



## RESOURCES FOR FAMILY MEMBERS

This list includes resources that ombudsmen can use to educate families about nursing facility requirements, assisted living, resident rights, family rights and decision-making, family councils and advocating for quality care.

### Advocating for Quality Care

#### **Consumer Voice Fact Sheets**

Free fact sheets addressing a variety of care issues in the following four categories: selecting a nursing home, getting quality care, residents' rights and family involvement (e.g. Family Involvement in Nursing Home Care, Assessment and Care Planning: The Key to Good Care, Basics of Individualized Care).

<http://www.theconsumervoice.org/familymember/factsheets>

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care and the chapter, "Problem Solving: Being Your Own Advocate" discusses specific tips for self-advocacy.

<http://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

**Consumer Guide - Restraints: The Exception, Not the Rule - A Guide for Residents, Their Families and Friends to Promote Good Care in Place of Restraints in California Nursing Homes.** Sarah Greene Burger. Produced by The National Consumer Voice for Quality Long-Term Care, supported by a grant from the California HealthCare Foundation, based in Oakland, California.

This guide introduces residents, their families and friends to care practices that preclude the use of physical restraints. Although written for California, the information and care practices apply to nursing home care everywhere.

**Available here:** <http://www.theconsumervoice.org/sites/default/files/family-member/NCCNHR-Consumer-Guide-COLOR-FINAL.pdf>

**To order the national guide:** <https://www.theconsumervoice.org/catalog/restraints-the-exception-not-the-rule>

**CA Voices for Quality (additional resources for quality care):**

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

**Piecing Together Quality Long-Term Care: A Consumer's Guide to Choices and Advocacy.** Consumer Voice. 2011.

This guide is designed for the individual who is currently receiving or who may in the future receive long-term services and supports. The purpose is to inform consumers about options for long-term services and supports. Its goal is also to empower - through education - to effectively advocate on one's own behalf.

<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**20 Common Nursing Home Problems—and How to Resolve Them.** Eric M. Carlson. National Senior Citizens Law Center. 2010.

This popular guide explains problems commonly faced by residents and families and gives a clear explanation of the relevant law. It provides instructions on how a resident, family member or advocate should proceed if there's a problem.

<http://www.nslc.org/wp-content/uploads/2011/02/20-Common-Problems-Nov-2010-Final.pdf>

**A Baby Boomer's Guide to Nursing Home Care.** Eric M. Carlson, Katharine Bau Hsiao. National Senior Citizens Law Center. 2006.

This guidebook takes a “nuts and bolts” approach to explaining the laws that protect nursing home residents and providing practical advice on how residents and their families can obtain the best nursing home care possible. *Available on Amazon.com and by other retailers.*

### **Advancing Excellence in America's Nursing Homes**

Consumer fact sheets on the following topics are available: pressure ulcers, restraints, pain, advance care planning, consistent assignment, staff retention, resident/family satisfaction and staff satisfaction. In addition, the *Advancing Excellence Guide for Consumer Participation* provides Family/Friend Worksheets on pressure ulcers, physical restraints, pain, resident and family satisfaction, and consistent assignment that build on the consumer fact sheets. The worksheets are designed to help families share key information about a loved one with nursing home staff and engage in a dialogue about how that information can be applied to a loved one's care.

[http://www.nhqualitycampaign.org/star\\_index.aspx?controls=consumer](http://www.nhqualitycampaign.org/star_index.aspx?controls=consumer)

### **Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes.**

Alzheimer's Association. 2006.

These care recommendations define goals in six care areas and present strategies for achieving them.

[http://www.alz.org/national/documents/brochure\\_dcprrphases1n2.pdf](http://www.alz.org/national/documents/brochure_dcprrphases1n2.pdf)

### **Hartford Institute for Geriatric Nursing**

This website serves as an online resource for geriatric nurses. It includes information on many care areas. While the website is designed for nurses, the information can be very helpful to families.

<http://consultgerirn.org/resources>

### **Quality Improvement Organizations (QIOs)**

This website provides quality improvement information including resources and interventions developed by CMS.

**CMS QIO webpage:** <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityImprovementOrgs/index.html?redirect=/qualityimprovementorgs>

**Quality Net webpage (consumers can find their state QIO in the QIO directory):**

<http://www.qualitynet.org/dcs/ContentServer?c=Page&pagename=QnetPublic%2FPage%2FQnetHomePage&cid=1120143435363>

### **Assisted Living and Board and Care**

Unlike nursing homes, assisted living facilities (also known as board and care homes) do not have federal requirements; therefore, assisted living facilities regulations vary by state. The resources below provide advocacy tips and information regarding assisted living.

### **National Consumer Voice for Quality Long-Term Care (Consumer Voice) - Assisted Living Information**

*Working with Families:*

*Tips for Effective Communication and Strategies for Challenging Situations*

<http://www.theconsumervoice.org/resident/assisted-living/quality-care>

**National Long-Term Care Ombudsman Resource Center (NORC) - Assisted Living Issue page**

<http://www.ltombudsman.org/issues/assisted-living>

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<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Assisted Living Consumer Alliance**

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

**Assisted Living State Regulatory Review.** National Center for Assisted Living.

<http://www.ahcancal.org/ncal/resources/Pages/AssistedLivingRegulations.aspx>

**Assisted Living Regulations and Licensing.** Assisted Living Federation of America (ALFA).

[http://www.alfa.org/alfa/State\\_Regulations\\_and\\_Licensing\\_Informat.asp](http://www.alfa.org/alfa/State_Regulations_and_Licensing_Informat.asp)

**NH Regulations Plus.** University of Minnesota. State Regulations by State (including state assisted living regulations).

[http://www.hpm.umn.edu/nhregsplus/NHRegs\\_by\\_State/By%20State%20Main.html](http://www.hpm.umn.edu/nhregsplus/NHRegs_by_State/By%20State%20Main.html)

**Effective Communication and Problem Solving Skills**

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care by discussing scenarios, sharing tips and resources for self-advocacy (e.g. Chapter 7- Problem Solving: Being Your Own Advocate), providing information regarding assessments and care plans and suggestions about providing helpful information to facility staff (e.g. Appendix 4" "I Want to Tell You About My Mother...").

<https://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

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<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Tips for Effective Family Communication with Long-Term Care Staff and Administration.** Robyn Grant.

This short PowerPoint with speaking notes covers some of the communication techniques (I-statements, reflective listening, etc.) that are particularly helpful for problem solving. Includes some practice exercises.

*Working with Families:*

*Tips for Effective Communication and Strategies for Challenging Situations*

<https://www.ltombudsman.org/sites/default/files/norc/communication-for-families.ppt>

**20 Common Nursing Home Problems—and How to Resolve Them.** Eric M. Carlson. National Senior Citizens Law Center. 2010.

This popular guide explains problems commonly faced by residents and families and gives a clear explanation of the relevant law. It provides instructions on how a resident, family member or advocate should proceed if there's a problem.

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**Guidelines for Presenting the Problem and PHI Coaching Approach<sup>SM</sup> to Communication.** PHI. Adapted from the PHI Coaching Approach<sup>SM</sup> to Supervision, with permission of the PHI, 2013.

[www.PHInational.org](http://www.PHInational.org)

These handouts provide helpful suggestions that families can use when speaking with facility staff about a concern.

<https://www.ltombudsman.org/sites/default/files/norc/guidelines-for-presenting-the-problem.pdf>

### **Missouri Miscommunication Training**

Developed by the Missouri LTCOP for Regional Volunteer Ombudsmen.

This material which was developed for ombudsmen can be adapted for teaching families how to avoid miscommunication.

[http://www.ltombudsman.org/ombudsman-support/training#Training\\_Programs\\_and\\_In-services](http://www.ltombudsman.org/ombudsman-support/training#Training_Programs_and_In-services)  
(under “Communication”)

### **Family Councils**

#### **National Consumer Voice for Quality Long-Term Care (Consumer Voice)**

A wide range of materials regarding family councils is available Family Council Center on the Consumer Voice website. The resources include family council tips, laws and regulations, fact sheets, DVDs, manuals developed by ombudsman programs and citizen advocacy groups around the country, and more. Families can also join a free listserv available just for family council members.

**Family Council Center:** <http://www.theconsumervoice.org/familymember/family-council-center>

**Family Member webpage:** <http://www.theconsumervoice.org/familymember>

**Family Council Brochure.** Consumer Voice. 2010.

This brochure addresses empowered, effective and independent family councils. The brochure includes information about what a family council is, rights and best practices, resources and grant opportunities, and examples of family council activities. <http://www.ltombudsman.org/sites/default/files/2010-Family-Council-Brochure%281%29.pdf>

**Supporting Family Council Development.** Consumer Voice.

This training provides tips and ideas for developing and supporting family councils and an overview of nursing home regulations regarding family councils.

*Working with Families:*

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<http://www.ltombudsman.org/sites/default/files/norc/issues/RR09-Training-Supporting-Fam-Council-Dev.pdf>

**Long-Term Care Ombudsman Guide to Developing and Supporting Family Councils.** Robyn Grant.  
<http://www.ltombudsman.org/sites/default/files/norc/issues/Omb-and-Family-Councils-LAFMC.pdf>

### **Family rights, Role, and Decision-making**

**Family Rights and Decision-making.** Robyn Grant.

This handout lists the rights that a family member of a nursing home resident has under federal law, talks about decision-making and powers of attorney, and outlines ways that families can support and empower a loved one.

<https://www.ltombudsman.org/sites/default/files/norc/family-member-rights-and-decision-making.pdf>

### **Nursing Facility Requirements**

**Federal Nursing Home Reform Act from the Omnibus Budget Reconciliation Act of 1987 or simply OBRA '87 SUMMARY.** Hollis Turnham. The National Consumer Voice for Quality Long-Term Care (Consumer Voice) *formerly NCCNHR*.

This summary discusses what OBRA is, how it came about and describes the major residents' rights provisions that are part of the law.

<http://www.ltombudsman.org/NORC-Library#laws> (titled "Summary" under "Nursing Home Reform Law of 1987")

**Nursing Homes: Getting Good Care There.** Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. Consumer Voice. 2<sup>nd</sup> edition. 2002.

This book discusses how to advocate for quality nursing home care.

<https://www.theconsumervoice.org/catalog/nursing-home-getting-good-care-there>

**Residents' Rights: An Overview.** Consumer Voice. 2011.

This fact sheet provides a description of residents' rights under the federal Nursing Home Reform Law.

<http://www.theconsumervoice.org/sites/default/files/resident/nursing-home/resident-rights-an-overview.pdf>

**Involuntary Transfer and Discharge.** Consumer Voice. 2007. National Consumer Voice for Quality Long-Term Care (Consumer Voice).

This fact sheet describes the federal protections that residents have in involuntary transfer/discharge situations.

[http://www.theconsumervoice.org/sites/default/files/advocate/advocacy-groups/involuntary transfer and discharge -7-08 update.pdf](http://www.theconsumervoice.org/sites/default/files/advocate/advocacy-groups/involuntary%20transfer%20and%20discharge%20-7-08%20update.pdf)

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<http://www.theconsumervoice.org/piecing-together-quality-long-term-care>

**Nursing Homes Regulations Plus.** University of Minnesota.

Families can learn about federal nursing home regulations and their own state nursing home regulations on this website, which can be searched by topic.

<http://www.hpm.umn.edu/nhregsplus/>

**Federal Interpretive Guidelines.** Centers for Medicare & Medicaid Services.

The guidelines can educate families about what the nursing home should be doing and help identify questions to ask regarding nursing home life and care.

[http://www.cms.hhs.gov/manuals/Downloads/som107ap\\_pp\\_guidelines\\_ltcf.pdf](http://www.cms.hhs.gov/manuals/Downloads/som107ap_pp_guidelines_ltcf.pdf)

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