The National CONSUMER VOICE for Quality Long-Term Care

Upholding Rights in Long-Term Services & Supports

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About the Consumer Voice

The leading national voice representing consumers in issues related to long-term care

- **Advocate for public policies** that support quality of care and quality of life responsive to consumers' needs in all long-term care settings.
- **Empower and educate** consumers and families with the knowledge and tools they need to advocate for themselves.
- **Train and support** individuals and groups that empower and advocate for consumers of long-term care.
- **Promote the critical role** of direct-care workers and best practices in quality care delivery.

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Residents' Rights and Quality of Life

Residents' Rights Matter

Nursing Homes, Assisted Living, Board & Care, Personal Care Homes

- Persons living in residential care settings are individuals with full civil and human rights
- Rights are the foundation of quality of life, not an add on
- Upholding rights improves outcomes, reduces harm

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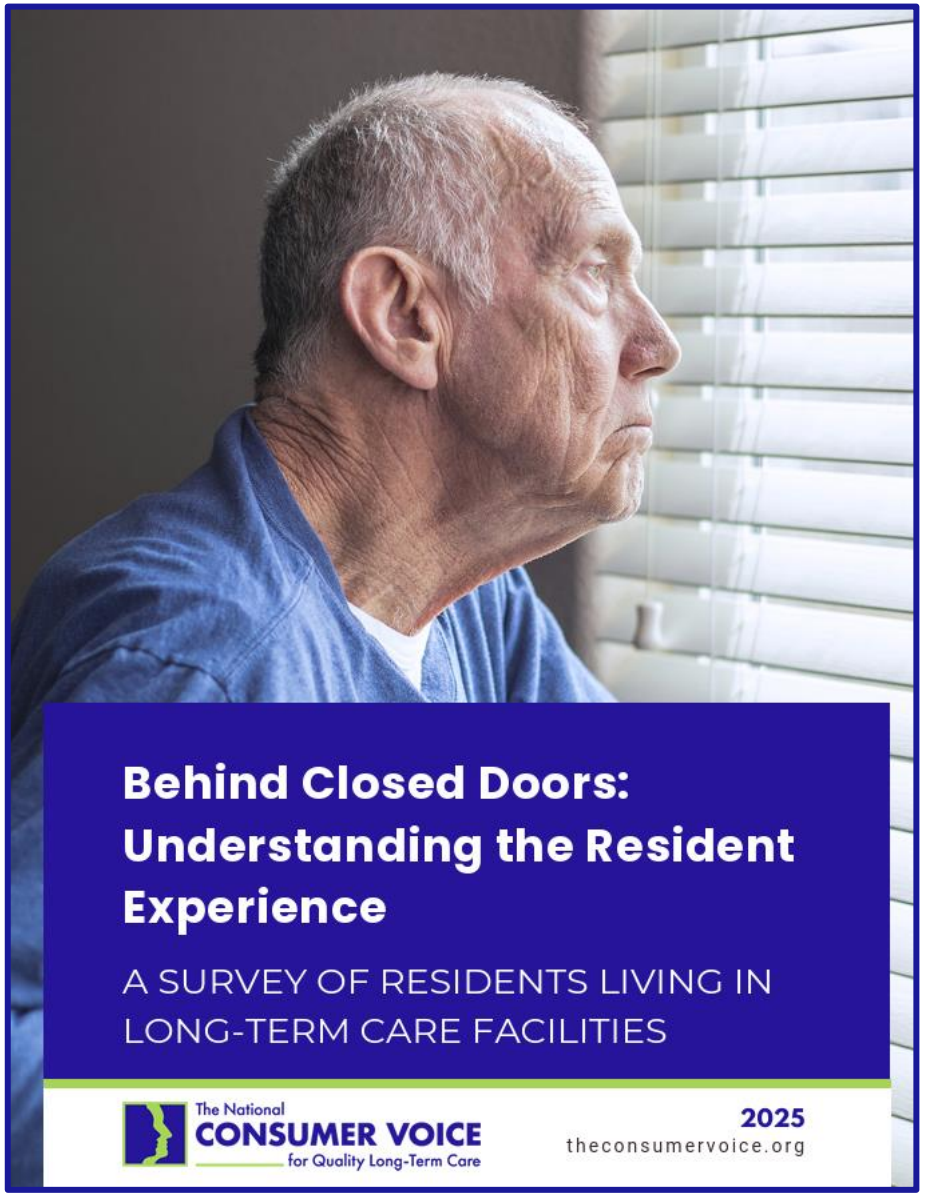
2025 Resident Survey

- 455 Responses
- Confirmed by a data scientist
- Over 40 states
- Residents from nursing homes, assisted living
- Private, nonprofit, government facilities
- Quantitative and qualitative data collected



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KEY FINDINGS

Of the residents who responded to the survey:

- **50%** say their quality of life got worse after moving into their facilities.
- **32%** say they are only sometimes, rarely, or never treated with dignity or respect in their facilities.
- **19%** say their opinions and preferences about their daily care and routines are rarely or never considered.
- Only **24%** say they always get the care they need in their facilities when they need it.
- **34%** report that the food at their facilities rarely or never looks or smells appetizing, with **25%** reporting they are rarely or never offered an alternative.
- **25%** say the activities offered by their facilities are rarely or never interesting or engaging.
- **97%** who have visitors can see their visitors when they want to see them.
- **40%** do not have a family caregiver.
- **39%** report that a lack of transportation prevents them from participating in community events.
- **52%** of respondents are able to participate in religious services of their choice, though this appeared truer for members of certain religions than others.
- **32%** report that members of their community visit their facilities to participate in or host events less than once a month, if at all.
- **50%** report that they have access to technology when they want to use it with **58%** reporting that they use technology daily.
- **36%** report there is rarely or never enough staff in their facilities to meet their needs in a reasonable amount of time.
- **43%** report that it is somewhat or very difficult to live life on their own terms at their facilities.

Quality of Life Comments

Resident comments include:

"My preferences and wishes are ignored..."

"I feel like it's a prison. Throw you in a room and throw away the key and let us rot away."

"Residents are basically confined to our rooms, no social activities at all."

"Your life is not your own here."

"Lack of good food, security, loneliness."

"Lack of staff/care, staff with training, bad attitudes and excuses."

"Staffing is down, food quality has gone from five star to one star, service by staff has gone from excellent to dismissive and retaliatory..."

"The nutrition is very poor and life enrichment activities are nonexistent."

"Although having assistance and care close at hand (sometimes) is an improvement in terms of my safety, in other ways my quality of life is much worse. The food is often unrecognizable and lacking in nutritional value. In addition, I'm lucky if I get a shower once a week and then only when I ask and insist many times..."

A Look at Residents' Rights

Key Sources of Rights

- Nursing Home Reform Act of 1987 – *nursing homes*
- CMS Requirements of Participation – *nursing homes*
- State residents' rights statutes and regulations – *all settings*
- Federal civil rights protections (Americans with Disabilities Act, Section 504 of the Rehabilitation Act, etc) – *all settings*

Important: Residents retain all rights unless specifically limited by law.

Nursing Home Residents' Rights

Federal and State Laws, Regulations

- Dignified Existence
- Self-Determination
- Fully Informed
- Raise Grievances
- Manage Financial Affairs
- Access
- Privacy
- During Discharge/Transfer

Nursing Home Residents' Rights[1]

[1]See 42 CFR §483 for a full listing of Residents' Rights

Residents of nursing homes have rights that are guaranteed by the federal Nursing Home Reform Law. The law requires nursing homes to "promote and protect the rights of each resident" and stresses individual dignity and self-determination. Many states also include residents' rights in state law or regulation.

Right to a Dignified Existence

- Be treated with consideration, respect, and dignity, recognizing each resident's individuality
- Freedom from abuse, neglect, exploitation, and misappropriation of property
- Freedom from physical or chemical restraints
- Quality of life is maintained or improved
- Exercise rights without interference, coercion, discrimination, or reprisal
- A homelike environment, and use of personal belongings when possible
- Equal access to quality care
- Security of possessions

Right to Self-Determination

- Choice of activities, schedules, health care, and providers, including attending physician
- Reasonable accommodation of needs and preferences
- Participate in developing and implementing a person-centered plan of care that incorporates personal and cultural preferences
- Choice about designating a representative to exercise his or her rights
- Organize and participate in resident and family groups
- Request, refuse, and/or discontinue treatment

Right to be Fully Informed

- The type of care to be provided, and risks and benefits of proposed treatments
- Changes to the plan of care, or in medical or health status
- Rules and regulations, including a written copy of residents' rights
- Contact information for the long-term care ombudsman program and the state survey agency
- State survey reports and the nursing facility's plan of correction
- Written notice before a change in room or roommate
- Notices and information in a language or manner he or she understands (Spanish, Braille, etc.)

Right to Raise Grievances

- Present grievances without discrimination or retaliation, or the fear of it
- Prompt efforts by the facility to resolve grievances, and provide a written decision upon request
- To file a complaint with the long-term care ombudsman program or the state survey agency

Right to a Dignified Existence

- Be treated with consideration, respect, dignity
- Recognize each person's individuality
- Freedom from abuse, neglect, exploitation
- Freedom from physical, chemical restraints
- Exercise rights without interference, discrimination reprisal
- Use of personal belongings, security of possessions
- Homelike environment

Right to Self-Determination

- Choice of activities, schedules, health care, providers
- Reasonable accommodation of needs, preferences
- Person-centered plan of care
- Organize and participate in resident and family groups
- Request, refuse, discontinue treatment
- Designate a representative to help with decision-making

Right to be Fully Informed

- Type of care to be provided, risks/benefits of proposed treatments
- Changes to plan of care, or in medical or health status
- Notices and information in a language or manner they understand
- Rights, responsibilities
- Information about the Long-Term Care Ombudsman Program
- State survey reports and facility's plans of correction

Right to Raise Grievances

- Present grievances without discrimination or retaliation, or the fear of it
- Prompt efforts by facility to resolve
- File a complaint with the Long-Term Care Ombudsman Program and/or State Survey Agency

Rights Regarding Financial Affairs

- Manage their financial affairs or designate a representative to do so
- Information about available services and the charges for each service
- Not be charged by services covered by Medicare or Medicaid

Right of Access

- Individuals, services, community members, and activities inside and outside the facility
- Visitors of their choosing, and the right to refuse visitors
- Personal and medical records
- Personal physician; representatives from the state survey agency and long-term care ombudsman program
- Participate in social, religious, community activities
- Assistance if sensory impairments exist

Right to Privacy

- Regarding personal, financial, and medical affairs
- Private and unrestricted communication with any person of their choice
- During treatment and care of personal needs

Upholding Rights

Enhance Self-Determination

Supporting Resident Choice means:

- Honoring daily routines
- Respecting cultural, religious, personal identity
- Allowing residents to take reasonable risks
- Ensuring residents lead their own care planning meetings
- Supporting autonomy even when staffing is tight

Support Relationships

Social connection is essential to health and well-being

- Support resident access to visitors; community engagement
- Support meaningful engagement, not just scheduled activities
- Avoid isolation - prioritize connection

Protect Residents from Harm

- Zero tolerance for abuse, neglect, exploitation, retaliation
- Trauma-informed care practices
- Sufficient staffing to meet residents' needs and promote highest practicable well-being
- Transparent communication with residents and families

Staffing as a Rights Issue

To fully realize residents' rights –

- Sufficient numbers of trained staff
- Consistent assignments that build relationships
- Time for staff to provide individualized care
- A culture that values resident voice and autonomy

Support the Resident Voice

Strategies include –

- Resident-led Resident Councils
- Regular listening sessions between Administration, Residents, Families
- Involving residents in facility operations
- Accessible and effective grievance processes
- Ensuring residents understand their rights in plain language
- Empowering residents to speak up without fear of retaliation

Enhance the Role of Families and Essential Caregivers

- Families are partners, not visitors
- Essential caregivers provide emotional support, advocacy, assistance with care, etc.
- Facility policies/practices should support, not restrict, family involvement
- During emergencies, access must be protected

Promote Oversight and Accountability

Residents' rights are strengthened by:

- Long-Term Care Ombudsman Programs
- State Survey Agencies
- Protection & Advocacy/Disability Rights Programs
- Public reporting of quality and staffing
- Transparent ownership and financial structures
- Strong enforcement of care standards

Create a Resident-Centered Culture

- Support resident decision-making
- Create an environment that feels like home
- Encourage staff to build relationships with residents and families
- Embed rights into all policies and practices
- Measure success by quality of life, not just compliance with regulations

Advocacy Opportunities

- Strengthen residents' rights laws and regulations
- Support the Essential Caregivers Act
- Push for staffing standards tied to resident needs
- Promote small-home and non-institutional models of care
- Support transparency in ownership and spending
- Elevate resident and family voices in policymaking

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