Effective Advocacy in Long-Term Care Settings

A Team Approach

Shannon Cupka, Education and Outreach Coordinator Long-Term Care Ombudsman Program New Mexico Aging and Long-Term Services Department



The Facts



National Data

- By 2030, the number of Americans aged 65 and older will more than double to 71 million older Americans, comprising roughly 20 percent of the U.S. population
- In some states, those over age 65 will equal roughly 25% of the population¹
- Trends indicate that for persons >25, there is a 1 in 4 chance of at least one nursing home stay during their lifetime²
- 78.2 million/7918

New Mexico Data

- Fastest growth rate is of those over 85.
- More than 38,000 New Mexicans suffer from dementia related illnesses.
- More than 13,000 New Mexicans age 65 and older suffer from depression.
- More than 12,000 New Mexicans live in LTC facilities.
- By 2030, individuals over 65 will out number those under 18.
- Center for Disease Control and Prevention and The Merck Company Foundation. The State of Aging and Health in America 2007. Retrieved 9/6/07 from www.cdc.gov/aging
- 2. National Long Term Care Ombudsman Resource Center. Retrieved 9/7/07 from: http://www.ltcombudsman.org/uploads/ODRwebStats0205.pdf
- 3. http://www.census.gov/popest/national

Aging Gracefully?

- Mission: The right service to the right person in the right setting
- Issues
 - Patient-hood vs. Person-hood
 - Surplus Safety vs. Dignity of Risk
 - Choice/Control and Independence
- Change the "Culture of Aging"
 - Presently "Just Don't Do It"
 - Long-term services not just for elders
 - Shared Voice

What are the tools of Advocacy?

- 1. Be Informed
- 2. Be Prepared
- 3. Be Present
- 4. Be Creative
- 5. Be Heard



Be Informed Quality of Care: Helpful Websites

Facility Quality

- www.medicare.gov *
 - Resource Locator Nursing Home, Home Health, Hospital Compare sites
 - CMS Facility 5 star rating system

New Mexico & Federal Regulations

- http://www.health.state.nm.us/HFLC/HFLCregindex.html
 - Regulations Governing NM Health Care Facilities
- http://dhi.health.state.nm.us/elibrary/regulations.php
- http://dhi.health.state.nm.us/providersearch/index.php
 - -Survey results, locate licensed residential care and nursing facilities

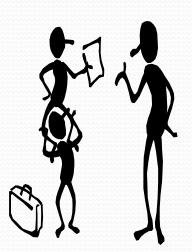
Rights, Advocacy and Quality Improvement

- www.theconsumervoice.org
 - Consumer Guides and Fact Sheets on Advocating for Good Care
 - National Ombudsman Locator
- http://assistedlivingconsumers.org

Guidebooks for Choosing a Facility

Medicare/Medicaid information

http://www.cms.hhs.gov



Request to see latest facility survey report!!

Finding the right place: What does one look for?

Environment

- appearance & cleanliness
- sounds, smells, temperature, etc
- home-like? personal possessions?

• Staff

- day/evening/weekend ratio of staff to residents
- Interaction: staff to resident, staff to staff, nametags worn?
- response time to call lights, requests for assistance
- training, availability of medical staff

Services/Policies

- included and add-on costs
- for special needs (e.g. therapies, dementia care, etc)
- discharge policies when care needs exceed facility's scope

• Activities

- posted activity calendar, observation
- gender-appropriate, multigenerational?
- variety/indoor-outdoor
- for bed or room-bound residents?

Residents

- appearance/grooming
- care planning/assessments
- engagement
- resident feedback

Licensing

- annual survey 9-15 month window, complaint surveys as needed
- indicators of care important to you e.g. infection control, pain management, medication administration

Meals

- choice? appetizing? variety? accommodate special dietary needs? alternatives? snacks?
- assistance with feeding

<u>Other</u>

- safety: smoke detectors, sprinklers, handrails
- turnover rates staff, administration
- unannounced visits

Be Prepared: What Resources are available for Long-Term Care/Benefits/Legal Decisions?

Aging and Disability Resource Center

- 1-800-432-2080
- http://www.nmaging.state.nm.us/Resource_Center.html
- http://www.nmresourcedirectory.org/

Consumer and Elder Rights Division - Benefits Counseling Programs, SHIP (state health insurance program), Senior Medicare Patrol

• 1-800-432-2080

Ombudsman Program

- Santa Fe: 1-866-451-2901
- Albuquerque: 1-866-842-9230
- Las Cruces: 1-800-762-8690

Senior Citizen's Law Office/Lawyer Referral for the Elderly Program

 505-265-2300
 1-800-876-6657

 www.sclo.net
 www.nmbar.org

Protecting Vulnerable Adults in Long-Term Care Facilities FACILITIES PROTECTIVE SERVICES CONTINUUM

Who: Caregivers

Ombudsman

APS

DOH/ HFLC*

Law Enforcement

Direct What: Hands-on assistance

Resident advocacy **Choices/Wishes Citations Investigations** Fines

Complaint investigations **Fines**

Annual& Complaint surveys Citations **Fines**

Prosecution Litigation

*HFLC = Health Facilities Licensing and Certification

Facilities Joint Protocol

New Mexico's 2003 Public Health Act states "The department (DOH) shall develop a health facilities protocol in conjunctionto ensure the health, safety and rights of individuals in health facilities.

- Department of Health
- Adult Protective Services
- Ombudsman
- •Human Services Department (Medicaid Fraud)

New Mexico LONG-TERM CARE OMBUDSMAN PROGRAM

Resident-Centered Advocacy Services

"To the world you may be one person, but to one person you may be the world"

~Anonymous

SCOPE OF THE OMBUDSMAN PROGRAM

- Federal & State Mandates
 - OAA
 - NM Long-Term Care Ombudsman Act
- Health Oversight Agency
- Authority to:
 - Conduct Investigations (overt, undercover, with "granny cams")
 - Access Medical Records
 - Assess Civil Monetary Penalties
- Systemic Advocacy
 - Community Education & Outreach
 - Facility In-service training
 - Legislative Advocacy

How we are different...

- Not regulators
- Facility access anytime, <u>for any reason</u>
- Can enter unlicensed facilities
- Can make recommendations for change
- Can negotiate a family/facility crisis
- Can contest an inappropriate discharge
- Resident-centered vs. Systems-centered



What is the role of an Ombudsman?

- **"Carrier of the Message"**
 - ⇒Finds out the resident's wishes/concerns
 - ⇒Advocates on behalf of the resident
- An Ombudsman investigates and resolves complaints and works towards empowering the resident
- An Ombudsman is <u>independent</u> of the long-term care facility
- Services are free and confidential

Rights of Residents

Long-Term Care residents have special rights; they are in addition to the rights we all have as citizens of the U.S.

- Fairness
- Freedom
- Choice
- Privacy

AND....

The <u>Right</u> to live in the least restrictive setting possible

Transition Advocacy Program: Background

- National trend toward Home and Community-Based Services
- In NM Managed Medicaid in operation since 2008
- Ombudsman program began transition advocacy services to:
 - Protect a resident's <u>right</u> to receive care in least restrictive setting possible
 - Promote communication and cooperation between all entities involved in discharge planning
 - Ensure that resident has a voice throughout the process
- Services are free. <u>Any</u> individual who wishes to transition to a less restrictive care setting, or return home, may request our services.

How the process works...



- Self-referral, referral through family or facility social services staff
- We meet with Resident to discuss:
 - His/her wish to return to the community
 - Our role in the transition*
 - Potential barriers/needs for successful transition *
- We discuss potential discharge with various entities
 - Type of transition to take place and technical assistance needed
 - Facility has ultimate responsibility to ensure a safe and appropriate discharge
- Post-discharge follow-up
 - Resident Permission
 - Up to 6 months (in-person, telephonically)

*Not every discharge will require our involvement *We promise a voice, we do not promise a particular outcome

Be Present: How can individuals and their loved ones ensure good care?

- Visit, Visit, Visit, Visit!
 - Different days, different times
- Participate in care plan meetings, physician visits, discharge planning, home health assessments
- Become familiar with standards of care and Resident's Rights
- Get to know the Ombudsman



Resolving Concerns/Complaints

Who can I call with concerns/complaints?

- Department of Health: 1-800-752-8649
- Adult Protective Services : 1-866-654-3219
- Ombudsman: 1-866-842-9230

Helpful Hints

- "Constructive Complaining"
 - identify which person can answer your questions
 - timing and approach
- What to Mention
 - who/what/where/when/what time?
 - one time vs. recurrent issues
- Request a care plan meeting

Be Creative: How can one participate in a loved one's care?

- Primary vs. Secondary Caregiver Roles
- Help caregivers know a loved one's "story"
 - (interests, habits, beliefs, likes/dislikes)
- Create a feeling of home
- Volunteer in the Activities Program
- Bring civic/social/spiritual organization to the facility

Be Heard: How can one participate in civic action and systems advocacy?

- Resident or Family Councils
- Federal & State Legislative efforts
- Join the Aging Network
- Become a LTC Ombudsman and advocate for residents



For More Information:

New Mexico Long-Term Care Ombudsman Program

Santa Fe & Northeastern NM: 1-866-451-2901

Albuquerque & Northwestern NM: 1-866-842-9230

Las Cruces & Southern NM: 1-800-762-8690