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NAVIGATING CARE SYSTEMS FOR AGING LOVED ONES

EXPLORING INSURANCE, CARE OPTIONS, AND ADVOCACY

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Our Mission

Patient Advocate Foundation (PAF) is a national 501(c)(3) non-profit organization, which provides case management services and financial aid to patients with chronic, life-threatening and debilitating illnesses.

Our History

PAF was founded in 1996 by Nancy Davenport-Ennis and co-founded by John H. (Jack) Ennis to help address the issues faced by patients like their friend Cheryl Grimmel, who had to battle not only her breast cancer but for access to affordable treatments. In PAF's first year, Nancy and a part-time volunteer staff of 2 provided case management assistance to 157 patients who faced barriers to prescribed care. Fast forward to 2024 and we've provided direct, hands-on help to more than 2.2 million patients nationwide.

PAF Engagement Areas



Case Management



Co-Pay Relief Program



**Financial Assistance
Services**



**Patient Education
& Communications**



**Health Equity &
Community Engagement**



Patient Impact



Special Events



**Health Services, Research,
Patient Experience &
Evaluation**

Who This Webinar is For

- Adult children of aging parents
- Spouses of aging partners
- Family caregivers facing new challenges
- Anyone preparing for future care decisions



What We'll Cover Today

- Understanding the care continuum and your options
- How Medicare and insurance coverage works across different settings
- Practical resources for finding quality care
- Essential advance directive planning
- Common challenges and ways to overcome them
- Advocacy Tips
- Resource Takeaways



THE LONG -TERM CARE LANDSCAPE



Setting the Scene



Understanding the Care Continuum

- Aging in Place (Home-Based Care)
 - Independent living with support services
 - Home health aides and nursing visits
 - Adult day programs
 - Family caregiver support



Understanding the Care Continuum

- **Community-Based Options**
 - Senior centers and meal programs
 - Transportation services
 - Respite care programs
 - PACE (Program of All-Inclusive Care for the Elderly)



Understanding the Care Continuum

- Residential Care Settings
 - Independent living communities
 - Assisted living facilities
 - Memory care units
 - Continuing Care Retirement Communities (CCRCs)



Understanding the Care Continuum

Skilled Care Facilities

- Nursing homes (skilled nursing facilities)
- Rehabilitation centers
- Hospice care (home or facility-based)





MEDICARE AND INSURANCE COVERAGE



Medicare Basics for Long-Term Care

- What Medicare DOES Cover:
 - Skilled nursing facility care (up to 100 days per benefit period with conditions)
 - Home health care (when medically necessary and intermittent)
 - Hospice care
 - Durable medical equipment
 - Some rehabilitation services



Medicare Basics for Long-Term Care

- What Medicare DOES NOT Cover:
 - Custodial care (help with daily activities like bathing, dressing)
 - Long -term nursing home stays
 - Most assisted living costs
 - Adult day care programs
 - Home modifications for safety



Coverage By Care Setting

Home-Based Care Coverage

- **Medicare Part A:** Skilled home health visits (nursing, therapy)
- **Medicare Part B:** Medical equipment, some services
- **Medicare Advantage:** May include additional home care benefits
- **Medicaid:** Extensive home and community -based services (income/asset limits apply)



Coverage By Care Setting

Assisted Living Coverage

- **Medicare:** does not cover room and board
 - Medicare may cover specific medical services provided in facility
- **Medicaid:** May cover services in some states through waiver programs
- **Private insurance:** Rarely covers assisted living
- **Long-term care insurance:** Often covers assisted living



Coverage By Care Setting

Skilled Nursing Facility Coverage

- **Medicare Part A:** Days 1-20 fully covered, Days 21 - 100 with copay (\$200/day in 2024)
- **Must meet specific criteria:** 3-day hospital stay, need for skilled care
- **Medicaid:** Covers long -term nursing home care (after spending down assets)
- **Private pay:** \$6,000 - \$15,000+ monthly depending on location



Coverage By Care Setting

Memory Care Coverage

- **Similar to assisted living for coverage**
- **Medicaid may cover through specialized waiver programs**
- **Long-term care insurance:** Often includes memory care benefits
- **Veterans' benefits:** May provide additional support



Understanding Medicaid for Long-Term Care

- Asset and income limits vary by state
- Look-back period of 5 years for asset transfers
- Spousal impoverishment protections
- Home and Community-Based Services (HCBS) waivers
- Application process can take 3-6 months



Private Insurance Options

Long -Term Care Insurance

- Traditional policies vs. hybrid life insurance products
- Best purchased while healthy and younger
- Review existing policies for benefits

Life Insurance with Long-Term Care Riders

- Growing option for middle-income families
- Provides flexibility if long-term care isn't needed





FINDING QUALITY CARE RESOURCES



Government Resources

- **Medicare.gov Care Compare:** Compare nursing homes, home health agencies
- **Eldercare Locator (eldercare.acl.gov):** Local services by zip code
- **State Department of Health inspection reports**
- **Area Agency on Aging:** Local resource hub
- **SHIP (State Health Insurance Assistance Program):** Free Medicare counseling



Professional Assessment Services

- **Geriatric care managers:** Professional advocates and coordinators
- **Hospital discharge planners:** Help with transitions
- **Social workers:** Navigate complex systems
- **Elder law attorneys:** Legal and financial planning



Evaluation Criteria for LTC Facilities

- Staffing ratios and turnover rates
- Inspection histories and complaint records
- Licensing and accreditation status
- Financial stability of the organization
- Cultural fit and philosophy of care
- Location and family access



Questions to Ask Any Care Provider

- What is your staff-to-resident ratio?
- How do you handle medical emergencies?
- What happens if care needs change?
- Can you provide references from current families?
- What are your policies on family involvement?



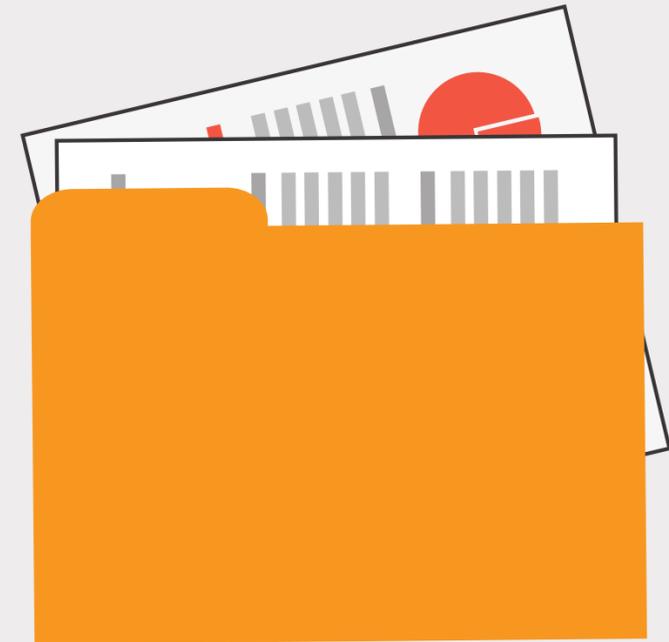


ADVANCE DIRECTIVES AND LEGAL PLANNING



Essential Documents Every Family Needs

- **Healthcare Power of Attorney (Healthcare Proxy):**
Names decision -maker
- **Living Will:** Outlines treatment preferences
- **POLST (Physician Orders for Life-Sustaining Treatment):** Medical orders for current conditions
- **HIPAA Authorization:** Allows information sharing



Financial and Legal Documents

- **Financial Power of Attorney:** Manages finances and benefits
- **Will and Testament:** Asset distribution
- **Trust documents:** May protect assets and provide flexibility
- **Representative Payee forms:** For Social Security benefits



Having “The Conversation”

Timing Matters

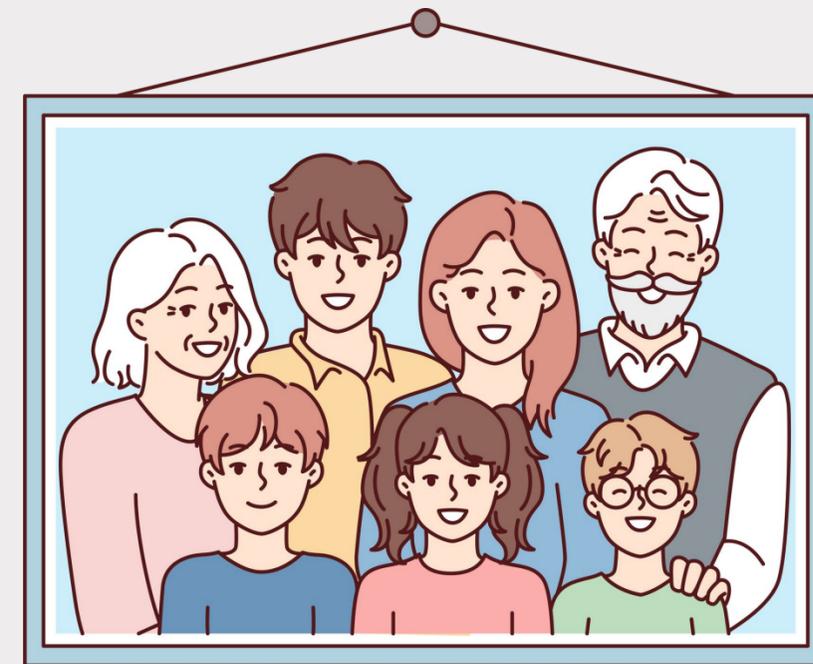
- Begin discussions while your loved one is cognitively able
- Don't wait for a crisis
- Revisit decisions as health changes



Having “The Conversation”

Key Topics to Discuss

- Values and priorities for end-of-life care
- Preferred living situations
- Financial resources and concerns
- Family roles and responsibilities
- Healthcare decision-making preferences



Having “The Conversation”

Making it Easier

- Use conversation starter tools (The Conversation Project, Five Wishes)
- Involve healthcare providers in discussions
- Document decisions clearly and share with family
- Review and update regularly





COMMON CHALLENGES AND SOLUTIONS



Challenge 1: Resistance to Care

Why It Happens:

- Fear of losing independence
- Denial about changing abilities
- Past negative experiences
- Financial concerns

Strategies That Work:

- Start with small, non-threatening services
- Involve your loved one in decision-making
- Focus on maintaining independence, not taking it away
- Address safety concerns without being alarming
- Consider professional assessment to validate needs



Challenge 2: Family Disagreements

Common Sources of Conflict:

- Different perceptions of needs
- Unequal caregiving responsibilities
- Financial disagreements
- Geographic distances

Resolution Approaches:

- Hold family meetings with neutral facilitators
- Get professional assessments to guide decisions
- Clearly define roles and responsibilities
- Consider hiring geriatric care managers
- Use written agreements to document decisions



Challenge 3: Financial Stress

Managing Costs:

- Apply for all available benefits (Medicaid, Veterans, local programs)
- Explore community resources and volunteer services
- Consider family pooling resources
- Look into reverse mortgages for homeowners
- Investigate long-term care insurance benefits

Budget Planning:

- Create realistic monthly care budgets
- Plan for increasing care needs over time
- Set aside emergency funds for unexpected needs
- Explore cost-sharing with siblings



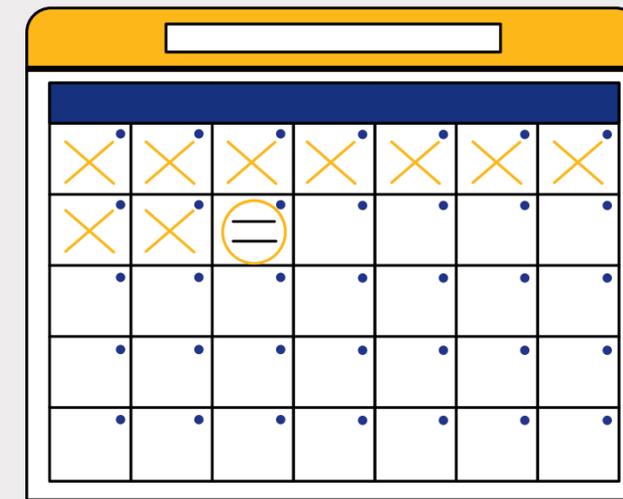
Challenge 4: Managing Multiple Providers

Coordination Strategies:

- Maintain a central medical information file
- Use patient portal systems when available
- Bring comprehensive medication lists to all appointments
- Ask for care coordination services
- Consider hiring a geriatric care manager

Communication Tools:

- Shared calendars for family members
- Medical information binders
- Contact lists for all providers



Challenge 5: Caregiver Burnout

Recognizing the Signs:

- Physical exhaustion
- Emotional overwhelm
- Social isolation
- Health problems
- Resentment or guilt

Prevention and Solutions:

- Accept help from others
- Use respite care services regularly
- Join caregiver support groups
- Maintain your own health appointments
- Set realistic expectations
- Consider professional care earlier rather than later





ADVOCATING FOR YOUR LOVED ONE



Building Your Advocacy Skills

Preparation is Key

- Keep detailed records of all interactions
- Bring written lists of questions and concerns
- Research beforehand to ask informed questions
- Bring a second person to important meetings when possible



Building Your Advocacy Skills

Effective Communication Strategies

- Be specific about problems and needs
- Request written summaries of important conversations
- Follow up on promises and commitments (and hold others accountable!)



Building Your Advocacy Skills

Know Your Rights

- Right to information about care and treatment
- Right to participate in care planning
- Right to file complaints and appeals
- Right to change providers or facilities



KEY TAKEAWAYS

- Start planning before care services are needed
- You have more options and resources than you might think
- Advocacy skills can be learned and improved
- It's okay to ask for help- professional and personal
- Plans should be flexible and regularly updated



QUESTIONS?

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