

LINKS

We have not tried to be exhaustive in discussing these topics, or including all the issues that will arise when families face the life changes of placing a loved one in a nursing home. And for many families, providing care at home is the best option – a decision which also brings challenges. These links to the resources of others will help to further equip families to become strong advocates not only for their own family members but also for systems change in the field of long-term care, whether that care takes place in a nursing facility or with assistance in the home. We encourage you to explore these resources; and if you find others that we haven't included, please let us know at contact@ourmothersvoice.org so that we can add them to our compendium.



"Spiral Galaxy" by Carol J Hay
mixed media on canvas

There's a great wealth of information available "out there" that many are not aware exists.

The Founder and President of Our Mother's Voice discusses the history and goals of the organization on the radio!

For the audio podcast:

<http://leojansen.net/WLMAMedia/Podcast/Kathy%20Bradley%20I-06-15.mp3>

For a video version of the interview:

<https://www.youtube.com/watch?v=DeTABWD798c&feature=youtu.be>

Topical Index

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NEW ON Our Mother's Voice LINKS

Justice In Aging has published a **primer on Home and Community Based Services through Medicaid**:

<https://justiceinaging.org/wp-content/uploads/2021/04/HCBSPrimer.pdf?eType=EmailBlastContent&eid=7d9cb25c-aaf1-4d70-827a-8ccda95ff8c5>

Justice In Aging sheds light on the **financial impact of Medicaid's Estate Claims practices**:

<https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf?eType=EmailBlastContent&eid=49402a41-1e4f-4346-90d5-84fca6d8c236>

The Center for Medicare Advocacy has a new factsheet on **Medicare coverage of Home Health Services** in light of the *Jimmo* court settlement:

<https://medicareadvocacy.org/wp-content/uploads/2021/05/Fact-Sheet-Home-Health-and-Jimmo.pdf?emci=a1145ccd-17bf-eb11-a7ad-501ac57b8fa7&emdi=be19fcef-1dbf-eb11-a7ad-501ac57b8fa7&ceid=8355898>

Medicaid has rules **safeguarding the assets of a spouse of a nursing home resident**, explained here:

<https://www.medicaid.gov/medicaid/eligibility/spousal-impoverishment/index.html>

Medicare **Hospice Care is not limited to comfort care**, but includes an array of services if they are needed:

<https://www.medicare.gov/coverage/hospice-care>

Full **federal regulations governing hospice care** may be found here:

https://www.ecfr.gov/cgi-bin/textidx?SID=e093ac853ec564a10cc78b244c8decd0&mc=true&node=pt42.3.418&rgn=div5#se42.3.418_156&node=pt42.3.418&rgn=div5#se42.3.418_156

Medicare will continue to cover services not related to the terminal condition, even when a person is receiving hospice care:

<https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-hospiceworks#:~:text=After%20your%20hospice%20benefit%20starts,terminal%20illness%20and%20related%20conditions.>

The Quality Improvement Organizations, under contract with CMS, has published a resource titled **All Cause Harm Prevention in Nursing Homes**, which offers many strategies for preventing a variety of adverse events:

https://qioprogram.org/sites/default/files/editors/141/C2_Change_Package_20181226_FNL_508.pdf

Justice In Aging has a page hosting all their recorded **webinars on a variety of advocacy topics related to the exercise of rights; from benefits, to admission, to care and**

treatment, to eviction:

<https://justiceinaging.org/resource-library/>

ONGOING RESOURCES, ALWAYS RELEVANT

QUALITY CARE for FACILITIES and IN YOUR HOME: LONG-TERM CARE REGULATIONS, SERVICES, and ADVOCACY

To learn about the **different types of care and services** for your loved one, including in one's own home, in the home of a family member, or in a residential setting such as assisted living or nursing home, and how to plan and implement quality care:

<http://theconsumervoice.org/issues/recipients/consumers-for-quality-care>

and for an extensive guide (for sale by the National Consumer Voice for Quality Long-Term Care):

<http://theconsumervoice.org/product/piecing-together-quality-long-term-care-a-consumers-guide-to-choices-and-advocacy>

Materials and information about **long-term services at home and in the community**: (please note that after page 14 of this document the remainder of the document's 68 pages provides a listing of proposed 2012 "fair market values" for housing)

<http://www.theconsumervoice.org/sites/default/files/nccnhr/Conference%20Call%20Materials.pdf>

2015 White House Conference on Aging materials:

Policy brief on long-term services and supports from the White House Conference on Aging:

<http://www.whitehouseconferenceonaging.gov/blog/policy/file.axd?file=/LTSS%20Policy%20Brief/WHCOA-LTSS-Policy-Brief.pdf>

For a **response by the National Consumer Voice** for Quality Long-Term Care to the **White House Conference on Aging brief on Long-Term Services and Supports**:

<http://theconsumervoice.org/uploads/files/actions-and-news-updates/WHCoA-statement-on-LTSS.pdf>

For a **policy brief on healthy aging** from the White House Conference on Aging:

<http://www.whitehouseconferenceonaging.gov/blog/policy/file.axd?file=/Healthy%20Aging%20Policy%20Brief/Healthy%20Aging%20Issue%20Brief.pdf>

For a **policy brief on elder justice** from the White House Conference on Aging:

<http://www.whitehouseconferenceonaging.gov/blog/policy/post/elder-justice-policy-brief>

For a **response by the National Consumer Voice** for Quality Long-Term Care to the **White House Conference on Aging brief on Elder Justice**:

<http://theconsumervoice.org/uploads/files/issues/WHCOAElderJusticeBriefComments.pdf>

For a policy brief on **retirement security** from the White House Conference on Aging:
<http://www.whitehouseconferenceonaging.gov/blog/policy/file.axd?file=/Retirement%20Security/Retirement%20Security%20Policy%20Brief%20FINAL.pdf>

For a **summary from the White House Conference on Aging** announcing new initiatives and updates:
<https://www.whitehouse.gov/the-press-office/2015/07/13/fact-sheet-white-house-conference-aging>

The White House Conference on Aging has issued a final report from its 2015 series of meetings:
<http://www.whitehouseconferenceonaging.gov/2015-WHCOA-Final-Report.pdf>

Federal Regulatory Agencies, Regulations

Agencies

Center for Medicare and Medicaid Services: <https://www.cms.gov/>
Search the site for information on various regulated services

US Department of Health and Human Services: <https://www.hhs.gov/>
Search the site for various programs and regulations

Regulations

Nursing Home

For the text of the **Nursing Home Reform Law of 1987**, which is the basis for Medicare and Medicaid regulations governing care and services in nursing facilities:

<http://www.law.cornell.edu/uscode/text/42/1395i-3>

and for a summary of this bill prepared by Hollis Turnham, Esquire, which explains the major provisions of the law:

<http://www.allhealth.org/briefingmaterials/OBRA87Summary-984.pdf>

To learn the **federal requirements for quality of care and quality of life in nursing homes** which accept Medicare or Medicaid funding, as defined in the Code of Federal Regulations for Nursing Facilities, 42CFR483 Subpart B:

The **Center for Medicare and Medicaid Services has released updated federal regulations governing nursing facilities**, which will be phased in over a 3-year period.

The new Revised Regulations for Long-Term Care Facilities (nursing homes) are now published as a single document available online:

[https://www.ecfr.gov/cgi-bin/text-](https://www.ecfr.gov/cgi-bin/text-idx?SID=f71e183fa73614bf5aa459e2af1a734d&mc=true&node=sp42.5.483.b&rgn=div6)

[idx?SID=f71e183fa73614bf5aa459e2af1a734d&mc=true&node=sp42.5.483.b&rgn=div6](https://www.ecfr.gov/cgi-bin/text-idx?SID=f71e183fa73614bf5aa459e2af1a734d&mc=true&node=sp42.5.483.b&rgn=div6)

The **Interpretive Guidance** for surveyors, which further defines the intent of the new regulations, is available here:

http://theconsumervoice.org/uploads/files/issues/SC17-36.03.Appendix_PP_with_Final_IGs.pdf

For a **version of the Guidance with a “clickable” Table of Contents** to enable the reader to “jump” to any section rather than searching the entire 700-page document:

1. Click http://theconsumervoice.org/uploads/files/issues/Revised_Interpretive_Guidelines_with_Clickable_TOC.pdf to download the Revised Interpretive Guidelines with the clickable Table of Contents.
2. Scroll down to page 2 of the document.
3. Move your mouse over the section you want to review (e.g. "Resident Rights," "Quality of Care," etc.). You should see your pointer mouse turn into a hand with a finger.

Click on the section you've selected. The document should immediately jump to that section of the Interpretive Guidelines.

The National Consumer Voice is publishing a series of **informative briefs highlighting some of the changes**, the first of which can be accessed here:

<http://theconsumervoice.org/uploads/files/actions-and-news-updates/A-guide-to-Revised-Nursing-Facility-Regulations.pdf>

For those who want a more **in-depth** review of the changes in the regulations, the following are two multi-page **summaries of key changes**:

<http://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-1-final.pdf>

<http://theconsumervoice.org/uploads/files/issues/summary-of-key-changes-effective-phase-1-part-2-FINAL.pdf>

and for a fact sheet that explains some of the **reasons these revisions are vital** to nursing home residents:

[http://theconsumervoice.org/uploads/files/issues/Why-the-Recently-Revised-Nursing-Home-Regulations-Are-Vital-for-Nursing-Home-Residents_\(1\).pdf](http://theconsumervoice.org/uploads/files/issues/Why-the-Recently-Revised-Nursing-Home-Regulations-Are-Vital-for-Nursing-Home-Residents_(1).pdf)

Topic-specific fact sheets on the new revised nursing home regulations from the National Consumer Voice for Quality Long-Term Care:

on **transfer & discharge**:

http://www.justiceinaging.org/wp-content/uploads/2017/01/Revised-Nursing-Facility-Regulations_Involuntary-Transfer-and-Discharge.pdf

on **unnecessary drugs and antipsychotic medications**:

http://www.justiceinaging.org/wp-content/uploads/2017/02/Revised-Nursing-Facility-Regulations_Unnecessary-Drugs-and-Antipsychotic-Medications.pdf

on **admission**:

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Admission.pdf

on **assessment, care planning, and discharge planning**:

<http://www.justiceinaging.org/wp-content/uploads/2016/12/A-Guide-to-the-Revised-Nursing-Facility-Regulations.pdf>

on **involuntary transfer and discharge**:

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Involuntary_Transfer_and_Discharge.pdf

on **nursing services:**

http://theconsumervoice.org/uploads/files/issues/Revised-Nursing-Facility-Regulations_Nursing_Services.pdf

on **visitation rights:**

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Visitation_Rights.pdf

on **specialized rehabilitation services:**

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Rehabilitation_Services.pdf

on **Grievances and Resident or Family Councils:**

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Grievances_and_Resident_or_Family_Councils.pdf

on **Return to Facility After Hospitalization:**

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Return_to_Facility_After_Hospitalization.pdf

on **Quality of Care:**

http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Quality_of_Care.pdf

For a summary of **key changes in “phase two” of the new federal regulations** that took effect November 28, 2017, from the Consumer Voice:

<http://theconsumervoice.org/uploads/files/general/summary-of-key-changes-effective-phase-2.pdf>

Information about the **agency that enforces these regulations:**

Center for Medicare & Medicaid Services (CMS): <http://www.cms.gov/>

What Medicare surveyors look for in quality for nursing homes:

http://cms.hhs.gov/manuals/Downloads/som107ap_pp_guidelines_ltcf.pdf

For facilities – and empowered advocates – CMS has released survey tools that can be used to **measure the quality of care for residents with dementia:**

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-16-04.pdf>

To **find your state’s** nursing home licensing agency, certification agency, Medicare & Medicaid administrative agency, and advocacy groups:

https://theconsumervoice.org/get_help

For a summary of **nursing home resident rights:**

https://theconsumervoice.org/uploads/files/long-term-care-recipient/CV_NHrights_factsheet_final.pdf

The Long-Term Care Community Coalition has published a **Primer on Nursing Home Quality Standards** including regulatory requirements considered most essential to resident safety, dignity and well-being, and featuring a Table of Contents with descriptive titles and clickable hyperlinks:

<http://nursinghome411.org/lccc-primer-nursing-home-quality-standards/>

Our Founder and CEO presented **testimony to the National Academies of Sciences, Engineering and Medicine’s Committee on the Quality of Care in Nursing Homes**, which is tasked with examining “how our nation delivers, regulates, finances and measures quality of nursing home care, including the long-standing challenges brought to light by the COVID-19 pandemic.” Her moving remarks begin at 3:26 of this recording: <https://www.nationalacademies.org/event/01-26-2021/the-quality-of-care-in-nursing-homes-public-webinar-1> and her **participation in the Q&A** at 1:09:50.

Assisted Living – While there are no federal regulations governing Assisted Living facilities, many states have regulations and “best practices” which are accessible here:

The LTCCC has published a report on **best practices in assisted living**: <https://nursinghome411.org/ltccc-report-assisted-living-promising-policies-and-practices/> and a state-by-state comparison of their **assisted living requirements and policies**: <https://nursinghome411.org/assisted-living-state-requirements-chart/>

Kaiser Health News has published a report detailing the **harm caused by absence of consistent, strong regulations governing assisted living for people with dementia**: <https://khn.org/news/assisted-livings-breakneck-growth-leaves-patient-safety-behind/>

Home & Community-Based Services

Justice In Aging has published a **primer on Home and Community Based Services through Medicaid**: <https://justiceinaging.org/wp-content/uploads/2021/04/HCBS-Primer.pdf?eType=EmailBlastContent&eld=7d9cb25c-aaf1-4d70-827a-8ccda95ff8c5>

For information and resources regarding the **new Home and Community Based Services (HCBS) settings rule** and steps each state is making to comply with the new rule: <http://hcbsadvocacy.org/>

The website features an [Advocates Checklist](#) which offers ideas and steps on how to get involved in a state's assessment and transition plan process, and the [HCBS Worksheet for Assessing Services and Settings](#), which is intended to help State agencies, community members and other stakeholders in reviewing HCBS are currently provided in their states prior to submission of the State's transition plan.

For an interesting **discussion of the pros and cons of a new Medicaid rule requiring more individualized care planning** in home-like community-based settings as alternatives to nursing homes for services for people with disabilities and the elderly: <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2014/11/19/new-medicaid-rule-could-challenge-state-shift-away-from-nursing-homes>

For a report on how the states are performing in their **compliance with federal regulations requiring Person-Centered Care Planning** for Medicaid Home and Community-Based Service recipients:

http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf

Often families are told their loved one cannot be served in a community-based setting because of **wandering or other challenging behaviors**. The Center for Medicare and Medicaid services has published **guidance for providers instructing them how they are to meet these needs within the federal regulations**:

<https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>

For a guide to **understanding this new rule and how it impacts care and services in adult day settings**, from the Consumer Voice and Justice in Aging:

<http://www.justiceinaging.org/wp-content/uploads/2016/10/Medicoids-New-Rule-to-Promote-Independence.pdf>

For information on how you can **advocate for person-centered services in adult day settings** who are governed by these rules, from the Consumer Voice and Justice in Aging:

<http://www.justiceinaging.org/wp-content/uploads/2016/10/HCBS-Regs-and-Adult-Day-Centers.pdf>

For a guide to **consumer rights in Medicaid-funded Home and Community Based Services (HCBS)**:

<http://www.nslc.org/index.php/new-advocates-guide/>

Consumer Voice has published a **guide to the new Home and Community Based Services rule**:

http://theconsumervoice.org/uploads/files/actions-and-news-updates/NAELA_guide_to_HCBS_settings_rule_FINAL.pdf

Home Health

Federal Regulations may be accessed at:

<https://www.law.cornell.edu/cfr/text/42/part-484/subpart-B>

For regulations related to **patient care, assessment, quality, care coordination, etc.**, click on sections 484.50 – 484.80 of this resource.

The Center for Medicare Advocacy explains that **home health aide services are often misrepresented and under-provided** by home health agencies:

<https://www.medicareadvocacy.org/home-health-aide-coverage-continues-to-shrink-attention-must-be-paid/>

and offers a case study as an **example of how to advocate for needed home health aide services**:

<https://www.medicareadvocacy.org/case-spotlight-a-medicare-beneficiary-in-need-of-home-health-aides/>

The Center for Medicare Advocacy has a new factsheet on **Medicare coverage of Home Health Services** in light of the *Jimmo* court settlement:

<https://medicareadvocacy.org/wp-content/uploads/2021/05/Fact-Sheet-Home-Health-and-Jimmo.pdf?emci=a1145ccd-17bf-eb11-a7ad-501ac57b8fa7&emdi=be19fcef-1dbf-eb11-a7ad-501ac57b8fa7&ceid=8355898>

Hospice

Full **federal regulations governing hospice care** may be found here:

https://www.ecfr.gov/cgi-bin/text-idx?SID=e093ac853ec564a10cc78b244c8dec0&mc=true&node=pt42.3.418&rgn=div5#se42.3.418_156&node=pt42.3.418&rgn=div5#se42.3.418_156

Financial (Medicare, Medicaid, Skilled Therapy Services)

Medicare Beneficiary Guide on **Payment for Nursing Home Care**:

<https://www.medicare.gov/Pubs/pdf/10153-Medicare-Skilled-Nursing-Facility-Care.pdf>

Medicare Beneficiary Guide on **Payment for Home Health Services**:

<https://www.medicare.gov/Pubs/pdf/10969-Medicare-and-Home-Health-Care.pdf>

Medicare Beneficiary Guide on **Payment for Hospice Care Services**:

<https://www.medicare.gov/Pubs/pdf/02154-medicare-hospice-benefits.pdf>

Medicare must now pay for “maintenance” therapies and treatments, not just “improvement” therapies and treatments! (This has always been the standard and federal regulation, but historically Medicare has denied payment for these services.) Read about the court settlement and its implications:

<http://www.medicareadvocacy.org/2013/01/24/judge-approves-settlement-in-jimmo-vs-sebelius-after-court-hearing/>

If you have had a claim denied for “maintenance” therapies or treatments, here is a resource to appeal the denial of payment for:

Skilled nursing facility care therapies/treatments:

<http://www.medicareadvocacy.org/2013/02/12/self-help-packet-for-expedited-skilled-nursing-facility-appeals-including-improvement-standard-denials/>

in-home care therapies/treatments:

<http://www.medicareadvocacy.org/2013/02/22/self-help-packet-for-expedited-home-health-care-appeals-including-improvement-standard-denials/>

The Center for Medicare and Medicaid Services (CMS) has issued a brief covering the **Jimmo V. Sebelius settlement and its impact on payment for skilled therapy care** in a variety of settings:

<https://www.medicareadvocacy.org/wp-content/uploads/2019/06/Jimmo-Improvement-Standard-Issue-brief-June-2019.pdf>

For a fact sheet on the **impact of the Jimmo v. Sebelius case on Medicare coverage for inpatient rehabilitation**:

<https://www.medicareadvocacy.org/wp-content/uploads/2019/04/IRF-JIMMO-Factsheet.pdf>

The Center for Medicare Advocacy has a new factsheet on **Medicare coverage of Home Health Services** in light of the *Jimmo* court settlement:

<https://medicareadvocacy.org/wp-content/uploads/2021/05/Fact-Sheet-Home-Health-and-Jimmo.pdf?emci=a1145ccd-17bf-eb11-a7ad-501ac57b8fa7&emdi=be19fcef-1dbf-eb11-a7ad-501ac57b8fa7&ceid=8355898>

Immediately following the CMS **change in payment models for therapies in nursing facilities (“Patient-Driven Payment Model”)**, a large number of facilities have drastically reduced the presence of therapists. This article from the Center for Medicare Advocacy describes the **change in payment model, the reduction in therapy staff, and what residents and advocates can do**:

<https://www.medicareadvocacy.org/skilled-nursing-facilities-lay-off-therapists-change-therapy-services-what-can-residents-therapists-do/?emci=9d342872-6023-ea11-a601-2818784d6d68&emdi=be1a6f0e-6b23-ea11-a601-2818784d6d68&ceid=4142979>

The Center for Medicare Advocacy explains that under certain conditions, **residents CAN leave a skilled nursing facility for short-term visits** without losing their Medicare funding for their stay:

<https://www.medicareadvocacy.org/you-can-leave-the-nursing-home/?emci=428713f1-2411-ea11-828b-2818784d6d68&emdi=a00092fd-4611-ea11-828b-2818784d6d68&ceid=4142979>

A Federal Court has ruled that **patients on “observation status” who are subsequently denied Medicare coverage of long-term care services have the right to appeal**.

Justice In Aging has prepared a press release announcing this “win”:

<https://www.justiceinaging.org/medicare-patients-placed-under-observation-status-win-right-to-appeal-federal-court-orders/>

Changes in Medicare payment processes DO NOT change eligibility and coverage for skilled therapies, although they do provide incentives for providers to change their practices – and not in the interest of consumers. For details of this issue:

<https://www.medicareadvocacy.org/wp-content/uploads/2020/03/Issue-Brief.-Medicare-Payment-vs.-Coverage.pdf?emci=7ea1b69b-865d-ea11-a94c-00155d039e74&emdi=b7eb2fbd-895d-ea11-a94c-00155d039e74&ceid=4142979>

Medicare payment processes for Home Health services have also changed, but **eligibility and coverage for Home Health services have not changed**; as this fact sheet from CMS confirms:

<https://www.cms.gov/files/document/se20005.pdf>

For information about **tax breaks available to offset buy-in to a retirement community**:

<http://www.dailyfinance.com/2013/07/28/retirement-community-tax-breaks/>

For a “primer” on **Medicare coverage for Home Health Services** from the Center for Medicare Advocacy:

<http://www.medicareadvocacy.org/?s=the+promise+of+medicare+home+health+coverage&op.x=0&op.y=0>

“Observation status” is NOT the same as inpatient admission to a hospital, and can affect one’s eligibility for Medicare coverage of not only the hospital stay, but also a skilled nursing home stay that may be needed after release from the hospital. To learn about this practice and what advocates can do to fight it:

<http://www.medicareadvocacy.org/wp-content/uploads/2016/11/Observation-Status-Infographic.pdf>

For a “toolkit” to **learn about “observation status”** and how to advocate, visit:

<http://www.medicareadvocacy.org/medicare-hospital-outpatient-observation-status-toolkit/>

The Center for Medicare Advocacy has developed a toolkit of information and tips to help empower Medicare beneficiaries and advocates to **appeal unfair denials of Medicare funding for skilled nursing facility care**: <http://www.medicareadvocacy.org/wp-content/uploads/2018/01/Medicare%20SNF%20Coverage%20and%20Jimmo%20v.%20Sebelius%20Toolkit.pdf>

From the Center for Medicare Advocacy, an article expressing concern about the **significant decline in appeals decisions favoring beneficiaries when claims are denied**:

<http://www.medicareadvocacy.org/senate-finance-committee-holds-hearing-on-medicare-appeals-backlog-proposed-solutions-are-of-great-concern/>

Justice In Aging sheds light on the **financial impact of Medicaid’s Estate Claims practices**:

<https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf?eType=EmailBlastContent&eld=49402a41-1e4f-4346-90d5-84fca6d8c236>

Medicaid has rules **safeguarding the assets of a spouse of a nursing home resident**, explained here:

<https://www.medicaid.gov/medicaid/eligibility/spousal-impoverishment/index.html>

Quality: How to Find It, How to Get It, How to Keep It

FIND IT

Nursing Home Five Star Ratings

The Center for Medicare and Medicaid Services has created a new portal to assist consumers and advocates to **locate and research certified nursing homes**, and to compare quality; and to find **information about quality of a variety of health care providers from a single Internet site location** rather than searching numerous help sites:

<https://www.medicare.gov/care-compare/>

On a cautionary note, **A study by the Center for Public Integrity Urges Caution**: the Nursing Home Compare website, published by the Centers for Medicare and Medicaid Services, lists information about nursing homes to aid consumers in choosing a facility.

Unfortunately, some information on Nursing Home Compare is self-reported by the nursing homes themselves, and some of that information has been shown to be inaccurate. One important inaccuracy is that prior to 2019, over 80% of nursing homes were reporting more coverage by registered nurses than their payroll records show, thus claiming better care than they actually provided. (WEB SITE OWNER'S NOTE: Recently CMS has begun using payroll data directly to develop these statistics. Some other information, however, continues to be either self-reported or indirectly influenced by self-reported information. Consumers should refer to Nursing Home Compare only with this caution in mind.) The study showing such inaccuracies, by the Center for Public Integrity, can be accessed here:

<http://www.publicintegrity.org/2014/11/12/16246/analysis-shows-widespread-discrepancies-staffing-levels-reported-nursing-homes>

For a report on trends **in care and deficiencies found in nursing facilities** throughout the country, 2009 – 2014, by the Kaiser Commission on Medicaid and the Uninsured:

<http://theconsumervoice.org/uploads/files/issues/report-nursing-facilities-staffing-residents-and-facility-deficiencies-2009-through-2014.pdf>

NOTE: this report is NOT just for those interested in care of people who receive Medicaid – it impacts every resident of a facility that participates in federal reimbursement programs, and is a benchmark for measuring the quality of care even in privately-funded facilities.

“Special Focus Facilities”

CMS oversees the **Special Focus Facility (SFF) program, which places special scrutiny on select nursing homes with a documented pattern of providing poor care.** Almost **400 facilities are eligible** for the Special Focus Facilities program because they have a “persistent record of poor care,” yet **only about 80 are selected** to participate due to CMS’ limited resources. For the **full list of facilities by state, including their participation status:**

<https://www.aging.senate.gov/imo/media/doc/SFF%20List%20with%20Cover%20Letter%20051419%20-%20Casey.pdf>

Senators Bob Casey (D-PA) and Pat Toomey (R-PA) have published a report exposing this situation because these facilities are “indistinguishable” from participants in the program.

"When a family makes the hard decision to seek nursing home services for a loved one, they deserve to know if a facility under consideration suffers from systemic shortcomings," Sen. Toomey stated. Find the full report here:

<https://www.aging.senate.gov/imo/media/doc/Casey%20Toomey%20SFF%20Report%20June%202019.pdf>

AP News covered this story:

<https://www.apnews.com/f1f93e5f11634ba994dfd21bbc32e73b>

Despite these findings, **the industry continues to claim they are providing good care, and getting better.** They want to reduce oversight. For a **“fact vs. fiction” report on those claims** from the Center for Medicare Advocacy and the LTCCC:

<https://nursinghome411.org/statement-nursing-home-safety-profits-june2019/>

and here is a report on staffing in nursing homes for first quarter 2019:

<https://nursinghome411.org/nursing-home-staffing-2019-q1/>

and a list of the 10 top and 10 bottom performing nursing homes in each state:

<https://nursinghome411.org/top-ten-bottom-ten-nursing-homes-for-each-state-2019-q1/>

The New York-based Long-Term Care Community Coalition (LTCCC) has created a [database](#) including all U.S. **nursing homes identified by CMS as SFF (Special Focus Facility) candidates**. The database is available at <https://nursinghome411.org/special-focus-facility-candidate-list-july-2019/>. It is easily searchable and sortable by facility name, address, city, state, zip code, months as an SFF candidate, overall star rating, and ratings for Health Inspections, Quality Measures, and Staffing.

Tips & Checklists – Nursing Home, Assisted Living, Day Services, Home & Community-Based Services, Home Health

For a **checklist to help** consumers and families **find the right nursing facility**:

<https://www.medicare.gov/files/nursing-home-checklist.pdf>

For **tips for choosing a nursing facility**:

http://theconsumervoice.org/uploads/files/advocate/Consumer_Guide_to_Choosing_a_NH.pdf

Questions to ask when choosing a nursing facility, from a consumer's and an advocate's perspectives:

<http://health.usnews.com/health-news/best-nursing-homes/articles/2015/03/05/crucial-questions-to-ask-when-youre-choosing-a-nursing-home>

For tips on **spotting a poor nursing home**:

<http://money.usnews.com/money/personal-finance/articles/2014/05/07/5-traits-of-the-worst-nursing-homes>

HOWEVER – a word about the article's link to “Best Nursing Homes 2014” at US News – this ranking is based on SELF-REPORTING OF THE NURSING FACILITIES and should be taken with that caution in mind.

This article from Consumer Voice offers more information:

<http://www.theconsumervoice.org/node/1234>

For additional information regarding this issue, the 2014 report on the “**scorecard**” status of **long-term care services** in the USA by state:

http://longtermscorecard.org/~link.aspx?_id=DCD2C261D26D414C971D574D577A78FE&_z=z#.U6IiVfldUud

THE NY based LTCCC has published a series of **guidebooks to assist those navigating the issues of assisted living**, available here:

<https://nursinghome411.org/assisted-living-guidebooks/?emci=1847a5d0-9a72-ea11-a94c-00155d03b1e8&emdi=10f5448d-5c73-ea11-a94c-00155d03b1e8&ceid=3994316>

For a state-specific tool to learn about the **quality of health care providers**, including doctors, hospitals, and nursing homes:

<https://www.informedpatientinstitute.org/>

CMS has launched a new web page for consumers and families seeking Hospice care, providing **comparative data on the performance of Hospice providers**:

<https://www.medicare.gov/hospicecompare/>

For a **primer on nursing home quality standards** based on the CMS federal regulations and produced by the Long-Term Care Community Coalition:

<https://nursinghome411.org/wp-content/uploads/2018/05/LTCCC-Primer-Essential-Nursing-Home-Quality-Standards-2018Update-May.pdf>

For a quick reference describing **culture change and person-directed principles** in long-term care:

[https://theconsumervoice.org/uploads/files/issues/culture-change-in-nursing-homes-fact-sheet-final_\(1\).pdf](https://theconsumervoice.org/uploads/files/issues/culture-change-in-nursing-homes-fact-sheet-final_(1).pdf)

For links to a number of resources related to **quality of life and resident-directed care**:

<http://theconsumervoice.org/issues/recipients/nursing-home-residents/getting-quality-care>

<http://theconsumervoice.org/issues/for-advocates/resident-directed-care>

For information on the **human and financial costs of poor nursing home care**:

<http://www.theconsumervoice.org/sites/default/files/advocate/action-center/The-High-Cost-of-Poor-Care.pdf>

Advancing Excellence Campaign's tips for **finding the right nursing home**:

<http://www.nhqualitycampaign.org/files/Tip%20Sheet%20Formatted.pdf>

GET IT

Advocacy Organizations

The National Council on Aging is a **national advocacy group with many resources** and partnerships with nonprofit, governmental, and business groups:

<https://www.ncoa.org/>

National Advocacy Groups for people living in long-term care facilities, their families and advocates:

<http://www.theconsumervoice.org> – National Consumer Voice for Quality Long-Term Care

<http://www.pioneernetwork.net> – The Pioneer Network

<http://aarp.org> – American Association of Retired Persons

Long Term Care Community Coalition, a national coalition **advocating for policy and practice** excellence in the treatment of the vulnerable elderly and disabled in all settings:

<http://www.ltccc.org>

Center for Medicare Advocacy, Inc., an organization dedicated to helping consumers **understand Medicare** and the current issues related to both policy and quality, and helping consumers advocate for Medicare coverage:

<http://www.medicareadvocacy.org>

For an Ombudsman's perspective on the **benefits of accessing the Ombudsman program**:

<http://health.usnews.com/health-news/best-nursing-homes/articles/2015/03/05/nursing-home-ombudsman-speaks-up-for-residents-rights>

For the **new federal regulations governing the operation of the states' Long-Term Care Ombudsman programs**:

<http://www.gpo.gov/fdsys/pkg/FR-2015-02-11/pdf/2015-01914.pdf>

The National Consumer Voice is on **Facebook!**

<http://www.facebook.com/pages/National-Consumer-Voice-for-Quality-Long-Term-Care/168090666588164>

The National Consumer Voice for Quality Long-Term Care was featured in the September 2016 issue of *Philanthropy Journal News* as an **outstanding advocacy organization that makes a difference**:

<http://pj.news.chass.ncsu.edu/2016/09/06/a-national-voice-for-long-term-resident-care/>

The **Long-Term Care Ombudsman Program** serves as the advocate for residents in various long-term care settings. Access a **national resource center** here:

<https://ltombudsman.org/>

and find **your state's Ombudsman offices** here:

https://theconsumervoice.org/get_help

Advocacy Training

The Consumer Voice has a **Podcast series focused on "Pursuing Quality Long-Term Care"**, available in two formats:

Apple podcasts:

<https://podcasts.apple.com/us/podcast/pursuing-quality-long-term-care/id1522955998>

and directly from the Consumer Voice web site:

<https://theconsumervoice.org/pursuingquality>

Justice In Aging has a page hosting all their recorded **webinars on a variety of advocacy topics related to the exercise of rights; from benefits, to admission, to care and treatment, to eviction**:

<https://justiceinaging.org/resource-library/>

For a fact sheet detailing the **rights of Resident Councils** in nursing homes, from the National Consumer Voice on Quality Long-Term Care:

http://theconsumervoice.org/uploads/files/long-term-care-recipient/Resident_Council_Rights_Fact_Sheet.pdf

For information about **Family Councils** and how to establish & operate one:

<http://www.theconsumervoice.org/familymember/family-council-center>

For a radio broadcast about **Family Councils** and how they work:

<http://www.blogtalkradio.com/kindethics/2011/03/21/jessica-brill-ortiz-the-consumer-voice-empowered-effective-and-independent-family-councils>

Consumer Voice has initiated a **newsletter for residents**, to empower them to be their own advocates (families can also benefit from this resource). Issues can be accessed and downloaded here:

<http://theconsumervoice.org/issues/recipients/nursing-home-residents/resident-advocate>

To help people think about **what makes “quality of life”** for themselves or for a loved one, Consumer Voice has developed a **simple questionnaire in fillable pdf format**:

<https://tcombudsman.org/uploads/files/library/my-personal-directions-blank-revised-fillable.pdf>

with a **sample to help with ideas** or to get the conversation started:

<https://theconsumervoice.org/uploads/files/long-term-care-recipient/my-personal-directions-example-revised.pdf>

The National Center for State Courts, with the assistance of the American Bar Association Commission on Law and Aging, has produced an online training on **how to support someone who needs help making decisions and managing life**:

<https://eji.courtims.org>

“Put a STOP to Poor Care” Webinar from the National Consumer Voice for Quality Long-Term Care, with **Our Mother’s Voice CEO as a panelist** (click on the image of the PowerPoint slide):

<http://theconsumervoice.org/news/detail/latest/put-a-stop-to-poor-care-webinar>

For long-term care information geared toward promoting **effective advocacy and consumer-directed care, as well as legislative activities** (this is a free service for which you can register):

clearinghouse.theconsumervoice.org

Webinar on how to **craft your message for successful advocacy**:

<http://assistedlivingconsumers.org/2013/webinar-successful-advocacy-crafting-and-delivering-your-message/>

For **materials from a series of 4 advocacy training webinars** from the National Consumer Voice for Quality Long-Term Care:

<http://theconsumervoice.org/issues/for-advocates/advocacy-toolkit>

and for **links to the webinars**:

<https://theconsumervoice.org/issues/for-advocates/advocacy-training-webinars>

For a number of educational resources for consumers and advocates for **quality care in home or in nursing facilities**, including several state-specific guides:

http://theconsumervoice.org/consumers-for-quality-care#Consumer_Educational_Materials

For an overview of the **concepts of individualized quality care**:

<http://theconsumervoice.org/uploads/files/issues/basics-of-individualized-quality-care-factsheet-final.pdf>

AARP article on the **concepts and principles of Person-centered care**:

http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/moving-toward-person-and-family-centered-care-insight-AARP-ppi-ltc.pdf

for brief and uplifting **examples of resident-centered care** that truly enhances quality of life:

http://pubs.aarp.org/aarpbulletin/20120708_DC?folio=14#pg14

for a **resident's perspective on what constitutes "quality of life"**:

<http://newoldage.blogs.nytimes.com/2013/03/20/how-to-live-in-assisted-living/>

For information about the Center for Medicare & Medicaid Services (CMS) initiative supporting and encouraging facilities to implement **person and family involvement in care planning**:

<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Person-and-Family-Engagement.html>

For a number of brief "fact sheets" on **how to plan and implement quality care** whether in-home, from a variety of sources, or in a long-term care facility:

<https://theconsumervoice.org/issues/family/fact-sheets#Getting%20Quality%20Care>

and for a **discussion of the guidebook** "Piecing Together Quality Long-Term Care" (book

available for sale at <http://theconsumervoice.org/product/piecing-together-quality-long-term-care-a-consumers-guide-to-choices-and-advocacy/>):

<http://www.blogtalkradio.com/kindethics/2011/07/27/piecing-together-quality-long-term-care-a-consumers-guide>

For examples of how to advocate for, design, and monitor **Individualized Quality of Care** and Quality of Life:

<http://theconsumervoice.org/uploads/files/family-member/basics-of-individualized-quality-care.pdf>

and for a guide to advocating for individualized quality care when the family is confronted with a loved one with **"behavioral issues"**:

http://theconsumervoice.org/uploads/files/family-member/INDIVIDUALIZED_ASSESSMENT_with_Behavior_Symptoms.pdf

for an **award-winning documentary view of assisted living in a NON-person-centered environment**:

<https://www.youtube.com/watch?v=UciTFCPCivI>

For a guide to **coordinating your own or a family member's long-term care in a home setting**:

http://www.nextstepincare.org/Caregiver_Home/Care_Coordination/

For several **resources on transitioning from a nursing facility to another setting**, including a status report on current practices nationwide, tips for successful transitions, and advocacy tools, from the National Consumer Voice on Quality Long-Term Care:

<http://theconsumervoice.org/issues/other-issues-and-resources/nh-transitions>

The Pioneer Network, trailblazers for **culture change** in nursing homes, has published a compilation of case studies demonstrating the **life-changing outcomes of person-directed care** in a variety of nursing homes – for both residents and facilities:

<https://www.pioneernetwork.net/wp-content/uploads/2016/10/Case-Studies-in-Person-Directed-Care.pdf>

2014 annual conference materials from the National Consumer Voice for Quality Long-Term Care, “Care Matters: Unlocking the Door to Quality” including a **presentation by the Founder & CEO of Our Mother’s Voice**:

<http://theconsumervoice.org/misc/2014-annual-conference/2014-annual-conference-materials>

To access workshop materials from the **2015 Consumer Voice annual conference**:

<https://theconsumervoice.org/events/2015-consumer-voice-annual-conference/archived>

The Long-Term Care Community Coalition has published a brief about the **importance of staffing levels to quality of care** in nursing homes, what the regulations say about “sufficient” staffing, and how advocates can find out about staffing levels:

<http://nursinghome411.org/lctccc-issue-alert-nursing-home-staffing-requirements/>

The National Consumer Voice web site page on **public policy, covering a multitude of issues**:

<http://www.theconsumervoice.org/advocate/policy-tools>

Fact sheet on the importance of the **Older Americans Act**, up for reauthorization this year:

<http://www.theconsumervoice.org/sites/default/files/CVFactSheetonOAA.pdf>

The National Consumer Voice web page on the **Older Americans Act**:

<http://www.theconsumervoice.org/advocate/reauthorize-older-americans-act>

The National Consumer Voice web page on the **Long-Term Care Ombudsman** provisions in the **Older Americans Act**: <http://www.theconsumervoice.org/lctcopandoaa>

For fact sheets on **many topics of interest for advocates**:

<http://www.theconsumervoice.org/resident/nursinghomes/fact-sheets>

National Consumer Voice **fact sheets on numerous topics** related to nursing home best practices, advocacy, care planning, advance care wishes, and other topics of interest:

<http://www.theconsumervoice.org/sites/default/files/resident/nursing-home/2011-resident-call-series-call-handouts.pdf>

The **threat of transfer or discharge from a nursing home** can be both frightening and stressful for residents and their families. Consumer Voice has a variety of **resources and materials about your rights and what to do next** if you've been given a discharge notice:

<https://theconsumervoice.org/nursing-home-discharges>

KEEP IT

Problem-Solving

Justice In Aging has updated their **guide for identifying and dealing with 20 common problems** experienced in nursing homes. Fill out the form and download it for free:

http://www.justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them_Final.pdf

and for a **webinar focused on the 10 most common problems** & how to solve them: <https://vimeo.com/339413587>

Justice in Aging has updated its essential guide, **25 Common Nursing Home Problems – & How to Resolve Them**. The revised guide includes, among other things, COVID-19 specific information, 2021 Medicare eligibility standards, and advice on how to refuse arbitration agreements under a recently revised federal regulation.

Even supposedly “good” nursing homes often follow standard procedures that violate federal law and put residents at risk. This updated version of the guide offers new information on resident and family rights regarding visitation during the pandemic, waivers and coverage flexibilities put in place during the pandemic, and updates relating to Medicare, arbitration, and other issues.

The 25 problems identified in the guide are common across the country and in all types of nursing homes. The guide gives residents, family members, friends, and other advocates the tools they need to identify and solve the problems residents most frequently face.

https://justiceinaging.org/wp-content/uploads/2019/01/25-Common-Nursing-Home-Problems-and-How-to-Resolve-Them_Final.pdf

For a Consumer Voice tip sheet summarizing **steps to problem-solving in a nursing home**:

http://theconsumervoice.org/uploads/files/long-term-care-recipient/9._How_to_Solve_Problems_in_a_Nursing_Home.pdf

For a report from the Center for Medicare Advocacy on the **truth about nursing home “discharge” determinations**:

<http://www.medicareadvocacy.org/discharge-from-a-skilled-nursing-facility-what-does-it-mean-and-what-rights-does-a-resident-have/>

(**HINT**: it’s not what you may be told by the facility. The truth is that when a SNF tells a beneficiary that he or she is “discharged,” at that point, **Medicare has not yet made any determination about coverage** and a resident cannot be evicted solely because Medicare will not pay for the stay.)

For audio and transcript of a NPR **segment on involuntary discharge or “nursing home evictions”**:

<http://www.npr.org/sections/health-shots/2016/02/25/467958665/nursing-home-evictions-strand-the-disabled-in-costly-hospitals>

For a summary of the federal **rules about discharge from a nursing home**:

<http://ltcombudsman.org/uploads/files/support/nursing-home-discharges-final.pdf>

The South Carolina Oral Health Coalition’s Older Adult Work Group, in collaboration with the James B. Edwards College of Dental Medicine at the Medical University of South Carolina,

has developed and distributed a **training curriculum in oral health care competency for certified nursing assistants and other caregivers** for those who need assistance with oral care. Oral health is essential for overall health, and especially so for those who are frail and at risk for nutritional deficits. This curriculum is available free online at <https://prezi.com/mpon3cvbck85/floss/>

Jimmo Implementation Resources

The **“improvement standard” can no longer be cited** as a reason to discontinue Medicare payment for therapies or other skilled services:

<http://www.medicareadvocacy.org/wp-content/uploads/2018/04/Jimmo-Fact-Sheet-04.2018-00293969xC6348.pdf>

Center for Medicare Advocacy has crafted **resources advocates can use to educate providers, contractors, and adjudicators who are not versed in the federal court decision Jimmo v Sebelius**, which made the so-called “improvement standard” invalid in determining the appropriateness of physical, occupational, speech, and other special therapies:

<https://www.medicareadvocacy.org/wp-content/uploads/2018/12/Jimmo-Fact-Sheet-for-Providers-Contractors-Adjudicators.pdf>

CMS has provided a web page with resources to assist consumers and providers to **understand and properly implement the Jimmo v. Sebelius court settlement** (which clarified that Medicare will pay for skilled nursing and therapy services regardless of anticipated improvement in the underlying condition):

<https://www.cms.gov/Center/Special-Topic/Jimmo-Center.html>

The Center for Medicare Advocacy has issued a **checklist to help patients when the so-called (and illegal) “improvement standard” is used to deny Medicare payment** for skilled nursing and therapy care:

<http://www.medicareadvocacy.org/wp-content/uploads/2018/08/Checklist.pdf>

The Kaiser Family Foundation’s news service has published an article highlighting the **challenges Medicare beneficiaries face in accessing Medicare funding for services despite the Jimmo ruling**:

https://retiredamericans.org/khn-analysis-home-care-agencies-often-wrongly-deny-medicare-help-chronically-ill/?link_id=3&can_id=ad0b69ff6bddf219e44617ec11f417f3&source=email-january-19-2018-friday-alert&email_referrer=email_288806&email_subject=january-19-2018-friday-alert

The Center for Medicare Advocacy has new resources on **navigating the “no improvement required” provision of the federal court case Jimmo V. Sebelius when patients and advocates encounter problems or barriers by providers of therapies**:

<https://www.medicareadvocacy.org/you-do-not-have-to-improve-new-jimmo-resources-for-appealing-medicare-denials-in-nursing-homes/?emci=936407f5-9cf9-e911-828b-2818784d6d68&emdi=c592b0df-b4f9-e911-828b-2818784d6d68&ceid=4142979>

The **new payment models** by which Medicare began paying for therapies beginning January 1, 2020, has already also resulted in **home health consumers not receiving prescribed care**. The Center for Medicare Advocacy has published a **case-study-based guide for consumers to respond to provider misinterpretations** of the new rule:
<https://www.medicareadvocacy.org/home-health-practice-guide/>

Find Your LTC Ombudsman

Find **your state's Ombudsman offices** here:
https://theconsumervoice.org/get_help

Abuse/Neglect/Exploitation

The Consumer Voice has several resources that include **important information about abuse prevention, abuse reporting, and protection of individual rights**:
<https://theconsumervoice.org/issues/other-issues-and-resources/elder-abuse>
And this guide **defining abuse, neglect, and misappropriation of property**:
<https://theconsumervoice.org/uploads/files/long-term-care-recipient/abuse-fact-sheet-18.pdf>
Resources from Consumer Voice to help advocates **recognize, prevent, and report abuse, neglect, and exploitation** of loved ones in long-term care:
Fact sheet and PowerPoint: <https://theconsumervoice.org/issues/other-issues-and-resources/elder-abuse#Abuse-Neglect>
Brochure and webinar: <https://theconsumervoice.org/issues/other-issues-and-resources/elder-abuse#put-a-stop>
Fact sheet and webinar on **financial exploitation**: <https://theconsumervoice.org/issues/other-issues-and-resources/financial-exploitation>

For a quick reference **defining abuse, neglect, exploitation, and the requirements for nursing homes to protect residents**:
<https://docs.google.com/viewerng/viewer?url=https://nursinghome411.org/wp-content/uploads/2017/09/LTCCC-Fact-Sheet-Nursing-Home-Reqmts-Abuse-Neglect.pdf&hl=en>

The LTCCC has also published a report **defining abuse and neglect, describing federal regulations** in place to protect residents, and **discussing promising practices** that can be adopted by facilities to address these issues.
<https://nursinghome411.org/ltccc-report-abuse-neglect-crime/>

Consumer Voice and NORC (National Ombudsman Resource Center) have created several new **training materials on the topic of abuse, neglect, exploitation and misappropriation of property**. The materials are based on the revised nursing home regulations. The new materials can be used together as an educational toolkit for training by and for Ombudsman program representatives, for members of resident and family councils, facility in-service training and community education.

- **Prezi** - A Prezi is a visual storytelling alternative to a PowerPoint presentation. The Abuse, Neglect, Exploitation and Misappropriation of Property Prezi uses the map-like layout to provide information on identifying, preventing and reporting abuse and

knowing the signs of abuse. The Prezi is available as a video with a voiceover at http://theconsumervoice.org/uploads/files/issues/Abuse_prezi_with_voiceover.mp4 or as a clickable presentation without voiceover at <https://prezi.com/view/VSszKpW4Z0Khre6UUEjW/>. Use the script at http://theconsumervoice.org/uploads/files/issues/ANE_Prezi_Script_FINAL_-_2018.pdf to follow along with the presentation and learn further details on each topic.

- **PowerPoint** – The downloadable PowerPoint can be used for training purposes. The slides include presenter notes and are customizable for state and local information. See the link for all materials, below, to download the PowerPoint.
- **Fact Sheet** - This updated fact sheet at <http://theconsumervoice.org/uploads/files/long-term-care-recipient/abuse-fact-sheet-18.pdf> is an easy-to-use handout with information on the topic.
- **All materials** are available on the Consumer Voice website at http://theconsumervoice.org/issues/issue_details/proposed-revisions-to-the-federal-nursing-home-regulations#education-materials and on the NORC website at http://ltcombudsman.org/library/fed_laws/federal-nursing-home-regulations#training.

Training Resources on Elder Abuse

from the University of Southern California:

<http://trea.usc.edu/>

and from the National Center on Elder Abuse:

<http://www.ncea.aoa.gov/Training/Curricula/index.aspx>

for information on **elder abuse and prevention**:

<http://www.centeronelderabuse.org>

The National Center on Law and Elder Rights has a collection of **resources available to assist those dealing with elder abuse**:

<https://ncler.acl.gov/ElderJustice-Toolkit/About-Elder-Justice-Toolkit.aspx>

For an interview from South Carolina raising awareness of **elder abuse**:

https://www.youtube.com/watch?v=q_J-MygPB94

Be sure to view the videos on the right side of the page related to dementia as well!

For a number of fact sheets related to **financial abuse and exploitation** in various residential settings:

<http://www.ltcombudsman.org/issues/elder-abuse-elder-justice>

For information about new laws to **protect vulnerable people from financial abuse** by telemarketer scams that access bank accounts and withdraw money:

https://www.ftc.gov/news-events/blogs/business-blog/2016/06/tsr-update-new-banned-payment-methods-now-effect?utm_source=govdelivery

For tips and tools for **preventing and responding to financial exploitation** in long-term care facilities:

<http://www.theconsumervoice.org/node/1237>

Stetson University's Elder Consumer Protection Program provides helpful guides to **state-by-state compilations of various elder protection laws**:

<http://www.stetson.edu/law/academics/elder/ecpp/statutory-updates.php>

For information about the **prevalence of malnutrition and dehydration** in nursing homes:

http://www.commonwealthfund.org/usr_doc/burger_mal_386.pdf

and for information about how dehydration can be assessed and treated:

http://consultgerirn.org/topics/hydration_management/want_to_know_more

Resident-on Resident Abuse is often cited as a reason to discharge an “aggressive” resident. For a **guide to successfully addressing these behaviors**, and avoiding the threat of involuntary discharge of the “aggressive” resident, the National Center on Elder Abuse has published this brief:

<http://eldermistreatment.usc.edu/wp-content/uploads/2016/10/RR-Aggression-Research-Practice.pdf>

Psychotropic/Antipsychotic Drug Misuse

The National Consumer Voice for Quality Long-Term Care has launched a consumer education campaign on the **misuse of medications to control behavioral “problems”**, often at the expense of the well-being and even the lives of consumers:

<https://theconsumervoice.org/stop-chemical-restraints>

The National Consumer Voice for Quality Long-Term Care has developed a campaign to empower consumers and advocates to speak out against the overuse and misuse of antipsychotic and psychotropic medications. “**Avoiding Drugs as Chemical Restraints: Changing the Culture of Care**” materials and resources are available here:

<https://theconsumervoice.org/stop-chemical-restraints>

A cooperative effort among multiple agencies including CMS has developed a **guide for physicians and other practitioners to avoid the inappropriate use of antipsychotic medications** for those in community settings, which consumers can use to advocate for proper treatment for their loved one:

https://store.samhsa.gov/system/files/pep19-inappuse-br_0.pdf

If this article doesn't convince you of the **benefits of person-centered care vs. anti-psychotic medications**, we don't know what will:

<https://www.mcknights.com/news/the-secret-ingredient-to-one-nursing-homes-dramatic-drop-in-antipsychotic-use/>

The National Consumer Voice's public policy resolutions, presented to Congress, on the serious problem of **over-prescribing of antipsychotic medications** in nursing homes:

Requesting Department of Health and Human Services intervention:

<http://theconsumervoice.org/sites/default/files/nccnhr/ResolutionOne.pdf>

Ending the practice of consulting pharmacists for nursing homes also being affiliated with long-term care provider pharmacies or drug companies:

<http://theconsumervoice.org/sites/default/files/nccnhr/ResolutionTwo.pdf>

Article describing the **extent of the problem of overuse of antipsychotic drugs** in nursing home patients:

http://oig.hhs.gov/newsroom/testimony-and-speeches/levinson_051011.asp

Center for Medicare Advocacy's 3-part series on **inappropriate use of antipsychotic drugs** in nursing facilities:

Part One: <http://www.medicareadvocacy.org/cma-report-examining-inappropriate-use-of-antipsychotic-drugs-in-nursing-facilities/>

Part Two: <http://www.medicareadvocacy.org/cma-report-on-inappropriate-use-of-antipsychotic-drugs-in-nursing-homes-part-two-what-the-surveyors-say/>

Part Three: <http://www.medicareadvocacy.org/cma-report-inappropriate-use-of-antipsychotic-drugs-in-nursing-homes-part-three-recommendations-to-improve-the-citing-of-deficiencies/>

For an article about the **abuse of antipsychotic medications** in nursing facilities:

<http://www.aarp.org/health/drugs-supplements/info-2014/antipsychotics-overprescribed.html?intcmp=BUBB2>

For a report from the federal General Accounting Office on the **use of psychotropic medications** in the elderly in various settings:

<http://www.gao.gov/products/GAO-15-211?source=ra>

and access the full report directly at:

<http://www.gao.gov/assets/670/668221.pdf>

Human Rights Watch has published an in-depth study of the **overuse of antipsychotic medications** in nursing homes, including its impact on the lives of residents:

<https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

Human Rights Watch released a **guide about nursing facility residents' rights concerning medication** in easy-to-read formats, available as an electronic or print leaflet and as a video here:

<https://www.hrw.org/news/2020/07/09/us-nursing-home-residents-should-know-their-rights>

For a report on the effectiveness of the partnership between CMS and the nursing home industry in **reducing the overuse of antipsychotic drugs**:

<http://www.medicareadvocacy.org/has-cmss-partnership-with-the-nursing-home-industry-really-reduced-the-inappropriate-use-of-antipsychotic-drugs-by-nursing-home-residents-as-much-as-cms-claims-no/> The report states, among many interesting facts, that “more than 200,000 residents who should not be taking these drugs continue to take them.”

For a report from the Center for Medicare Advocacy on **overuse of antipsychotic medications** in nursing homes:

<http://www.medicareadvocacy.org/elder-abuse-in-nursing-facilities-the-over-administration-of-antipsychotic-drugs-to-nursing-home-residents/>

Adverse Events

The Office of the Inspector General of the United States has issued a report about the incidence of adverse events in nursing homes which can be accessed at

<http://oig.hhs.gov/oei/reports/oei-06-11-00370.pdf>

Despite this highly critical report, the Center for Medicare and Medicaid Services is considering loosening its regulation of nursing facilities and its enforcement processes even more than in recent years under the current standards. A report on the **reduction in enforcement actions nationwide** can be found at

<http://www.ltccc.org/news/documents/EnforcementTrends--2007-2013-June2013.xls>

The National Consumer Voice for Quality Long-Term Care is **urging CMS not to change the regulations**, but to step up its enforcement of sanctions and penalties for facilities that are in violation of the current regulations. Visit www.theconsumervoice.org to learn about various quality initiatives you can support with your voice to Congress.

The Center for Medicare and Medicaid Services has released a “Change Package” resource of **best practices to prevent harm from all causes in nursing homes**. The project explanation and content of the resource are described here:

<https://qioprogram.org/all-cause-harm-prevention-nursing-homes>

and the **resource can be downloaded** here:

https://qioprogram.org/sites/default/files/editors/141/C2_Change_Package_20181226_FNL_508.pdf

Article about **underreporting of adverse events** in Medicare patient care:

<http://www.everydayhealth.com/healthy-living/0109/harm-in-hospitals-seldom-reported.aspx>

The Quality Improvement Organizations, under contract with CMS, has published a resource titled **All Cause Harm Prevention in Nursing Homes**, which offers many strategies for preventing a variety of adverse events:

https://qioprogram.org/sites/default/files/editors/141/C2_Change_Package_20181226_FNL_508.pdf

Other “At-Risk” Issues

On the **use of certain medications and supplements** with elderly patients:

<http://www.aarp.org/health/drugs-supplements/info-07-2011/medications-older-adults-should-use-with-caution.1.html>

For a personal story about the **dangers of misdiagnosis** and how that **puts a life at risk** when medical professionals stop looking for answers:

https://www.washingtonpost.com/lifestyle/2018/11/23/doctors-said-my-mother-was-her-death-bed-she-actually-just-needed-bananas/?noredirect=on&utm_term=.e0cabfd3c889

For a fact sheet on **surveillance cameras in rooms** of nursing home residents:

http://theconsumervoice.org/uploads/files/long-term-care-recipient/CV_NCEA_Surveillance_factsheet_web.pdf

The Office of the Inspector General of the US has issued a **report on the performance of nursing homes in investigating complaints 2011-2015**, available here:
<https://oig.hhs.gov/oei/reports/oei-01-16-00330.pdf>

The Center for Medicare Advocacy publishes newsletters discussing the **true impact of so-called “no-harm” deficiencies**, providing real-life examples. The issues are available here:
<https://www.medicareadvocacy.org/newsletter-elder-justice-what-no-harm-really-means-for-residents/?emci=5251ab41-1633-ea11-a1cc-2818784d084f&emdi=95104e56-2233-ea11-a1cc-2818784d084f&ceid=4142979>

Illustrating further the **failure of nursing homes to provide even basic quality of care**, the Long-Term Care Community Coalition (LTCCC) has published an alarming report:
<https://nursinghome411.org/wp-content/uploads/2020/01/LTCCC-Report-Resident-Care-Experience-vs-Animal-Care-Stds.pdf>

For an explanation of the **dangers of insufficient fire protection in nursing homes** and a state-by-state list of facilities that are out of compliance with federal fire sprinkler regulations:
<http://www.theconsumervoicework.org/HallOfFlame>

The Long Term Care Community Coalition (LTCCC) has published a **report on nursing home ownership** which identifies promising practices among states for evaluating nursing home owners for state licensure and provides essential principles for improving accountability and integrity in the licensure process. The report can be accessed at:
[*Meaningful Safeguards: Promising Practices & Recommendations for Evaluating Nursing Home Owners.*](#)
Consumers can **speak out in support of these measures** by writing to their representatives via the LTCCC’s Action Center:
https://secure.everyaction.com/Y0f9xL5M5Uul_UUS3fgp0g2

Corporate Takeover Issues

This New York Times article from January 2018 illustrates a growing trend in a **get-rich scheme in which owners of nursing homes also have ownership interest in numerous support services companies** (therapy, meal service, etc.) with whom they contract – and overpay – for these support services, thereby reaping large profits while underfunding the nursing homes.
https://www.nytimes.com/2018/01/02/business/nursing-homes-care-corporate.html?_r=0

An article from JustCare warns that **“chain” (i.e. corporate-owned multi-location) nursing homes may not mean quality**:
<http://justcareusa.org/beware-of-chain-nursing-homes/>

For an article on just how bad the **profit motive has become in the “market” of “treating” people with dementia** in nursing homes:
<https://www.medicareadvocacy.org/drug-company-sued-over-kickbacks-for-off-label-marketing-of-psychotropic-drug-for-nursing-home-residents-to-pay-over-115-million/?emci=6d6c72cd-15f1-e911-b5e9-2818784d6d68&emdi=e914e13d-21f1-e911-b5e9-2818784d6d68&ceid=4142979>

Quality of Care, Quality of Life, and Advocacy – Learning Resources for Nursing Home Staff and Advocates

For a guide book containing **best practices for preventing harm** to residents in nursing homes from a variety of causes:

https://qioprogram.org/sites/default/files/editors/141/C2_Change_Package_20181107_FNL_508.pdf

For a personal story about the **dangers of misdiagnosis** and how that **puts a life at risk** when medical professionals stop looking for answers:

https://www.washingtonpost.com/lifestyle/2018/11/23/doctors-said-my-mother-was-her-death-bed-she-actually-just-needed-bananas/?noredirect=on&utm_term=.e0cabfd3c889

We mention inexpensive resources for staff training on our site, and CMS has just updated one **FREE resource**, its **“Hand-In-Hand” training for staff working with people with dementia**. Anyone can access it FREE at this link:

https://surveyortraining.cms.hhs.gov/pubs/ClassInformation.aspx?cid=0CMSHIH_ONL

Feel free to PASS IT ON if a facility you know needs training (whether they claim they have trained staff or not!)

Dr. Macie Smith, a South Carolina expert on dementia and caregiver issues, has published a downloadable training video for families, caregivers, and staff on the topic of **dealing with some of the challenging behaviors** that dementia often brings:

<https://www.youtube.com/watch?v=r5hNwIOL6Eo&feature=youtu.be>

Dr. Smith also presents a down-home and practical approach to **understanding dementia**:

<https://www.youtube.com/watch?v=BhZpZSFZgNU&t=1629s>

Our Mother’s Voice CEO discusses how Quality of Life changes when caregivers begin to understand the **communicative intent of behavior in people with dementia**, in the video presentation “Behavior IS Communication! – My Mother’s Story”:

<https://vimeo.com/462311247>

The Pioneer Network, trailblazers for **culture change** in nursing homes, has published a compilation of case studies demonstrating the **life-changing outcomes of person-directed care** in a variety of nursing homes – for both residents and facilities:

<https://www.pioneernetwork.net/wp-content/uploads/2016/10/Case-Studies-in-Person-Directed-Care.pdf>

CMS has also begun developing a series of **“toolkits” to help nursing homes improve care and safety for residents**. The first is now available (scroll about 2/3 down the page), along with a list of their ongoing activities in this nation-wide project:

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/LTC-CMP-Reinvestment.html>

The South Carolina Oral Health Coalition's Older Adult Work Group, in collaboration with the James B. Edwards College of Dental Medicine at the Medical University of South Carolina, has developed and distributed a **training curriculum in oral health care competency for certified nursing assistants and other caregivers** for those who need assistance with oral care. Oral health is essential for overall health, and especially so for those who are frail and at risk for nutritional deficits. This curriculum is available free online at <https://prezi.com/mpon3cvbck85/floss/>

Oral Health America and their resources are now owned by Authority Dental, which features pages dedicated to **oral care for seniors**:
<https://www.authoritydental.com/senior-dental-care> and
<https://www.authoritydental.com/toothwisdom>

YouTube hosts many instructional videos, both stand-alone and in series, for **providing oral care for those with dementia**:
https://www.youtube.com/results?search_query=daily+oral+care+for+people+with+dementia

For numerous training **modules in many aspects of care for people with Alzheimer's disease and other types of dementia** from the National Council of Certified Dementia Practitioners:
<http://www.nccdp.org/staff-education-week.htm>

See how one nursing home is bringing **new meaning to the lives of residents with dementia** as they nurture orphaned kittens:
<http://www.upworthy.com/how-one-nursing-home-is-helping-its-residents-regain-a-sense-of-purpose?c=upw|&u=6df6|ed4fafa7b4005572|db3ad0f6dabe20df7a>

For information on the **“Advancing Excellence in America's Nursing Homes”** Campaign:
<http://www.nhqualitycampaign.org/>

Advancing Excellence Campaign **Implementation Manual** for nursing homes implementing culture change toward excellent care:

http://www.nhqualitycampaign.org/files/Implementation_Manual_Part_I_FINAL.pdf

Advancing Excellence Campaign's ten ways to **involve staff in culture change** for excellence:
<http://www.nhqualitycampaign.org/files/toptenInvolveAE.pdf>

Advancing Excellence Campaign's **implementation guides** for nursing homes to implement excellence:

http://www.nhqualitycampaign.org/star_index.aspx?controls=resImplementationGuides

For a **review and analysis of data** of nursing facilities participating in the **“Advancing Excellence”** campaign, **revealing that participation does not result in higher quality care**:
<http://www.medicareadvocacy.org/advancing-excellence-very-few-nursing-homes-are-full-active-participants-and-nearly-half-of-them-provide-poor-care/>

Video of **training from CMS in their initiative to improve behavioral health and reduce the use of antipsychotic medications** in nursing homes:

<http://surveyortraining.cms.hhs.gov/pubs/Videoinformation.aspx?cid=1098>

curriculum, referenced in the above video training from CMS, which **trains staff to avoid unnecessary hospitalizations or other escalations of problems**:

<http://www.interact2.net/>

For educational information and toolkits to assist facilities and advocates in providing **person-centered dining practices**, from the Pioneer Network:

<http://pioneernetwork.net/Providers/JustInTime/Dining>

For an excellent resource on **new best-practices guidelines for food and dining services** for nursing home residents, with consensus from numerous dietary, health, gerontology, and therapy professional organizations:

<http://www.pioneernetwork.net/Data/Documents/NewDiningPracticeStandards.pdf>

The Long-Term Care Community Coalition has published a **Primer on Nursing Home Quality Standards** including regulatory requirements considered most essential to resident safety, dignity and well-being, and featuring a Table of Contents with descriptive titles and clickable hyperlinks:

<http://nursinghome411.org/lctccc-primer-nursing-home-quality-standards/>

MORE RESOURCES

ON CAREGIVING, for family members providing care

National collaborative group of professional service providers for **resources and planning for in-home care** for senior citizens:

<http://www.ageinplace.org/>

The Administration on Community Living and the Administration on Aging partner for a website containing information on many **support resources for caring for an elder loved one**:

<https://eldercare.acl.gov/Public/Index.aspx>

For tips on **helping an older loved one age in place safely**, from the National Center on Elder Abuse:

<http://eldermistreatment.usc.edu/wp-content/uploads/2016/10/Home-for-the-Holidays-What-to-look-for-when-visiting-an-elderly-relative.pdf>

The National Center for State Courts, with the assistance of the American Bar Association Commission on Law and Aging, have created a training designed to assist individuals in exploring ways to help someone who may need **assistance in making decisions with informal supports, legal options, and/or adult guardianship**:

<https://trea.usc.edu/resource/finding-the-right-fit-decision-making-supports-and-guardianship-2/>

AARP's Caregiving Resource Center:

<https://www.aarp.org/caregiving>

Official website of the **National Family Caregivers Association**. Offers information and support for caregivers:

<http://www.nfcacares.org/>

Leeza Gibbons' website dedicated to caregivers:

<http://www.leezascareconnection.org/>

Official website of the **National Alliance for Caregiving:**

<http://www.caregiving.org/>

Official website of the **Family Caregiver Alliance:**

<http://www.caregiver.org/>

Caring Today e-magazine:

<http://www.caringtoday.com/>

For **coping tips for caregivers** of loved ones with dementia:

http://www.agingcare.com/Articles/stress-management-dementia-caregivers-155666.htm?utm_source=Newsletter&utm_medium=Email&utm_campaign=Newsletter%20-%20February%2027,%202013

For a **“one-stop shop” of resources**, from a family's blog to emotional support to myriad “how-to” tips for dealing with a family member's illness:

<http://www.incareofdad.com/>

For a **nationwide resource to assist in locating various types of care** for elders:

<https://eldercare.acl.gov/Public/Index.aspx>

ON ALZHEIMER'S DISEASE AND OTHER DEMENTIA

The **Alzheimer's Association** has released its **2021 report** on the state of the disease and caregiving. The **infographic** is available here:

<https://alz.org/media/Documents/alzheimers-facts-and-figures-infographic.pdf>

and the **full report** here:

<https://alz.org/media/Documents/alzheimers-facts-and-figures.pdf>

Teepa Snow is a well-known teacher and advocate for **positive approaches to care** for people with dementia and other cognitive challenges. A myriad of resources and contact information are available on her web site:

<https://www.teepasnow.com>

Our Mother's Voice CEO discusses how Quality of Life changes when caregivers begin to understand the **communicative intent of behavior in people with dementia**, in the

video presentation “Behavior IS Communication! – My Mother’s Story”:

<https://vimeo.com/462311247>

A 15-year-old boy created an **app to help his grandmother with dementia**. Now it's free for all. Read about it and download it here:

<https://www.carezare.com/>

We could all use an **uplifting story** these days. This is one: an old jazz musician with dementia reunited with his band mates and his music! A testament to the **power of music and memory**:

https://www.youtube.com/watch?v=Tp6c_oGISBk

One daughter has chronicled her **experiences with her father’s dementia on Facebook**:

<https://www.facebook.com/PaintingToRemember/>

For a new report on the **impact of Alzheimer’s disease**:

<http://www.alz.org/facts/>

The Alzheimer’s Association has an **interactive resource and planning tool for those addressing care needs for a loved one with dementia**:

<https://www.alzheimersnavigator.org/>

For links to various informational **resources for caregivers of loved ones with dementia**:

<http://ltcombudsman.org/issues/dementia-care>

and: www.nia.nih.gov/health/alzheimers/caregiving

For an interesting example of how **dementia can be something else entirely**:

<http://theboot.com/kris-kristofferson-lyme-disease-memory-loss/>

Lesson learned: rule out physical illness and medication side-effects before assuming it’s dementia!

To learn about the **national plan to address Alzheimer’s disease** – which focuses on research, prevention, cure, and best practices for treatment:

<http://alzheimers.gov/pdf/NationalPlanToAddressAlzheimersDisease.pdf>

For a variety of **resources and tools** for families, caregivers, and communities dealing with **dementia care issues**:

<http://www.actonalz.org/communities-action-resources>

for a video depicting **person-centered care for those with dementia**:

<http://www.ccal.org/person-centered-matters-video/>

See how one nursing home is bringing **new meaning to the lives of residents with dementia** as they nurture orphaned kittens:

<http://www.upworthy.com/how-one-nursing-home-is-helping-its-residents-regain-a-sense-of-purpose?c=upw|&u=6df61ed4fafa7b40055721db3ad0f6dabe20df7a>

For consumers, families, and professionals, **resources covering a broad range of topics and tools**, from the National Partnership to **Improve Dementia Care** in Nursing Homes: <https://www.nhqualitycampaign.org/dementiaCare.aspx>

CMS held a teleconference about **innovations in dementia care featuring two facilities** that have implemented culture change to better meet the needs of residents with dementia. The materials from that teleconference are available halfway down this web page: <https://www.cms.gov/Outreach-and-Education/Outreach/NPC/National-Provider-Calls-and-Events-Items/2015-09-03-Dementia.html?DLPage=1&DLEntries=10&DLSort=0&DLSortDir=descending>

For **strategies for working with first responders** when a **loved one with dementia** is at risk, see [The Role of First Responders and Dementia](#), from Banner Alzheimer's Institute. It includes practical advice for these circumstances and others and features tips from an experienced Alzheimer's caregiver.

For a PowerPoint presentation on **enhancing well-being in older adults living with dementia**: <http://theconsumervoicework.org/uploads/files/events/AIPowerPPT1.pdf>

The Dementia Action Alliance has published a paper discussing the **use of language when communicating with people with dementia**, and the importance of using positive and supportive words to describe and to interact with people with dementia. The paper can be accessed here: http://daanow.org/wp-content/uploads/2015/07/Living_Fully_with_Dementia-Words-Matter_DAA.pdf

For a perspective in understanding how **people with dementia can still have quality of life**: http://www.huffingtonpost.com/marie-marley/people-living-with-alzheimers_b_8024486.html

Three articles about **travel and activities for those caring for a loved one with dementia**: http://www.huffingtonpost.com/jan-dougherty/traveling-with-alzheimers_b_5605422.html
<http://www.alz.org/care/alzheimers-dementia-activities.asp>
<http://www.nia.nih.gov/alzheimers/publication/caring-person-ad/adapting-activities-people-ad>

For a guide on how to **prepare for and deal with hospitalization of a loved one with dementia**: http://www.nia.nih.gov/sites/default/files/hospitalization_happens_0.pdf

for an explanation of **assistive devices that can help both the dementia patient and the caregiver** succeed at home: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1779

for a short video illustrating **how a caregiver might handle dementia with agitation**:
<http://www.youtube.com/watch?v=h-MP21VW4M0>

for a tool from the Alzheimer's Association to help **plan care for a loved one with Alzheimer's Disease**:
https://www.alzheimersnavigator.org/?utm_source=DM&utm_medium=email&utm_campaign=navigator

For tips and information from the Alzheimer's Association about **engaging those with dementia in activities that improve the quality of life**:
<http://www.alz.org/care/alzheimers-dementia-activities.asp>

For a booklet from the **World Health Organization's Alzheimer's Disease International** project that provides information for families related to coping with the disease and supporting the caregivers:
http://apps.who.int/iris/bitstream/10665/62579/1/WHO_MNH_MND_94.8_eng.pdf

For information from the Alzheimer's Association on the **issues in late-stage dementia** and managing caregiving concerns:
<http://www.alz.org/care/alzheimers-late-end-stage-caregiving.asp>

For information and resources on **palliative care for dementia, end-of-life care**, and related topics, from the Polisher Research Institute:
<http://www.pdcronline.org/index.php>

for a view of what **palliative care** should include for people with dementia:
http://theconsumervoice.org/uploads/files/general/Case_Statement_Dementia_Lens_final_%283%29.pdf

For a series of brief but excellent **videos providing tips for family caregivers** journeying with a loved one through dementia:
https://www.youtube.com/channel/UC6jHyTO7be_IPyHQaL96kpg

For a brief brochure-style fact sheet on many **challenges of caregiving for a loved one with dementia**, from the University of Southern California School of Family Medicine:
<http://www.ncea.aoa.gov/Resources/Publication/docs/Archstone-Caregiver-Brochure-Print.pdf>

For facilities – and empowered advocates – CMS has released survey tools that can be used to **measure the quality of care for residents with dementia**:
<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-16-04.pdf>

<http://www.alzfdn.org/> Official website of the **Alzheimer's Foundation of America**

<http://www.alzstore.com/> The Alzheimer's Store. **Products for caregiving.**

<http://www.alznews.org/Library/InfoManage/Guide.asp?FolderID=53> Alzheimer's Daily News
online newspaper

one writer shares her experience with her father's dementia and the emotions her family feels:
http://www.huffingtonpost.com/lee-woodruff/dementia-grief-and-guilt_b_1231581.html

for a video about the **effect of music on people with dementia** from the point of view of the family members who care about them:

http://www.youtube.com/watch?feature=player_embedded&v=NKDXuCE7LeQ

For a resource on **dealing with dementia when medication is not the answer**, a powerful book is summarized here:

<http://lifeforce-in-later-years.org/LiLY-blogs/Public-Forum-Blog/2010/05/09/guest-blogger-al-power-md-dementia-beyond-drugs/>

From this page you can click on the title of the book, and be taken to the publisher's web site where the book can be purchased.

Frontotemporal Degeneration is a rare and specific **type of dementia** with unique challenges. It is often mis-diagnosed. Access the Association for Frontotemporal Degeneration to learn about this form of dementia:

<https://www.theaftd.org/>

For a series of **brief video presentations on many aspects related to dementia**, presented by an expert from the University of South Carolina's Arnold School of Public Health Office for the Study of Aging and Institute of Medicine and Public Health:

https://www.youtube.com/channel/UC6jHyTO7be_IPyHQaL96kpg/videos

ON AGING AND ELDERCARE

<http://www.ncoa.org/> Official website of the **National Council on Aging**

<http://www.aging-parents-and-elder-care.com/> Clearinghouse for all kinds of information.

<http://www.edenalt.org/> Official website of the **Eden Alternative**, a nonprofit organization dedicated to "de-institutionalizing" the care of elderly people.

For an uplifting view of **graceful aging in one's own home**, with volunteer support, and what you can do to participate:

<http://lifeforce-in-later-years.org>

<http://www.naela.org/Public/> Official website of the National Academy of **Elderlaw Attorneys**

<http://www.asaging.org/index.cfm> Official website for the **American Society on Aging**. Caregivers may join. Offers free web seminars for members and continuing education courses for health care professionals.

Resources for **Veterans needing in-home or nursing home assistance**:

<http://www.va.gov/GERIATRICS/index.asp>

ON END-OF-LIFE CARE: ISSUES AND RESOURCES

The **National Association for Home Care and Hospice**, a nonprofit organization that supports providers of these services and advocates for highest quality of care:

<http://www.nahc.org/>

This site has a wealth of information on the subject.

For a **new resource about end-of-life choices**, links to your state's Advance Healthcare Directives forms and other helpful information:

<https://www.compassionandchoices.org/what-we-do/eolc-resource-center/>

Medicare **Hospice Care is not limited to comfort care**, but includes an array of services if they are needed:

<https://www.medicare.gov/coverage/hospice-care>

Medicare will continue to cover services not related to the terminal condition, even when a person is receiving hospice care:

<https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-hospice-works#:~:text=After%20your%20hospice%20benefit%20starts,terminal%20illness%20and%20related%20conditions.>

End-of-life care is also called **“palliative care”** although the two are not identical in that palliative care can be rendered when one is not in the end stages of an illness. See this site for more information:

<http://www.getpalliativecare.org/>

To learn **how the states are addressing palliative care**, this page links to the full report from the National Academy for State Health Policy, and to state-by-state information:

<https://www.johnahartford.org/events/view/report-advancing-palliative-care-for-adults-with-serious-illness-a-national/>

For **information on governmental, regulatory, and other** references – from what's happening right now in Congress to the Code of Federal Regulations for Hospice and Home Care:

<http://www.nahc.org/resources-services/home-care-and-hospice-links/>

for information about the **basics of home care and hospice, your rights**, and regulatory oversight:

<http://www.nahc.org/consumer-information/home-care-hospice-basics/>

For a “locator” to **help find providers of hospice care**:

<http://www.nahcagencylocator.com/>

or

<http://www.getpalliativecare.org/providers/>

For information from the Alzheimer's Association on the **issues in late-stage dementia** and managing caregiving concerns:

<http://www.alz.org/care/alzheimers-late-end-stage-caregiving.asp>

For information and **resources on palliative care for dementia, end-of-life care**, and related topics, from the Polisher Research Institute:

<http://www.pdcronline.org/index.php>

Medicare coverage of hospice care services:

<http://www.medicare.gov/publications/Pubs/pdf/02154.pdf>