home or residential care by improving the lives of the workers who provide that care: www.phinational.org

Reading

- Age of Dignity by Ai-jen Poo is an accessible and thoughtful reflection on the demographic shifts under way in the United States that will result in an elder boom in the near future: thenewpress.com/books/age-of-dignity
- Caregiver Action Network is a listing of caregiver organizations, information, advocacy, and support across the country: www.caregiveraction.org/resources/agencies-and-organizations

- Families Caring for an Aging America is a 2016 report on what is known about the nation's family caregivers of older adults. with recommended policies to address their needs: www.nationalacademies.org/hmd/-/media/Files/Report%20Files/2016/Caregiving-RiB.pdf
- Health and Human Services Department Resource Locator is a tool to help you locate various services that support healthy aging: www.hhs.gov/aging/healthy-aging/
- Home Care Workers: Key Facts provides a useful breakdown of data about this workforce: phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf
- Implementation Resources for Department of Labor Regulations for home care workers are compiled here: www.domesticworkers.org/department-of-labor-regulations-for-home-care-workers
- Medicaid Home- and Community-Based Services Programs: 2013 Data Update by the Kaiser Family Foundation presents key national trends related to three main Medicaid HCBS programs: (1) mandatory state home health services, (2) optional state personal care services, and (3) optional HCBS waivers. kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/
- National Association of Area Agencies on Aging is a national network of 622 Area Agencies on Aging that provide aging services across the country and useful information about services, initiatives, advocacy, and resources: www.n4a.org
- The National Consumer Voice for Quality Long-Term Care provides a host of resources to assist individuals and/or groups in advocating for quality long-term care: theconsumervoice.org/issues/for-advocates
- Upholding Labor Standards in Home Care by the National Employment Law Project is a resource for home care employers and provides a robust overarching look at paid home care issues and policy and action recommendations: www.nelp.org/content/uploads/Report-Upholding-Labor-Standards-Home-Care-Employer-Accountability.pdf
- The Voice is a weekly e-newsletter by the National Consumer Voice for Quality Long-Term Care and the National Long-Term Care Ombudsman Resource Center, providing short posts about the latest news affecting long-term care and links to useful resources: theconsumervoice.org/about/the-gazette/past-gazettes

MORE ABOUT TRAINING AND INVESTMENT IN THE WORKFORCE

- Advanced Direct Care Worker: A Role to Improve Quality and Efficiency of Care for Older Adults and Strengthen Career Ladders for Home Care Workers by the Eldercare Workforce Alliance -- proposes how an enhanced role for home care workers can lead to better health, better care, and potential cost-savings: http://eldercareworkforce.org/wp-content/uploads/2018/03/EWA_Advanced_DCW_Issue_Brief-pub2014.pdf
- Aging in Place Will Require Investing in Home Care Workers by the National Employment Law Project : www.nelp.org/content/uploads/Aging-in-Place-Investing-in-Home-Care-Workers.pdf

- The California Long-Term Care Education Center report is an impact study of care team integration and training of home care workers:
<https://cltcec.org/wp-content/uploads/2018/08/CLTCEC-IHHS-Year-1-Final-Report-July-2018.pdf>
- A collection of resources about training and credentialing the home care workforce. phinational.org/policy/issues/training-credentialing

STATE BENEFITS OF FAIR PAY

- Report: Fair Pay for Quality Care by the North Carolina Justice Center outlines how fair wages for home care workers ensure economic stability and increase continuity of care: www.ncjustice.org/?q=workers-rights/report-fair-pay-quality-care
- How Raising Incomes for Home Care Workers Boosts the Economy is a report by the Washington State Budget and Policy Center on how it worked for Washington: budgetandpolicy.org/how-raising-incomes-for-low-wage-workers-boosts-economy/pdf_version



HELPFUL RESOURCES ON STRUCTURAL RACISM

Conversations about the film and U.S. care system can lead to the topic of structural racism. For help on the topic, see:

- Everyday Democracy—They have a host of useful resources for about structural racism. Start with this one about racial dynamics to watch for. www.everyday-democracy.org/resources/racial-dynamics-watch
- Teaching Tolerance—Let's Talk: Discussing Race, Racism, and Other Difficult Topics with Students. While this is made for students, it's a useful and handy tool to help you get prepared. <https://www.tolerance.org/magazine/publications/lets-talk>
- Welcoming America—America Needs All of Us: A toolkit for talking about bias race and change, especially useful for conversation about immigrants. <https://www.welcomingamerica.org/sites/default/files/America%20Needs%20All%20of%20Us.pdf>

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Caring Across Generations

Film website: caredocumentary.com

To order: www.newday.com/film/care