

## 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](mailto: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%201-06-15.mp3>

For a video version of the interview:

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

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## NEW ON Our Mother's Voice LINKS

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/>

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](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=0CMSEIH\\_ONL](https://surveyortraining.cms.hhs.gov/pubs/ClassInformation.aspx?cid=0CMSEIH_ONL)

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

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>

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

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

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>

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>

## 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>

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/20-common-nursing-home-problems/>

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

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

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>

**"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>

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

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

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

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

## **2015 White House Conference on Aging materials:**

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

<http://theconsumervoic.org/uploads/files/issues/WHCOAElderJusticeBriefComments.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://theconsumervoic.org/uploads/files/actions-and-news-updates/WHCoA-statement-on-LTSS.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>

## **Regulations and Regulatory Agencies:**

**NEWS YOU MAY NOT KNOW!** 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/>

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 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-idx?SID=f64b6edcc2b2ee52bf5de8e19a340569&mc=true&node=sp42.5.483.b&rgn=div6#se42.5.483\\_140](https://www.ecfr.gov/cgi-bin/text-idx?SID=f64b6edcc2b2ee52bf5de8e19a340569&mc=true&node=sp42.5.483.b&rgn=div6#se42.5.483_140)

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](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](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](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](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](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](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](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](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](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](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](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](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](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:

<http://www.theconsumervoice.org/ombudsman>

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>

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

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

<http://www.theconsumervoic.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](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](http://consultgerirn.org/topics/hydration_management/want_to_know_more)

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

**NEW 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, 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 over 80% of nursing homes report more coverage by registered nurses than their payroll records show, thus claiming better care than they actually provide. Consumers should refer to Nursing Home Compare only with great caution, if at all. 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://theconsumervoic.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.

**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](http://www.theconsumervoice.org) to learn about various quality initiatives you can support with your voice to Congress.

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://tcombudsman.org/uploads/files/support/nursing-home-discharges-final.pdf>

## **Quality of Care, Quality of Life, and Advocacy – Learning Resources for Consumers & Families:**

**“Resident-directed care”** fact sheet for consumers (What to look for in a nursing facility that provides Quality of Life):

<http://theconsumervoice.org/uploads/files/advocate/Culture-Change-in-Nursing-Homes.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>

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>

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>

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/faq|2|5|6.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>

**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>

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

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

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

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:

[http://www.theconsumervoicework.org/piecing-together-quality-long-term-care/pdf#National\\_Fact\\_Sheets](http://www.theconsumervoicework.org/piecing-together-quality-long-term-care/pdf#National_Fact_Sheets)

and for a **discussion of the guidebook** “Piecing Together Quality Long-Term Care” (book available for sale at <http://theconsumervoicework.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://theconsumervoicework.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://theconsumervoicework.org/uploads/files/family-member/INDIVIDUALIZED\\_ASSESSMENT\\_with\\_Behavior\\_Symptoms.pdf](http://theconsumervoicework.org/uploads/files/family-member/INDIVIDUALIZED_ASSESSMENT_with_Behavior_Symptoms.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/>

And for additional training in **providing oral care for those with dementia**, Oral Health America has this resource:

<https://www.youtube.com/watch?v=jPEQm3Yn33k&list=PLSphHyoZaAmfEnjVt9A9N4LpwgJfA09bl&index=4&t=0s>

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>

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 **tips for choosing a nursing facility**:

[http://theconsumervoicework.org/uploads/files/advocate/Consumer\\_Guide\\_to\\_Choosing\\_a\\_NH.pdf](http://theconsumervoicework.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>

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/>

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/](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>

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

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

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>

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](http://clearinghouse.theconsumervoice.org)

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>

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

**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://theconsumervoices.org/events/2015-consumer-voice-annual-conference/archived>

### **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>

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

[https://www.youtube.com/watch?v=q\\_J-MygPB94](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.ltombudsman.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](https://www.ftc.gov/news-events/blogs/business-blog/2016/06/tsr-update-new-banned-payment-methods-now-effect?utm_source=govdelivery)

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

[http://theconsumervoices.org/uploads/files/long-term-care-recipient/9.\\_How\\_to\\_Solve\\_Problems\\_in\\_a\\_Nursing\\_Home.pdf](http://theconsumervoices.org/uploads/files/long-term-care-recipient/9._How_to_Solve_Problems_in_a_Nursing_Home.pdf)

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 **“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>

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://theconsumervoices.org/uploads/files/actions-and-news-updates/NAELA\\_guide\\_to\\_HCBS\\_settings\\_rule\\_FINAL.pdf](http://theconsumervoices.org/uploads/files/actions-and-news-updates/NAELA_guide_to_HCBS_settings_rule_FINAL.pdf)

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

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

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](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](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/>

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>

Many people do not realize that hospitals often keep patients on "observation status" – which is an outpatient "admission" – thus delaying or even removing the ability for Medicare to pay for in-patient admission to a rehabilitation or long-term care facility once they leave the hospital.

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

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

For answers about **Medicare payments** for nursing home, in-home health care, and hospice care:

Medicare coverage of nursing home services:

<http://www.medicare.gov/Publications/Pubs/pdf/10153.pdf>

Medicare coverage of in-home health care services:

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

Medicare coverage of hospice care services:

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

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/>

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 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](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 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/>

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>

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>

Consumer Voice and NORC 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](http://theconsumervoice.org/uploads/files/issues/Abuse_prezi_with_voiceover.mp4) or as

a clickable presentation without voiceover at

<https://prezi.com/view/VSzKpW4Z0Khre6UUEjW/>. Use the script at [http://theconsumervoice.org/uploads/files/issues/ANE\\_Presi\\_Script\\_FINAL\\_-\\_2018.pdf](http://theconsumervoice.org/uploads/files/issues/ANE_Presi_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](http://theconsumervoice.org/issues/issue_details/proposed-revisions-to-the-federal-nursing-home-regulations#education-materials) and on the NORC website at [http://tcombudsman.org/library/fed\\_laws/federal-nursing-home-regulations#training](http://tcombudsman.org/library/fed_laws/federal-nursing-home-regulations#training).

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>

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](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>

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.”

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

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

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/>

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

[http://theconsumervoicework.org/uploads/files/long-term-care-recipient/CV\\_NCEA\\_Surveillance\\_factsheet\\_web.pdf](http://theconsumervoicework.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>

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>

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/>

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/tccc-issue-alert-nursing-home-staffing-requirements/>

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

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

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

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

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

<http://www.theconsumervoicework.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.theconsumervoicework.org/lcandooaa>

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

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

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

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=upw1&u=6df61ed4fafa7b40055721db3ad0f6dabe20df7a>

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](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](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 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>

## MORE RESOURCES

**ON CAREGIVING**, for family members providing care

<http://www.ageinplace.org/> National collaborative group of professional service providers for **resources and planning for in-home care** for senior citizens.

**AARP's Caregiving Resource Center**:

<http://www.aarp.org/relationships/caregiving-resource-center/?Cmp=NLC-IVS-Caregiving-111711>

<http://www.familycaregiver.org/index-3.html> Family Caregiver **e-magazine**. For all caregivers, whether full- or part-time, in the home or long-distance

<http://www.nfcacares.org/index.cfm> Official website of the **National Family Caregivers Association**. Offers information and support for caregivers.

**Caring for a Loved One with Alzheimer's Disease: A Guide for the Home Caregiver.** Dr. Peter V. Rabins, Johns Hopkins Special Reports. Downloadable at [http://www.johnshopkinshealthalerts.com/special\\_reports/memory\\_reports/HomeCaregiver\\_landing.html](http://www.johnshopkinshealthalerts.com/special_reports/memory_reports/HomeCaregiver_landing.html)

<http://www.leezascareconnection.org/> **Leeza Gibbons' website** dedicated to caregivers.

<http://www.caregiving.org/> Official website of the **National Alliance for Caregiving**

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=2224](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2224) Official website of the **Family Caregiver Alliance**

<http://www.caringtoday.com/> **Caring Today e-magazine**

For an article from AARP chronicling three sisters' experiences in **arranging long-term care** for their mother, both in a facility and at home:

[http://pubs.aarp.org/aarptm/20120607\\_PR?folio=40#article\\_id=167984](http://pubs.aarp.org/aarptm/20120607_PR?folio=40#article_id=167984)

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](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**

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

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

For the **2018 report on Alzheimer's facts and figures** from the Alzheimer's Association:

[https://www.alz.org/documents\\_custom/2018-facts-and-figures.pdf](https://www.alz.org/documents_custom/2018-facts-and-figures.pdf)

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

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

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/>

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://theconsumervoice.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](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-alzhei\\_b\\_8024486.html](http://www.huffingtonpost.com/marie-marley/people-living-with-alzhei_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.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](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](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-MP2lWW4M0>

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](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/I0665/62579/I/WHO\\_MNH\\_MND\\_94.8\\_eng.pdf](http://apps.who.int/iris/bitstream/I0665/62579/I/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](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\\_I PyHQaL96kpg](https://www.youtube.com/channel/UC6jHyTO7be_I PyHQaL96kpg)

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](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](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](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/>

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/>

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>