LTC Information Series

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Dedicated To Long Term Care Medicine

The Younger Adult

in the Long Term Care Setting

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III. CASE STUDIES

I. WHY A TOOL KIT ON YOUNGER ADULTS IN LONG TERM CARE?

Mina is 42. She has multiple psychiatric diagnoses, including schizophrenia and schizoaffective disorder, with multiple psychiatric hospitalizations and suicide attempts since age 18. She ambulates, makes delusional statements, keeps to herself, and needs prompting to do activities of daily living. She looks like she is in her 60s.

Frank is 62. He required ongoing care of extensive leg wounds and continues to have recurrent cellulitis owing to poor self-care. He is unable to manage his diabetes, cannot walk well, and requires increasing help with activities of daily living. His short rehabilitation stay is being extended because of a lack of discharge options.

Jackie is 27 years old. She has Huntington's disease (HD) and her family cannot manage her anymore.

Martin is 22. A spinal cord injury after an automobile accident left him a quadriplegic and requiring a tracheostomy. He requires heavy physical care but also psychologic interventions because he is angry, belligerent, demanding, and often nonadherent.

Mina, Frank, Jackie, and Martin are the faces of a growing population in long term care (LTC). When we think of the typical LTC resident, people like Mina, Frank, Jackie, and Martin do not come to mind. The "typical" resident averages 79 years of age at admission (more than half are over 85) and is three times as likely to be female as male.[1] Increasingly, however, we need to expand our understanding of the LTC population to include those adults under age 65 or even under age 50.

LTC is no longer synonymous with "geriatric care." In fact, in the past 10 years, adults aged 31 to 64 years have been the fastest growing population in LTC facilities.[2] Although the United States as a whole is graying and LTC facilities are still filled with the oldest of the old, the latest trend in LTC is an increasing percentage of younger adults. In the period from 2000 to 2007, LTC facility use declined among older adults (aged 65 and older) in more than two-thirds of states and the District of Columbia, but increased among working-age adults (aged 31 to 64 years) in all but two states.[3] The last national LTC survey sponsored by the CDC in 2008 estimated that nearly 12% of LTC residents are aged less than 65 years.[4]

Who Are the Younger Residents in Long Term Care?

For this tool kit, we define **younger** as those aged 18 to 64 years. Although some individuals under 18 years of age require LTC services, very few of them are housed in traditional LTC settings. Children under 18 are generally cared for at home or in community-based homes that receive government funding. The younger adults group includes **middle-aged** adults, who are those aged between 50 and 64 years. Younger and middle-aged adults are differentiated from their older counterparts in more ways than merely age, and this poses unique challenges and opportunities. For example, the clinical syndromes afflicting the various groups differ. Compared with older residents, younger adults in LTC have more diagnoses related to mental retardation and developmental disabilities and a higher prevalence of hemiplegia and quadriplegia, especially related to trauma.[5] Middle-aged adults in LTC facilities suffer an increased prevalence of chronic disorders, such as cerebrovascular accident, Alzheimer's disease, Parkinson's disease, peripheral vascular disease, and cardiac diseases (in a study in which middle-aged was defined as 45 to 64 years).[5] Psychiatric diagnoses are significantly higher among middle-aged adults in LTC settings, and these adults are more likely to have residential histories of prior stays in psychiatric facilities than are older adults.[6]

Younger adults are demographically different as well. Males are overrepresented among younger LTC populations compared with older populations, which are predominantly female. Data from the 2004 National Nursing Home Survey showed that the chance a man under 65 was institutionalized was 7.3/10,000 compared with 6.4/10,000 for a woman. By comparison, the rate for an elderly (65 years and older) man was 223.3/10,000 and that for an elderly woman was 463.8/10,000. Black and Hispanic/Latino individuals of all ages were less likely to be institutionalized than whites, but among those under age 65, blacks were twice as often institutionalized (11.9/10,000 for blacks compared with 6.3/10,000 for whites).[4] In another study of 45 states and the District of Columbia, black middle-aged adults were shown to be overrepresented in LTC facilities relative to their share of the state population.[6]

Younger adults also seem to come with increased costs of care and less funding for that care. Some younger residents have much longer stays than older residents, and younger residents may be more likely to be funded by Medicaid. Overall, the youngest LTC residents are the most costly to care for as measured by the RUG-III (Resource Utilization Groups, Version III) case-mix index.[5]

In general, younger LTC residents fall into four general groups on the basis of the etiology of their illnesses and disabilities, and each of these groups requires different approaches by LTC staff.[7] The main categories of younger adults are those with

- illnesses from capricious fate, including chronic, progressive, psychiatric, or neurologic illnesses such as multiple sclerosis (MS), Huntington's Disease (HD), amyotrophic lateral sclerosis (ALS), or schizophrenia that they have been coping with for years;
- illness and possibly institutionalization from birth or childhood; or
- a sudden onset of physical problems related to injury (such as a traumatic brain injury), misfortune, or lifestyle choices.

what Are the goals of this tool kit?

Questions to be considered by LTC organizations in the care of younger adults include the following: 1) What are the needs and goals of care for these residents? 2) How will these residents' psychologic, social, psychiatric, sexual, and other basic human needs be met? 3) How do facilities assist younger residents in coping with the possibility of spending 30, 40, or even 50 years or more in a LTC facility? 4) What activities does the facility offer specifically for younger adults?

Ideally, well-conducted studies would answer these questions, but such studies are lacking. Literature searches reveal only a few articles, most of which relied on expert opinion, discussed cases only, or provided comparisons on only a narrow aspect of care. In the absence of a strong evidence base, we instead conducted a survey of the AMDA membership, interviewed some younger adults residing in skilled nursing facilities around the country, and convened a group of experts to review the literature and their experiences to develop a set of best practices. These LTC experts included AMDA medical directors as well as psychologists, social workers, and nurses who have successfully cared for younger residents in the LTC setting. We shared challenging cases and found common threads in our analysis of ways to deal with these challenges. We have mirrored this analytic approach in this tool kit by presenting a case, describing the challenges, and sharing the strategies we used successfully under similar circumstances to help residents to become happy and productive members of their communities.

Although each individual has unique needs, it is important to develop a framework that enables any care provider to formulate individualized treatment and care plans. This tool kit serves that purpose and assists in identifying and prioritizing needs to obtain optimal outcomes for each resident. The tool kit is designed for use by all professionals of the interdisciplinary team, including practitioners and medical directors, social workers, nurse clinicians and administrators, psychologists, and recreational and rehabilitation professionals, and aims to be practical rather than theoretical. The tool kit also addresses problem-solving methodology that can be applied to other populations and concerns within the LTC field. Specifically, the goals of this tool kit are

- to expand our view about what a LTC resident "looks like,"
- to provide a resource for managing difficult cases in LTC settings along with care planning tips and effective interventions, and
- to identify best practices and specific tools used by facilities with a higher proportion of younger residents that can be adapted to other settings.

This tool kit is organized initially around one case—a young man named Martin—and follows some of the challenges faced in his care from his admission through his eventual successful integration into the life of the facility. In the second half of the tool kit, other cases highlight problems and solutions encountered in caring for various subpopulations of younger adults. The tool kit also includes a brief discussion of the roles of the medical director and the interdisciplinary team in best practices and concludes with recommendations and a resource list.

Throughout the tool kit, references are made to supplemental resources that are available online. These online resources can be accessed through AMDA's Clinical Corners page.[a]

Martin's case:

Martin is referred to the LTC facility from a local hospital. He is 22 and had suffered a spinal cord injury following an automobile accident that left him a quadriplegic and requiring a tracheostomy. He has Medicaid for LTC services only, but the application for long term health care and disability benefits has been started. Martin spent a protracted time in the hospital. He required intensive care because of his multiple comorbidities, and therefore no facility wanted to accept him. Will you accept him?

On the one hand, your facility needs admissions because you have too many empty beds. On the other hand, is your facility equipped to care for Martin? Before you answer, consider some of the barriers that your facility may encounter when accepting and caring for a younger resident like Martin (See Table 1).

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[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

TABLE 1. Barriers to Accepting and Caring for Younger Residents

BARRiERs

Clinical

- LTC practitioners, who are often geriatricians, may not be experienced in the care of younger populations.
- Clinical staff may lack expertise and perhaps even interest in managing the conditions or diagnoses of younger residents.
- Some conditions, such as pregnancy and sexually transmitted infections, are less common in elderly LTC populations.
- Transition to palliative care and “allow natural death” orders are particularly challenging in younger residents.
- Younger residents may have medication regimens that are unfamiliar to staff.

Financial

- Reimbursement issues may pose problems (e.g., locking up a bed for a long time. with a resident who has high demands and low reimbursement).
- Younger residents may require greater physical care but have intact cognition and therefore more preferences or demands; the combination can be resource-intensive and expensive.
- Funding or insurance may not cover specialty treatments.
- Fewer younger adults have Medicare funding.
- Immigrants or younger adults without a work history may have “LTC only Medicaid.” These residents cannot be discharged unless they are well enough to live without health insurance or income. This type of insurance doesn’t pay for out-of-facility consultation services, except in emergencies, which limits the services the resident can receive.
- Facilities may have to work to obtain SSI and SSDI for residents if there is any chance of discharge.
- Financial risk related to litigious or risky behaviors is higher.

Novel Psychosocial and Behavioral

- Variable life experiences and maturity; greater diversity of needs.
- Visitors/family with little experience of health care facilities, let alone the highly rule-governed LTC setting.
- Behavioral and personality issues that are unfamiliar to many LTC practitioners
- Sexually inappropriate activity or advances.
- Minor children or parents as decision makers.
- Increased rate of developmental disability and mental illness.
- Different life stages, expectations, and hopes.
- Vices (sex, drugs, rock and roll, and crime) with which staff may lack practical coping experience.
- Higher risk of aggression toward other residents, staff, or property.
- Potentially varying sleep-wake cycles.
- Impact of technology and social media on activities, psyche, and expectations.
- Potentially problematic visitor behavior or presentation.

Regulatory

- Federal and state regulations are not designed for younger populations.
- MDS screening and assessments are not validated for younger residents.

(continued)

TABLE 1. (Continued)
Barriers to Accepting and Caring for Younger Residents

- Federal and state regulations are not designed for extensive stays in LTC facilities.
- Challenges exist in developing policies that address younger residents' needs while maintaining safety.

Practical

- Younger residents may resent or dislike elderly people, or have very limited experience with older people, and want to be with similarly aged peers.
- Appropriate activities are needed for younger residents that meet developmental needs and interests.
- Space requirements are greater (younger residents have more stuff—e.g., power wheelchairs, computers).
- Younger residents may be physically stronger.
- Because the number of younger residents may be low in any facility, it is unlikely that a therapeutic (i.e., age-based) cluster will be developed. Therefore, the skill set required for the care of this type of resident may be difficult. The specificity of the plan of care for these individuals is then of utmost importance.

Staffing

- Staff may have been attracted to LTC by a desire to care for older people—therefore, caring for younger people requires a change in mindset toward the job and with respect to the rewards of caring for younger residents.
- Boundaries can be a struggle when caregivers and residents are similarly aged or when residents are younger, which may evoke feelings of a parental relationship.
- Privacy may be a concern—residents may intrude into the personal lives and work of staff.
- Aggressive or highly mobile younger residents can pose a safety threat.
- Power wheelchairs can be hard on the environment and require maintenance.
- Heavy physical care may cause staff injuries.
- Younger residents may be very adept at projective identification ("pushing the buttons") of staff and other residents, causing conflict and chaos.
- Displacement—staff dealing with their own children or family members with similar behaviors may react to residents on the basis of their experience.
- Staff may be less familiar with technology compared with younger residents.

Reputation

- Younger male residents or visitors may frighten older residents (and their families).
- Younger and older residents may or may not mix well.
- Younger residents may be visible or troublesome and may reduce the curb appeal of the facility or make it difficult to attract volunteers.
- Families of younger individuals may be reluctant to place their loved ones in an "old folks' home"—even when the finances, emotions, and health of family caregivers have been exhausted.
- It is very difficult to "get rid of" problematic young residents who know their rights.

LTC, long term care; MDS, minimum data set; SSI, supplemental security income; SSDI, social security disability insurance.

See also: Hall et al, 2012.[8]

II. Best PRActIces FRom tHe eXPeRts

Martin’s case:

You decide that you need to fill the bed and you hope that Martin will be here only a little while. Within the first week, you begin to second-guess your decision. You see that Martin had some contact with the mental health system as a teenager and may have a history of alcohol or drug problems. His family is not involved. He requires heavy care, shouts aggressive and profane things at staff, and often refuses interaction. All he wants to do is smoke and be left alone.

Younger residents pose special challenges in the LTC setting, but the successful management of these adults can bring great rewards as well. Little has been written on research-based strategies for dealing with younger residents in institutional LTC settings, but those writing and thinking on the topic and successfully caring for these individuals have identified certain strategies that often bring success. These best practices can be summarized as follows:

- Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.
- Take a long term perspective.

Each of these strategies or best practices is discussed in turn in this section of the tool kit.

1. Best PRActIces: IdentIFY IndIVIdUAl PeRsPectIVes tHAt InFoRm needs And wAnts

Best Practices:

u Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.
- Take a long term perspective.

Martin’s case:

Martin was 22 when he suffered a spinal cord injury that left him a quadriplegic and required him to undergo a tracheostomy.

In caring for Martin, it is important to consider his perspective as a young man who experienced an unexpected tragedy that changed his life suddenly and permanently.

Just as he was becoming independent, he became dependent. His hopes and dreams for the future likely feel futile. Caring for Martin begins with understanding him as an individual. This strategy of treating people as individuals to understand their unique points of view and perspectives is the key to understanding and managing behavior and quality of life and is not unique to younger adults. When dealing with younger residents, however, it is critical to understand the unique aspects of their life experience, such as cohort effects, developmental tasks, and common feelings about developing a chronic illness while so young.

Cohort or Generational Differences

It is important when dealing with younger residents to understand cohort differences, which, simply put, are differences between people of various generations in perspectives, priorities, approaches to problems, and preferences. If Martin is admitted in 2013 at 22 years of age, he was born in 1991. Other more typical residents of the facility may be aged 65 years (born in 1948), 80 years (born in 1933), or 90 years (born in 1923). The older residents are part of the Silent Generation born mostly before World War II (born 1922–1943). This generation is characterized by values such as respect for authority, loyalty, hard work, and sacrifice for the common good. Their preferred activities, the music that excites and interests them, and the television shows and movies they love and relate to, all are substantially different from those for a younger person. The older generation may have different social or political ideas about race, sexual orientation, immigration, fashion, and music. In contrast, the growing population of younger residents may belong to the Baby Boomer, Generation X, or Millennial generations. The Baby Boomers (born approximately 1943–1960) are associated with a sense of security, which left room for exploration and protest. They place a high value on youth, personal gratification, health, and material wealth, and are generally optimistic. They value hope and peace and believe that their generation changed the world. Martin's parents are Baby Boomers, and understanding their perspective will help you to understand him as well. The Generation X cohort (born 1965–1980) desires balance in their lives, views diversity as the norm, is motivated by money, is self-reliant, and values free time and fun. They are the first generation to embrace the personal computer and the Internet. Martin belongs to the Millennial generation (1980–2000), which is characterized by use of and access to global information via the World Wide Web, loyalty to peers and family, and relationship with technology as a social medium. They are the most globally oriented generation and are interested in health, exercise, and body adornment (tattoos, piercings). This is a generation raised on reality shows, MySpace, Facebook, and Twitter; the narcissism of constant self-promotion; and many associations that are often superficial.

In their own words:

"I advocate for myself more than [the older residents] do, and sometimes the staff think I am being a pain.''

Imagine Martin being admitted to a facility of his grandparents' generation. The Silent Generation populates many LTC facilities, with mostly female older adults with medical needs. Even without asking, we can understand that Martin may feel out of place and have a sense that others cannot possibly understand how he feels. Martin may lack a strong social support network. If his family could care for him, they likely would, but the fact that he is in a LTC facility suggests that he cannot go home. He may struggle with where "home" is. He may identify his home as being with his friends, whereas his parents, rushing back to help care for him, may feel that his real home is with them. The few other younger people he sees in the facility will not feel "like him" and he will often find them "freaky" and different. There may also be personality conflicts between the younger residents, such as competition between them to be "special" within the facility and, perhaps, pressure from the staff to hang out together. Some of the residents Martin sees may have developmental delays or chronic medical illnesses; others may be disfigured and repulse him, and some who look more normal may actually be very impaired mentally.

In their own words:

"The cognitive impairments of other residents makes it hard to find people to talk about politics or current events with.''

Residents like Martin give us a sense of the future of health care, where there has been a shift from compliant, patient, and paternalistic care to a greater focus on the individual, autonomy, and choice. As this applies to LTC, a shift from generally compliant (e.g., respectful of authority and sacrifice) Silent Generation residents to Baby Boomers (greater focus on protest and personal gratification) may result in different and likely greater demands for control in care and less compliance with facility rules. Caring for a resident like Martin can tap into the parental feelings of caregivers, who can become attached and may play out issues related to parenting. These could be negative, such as a paternalistic over-control or over-mothering, or positive, such as investment in and celebration of success. At the same time, Martin, who was in the process of becoming an adult, may rebel against what he perceives as his being "treated like a child" again. This may worsen an already difficult transition for Martin in adapting to being cared for when he had been striving for independence. The interaction between these two possible staff and resident reactions may lead to much conflict.

The Importance of Privacy

One issue that is often mentioned by staff caring for younger residents and by the younger residents themselves is the importance of privacy. Having or wanting a private room was mentioned in nearly every survey we received from younger residents. The importance of privacy is seconded by other professionals in the field as well. In their experience with a nursing unit for younger adults in Toronto, Canada, Edney at al[9] found that younger adults do better in long term care if they have more space and privacy. Not all facilities have private rooms. In the absence of these, selection of a roommate is important. Sometimes a severely impaired roommate with minimal communication ability can be a good choice, because this permits the younger resident to be an advocate and to watch out for a peer. Considering care and sleep schedules can help to ensure good roommate selection. Some facilities have had success in grouping younger adults in a separate wing, which allows staff selection and activities appropriate to this cohort.

The Importance of Age-Appropriate Activities

To meet the requirement for age-appropriate activities, separate activity programs are often needed for the young adults. Younger residents often ask for entertainment and activities that don't interest elderly residents, and they want these on a regular basis.[10] If several younger residents live at the facility and have some compatibility, they can form a community and activities can be geared to them. If there are only one or two residents, then staff can develop alternatives, such as making good use of the Internet or making it possible for younger residents to connect with nearby peers. (See Case #17, page 72, for a detailed discussion of activities for young adults.)

Developmental Stages

Young adults in our cultural understanding are meant to be free, leaving and separating from the family and establishing their own identities, goals, dreams, relationships, and families. When this is interrupted by illness or trauma, younger residents may feel as if they have failed and must now return to a state of dependence on their parents or others. Familiarity with developmental stages can help us to understand younger residents and what informs their needs and behaviors.

From a psychologic perspective, one model that illustrates the challenges of maintaining a younger long term resident's well-being is that of Erik Erikson. He presented a series of stages of development illustrated in Table 2.

TABLE 2. Erikson stages of Development

stage	Basic Conflict	important Events	Outcome
Infancy (birth to 18 months)	Trust vs. Mistrust	Feeding	Children develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust.
Early Childhood (2 to 3 years)	Autonomy vs. Shame and Doubt	Toilet Training	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy; failure results in feelings of shame and doubt.
Preschool (3 to 5 years)	Initiative vs. Guilt	Exploration	Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.
School Age (6 to 11 years)	Industry vs. Inferiority	School	Children need to cope with new social and academic demands. Success leads to a sense of competence, whereas failure results in feelings of inferiority.
Adolescence (12 to 18 years)	Identity vs. Role Confusion	Social Relationships	Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to oneself, whereas failure leads to role confusion and a weak sense of self.
Young Adulthood (19 to 40 years)	Intimacy vs. Isolation	Relationships	Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, whereas failure results in loneliness and isolation.
Middle Adulthood (40 to 65 years)	Generativity vs. Stagnation	Work and Parenthood	Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, whereas failure results in shallow involvement in the world.
Maturity (65 to death)	Ego Integrity vs. Despair	Reflection on Life	Older adults need to look back on life and feel a sense of fulfillment. Success at this stage leads to feelings of wisdom, whereas failure results in regret, bitterness, and despair.

Although some of these stages refer to younger ages of children, they also inform the struggles that occur in adults who are forced into a period of dependency, which may trigger a regressive trend.[11] After a catastrophic loss of function, the younger resident may revisit a previously resolved (or negatively resolved) basic conflict. For example, a resident who had managed some success in developing his or her identity and had perhaps been working, thus consolidating a sense of industry, may have lost the ability to work and also to relate to others in the manner he or she had established. As a result, inferiority and role confusion may occur, even in a resident who is well beyond the ages at which these issues were primary. Even very basic conflicts related to infancy and early childhood may be reawakened as the resident copes with again relying on others for such basic care as toileting and feeding and the extreme dependence and vulnerability associated with this. Those who have engaged in substance abuse in their younger years may also have missed developmental milestones, as have those with developmental disability or severe childhood illness. As the result of losses and impairments, the resident may be facing isolation, stagnation, regret over past actions, and despair—either as a reaction to his or her losses or as a now-heightened probability as the resident ages in the context of those losses and subsequent institutionalization.

Older or “typical” LTC residents (i.e., aged over 65 years) are more likely to have resolved the majority of Erikson’s stages and, because decline is anticipated, may cope better with it. A history of successful work, relationships, and life experiences equips individuals with the coping skills to deal with loss. Younger residents, in contrast, may not have had successful relationships, jobs, or a sense of purpose and may lack durable social supports or coping skills. They need to find a new role in the world regardless of whether their old role or identity was successful. Their experience informs their behaviors, goals, needs, struggles, and the ways we need to work with them to move them forward.

Younger residents may have less-mature psychologic coping skills and defenses than older residents, which presents both a challenge and an opportunity for growth. In general, ego development may be seen as a progression from a more childlike or teenager-like impulsivity, self-absorption, and stereotypical thinking to a more adult stage of capacity for introspection, appreciation for individual differences, and greater conceptual complexity in later stages.[12] Parallel to this is a generally age-related progression of development of defense mechanisms.

Defense mechanisms (or coping styles) are automatic psychologic processes that protect individuals from anxiety and awareness of internal or external dangers or stressors.[13] Defense mechanisms may serve to manipulate, deny, or distort reality. Immature defenses like projection (attributing your own feelings to others; e.g., “I feel bad about myself – you hate me”), denial, and acting out are typically seen in the very young. Mature defenses like altruism and humor allow acceptance of difficult circumstances without the distortion inherent in immature defenses.[14]

Because of more mature ego development and defenses, older residents may be more tolerant of the numerous challenges involved in institutional life, as well as exhibiting the Silent Generation cohort traits of respect for authority, loyalty, hard work, and sacrifice for the common good. In contrast, the more individualistic and demanding cohort traits of younger groups, coupled with expectedly less mature ego development, defenses, and life stage resolutions and needs, may present a much bigger challenge in the LTC setting. In some cases, where generally healthy psychologic development has occurred, residents may employ the same processes and resulting resilience to adapt to their new circumstances and to continue to mature. In others, where psychologic development has been less healthy, residents may respond to the regression that may be triggered to re-work past conflicts, ideally in a healthier manner. In some cases, poor resolution of past conflicts and developmental tasks may even be exaggerated by institutionalization and personality disorder traits may manifest.

The Unique Perspectives of Younger Adults With Disability and Chronic Illness

Disability in a younger adult has a different meaning—life interrupted—than does disability in older adults. Social disengagement theory suggests that mutual withdrawal between an individual and society is inevitable with aging. Young disabled residents in LTC, however, experience this social withdrawal and disengagement prematurely. Such social disengagement at an early age critically impacts the quality of life of younger residents.[15] Social withdrawal may be aggravated for a resident who is the only younger resident in the facility.

In Martin's case, it isn't difficult to guess at what may be informing his behavior. Suffering a catastrophic accident with permanent loss of mobility results in huge emotional difficulties, and acclimation can take months or years, or not occur at all. Young people who become ill or disabled suddenly and unexpectedly are grappling concurrently with LTC facility admission; new physical dependence and embarrassment; and losses such as a future they can readily imagine, independence, and ability to procreate, achieve a satisfying relationship, excel in a job, and realize the American dream. Those whose lifestyle contributed to their illness and who were not functioning well in society have even more challenges functioning in the LTC community.[7]

Tips for Addressing Developmental Issues

How can we begin to address these developmental issues to help residents to better imagine themselves in a successful future? One approach is a mentoring program in which those with disabilities meet more functional adults with similar disabilities and have a chance to talk about the adaptation, strategies, and potentialities. These relationships may occur spontaneously or may need to be staged. Many younger residents surveyed said that they achieved joy in helping others to adapt to disability through these kinds of relationships. Group therapy, shared activities, and buddy programs are all ways to make this happen. A chance to see severely disabled people who live in the community can be helpful.

Regardless of age, when encountering difficult residents, the basic conflicts of the relational stages (Intimacy vs. Isolation and even Identity vs. Role Confusion) may often be very effective points of intervention (and likely were not resolved positively in the past). When the resident is engaged by staff and meaningful connections are developed, many "difficult" behaviors may decrease and the resident's quality of life may improve. (See the section *2. Best Practices: Facilitate Appropriate Relationships Between Residents and Staff*, page 13, for further discussion.)

2. Best PRActIces: FAcIlItAte APPRoPRIAte RelAtIonsHIPs Between ResIdents And stAFF

Best Practices:

- Identify individual perspectives that inform needs and wants.
- u Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.
- Take a long term perspective.

Martin's case:

Martin has adjusted a bit, but is still unfriendly to most staff, who may call in sick when asked to care for him . He continues to yell at the staff to leave him alone, therefore not allowing proper turning or bowel hygiene care . He has, however, bonded with a few staff members and he permits them to give him care . But these staff members are fatigued and resentful about having to do "all the work ."

Relationships have the power to heal. Developing relationships between residents, families, and caregivers is the most important component of mutual satisfaction with care and can be more important than the physical environment in creating a sense of well-being.[16] These relationships can be challenging in an environment with high turnover and rotating assignments, but are critical for younger residents to integrate into the life of the facility. Later, they develop relationships with other residents and begin to form a sense of community.

In their own words:

"They are so irritating, but once you are around people so long, you start to care about what happens to them.''

Social interactions and mutual relationships with staff are the glue of caregiving and contribute to caregiver job satisfaction and much-improved quality of life and adherence to facility norms for residents. As caregivers and residents form bonds, they can better identify needs and the best strategies to meet them and achieve facility objectives.

How do relationships blossom? Consistent assignments are key: if staff personnel are constantly rotating, they have little time to get to know the residents. Set the relationship as a goal and work to overcome barriers. In our case, tell Martin, “The only way you will ever do well here is to find someone you like who can be your friend—someone to advocate for you, to watch out for you, to laugh with. Which staff member connects best with you?” Observe which staff member works best with Martin and reward him or her with, perhaps, one less resident assignment or a public mention. Make staff feel that improvements in Martin are directly attributable to their work. Write a care plan goal to develop at least one mutual relationship with staff. Train staff on the importance of relationships and specific strategies that work to develop relationships. These could include checking in with residents frequently, even if not necessary; showing interest in what they have to say; bringing up in conversation good times from the past or memories they have shared with you; reassuring them that providing care is not distasteful to you; developing special routines or inside jokes; and advocating for their needs. Also train staff on habits that can destroy relationships, such as inconsistent behavior from one day to the next, harsh tone or words, speaking about one resident to another, talking too much about the staff member’s personal life, speaking negatively about care, or implying that the resident is hard to care for.

> In their own words:
>
> “Sometimes staff get upset because they have so much work to do, but others appreciate that listening first makes everything else go smoothly.’’

Take the Time to Listen

Spending time listening carefully to concerns and identifying unmet needs are the first steps in negotiating a win-win strategy. As noted in a focus group interview conducted by Persson and Ostwald in their survey of younger residents and the staff who care for them in eight Texas LTC facilities, the most effective strategies in caring for young residents are to learn more about them, talk to them, and listen to them.[17] One staff member noted, “Sometimes, they just want to talk. They don’t want to *do,* they want to talk. And you’ve got to have at least 15 minutes to sit there and listen to their wants and needs.” Listening involves giving your full attention, even if for only a few minutes. Studies in medical malpractice suggest that listening, spending time sitting, and giving your full attention, even if only for 20 seconds, reap huge dividends in reduced malpractice suits and higher satisfaction.[18,19]

Acknowledge and validate the resident’s point of view as expressed both verbally and nonverbally. Put words to difficult feelings and normalize them. “I bet sometimes you think your life is over—all the stuff you like to do, ride motorcycles, run track—it seems it was all taken away so quickly and you may feel there is nothing left.” Or listening may involve just being silent, being with the resident in his or her emotion.

When it is time to talk about your point of view, use the resident’s own words or examples from their experiences to communicate. If he says, “I hate her; she is so annoying with her scratchy voice!”, say, “Listen, I know you hate when the physical therapist comes here, and you find her voice and manner annoying. You’re not the first one to say that, but I have to tell you she has done wonders for others like you.” Alternatively you could say, “Remember, you were kind of annoyed by that old roommate of yours, but once you got to know him, he didn’t bother you so much. Maybe that will happen again! Give it a try. You wanted to learn to use the mouthstick better, and I think in two weeks you could meet that goal.”

Make sure that listening time occurs on a routine basis. Do not fall into the trap of only listening when the resident is complaining. This may inadvertently increase complaining because this is the only chance a resident has to interact with you. In one facility, a younger resident began to manufacture all sorts of somatic complaints, getting more and more outlandish, because he wanted to see the nurse more often. The team developed a care plan that monitored the resident for complaints. If the resident did not complain for an entire shift, he was given 10 minutes with the staff at the end of the shift to chat, which effectively used staff time as a reinforcement.

Create a Therapeutic Milieu

Milieu therapy is based on the theory that an individual can rely on his or her own inner strengths to change undesirable behaviors. A therapeutic milieu means that all members of the community use all contacts with residents and each other to model effective communication, conflict resolution, and caring. It is as if staff are always on a stage and residents are the audience; a therapeutic milieu asks staff to use every interaction to model excellence. For example, residents see the way that staff personnel interact with their peers. Harsh words spoken or overt conflict can cause agitation among those observing. Agitation in one resident can be contagious, spreading to others in the environment. Likewise, if the milieu is calm, supportive, and pleasant, the residents are more likely to feel safe and comfortable.[20] That is, the environment should be therapeutic, modeling proper communications, respectful interactions, friendliness, self-motivation, forgiveness, and unconditional caring. Autonomy and personal responsibility are key elements, but there is also the assumption that social interactions can benefit the individual.[21]

Such an approach may especially benefit younger residents who have substance abuse and lifestyle issues. Although a frequent response may be “We’re not a psych facility” or “We don’t have time to do that,” careful examination of the time spent dealing with complaints, behavioral problems, and other time-consuming responses to negative behavior may shift this view. Many behavior problems, especially in younger, generally cognitively intact residents, are iatrogenic (i.e., created by lack of therapeutic milieu). With increasing numbers of younger residents, failure to change traditional approaches will result in more time spent for poorer outcomes.

3. Best Practices: Anticipate Cognitive Problems

Best Practices:

- Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- ➢ Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.
- Take a long term perspective.

Martin's case:

Martin repeats the same thing over and over and gets angry when asked questions. His answers are short and often hostile, or he may refuse to answer. He tells you his thinking is fine and follows this with choice expletives. You notice he speaks in short sentences and sometimes forgets why he has called staff to help him, but blames others for their shortcomings.

Cognitive problems often underlie behavioral problems and may be under-recognized in LTC, especially among younger residents. Martin may or may not be aware of having cognitive problems; however, it is likely his cognition is not normal. Also, with many forms of cognitive impairment, word usage may remain good. Confabulation in cases where we have little information may serve to mask deficits with younger adults who "sound good." Thus, a tendency may exist to view them as more cognitively intact than they are. This is often evident when residents try to negotiate novel situations, either in their environment (rare in the structured setting of life) or on structured cognitive assessments.

Almost all traumas serious enough to cause LTC placement can result in some brain damage, and many younger residents have conditions that affect cognition (e.g., smoking, seizures, head injuries, alcohol or drug use, MS, HD). If feasible, a comprehensive neurocognitive exam can assist the interdisciplinary team early in the care planning for a new resident. If this sort of comprehensive neuropsychologic evaluation can be funded, or even tolerated, by the resident, it can be quite informative. In most cases, however, a neuropsychologic screen like the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) or Cognistat or cognitive assessment via the Wechsler Adult Intelligence Scale (WAIS) III is adequate to identify cognitive deficits and is also likely more available and billable under the Neurobehavioral Status Exam CPT codes or psychologic testing.

Pinpointing the resident's cognitive difficulties assists the interdisciplinary team in anticipating situations that will be difficult for him or her. This can enable the team to alter the environment or provide the supports necessary to decrease toxic stimuli and create opportunities for success. Although the assessment rarely identifies who is competent versus incompetent to make all types of decisions, a good assessment will identify where a resident's critical thinking and problem solving are intact and where they are not. Such assessment also serves to quantify or identify deficiencies not already evident, which can further serve to provide justification for the level of care and reimbursement. If such testing in not available, an occupational therapist can do some cognitive testing that will shed light on some of these factors. See Box 1 on Cognitive Screening Guidelines for Younger Adults.

BOX 1. Cognitive screening Guidelines for Younger Adults

Screening tools can identify who may experience further cognitive decline and need prompt evaluation by a neuropsychologist. No single tool fits all, and given the wide range of diseases that younger adults in LTC settings have, it may take a professional neuropsychologic evaluation that incorporates several different approaches depending on the physical disabilities and attention deficits of the individual being tested. Make every effort to get a copy of any neuropsychologic testing that has been done prior to admission.

All residents are screened as part of the Minimum Data Set (MDS) process by use of the Brief Interview for Mental Status (BIMS). Standard cognitive screens such as the BIMS and Mini-Mental State Examination (MMSE) can be helpful if the deficits are profound and the scores are low; however, too often, the scores on these cognitive screening tests are “high” when the resident’s function is clearly lower. Data from a poster presented at the 2011 California Association of Long Term Care Medicine meeting[22] found that in a sample of 30 residents whose mean age was 54 years (range, 26–76 years) with severe non-Alzheimer’s type dementia (per clinical assessment), 12 (40%) were classified by the BIMS as cognitively intact, 15 (50%) were classified as having moderate impairment, and three (10%) were correctly classified with severe impairment. The average BIMS score was 11.13 (range, 3–15). The RBANS had been attempted on 11 of the sample residents, with three failing to complete. Scaled scores ranged from 45 to 79, with percentages of less than 0.1% to 8% (seven of the eight scores were less than 1%). A concern with the BIMS may be that a very easy task was created, thus leading to false-negative results (i.e., impaired people incorrectly identified as cognitively intact).

Another concern, especially for younger adults who spend a longer time in LTC, is the issue of residents learning the test (practice effect) as a result of one form of a brief test being repeated quarterly or more for the MDS 3.0. Anecdotal reports from some administering the BIMS have been that, upon stating their purpose, they hear “sock, blue, bed” before even beginning the test. Although somewhat more extensive, the MMSE appears to have similar limitations to those of the BIMS, particularly with non-Alzheimer’s dementia. These tests have not been validated for use with younger populations or with other types of dementia that are less progressive and more associated with disturbances in executive function (e.g., traumatic brain injury, Acquired Immune Deficiency Syndrome [AIDS] dementia, HD).

Some other screening tools that can be used by licensed staff other than psychologists, with training in the ethical and proper use and interpretation of such tools include the following:

- Clock Drawing Test—assesses a wide range of cognitive abilities including executive functions and is quick and easy to administer and score.[23]
- Cognistat Exam—a cognitive screening instrument that assesses the five major ability areas: language, spatial skills, memory, calculations, and reasoning. Available at: http://www.cognistat.com/about-exam (Accessed 01/31/13).

(continued)

BOX 1. (Continued)
Cognitive screening Guidelines for Younger Adults

- MoCA (Montreal Cognitive Assessment tool)—a cognitive screening test designed to assist in the detection of mild cognitive impairment that is relatively short and easy to use. Available at: http://www.mocatest.org/ (Accessed 01/31/13).
- RBANS—helps to determine the neuropsychologic status of adults aged 20 through 89 years who have neurologic injury or disease such as dementia, head injury, and stroke. Available at: http://www.pearsonassessments.com/pai/ (Accessed 02/28/13).
- SLUMS (Saint Louis University Mental Status) Examination—a brief oral and written exam given to people who are suspected of having dementia or Alzheimer's Disease. The exam serves as a tool to indicate whether a doctor should consider further testing to diagnose dementia. Available at: http://www.elderguru.com/download-the-slums-dementia-alzheimers-test-exam/ (Accessed 01/31/13).

4. Best PRActIces: mAke FAcIlItY PolIcIes And BeHAVIoRAl mAnAgement PRActIcAl

Best Practices:

- Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- u Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.
- Take a long term perspective.

Martin's case:

Martin is thought to be a "problem resident." He makes frequent complaints and demands and can be mean or degrading to staff by using offensive language. He often doesn't adhere to his plan of care and pushes the boundaries of what is allowed. He doesn't want to engage in activities and has few friends within the facility.

Martin is ineligible for a power wheelchair financed by Medicaid while a resident of a LTC facility. He purchases a scooter-type chair on Craigslist that is not really safe for him, but insists that the staff place him in it. They do a few times and he immediately leaves the facility and comes back drunk with cigarette burns on his finger and thigh (dropped it).

He is counseled about the risks of the chair. One day, he slips and falls from it on the street. Another day, the battery dies and he calls the facility, asking them to pick him up.

Martin also runs errands for other residents—he may give them a little help by letting them hang onto his scooter, buying them food, or taking them out for a smoke. Neighbors complain that he looks scary on the street and ask you to "contain him." You notice, however, that Martin is happier with the chair, complains less, and demands less of staff.

His scooter breaks and he returns to the manual wheelchair. After having the powered one, he misses his freedom and autonomy, and he becomes depressed and more irritable with staff. Someone dies in the facility and a wheelchair is donated. The wheelchair fits Martin. The staff ask that he be permitted to use it because they find him so challenging when confined to the manual wheelchair. The facility allows him to have it after making some agreements with him about how he will use it; however, he is soon speeding around the corners too fast and bumping into others and still going out daily to smoke and panhandle and run errands for his friends. He also decides he wants to go back to school and take a few classes toward his GED.

Young adults, especially those with more cognitive ability, are widely believed to be more demanding, have high expectations, and find institutional life constricting and frustrating. Often, they are coping with significant losses, dealing with feelings of anger and withdrawal, and acting out. In addressing these problems, we have already talked about laying the groundwork. That is, understanding Martin's needs for control and autonomy and to feel like an adult, and the impact the trauma had on his life trajectory and goals. We have established that he has some cognitive decline and preferences for some staff. We are pleased that staff members are choosing to advocate for him to improve his quality of life by obtaining a borrowed power wheelchair; however, we are still left with some problematic behaviors, both within the walls of the facility and outside its boundaries. When addressing these behaviors, staff should strive to both be honest and practical.

Honestly Convey the Facility's Point of View and Focus on Health Care and Safety

This case highlights many situations that make those in a LTC facility uncomfortable. LTC professionals are accustomed to more control over residents; most residents do not stray far from the facility because they are ill or disabled, don't desire to do so, or perhaps are more likely to passively accept the rules and advice of the facility. Although Martin perceives himself as an adult making his own choices, LTC professionals and the courts look at him as a vulnerable, disabled, dependent adult and hold the facility and its staff somewhat accountable for his safety. How do we resolve this conflict in expectations? Experience suggests that the best approach is less paternalistic and more of a risk sharing. Honest discussion of these two reasonable viewpoints is needed and an attempt should be made to find common ground. Also needed is clear documentation of a resident's decision-making ability or limitations. As LTC professionals, we must be honest with Martin about the perspective of the facility. The facility has limited resources and authority, liability concerns, and the imperative to comply with regulations both for safety and resident rights.

Federal Regulations and Resident Rights

Although striving to be homelike, LTC environments are not home, and people in the LTC environment cannot do what they want all the time. The facility bears the liability for issues that pose a safety risk. In addition, although residents may be permitted to endanger themselves with their decisions (e.g., the right to refuse care), their rights end when the safety of other residents or staff is threatened. Thus, facilities are faced with the challenge of respecting the human rights of each resident in accordance with federal and state laws, while at the same time nurturing a sound and safe environment for both the residents and staff and complying with current federal regulations.

LTC facilities are governed by a complex set of state and federal regulations. Federal regulations, originating in 1975, are often called OBRA or F-tags, but are more precisely defined as the Code of Federal Regulations (CFR) (42CFR483.1-483.75). Additionally, states have their own regulations. Federal regulations have precedence over state regulations, but state regulations may add to federal regulations or address issues not accounted for by them. Once a person is admitted under the umbrella of LTC, all federal and state regulations apply, regardless of age. With longer stays and different needs and expectations, this can create challenges when dealing with younger adults. For example, Section §483.10 of the Center for Medicare and Medicaid Services (CMS) State Operations Manual (SOM)[24] states that "the resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility." But rights such as free choice (42 CFR 483.10[d]),[24] privacy (483.10[e]),[24] grievances, access and visitation, personal property, and married couples (all 483.10)[24] may be exercised quite differently by younger residents than by older residents and may raise issues when the exercising of these rights places the individual, staff, or facility at risk. Self-determination, accommodation of needs, and dignity (all of which are in 42 CFR 483.15[24]) may also raise issues. The F-tags most likely to impact younger adults are listed in Table 3.

TABLE 3. Federal Tags Relevant to Young Adults With a Focus on Care Plans, Choices, Activities, and Quality of Care

F151	Exercise Rights/Vote/Free of Coercion
F152	Resident Competency
F154	Informed of Health Status/Medical Condition
F155	Right to Refuse Treatment/Research **F156**
	Inform of Services/Charges/Legal Rights
F157	Notify of Accidents/Sig Changes/Transfers
F164	Privacy and Confidentiality
F165	Voice Grievances without Reprisal
F166	Facility Resolves Resident Grievances
F172	Access and Visitation
F176	Self-administration of Drugs
F223	Abuse
F224	Staff Treatment of Residents
F240	Facility Promotes/Enhances Quality of Life

(continued)

TABLE 3. (Continued)
Federal Tags Relevant to Young Adults With a Focus on Care Plans, Choices, Activities, and Quality of Care

F241	Dignity
F242	Self-determination-Resident Makes Choices
F244	Facility Listen/Responds to Res/Family Groups
F245	Resident Participation in Activities
F246	Accommodation of Needs and Preferences
F248	Activity Program Meets Individual Needs
F252	Safe/Clean/Comfortable/Homelike Environment
F280	Development/Prep/Review of Comprehensive Care Plans
F309	Necessary Care for Highest Practical Well Being
F311	Resident Treatment to Improve/Maintain ADLs
F314	Treatment to Prevent Pressure Ulcers
F323	Facility Free of Accidents and Hazards
F325	Maintain Nutritional Status/Therapeutic Diet
F329	Free from Unnecessary Drugs
F500	Use of Outside Professional Resources

ADLs, activities of daily living.
Sources:
www.nursinghomepro.com (Accessed 01/29/13)
Barnett, 2008.[10]
Edelman, 2010.[25]

Violating the rights outlined in the CFR will result in a deficiency, unless clear reasons exist to do so. The facility is less likely to be cited for a violation of rights if they carefully document the link between the behavior and the consequence, the concern for safety, alternatives, and compassion to the resident. The documentation needs to identify the facility's right to withhold assistance for an unsafe practice. (For more information, see the section *Violation of Rights*, page 28.) Conversely, the facility is less likely to be cited for deficiency in safety if they clearly document that the resident has the capacity to understand and has been informed of risks and alternatives and is exercising his or her right to make a poor decision.

When analyzing the conflicts that can arise when balancing the rights of younger residents with risk and safety, it is important to look at safety and risk in an analytical way. First, which part of the risk impacts just the individual and which impacts others? For example, a resident has the right to refuse to have his own leg amputated, even if it risks death. This action impacts him personally. If he has the capacity, he has the right to refuse treatment. In contrast, who is at risk if he chooses to go out of the facility to buy snack foods for another resident on a modified diet? Who is at risk if he helps a peer who would otherwise be unable to go out into the community by using his power wheelchair as an "engine?" In this case, one resident exercising his rights to move and shop is violating the safety of another resident. When a resident's exercise of his own rights impacts the rights and safety of others, the facility is more justified in restricting the first resident's rights (e.g., reduce access to money, search for chips on arrival). Once the risks have been analyzed, the next step is to analyze the regulations, resident rights, and facility responsibilities. The final step is to determine what the facility can do, what the facility should do without making the situation worse, and how to document it. Make sure to document acknowledgment of the right, the rational for violating it, alternatives considered, and the response of the resident.

Those caring for younger residents may be fearful of receiving more deficiencies for care provision. Although we were unable to find studies indicating a higher rate of deficiencies or citations or a more severe level in younger residents, our panel believes that there is more sympathy toward disabled younger residents in LTC facilities who appear to have more of their life ahead of them compared with older residents. In addition, cognitively aware residents may be more likely to make complaints that result in deficiencies; however, this is only conjecture. Those in the field who care for younger residents indicate that individualized care plans, age-appropriate activities, and the ways autonomy issues are handled (e.g., giving younger adults more access to the community but ensuring that adequate safety assessments and oversight protocols are in place) are the regulations most often cited.

Case Analysis: Balancing Rights With Risks and Safety

Let's return to our case to practice doing an analysis of Martin's risky behavior outside the facility. First, what are the risks Martin is facing? There are several. There is a risk of harming someone else or the property with unsafe operation of the power wheelchair. There is a risk that the chair batteries will die and Martin will be stranded and unable to get help. He risks harming peers with unsafe food or activities or damaging his or their chairs. There is a risk that the chair he borrowed (or you gave to him) is defective and perhaps injures him. As a disabled adult, he has a risk of being taken advantage of in the community or being a victim of crime. Smoking is a risk because he cannot do it himself safely; he may harm himself through burns that he cannot feel or respond to. He may harm others by setting fires in outdoor areas or even within the home if he chooses to violate the facility's rules and smoke. He may be subject to a law enforcement action for loitering or for littering and storm drain contamination for smoking in public areas and not disposing of his waste safely. If Martin attends school, there is a risk that he will become injured or ill at school, and there is a risk that he will have a negative impact on the community. Sitting up all day in the chair may aggravate his health or could result in sunburn, temperature irregularities, or pressure ulcers. He may not have access to assistance with toileting or eating, which can result in dehydration, odor, and skin irritation. There is a risk that Medicaid may not think he needs a LTC facility if he can spend all day at school.

What is the facility's role regarding these risks faced outside the facility? The facility has the obligation to inform Martin of these risks and to ensure he understands and has the capacity to make these decisions for himself and assume the risks. The facility can set some limits on actions where Martin requires the assistance of the facility staff to engage in the behavior. For example the next section discusses ways that the facility can set and enforce rules about placing the resident in the power wheelchair. Finally, the facility can consider the risky activities and whether there is a way to help Martin to engage in these behaviors more safely. For example:

- Facility Staff may
  - dress him in layers that can be easily removed by a passerby,
  - apply sunscreen,
  - pack a lunch that requires the least amount of assistance,
  - encourage a buddy system, or

    - call the school on his behalf to find out what programs are available for the disabled.

- The facility may offer
    - a computer to permit the resident to take online classes,
    - occupational therapy for strategies to enhance the safety of smoking,
    - offer a wearable ID card, a med-alert bracelet,
    - assistance in obtaining a cellphone that can be used hands-free, or
    - a shopping service or another way for Martin to earn money.

- The social worker may
    - help him to obtain a low-cost disabled bus pass,
    - work with him to determine the distance and route to school,
    - help to coordinate a schedule with nursing staff to ensure that he is up and dressed, or
    - have assistance with activities of daily living (ADLs), and eats before his first class.

- The nursing staff may
    - work with him to arrange any assistance he needs with studying (e.g., set up a computer or reading stand or mouthstick, storage of belongings), or
    - schedule medications and treatments around his school or going-out schedule.

Power Struggles: Use of Power Wheelchairs in Long Term Care

As in Martin's case, an individual who has a wheelchair removed for using it at unsafe speeds may be told that although he has a right to autonomy and freedom of movement, his dependence on staff to place him in the chair gives the facility a right to restrict the use of wheelchairs within the facility to those who can safely use them. Therefore, the facility staff will only place him in (or let him use) a wheelchair deemed safe for use in the facility. He has a right to leave and seek care elsewhere, but he does not have the right to operate a chair unsafely in the facility, risking his own safety and that of others.

As presented at the California Association of Long Term Care Medicine annual meeting,[26] the facility can take the following steps to promote safety:

- Require functional assessment of the resident's ability to safely use the chair upon initial acquisition of the chair and periodically, especially if a problem is observed, and prohibit use until the completion of a functional assessment. Martin's ability to safely operate the chair can be documented and assessed by using observations or a computer program such as WheelSim.[a] See also the protocol by Mendoza et al[27] for assessing the risk of wheelchair driving in a LTC facility.
- Evaluate the resident's medication profile to ensure that there are no medications that may cause sedation or impair driving, and limit use of the chair when the resident takes those medications (e.g., opioids, benzodiazepines, or other medications that cause sedation).
- Require a wheelchair agreement, which could include statements such as "I understand that if I exceed this speed, the motor on the power wheelchair can be adjusted to reduce speed or I may lose the privilege to operate the power wheelchair." (See a sample wheelchair agreement online.[a])

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[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

- Limit the use of the chair in the facility (e.g., permit only for passes outside the facility but not inside, or inside only with certain conditions).
- Establish a mechanism for initial and ongoing safety checks of the chair.
- Require a doctor's order for the chair and prohibit the resident to use the chair within the facility or be placed in it by facility staff without the doctor's order. Set criteria for the doctor's order (e.g., functional assessment, wheelchair agreement, absence of sedating medications).
- Promote staff accountability (i.e., not putting someone who is sick or confused in a chair).

Martin may argue that the chair is his and assert his right to his belongings or to this mobility device. Martin may have a right to his belongings, but the facility can choose which belongings are permitted to be stored and operated in the facility. How much control the facility can exert depends on who owns the chair and how much help the resident needs to get into and use it. *Martin's rights end where staff responsibilities begin,* and the more help Martin needs from staff, the more leverage the facility has. The facility may decide that Martin's unsafe behavior will cost him the privileges of operating the chair in the facility, that the facility will not permit storage of the chair, that the staff will not help to charge the chair, or that the staff will not help Martin into the chair unless he follows the rules. Document safety issues to justify restriction of privileges. Remind Martin that he cannot get into the chair on his own and that staff cannot put him in a situation that is dangerous to him or others. Provide Martin with a path to earn the privilege of operating the chair as a positive reinforcement—use of the power wheelchair can be a powerful one.

Assessing the Risks of Smoking in Long Term Care

Smoking is highly risky for all ages, and the CFR requires that all smoking in LTC facilities be supervised. Importantly, however, the CFR does not stipulate that LTC facilities must offer smoking, and many have gone smoke-free. In this case, Martin is in a smoke-free facility and the facility can enforce this policy within its grounds. When the resident leaves or signs himself out, the facility is not legally or practically able to restrict his smoking. The facility can, however, restrict storage of his smoking materials within the facility. The facility is obligated to clearly inform him of the risks of smoking with his condition and to offer smoking cessation support if he is interested. The facility is also obligated to develop a care plan for this problem, such as skin inspection of his hands after smoking outings, provision of gloves, and reminders of safety recommendations and negative consequences.

If the facility were to permit smoking, they may require a smoking safety assessment of cognitive and physical skills related to smoking and only permit smoking by residents who have no evidence of smoking-related problems or can safely perform all aspects of the habit unaided. Smoking assessments should include a skilled observation of the resident smoking to ensure that all aspects can be performed safely and also a clause that littering, burns, giving cigarettes to or lighting for others, failure to store effectively, and other unsafe behavior will result in removal of the privilege. The facility could refer Martin to rehab for safe-smoking training.

In this case, Martin is counseled regarding the health risks smoking poses for him owing to his history of pneumonia and his weakened intercostal muscles, which increase his risk of further occurrences. He insists that he understands the risks and wants to continue to smoke. The social worker reviews with him the rules of the facility and that he may not have a lighter or cigarettes in his room because they endanger the safety of other residents as a fire hazard. He agrees to keep the lighter and cigarettes at the nurse's desk, where they will be given to him when he is going off campus. He also understands that there will be consequences if he smokes on campus, which could include his moving to another facility that allows smoking. Smoking cessation assistance is offered but Martin declines. He is offered the opportunity to speak to the ombudsman further about his rights and responsibilities. He states that he will think about it. The pharmacy reviews his drug regimen and notes that the combination of baclofen, valium, and hydrocodone can be sedating, and these medications are therefore eliminated or reduced.

Recall the F-tags listed in Table 3. Will the handling of this case result in any deficiencies?

F-tag 151: Martin has been informed of the specific risks to his health that he is taking by smoking, leaving the facility without accompaniment, and going to school. He has refused smoking cessation assistance. He has accepted some of the team's recommendations to reduce risk such as permitting sunscreen, contacting the school's disabled services, bringing a water bottle he can access hands-free, and taking an online class.

F-tag 152: Martin has the capacity to understand the risks and benefits of leaving the facility, smoking, and going to school. He is able to express his choice clearly, to reason, and to assume personal responsibility.

F-tag 156: Martin has been informed of the rules of the facility and his option to leave; in addition, he has been told which behaviors are unacceptable to the facility, including smoking within the grounds. He was offered the opportunity to speak to an ombudsman.

F-tag 240: Martin was informed before admission that smoking is not allowed on campus. He chose to be admitted because of the other benefits available to him to enhance his quality of life. He participates in many of these other activities. The facility is not required to create an opportunity for him to smoke under supervision because he was notified before admission that smoking is prohibited.

F-tag 241: Martin is treated with dignity throughout this discussion about behaviors and expectations. He is assured privacy during the discussion with the social worker, nurse, and physician and is not ridiculed, threatened, or chastised for his choices.

F-tag 242: Martin is allowed to make his own decisions about smoking, leaving the grounds, and going to school and is assisted in exploring the potential risks to health and safety as well as the consequences of violations of the agreements.

F-tag 246: The facility does not need to accommodate Martin's need to smoke because Martin made the choice to come to a nonsmoking facility.

F-tag 248: Martin is offered activities within the facility, and with interest expressed in education, special efforts are made in this area (e.g., purchasing a GED book and working with him). Activities staff document his time off campus to understand his preferences for activities of community reintegration. Activities staff may help him to meet other younger adults who are leaving campus and encourage a buddy system to maximize safety.

F-tag 280: Martin's care plan will include a discharge plan to a facility that allows smoking should Martin find that he cannot abide by the nonsmoking rules of this facility.

F-tag 252: Martin's safety is protected while on campus by storing his lighter and cigarettes at the nursing desk. If he does not abide by this agreement, he places other residents at risk and the facility has the right to confiscate the cigarettes and lighter (and keep with his belongings).

F-tag 323: The facility's fire prevention plan includes its being a nonsmoking facility.

F-tag 280: The facility-developed care plan goals and interventions are patient-centered and are based on discussion and agreements developed collaboratively.

F-tag 323: By ensuring safe operation of wheelchairs within the facility and ensuring that those residents who are impaired are not placed in them, the facility is ensuring the safety of both Martin and others. A nonsmoking facility with lighters and cigarettes secured where they cannot be accessed by other residents promotes safety within the facility. Alternatively, a facility that prohibits lighters and cigarettes in the building can also promote safety.

F-tag 329: The facility reviewed medications that may be harmful when operating a power wheelchair and reduced all those that interfere.

F-tag 500: Martin has been offered outside professional assistance to quit smoking and the facility may assist in contacting the school's disabled programs to facilitate safe attendance and the requisite assistance.

If the whole situation can be handled in a way that promotes Martin's autonomy and choice, is nonpunitive, and is collaborative, it is unlikely that the facility will have any F-tag citations related to their handling of Martin's desire to exercise his rights to leave the facility and engage in potentially unsafe behaviors.

Establishing Practical Facility Policies

In addition to being honest, we need to be practical and pragmatic with our recommendations. What can we agree to do that we are sure we will really do? It's more pragmatic to establish policies that anticipate problems with younger residents than to react with policies after the problems have occurred. It is important to establish practical and enforceable policies on issues such as possessions, clutter, smoking, belongings, food storage, drinking, visitors, and sleepovers that can be reviewed with residents on admission. (Many sample policies are available online.[a])

Facilities use federal and state regulations to develop operational policies to ensure that care meets high standards and complies with regulations. The facility should not mandate rules or policies that are impractical to implement. It is not unusual for some facilities to establish policies that reflect wishful thinking and fail to acknowledge reality. In general, policies should reflect solutions developed and implemented by the facility to comply with regulations. Facilities may be found deficient for not following their own policies, even if they comply with the regulations. For

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[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

example, in one facility, a family requested that a particular person not be allowed to visit. The facility added this to the care plan but later discovered that the visitor had been admitted multiple times. The facility did not have effective systems in place to effectively screen and exclude unwanted visitors. The facility was honest with the family about their enforcement capabilities and offered them the options of staying with the imperfect system or seeking alternative placement. The family chose to stay.

Most LTC residents are unfamiliar with regulations and facility policies and it is unrealistic to assume that they will be able to understand all policies relevant to them. Thus, all staff personnel should be familiar with the policies and enforce them uniformly. Younger residents often "push the envelope," and in caring for them, facilities find flaws in their current policies. When policies change, let the younger residents know individually. They want to feel included and not be embarrassed or surprised by new policies. Younger, more alert residents may require more explanation of why the changes are being made and may need more time to acclimate to the new way of thinking. When a policy is changed or a concerning behavior is noted, one approach is to notify the resident verbally, preferably by a staff member with a close connection to the resident and who has excellent communication skills with "bad news." It is important that the person explaining a change use a compassionate tone of voice and acknowledge the resident's point of view in the issue. In addition, a written communication can be very helpful. Write a letter to the resident that is thoughtful, clear, and vetted and give the resident time to acclimate to the change. For example, "The wheelchair will be removed in five days if an alternative plan is not identified; staff will assist in contacting your loved ones to assist" (this allows the resident to save face). In these communications, remind residents of the difficulty you face with the regulations and empathize with the resident about the inconvenience or frustration he or she is experiencing.

When talking about difficult issues, remind residents of their options to stay in this place with these rules or to leave. Keep in mind that any discussion of leaving needs to be approached carefully. Many residents find it frightening or threatening if they hear you say, "Do this or we will kick you out." Despite the conflict, most of them identify your facility as their home and want very much to stay. Conversations that appear threatening or harsh can reduce trust and cooperation and harm the relationships that are often the key to obtaining compliance. Also, because of the challenges in discharging disabled younger residents (a lack of alternatives), forcible discharge is often not possible legally or ethically. This threat should not be used unless it can be enacted. Even if a resident is discharged, he or she can contest the decision and often wins.

Statements of understanding can be used to document conversations on facility policies and risk. As mentioned, Martin may sign a statement of understanding regarding use of power wheelchairs which has a step-by-step list of statements regarding facility policies, consequences, and assumptions. These statements can be developed for many high-risk areas or to document discussions of problems or new policies. See examples of statements of understanding for power wheelchairs, leaving the facility, nonadherence, and narcotic painkillers online.[a] These statements of understanding often list the consequences of violation of facility policies and can be used in behavioral contracts as well (see the section *Behavioral Contracts*, page 30).

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[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

Violation of Rights

There are no particular regulations that specify when rights can be restricted. Although we are charged to support resident autonomy to the degree possible, it is assumed that when the exercise of an individual's rights jeopardizes that resident's safety or the safety or autonomy of another individual, skilled clinicians will examine whether rights can or should be restricted.

A resident's rights should be restricted only with clear justification and based on imminent (not theoretical) danger to self or others. When a facility or caregiver elects to restrict a right, it is important to notify the individual or legally authorized representative of the right and the plan to restrict it, the reason for restriction, and what options still remain. The following are the recommendations of the panel:

- Come into the situation with caring for the resident and other people, not the facility, as the number one concern. Make that caring apparent in all interactions and writings.
- Use your most skilled communicators for verbal discussions and documentation.
- Consider a good cop/bad cop approach so that the resident has someone with whom he or she can talk about the "bad administration" without feeling like a close staff member was "in on it" or that he or she was ganged up on. The bad cop could be the administration or even the physician.
- Ensure that no negative emotion is directed at the resident, except perhaps sorrow or frustration that this restriction is necessary. Consider the resident's perspective to reduce the chance of a dignity violation. To preserve dignity:
    - Notify of policy changes before implementation to give resident time to acclimate. This will maximize the resident's sense of control (e.g., giving a resident 24 hours to give up his cigarettes rather than insisting it be done immediately).
    - Inform the resident of changes in writing with a due date from someone outside the interdisciplinary team. In this way, the team can maintain a relationship with the resident by being on his side in helping him to comply.
    - Have the resident present for searches.
- Have clear, proactive guidelines in which staff have been trained and define immediate consequences that are delivered without anger, are not overly punitive, and are focused on resident safety. In many cases, however, a resident's action may take the team by surprise. In this case, the team may take an initial action to ensure everyone's safety and then investigate and gather to make a plan.

BOX 2. Exercise of Rights

F151
§483.10(a) Exercise of Rights

§483.10(a)(1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United states.

§483.10(a)(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights.

interpretive Guidelines §483.10(a)(1)

Exercising rights means that residents have autonomy and choice, to the maximum extent possible, about how they wish to live their everyday lives and receive care, subject to the facility's rules, as long as those rules do not violate a regulatory requirement.

Don't Promise What You Cannot Deliver and Choose Your Battles When Dealing With Behavioral Problems

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Martin's case:

Martin keeps finding staff he doesn't get along with and refuses to have them care for him. The facility tries to accommodate, but staff complain. Martin requires heavy care, and the staff think his care should be shared; however, some state that they are afraid to care for him because he often makes complaints about staff he doesn't like and they fear they could lose their license. In addition, Martin can be demanding. He insists on having his shower on a particular day or time and is inflexible about change. He wants to get up at 6:30 a.m., which is when the change of shift occurs. He has a personal care routine that takes extra time and strong personal preferences about how every task is done and who does it (hair, shaving, dressing, catheter care), and he requires extra help to get ready for school (e.g., packing backpack; shutting down and packing computer; positioning cell phone, iPod, adaptive equipment).

When addressing the issues of young residents, it is important to stay focused on what is most important and to maintain a practical approach. It is easy to fall into a habit of giving in and providing more and more care to a demanding resident owing to compassion or for fear of lawsuit, complaint, or deficiency. We can sometimes, however, create "monsters" in residents through this accommodation. We need to develop strategies to cope with demanding individuals. There are a number of issues here. The first involves staffing. One of the benefits and challenges of longer term residents is that they develop attachments to certain staff members. This can be therapeutic, and a facility is wise to accommodate preferences as much as possible to decrease complaints. The fact remains, however, that the staffing is not guaranteed and that staff need to go where they are most needed. They take time off, and they may need a break from time to time. Although the care plan may document a preference for staff which is accommodated when possible, it is important to inform

Martin that the facility cannot guarantee only female staff or only male staff or that Martin won't see Betty or Sara or Blake. Staff need to explain the situation to Martin and ensure that they are clear about what the facility can offer (a staff member who will clean him and get him up) and what they cannot (Betty Lou cannot be in your room for an hour and do everything you wish).

Although it is nice to try to accommodate some of Martin's wishes, the facility needs to remember that they are obligated to provide "all of the needs and some of the wants." In a person-centered environment, where preferences are sought and honored as much as possible, staff may run the risk of bending over backwards to meet a bevy of demands from one resident, thus unfairly distributing staff resources. Staff and residents need to know that although every resident can have some preferences honored, not all preferences can or should be accommodated. If a resident is demanding something new, staff may ask, "What are you willing to give up to allow time for this request?" Let the resident participate in the prioritization of preferences.

Management staff should ensure that facility resources are fairly distributed. When an outlier is identified, management should consider whether the outlier has unusually high (or low) needs or demands. Younger residents are often very focused on fairness, and a resident may observe what others are getting and want the same. This focus on fairness (particularly for the complainer) can be challenging, and many facilities choose to make rules to make things "fair." It may be better to focus on needs and wants. Explain to residents that the facility focuses primarily on needs (to be clean, dry, fed) and only secondarily on wants or preferences (strawberry shampoo left on for 15 minutes, followed by a cleaning rinse, then a leave-in conditioner, and then 20 minutes blow drying and flat ironing). Also explain that residents' needs may differ, and what seems "unfair" may reflect very different actual needs. Finally, remind residents that everyone is special and gets some special things, but no single resident can have everything he or she wants.

Like many residents, Martin has developed a preferred routine. This is positive because his care needs are predictable, but less so because the routine has stretched until it is overwhelming and Martin is likely consuming more than his share of facility resources. This is not unusual and may require periodic reassessments by the interdisciplinary team and discussions with the resident to prioritize the components of his routine and distinguish wants and preferences from needs. Staff need to set limits and, equally importantly, enforce them.

All staff need training in policies. Training and support help to avoid the splitting of staff that frequently occurs when there are younger residents. It is important for staff to recognize the need for a united front. Front-line staff are ultimately responsible to report violations and often are hesitant and keep residents' secrets to maintain good relationships. Find a way to protect the dignity of the resident and preserve the facility-caregiver relationship while still enforcing policy. Often, having difficult decisions come from the team or some other authority may serve to protect caregiver-resident relationships (e.g., "I know it's difficult, but the team administrator, Don, told me I have to.").

Behavioral Contracts

Behavioral contracts are often helpful in situations where a negative behavior occurs over which the resident has some control and that the facility wants to reduce.

A behavioral contract implies that all parties are working together. This is not always the best approach for behavioral management, because sometimes residents lack the motivation, cognition, or cooperation to participate in the process of developing a contract. Troublesome behaviors still need a behavioral management plan with goals, interventions, and methods to monitor its effectiveness. For example, the plan may include such things as total duration of care, specific things to be said to residents in certain situations, or which care practices occur when. Behavioral contracts can improve resident accountability. Just the process of developing a behavioral contract can be helpful, because expectations and points of views are explored, as well as which consequences or rewards are meaningful to the resident. The guidelines for creating behavioral contracts are summarized in Table 4.

The best behavioral contracts are developed when there are at least some positive relationships with staff so that the resident has some investment in improvement. Relationships defined by mutual respect and caring between residents and staff can influence behavior. The behavioral contract is developed with the resident, incorporating his or her goals and perspectives. The team explains their point of view and outlines their roles, responsibilities, and any necessary restrictions with reasons (e.g., safety, regulations). Allow the resident to participate in setting priorities. For example, say, “Your things must fit into this drawer—let’s pick what you want to keep. If you don’t choose, I will choose for you.”

To be effective, behavioral contracts must be simple and enforceable by busy shift workers and line staff. A behavioral contract obligates the facility to follow through on their part of the bargain. If the facility feels that they cannot do this, it should not enter into a contract. When caregivers have developed an honest relationship with residents regarding needs, they can often successfully negotiate a win-win strategy. Caregivers should remember that the process of negotiation is an important part of the resident’s rehabilitation and is a real-world skill that he or she may not have acquired before coming to the facility. This process of negotiation can be a learning experience for both the resident and the staff.

Facilities need assistance in determining appropriate, enforceable consequences. Behavioral consequences can be challenging. Ideally, the team makes a clear clinical connection between the behavior and the consequence. All consequences must be enforceable and should not be perceived as punishment. A consequence may be the withdrawal of a privilege such as staff assistance with Skype calls; facility fun money for activities, items, or foods; or special outings with a favorite staff member. Another idea is the reduction of a privilege such as the frequency or duration of smoking privileges. The facility could also limit the location for family and friend visits (e.g., not in the room, but in common areas) or could limit special errands or outings such as for takeout food.

An effective consequence can tie prescribing practices to behaviors, but it is important that the justification focus on the medical needs of the resident and not on withholding the medication as a punishment. For example, justify limiting opioid prescription when a resident uses the power wheelchair because the medication is sedating and may result in adverse consequences. The facility may also justify limiting opioid prescription for a resident who is nonadherent to recommendations to alternate time in bed and chair owing to the presence or risk of pressure ulcers because of concern with his overall health. An example that has been used extensively in one facility without any complaint by residents or surveyors (because it is clear that the physician is acting in the interest of the resident) is, "I cannot give you opioids to reduce pain that is caused by you sitting in your chair all day. Pain is a signal to your body that you need to change positions. If I give you a pill to dull that sensation, I am keeping your body from sending you an important message. I do not feel comfortable prescribing opioids that make it easier for you to harm yourself, and I would be partially responsible for any wounds you may incur. I am only comfortable prescribing opioids that enhance your quality of life and health. If you will alternate time in bed and the chair, then I will prescribe them." Another option is to time the medication in a way that promotes health. For example, "I'll give you a Vicodin when you get up, and you can have the next dose once back in bed. I can justify this because the medication may cause sedation and also because I am worried that too much pain medication will prompt unhealthy staying-up behavior."

Another consequence could be to limit preferences while still meeting needs. A resident who wants a certain caregiver and an extended care routine can be given the opportunity to prioritize. For example, "You cannot have Susie care for you if it takes her 1.5 hours to do the care—this means she cannot care for anyone else. It's quicker with other staff. If you want Susie, you have to pick what you want done and limit it to 20 minutes." If he does not choose or cooperate, his care may be limited to the basics and may not be performed by the staff member he most prefers.

Consequences work best when enforced by the entire team; if not, splitting will occur. Everyone working with the resident on every shift and in every department should be aware of the contract. Supervisory staff must be alert to situations where staff members with special relationships to residents violate the rules or contract and be ready to intervene. If the chart is reviewed by regulators, they will want to ensure that the behavioral contract is in place, enforced, and fair. Only keep it there as long as it is being implemented, is working, and is needed. When the problem resolves, the contract should be dissolved and the resident's achievement celebrated; a return to more flexible care patterns can then resume.

What doesn't work? The biggest problems are unenforced contracts and unenforceable consequences. Behavioral contracts should be practical and developed with the input and revision of direct caregivers. They can be complex and time-consuming to develop, implement, and monitor, and facilities will need to invest the resources to do it correctly. Although the facility may strongly desire to enforce the consequence of discharging the resident, in many settings, the facility cannot discharge owing to a lack of safe and appropriate alternatives. Threatening discharge when it is not possible is a good way to lose credibility and to destroy relationships. Some facilities may want to remove the privilege of off-campus passes, but this may not be enforceable because capable residents assert their right to come and go from the facility at will (see the section *Federal Regulations and Resident Rights,* page 20). Some facilities find that withholding a favorite staff member is perceived as too punitive and is not effective, because these relationships can be the best inducement to better behavior and be helpful in coping with the loss of other privileges. Short term reassignments, however, especially for some tasks, can be presented to the resident and staff. Even when warranted, some suggest that complete elimination of smoking can backfire with the increased irritability and behavioral acting out related to nicotine withdrawal; however, other facilities have found this concern to be overblown and that there is a reduction in irritability and behavioral acting out in smoke-free environments.

The consequences of not following a contract cannot be perceived as punishment. **Punishment is not allowed in the ltc facility,** nor is it the most effective approach. A harsh approach does not build a relationship; in contrast, it is likely unenforceable and makes the resident want to test your resolve. Instead of taking a punishing tone, staff are encouraged to try rewarding approximations of the desired behavior. For example, "If you can go without smoking in your room for two weeks, your favorite staff member, Christy, will take you to a movie." Other examples include food rewards such as takeout or a special meal from the dietary department, setting up family contact such as a Skype call with a faraway relative, campus cash that can be turned in for quarters for the vending machines, or having family members bring in a reward to be given upon success. Consequences that naturally flow from the behavior are better than those that are unrelated. For example, if the visitors are too loud, it is easy to restrict them from the bedroom areas. Because drinking alcohol interferes with driving, it is logical to restrict use of the power wheelchair for a resident who consumes alcohol.

Establishing general policies that residents sign upon admission may be easier than creating individual behavioral contracts and reduces the impression of special treatment (residents receiving different consequences for the same behavior). Setting up policies and training staff in advance creates a proactive approach that prevents problems occurring or escalating rather than reacting after problems have occurred and possibly been mishandled.

TABLE 4. Guidelines for Creating a Behavior Management Plan

1. Identify the behaviors you want to eliminate or reinforce. Write the target behaviors down.
2. Create measurable goals that are specific and time limited. Some can be short term and others longer term. Define how the goals will be measured and what will count.
3. Select rewards for successful completion of short and long term goals. The reward must be sufficient motivation—finding something that the individual wants is part of the challenge in creating a behavioral contract and serves to build the relationship by focusing on the positive.
4. Select consequences. Make sure they are not punishments, are short-lived, and are agreed upon by all parties.
5. Create a time for evaluation—how frequently will the behavior be evaluated and by whom?
6. Sign and date the contract and make sure you follow through.

BOX 3. Managing Difficult People or Problems: Advice From the Experts

- Remind yourself that they are sick and you are well.
- Remember, they don’t choose to be this way and they are suffering.
- Look for the unmet need that informs the behavior.
- Keep your boundaries and don’t get too drawn in or make the conflict worse by taking sides with the resident against other staff.
- If you try something and it doesn’t work, try something else.
- Disengage if you feel strong emotions.
- Believe and support other staff and let them support you.
- Watch your tone when speaking and documenting.
- Identify the specific behavior that is troublesome and approach it systematically.
- Be empathetic and try to view the behavior through the resident’s perspective.

Ask:

- What is the behavior?
- Is it under the control of the individual or not?
- Why may it be happening?
    - o Can we identify antecedents that make it more or less likely?
    - o Is there a diagnosis (e.g., anxiety, depression, personality disorder, psychosis, dementia) influencing the behavior?
    - o Can we identify an underlying emotion driving the behavior (e.g., fear, guilt, loneliness, confusion) and find another way to influence that emotion?
    - o Can we identify a need that the behavior is meeting (e.g., need for control, connection, reassurance) and find an alternative way to meet that need?
- Who is negatively affected (e.g., staff, other residents, this resident)?
- What makes it worse?
- What makes it better?
- What are we doing now? (Consider the resident’s behavior with differing environments and people for ideas.)
- Is anything working? Can we do more of that?

It is important for staff to remember that behavioral problems cycle and there is some self-regulation. Often, just waiting a day or two can result in a new perspective, better ideas, and even an improvement in the behavior. Conflict can build with associated anxiety, anger, and frustration, but often when staff relationships have been established, the exacerbation will pass and equilibrium will be restored. Staff ask themselves, “Can it wait a day?” Sometimes a safety issue is present or the behavior is serious and requires a rapid response, but at other times, an immediate response is not necessary or desirable. Remember also that the natural variation among people can be a great laboratory for experimentation. Often, changing the environment or personnel involved and observing which factors influence residents’ behavior can be eye-opening. Staff can also be more proactive by implementing new strategies, measuring their effectiveness objectively, and determining which are most effective. **Assessing what works best and doing more of that can be the most effective way to modify problematic behavior.**

5. Best Practices: Prepare Staff to Care for Younger Residents

Best Practices:

- Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- ◆ Prepare staff to care for younger residents.
- Take a long term perspective.

Martin's case:

Over the next two years, Martin faces some challenges. His power wheelchair breaks and takes two months to fix and he misses school. He gets depressed and irritable, but then improves when school is in session. A staff member who had cared for him starts going back to school herself and asks if she can help him to study when she has extra time. You think he may be burning music CDs on his computer from the Internet and giving these to staff for their personal use. He develops a relationship with another student and asks staff if he can get her pregnant as a quadriplegic and what kind of sexual positions are safe for him. A son he didn't know he had comes into the picture and evokes feelings of pride and guilt. Martin ends up giving the son many of his possessions, and then the son leaves again. Martin develops penile discharge and is diagnosed with chlamydia. You find out that staff are "friending" Martin on Facebook and bringing him home-cooked traditional Mexican food on the evening shift. A nursing assistant tells him that if he marries a nursing assistant, that person can then take him home and care for him and they can live off his Supplemental Security Income (SSI). You wonder if there is a staff member who is getting too attached. He created a mouth-painted picture and gave it to a staff member, who hung it in her home. He is grateful to staff for their assistance and wants to give back. He went on a two-night pass and there is a rumor that he stayed with a nursing assistant from the facility.

The problems that Martin has are common for his age and disability, but may not be expected in the LTC environment. Staff personnel receive training in caring for the bodies of people, but often are not adequately trained about appropriate relationships, managing conflict and boundaries, negotiation, and dealing with difficult people. Turnover of staff is rapid in LTC; they are often young, foreign-born, struggling with English, and exhausted from multiple jobs and family responsibilities. They are insufficiently educated about professionalism and boundaries. There are risks to staff of inappropriate relationships and transference. Younger residents can require more care, may be more demanding, or can be sadder. Staff become attached and may think of Martin as their son or friend. Facilities need clear policies on personal and social boundaries between residents and staff and ways to educate staff on policies and track compliance. These policies may include definitions of appropriate and inappropriate gifts, limitations on caregiving and friendships outside the facility, and rules for social interactions on and off duty. For example:

1. A facility may permit homemade gifts valued under $5, or may permit gifts only if disclosed.
2. Facilities may prohibit staff from providing personal phone numbers, connecting on social media, or being involved personally with residents, or may require that any outside contact with residents be reported (including any relationships that occur before or after institutionalization).

Things get more complicated in smaller towns or when there are previous relationships or associations (six degrees of separation), and there are many gray areas that make education difficult.

Often, staff who are educated on policies do not recognize their own behavior as aberrant or concerning. Supervisory staff must be vigilant against inappropriate relationships, but deal sensitively with them if they occur, because both parties can easily feel punished and become more secretive.

Another challenge in caring for younger residents in the LTC setting is lack of expertise in their conditions or diagnoses (see Table 1, page 4). These may include pregnancy, birth control, sexually transmitted infections, chronic pain with drug seeking, addictions, morbid obesity, developmental delays, mental retardation, MS, rheumatoid arthritis, AIDS, HD, genetic diseases, spinal cord injury, brain injury, and health maintenance and routine care for those aged 18 to 64 years. This tool kit addresses some of these issues; those working in LTC need to research other conditions with which they are unfamiliar.

Caregivers may also lack expertise in the medication regimens of younger residents, such as those for AIDS, MS, or new disease-modifying therapies. Although potentially time-intensive, adequate staff education and training will improve the efficiency and effectiveness of care for these younger residents. It will also enable better communication with families and guardians of the residents.

First, conduct an educational needs assessment. Identify the areas and types of information with which your facility needs outside assistance (e.g., in-service, mentoring, consult), and then identify strategies to obtain that assistance. One strategy is to focus on a particular resident or specific resident populations relevant to your facility; this type of targeted training is more effective and may be better retained.

Once the facility's educational needs have been established, retain a consultant or look within the facility or community for someone who can help with training. Sources for staff education and training are numerous and include the following:

- The Internet. There are huge quantities of free or low-cost written and video materials that are easily found by most search engines.
- Professional networks. The authors of this monograph have provided their contact information and are available for consultation.
- CMS Quality Organizations for each state or region. These groups may provide special training to individual organizations based on need. They also work on improvement of specific topics of concern in each region, such as improved drug monitoring (e.g., warfarin, anti-epileptic drugs) and antipsychotic use.
- Local educational institutions. Affiliated hospitals, medical schools, nursing schools, and residency programs are frequently available and willing to assist with staff education and training.
- Specialty organizations and special interest groups. Organizations such as AMDA, state LTC groups, Alcoholics Anonymous (AA), and local or regional groups supporting education and care of individuals with brain injury, obesity, long term disability, and drug or alcohol addictions can provide support.
- Meetings of specialty organizations. Annual meetings of specialty organizations such as the Huntington's Disease Society of America, the Multiple Sclerosis Association of America, and AMDA may include educational sessions related to special concerns of younger residents.
- Outside educational providers. Private contractors can be hired for specialized on-site training.
- Inservice publishers.

When developing training for staff on caring for younger residents, it is important to include topics such as developmental stages, maintaining boundaries and developing appropriate relationships, dealing with minor children and parents, dealing with the particular issues of young people (e.g., circadian rhythms, guests, substance abuse, electronics, belongings, pain management, risk management, demanding behaviors, personality disorders, criminality), care planning, resource allocation, recreation for the younger set, common diseases, and behaviors. The important thing is to provide support to staff, encourage truth telling, and answer questions as best you can, even if the answer is, "I don't know." Engage staff in the process of finding answers you cannot find elsewhere—staff are incredible sources of information on making connections with the residents for whom they provide such personal care. Remember to include staff not traditionally considered "clinical" in training, such as housekeeping, dietary, laundry, and business office staff. They will also need education on the situations that can occur. Some specific sources of educational training are listed in Table 5.

TABLE 5. Educational Training Resources

Alcoholics Anonymous. Available at: http://aa.org (Accessed 02/01/13).

American Medical Directors Association. Available at: http://www.amda.com/ (Accessed 02/01/13).

Christopher and Dana Reeve Foundation. Available at: http://www.christopherreeve.org/site/c.ddJFKRNoFiG/b.4048063/k.C5D5/Christopher_Reeve_Spinal_Cord_Injury_and_Paralysis_Foundation.htm (Accessed 02/01/13).

"Discovering Appropriate Activities for the Young Resident." DVD produced by University of Maryland School of Medicine. Available at: http://www.videopress.umaryland.edu/careelderly/activitiesforyoung_CE616.html#program (Accessed 02/01/13).

Huntington's Disease Society of America. Available at: http://www.hdsa.org (Accessed 02/01/13).

In the Know. "Younger Adults in Long Term Care." Inservice. Available at: http://www.knowingmore.com/e-learning-module-details?id=123 (Accessed 02/01/13). *In the Know is a publishing company that offers inservice solutions for health care organizations.*

Multiple Sclerosis Association of America. Available at: http://msassociation.org/ (Accessed 02/01/13).

My Better Nursing Home. http://www.mybetternursinghome.com/ (Accessed 02/01/13). *Dr. Eleanor Feldman Barbera offers talks, workshops, training, and teleseminars.*

National Multiple Sclerosis Society. Available at: http://www.nationalmssociety.org/index.aspx (Accessed 02/01/13). *Publications such as "Nursing Home Care of Individuals with Multiple Sclerosis" have many helpful hints about caring for younger adults in LTC settings.*

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6. Best PRActIces: tAke A long teRm PeRsPectIVe

Best Practices:

- Identify individual perspectives that inform needs and wants.
- Facilitate appropriate relationships between residents and staff.
- Anticipate cognitive problems.
- Make facility policies and behavioral management practical.
- Prepare staff to care for younger residents.

u Take a long term perspective.

Martin's case:

Martin has been at your facility for five years. During this time he went back to adult school and received a high school diploma. Two nursing assistants and the social worker from the facility went to his graduation, took pictures, and posted them on his wall. He was interviewed by the local paper for his accomplishments and he even wrote an article.

Celebrate Successes

It is easy to see from a distance of years the great strides Martin has made, but along the way, it was so much harder to notice and celebrate the smaller steps. How about his first real connection with a staff member or his first mutual friendship with a peer? When did staff stop complaining about having to help to set up his books and computer for studying and start speaking with pride about how they had helped him to get where he is today? Look, it has been months since he complained about staff or called the administrator and we didn't even notice it! Can you believe that a month has gone by without him cursing at a nurse? It is easy to focus our attention on people with behavioral problems, but when they start improving, our focus may shift to other residents with behavioral problems. We are trained to look for problems, not successes. If a person's behavior improves by 15%, this may not be noticeable to staff who still notice too much of the bad behavior. The resident does not get positive reinforcement for the efforts and improvements made and gets frustrated or feels hopeless. Many people find it much more challenging to note and reinforce improvements (either efforts or approximations of success), especially when there is still a big problem. We need to teach ourselves, our staff, and our residents to notice and celebrate the improvements and to not focus on the negative. For example, Martin may get up for breakfast one day, then skip lunch and dinner with his head under a blanket. Instead of focusing on lunch and dinner, consider breakfast. Why did he get up? What was good about it? What made him change his mind about lunch and dinner? Focusing on the positive helps the resident to see his or her own potential and helps the staff to recognize and share in the joy of success. Focusing on the negative makes residents and staff feel the situation is hopeless and reduces everyone's self-efficacy.

An example of a young quadriplegic male who was able to overcome some of his angry reactions and to move forward in his life is that of Edgemoor resident Jesus

Montoya, who has told his story publically on his blog and in the news. He was able to rise from years of anger and frustration to complete high school and enter a four-year college while a resident at a LTC facility in Santee, CA.[28]

We celebrate Martin's success, but even as he has improved, he still faces problems. These impact his ability to leave the facility and return to the community. The biggest issues are money and the availability of a willing caregiver.

Address the Ever-Present Problem of Money

Money is a big issue for younger adults in LTC, both for the facilities in terms of reimbursement and for the younger people who may live there for weeks, months, years, or decades. A resident's financial circumstances might have prompted his or her placement in a LTC facility, and his or her level of income and assistance will help to determine whether discharge is possible. While in the facility, residents lament that the small amount of spending money provided by Medicaid is not enough to allow them to purchase things they need.

Most LTC residents are eligible for a Personal Needs Allowance (PNA) from Medicaid, which varies from state to state. In New York, for example, the PNA is $50/month and has been since 1980. There is no adjustment for inflation, making $50 in 1980 the equivalent of $18.71 now.[29] From this PNA, the resident is expected to purchase clothing, cigarettes, toiletries not provided by the facility, electronics, gifts for others, food, books, computers, entertainment, and even a burial plan. Some residents may get slightly larger allowances or have spend-downs or accumulated benefits that provide a brief respite from this poverty or the opportunity to spend a larger sum of money quickly, but most long term residents are relegated to a very low income status. For a smoker, nearly the whole allowance is used to purchase cigarettes. Focusing on money and how to get more can lead younger residents to consider behaviors such as panhandling, offering to run errands for a fee, stealing, and even illegal activities such as prostitution, shoplifting, or drug sales.[15] Imagine the difficulty of a resident who is also a parent trying to provide both for his or her needs and those of children.

Some facilities have had success in improving the quality of life and compliance of younger residents through programs that offer financial rewards. For example, facilities can use donated funds to supplement residents' income with rewards for health-promoting behaviors or reimbursement for work. It may be challenging to define "meaningful work" for which residents could be reimbursed, however, because of the many regulations affecting privacy, infection control, and abuse that limit the work residents can perform. Usury rules stipulate that a resident must be paid an appropriate wage for work that should be performed by an employee. These rules, although well-meaning, miss the point that working and contributing to the care of a community are important to rehabilitation and quality of life. Residents cannot be required to work, but contributing to the community or engaging in meaningful and important work activities brings meaning to life and builds self-esteem, purpose, confidence, pride, and a sense of community.

This issue can be addressed with educational or work activities. For example, residents can be provided with a gift card for engaging in activities themselves, helping to set up and run activities, or assisting others. One facility offers "bucks" for participating in activities that can be redeemed at rummage sales of donated items. In this facility, the residents often purchase gifts for family members living outside the facility rather than things for themselves. Another facility provides a debit card linked to the resident’s facility account. Some particularly industrious residents may be able to start a business of sorts—selling handmade cards, running errands for peers, or sewing other residents’ torn clothing, as long as the money earned is below Medicaid limits. With proper adherence to rules and regulations, such options could improve residents’ quality of life.

In their own words:

If you could change 3 things at this nursing home that would make your life better, what would they be?

“More money to spend.’’

“Get more than the measly $40 a month allowance from Medicaid.’’

“More money – that $40 monthly allowance doesn’t go far.’’

“Larger allowance.’’

From the facility’s point of view, younger residents are a financial challenge because their primary funding source, Medicaid, pays little. Medicaid provides critical health services and long term care for eight million people under the age of 65 and accounts for a significantly larger portion of LTC financing for younger adults than for older adults with disabilities.[30] Data from 2005 show that almost two-thirds of LTC residents had Medicaid as the primary payer.[31] Younger adults may be eligible for Medicaid after suffering a catastrophic illness or injury resulting in disability or may age into the program if they suffer from congenital or developmental disability.[32] Although Medicaid offers nationwide coverage, states have considerable flexibility to set their own income eligibility levels and to define covered services. States spend much more on LTC for younger people than for elderly people. Not including Medicaid matching payments, states contributed 20% of the total LTC expenditures for the nonelderly in 1993 compared with just 1% for older adults.[30]

In general, Medicaid services cover room and board and all nursing costs and supplies at a per diem rate. Medications often are separately billable to Medicaid, but therapy services are usually covered by per diem. A resident covered by Medicare disability may be able to use Part B for therapy and durable medical equipment and Part D for medications if the state Medicaid program agrees to pay for the premiums. Medicaid has a lower rate of reimbursement than Medicare, private insurance, or cash payment services, so facilities prefer to limit the numbers and lengths of stay of these residents. With younger residents more likely to be covered by Medicaid and longer lengths of stay, they can be perceived as too expensive to facilities. In addition, Medicaid does not provide higher rates of reimbursement for younger residents with more-complex conditions (e.g., HD, quadriplegia, MS) than for those with less-complex care needs, providing another disincentive to accept and care for these people.

Discharge

Although some younger residents stay in LTC for months or years, some can be discharged. Rehabilitation with the goal of community discharge is an increasingly important focus for LTC, and social workers and discharge planners need expertise in transition, options, community support, and means to motivate those who may be frightened of the transition. Available resources may include Medicaid-funded programs for home health or homemaking services, day programs for younger adults (e.g., brain injury programs), mental health services, or support programs for the disabled.

Discharge planning for younger adults with disabilities to independent living can be challenging and must consider the availability of low-cost housing as well as the resident's cognitive ability to budget and manage money and interpersonal skills to retain a caregiver. States may use Medicaid to provide personal reimbursement to individuals (family or not) to provide care to Medicaid patients at home to promote cost savings through deinstitutionalization. Sometimes special waivers or community agencies specializing in facilitating deinstitutionalization are available. A frequent challenge of discharge is meeting upfront costs (e.g., first and last month's rent, groceries, deposits). Some younger individuals lack Medicaid insurance if living outside a skilled nursing facility, which limits their discharge options.

Sometimes discharge requires a little "push," because residents and families can get comfortable with the institutional lifestyle and are fearful. One facility developed a peer mentor program where each younger resident was paired with another younger adult who had been successfully discharged and reintegrated into the community. This facility also cohorted some of the residents (mostly younger) into a discharge "household" within the facility, offering intensified discharge-focused programming including occupational therapy, physical therapy, social work, and therapeutic recreation activities.

III. Case Studies

The case studies in this section address common issues encountered when caring for younger adults in LTC settings as well as suggestions from the experts for strategies that can facilitate risk management and quality of life for both staff and residents.

CASE #1

Case #1: Mina Has Chronic Mental Illness

Mina is 42 and has had schizophrenia or schizoaffective disorder with multiple psychiatric hospitalizations and suicide attempts since age 18. She has a family who cares, but stays away because she is so angry at them for acting as her son's conservators on and off for years and doesn't recognize her own need for assistance. She has had protracted periods of homelessness, during which she was the victim of many crimes, including rapes and robberies. She used drugs, smoked and drank, and was likely a prostitute for drugs. She speaks in wild delusional statements, gets irritable, and mostly keeps to herself; however, if staff argue with her delusions, she may get frustrated and slap them, and she occasionally gets angry at a peer who gets incorporated into a delusion. She is on two antipsychotics, a mood stabilizer, and an antidepressant. She ambulates, but needs prompting to do ADLs. She needs a modified diet. Her cognition seems poor. She looks like she is in her 60s.

Miller et al report that middle-aged adults admitted to LTC have more mental-illness diagnoses and more previous stays in psychiatric hospitals than do elderly people.[6] In 2005, the average age across all new LTC facility admissions was 77 years, and only 14% of new admissions were younger than 65 years. In contrast, the average age for LTC facility admissions for residents with schizophrenia or bipolar disease was more than 10 years younger (62 years), with 54% aged 18 to 64 years and 23% aged 55 to 64 years. Overall, 16,796 residents aged 18 to 64 years were admitted to LTC facilities with schizophrenia or bipolar disease. Furthermore, younger residents with mental illness who were admitted to LTC facilities were more likely to remain in the LTC facility for at least 90 days, compared to those admitted without mental illness.[33]

LTC facilities may be the only option for those with mental illness, even for those with fewer medical needs.[33] More than 500,000 people with mental illness (excluding dementia) reside in U.S. LTC facilities, more than in all other health care institutions. Statistics vary by methodology, definition, and state, but the data suggest that between 1% and 24% of LTC residents are younger and have significant mental illness, with lower estimates for schizophrenia and bipolar disease and higher estimates if depression and anxiety are included.[33]

The increased number of residents in LTC facilities with mental illness is a concern to policymakers, because LTC facilities were not designed to meet the needs of the mentally ill. OBRA 1987 contained a major policy reform of screening and assessment of mental illness in LTC facilities. These regulations mandate a preadmission screening and resident review (PASRR) program to identify this population. The PASRR aims to ensure that LTC facility placement is appropriate and meets the social and psychiatric needs of those with mental illness. Implementation varies by state, and many states are unable to implement the recommendations; as a result, PASRRs may be conducted, but then partially ignored.

In *Olmstead v. LC* (U.S. Supreme Court 1999), the U.S. Supreme Court decided that confining persons with disabilities in institutions without adequate medical reasons is a form of discrimination that violates the Americans with Disabilities Act (ADA) of 1990. The Court held that states are required to make reasonable modifications to programs and policies to avoid unnecessary institutionalization. In general, the Olmstead decision impacts a state stipulating a duty to fund and create programs for persons with disabilities to provide community-based care (e.g., Medicaid Home and Community-Based Service Waivers). This decision impacts younger residents with disabilities by affecting their options both for community discharge and for services they may receive while in the LTC facility.

The decision may make state and community resources available to enable younger residents to return to the community. It may also suggest a duty on the part of LTC providers to aggressively assist residents, both younger and older, to access these resources and to leave the facility, either permanently or on a part-time basis (e.g., supporting attendance by residents in outside activities, a point consistent with typical PASRR recommendations). Those in the field note, however, that these services are often not available or not appropriate. Individuals with serious mental illness in the skilled nursing setting often have cognitive difficulties, self-care issues, and often limited ability to benefit from structured mental health treatment. Nevertheless, even accommodations for excursions to attend school; policies, procedures, and practices to facilitate younger residents leaving campus for other reasons; acknowledgment of differing expressions of sexual and relational needs; and pursuit by younger residents of different activities and access to technology may be relevant exercises of the Olmstead decision for residents who cannot be placed in the community. This issue of pursuing placement to allow residents to actualize their remaining potential may have much greater significance for younger residents. Younger residents have a greater likelihood of placement in LTC for spinal injury, brain injury, psychiatric disorders, and other conditions that leave them with significant areas of good functioning (e.g., a quadriplegic who is physically limited but cognitively intact, or a brain-injured resident who is ambulatory and requires engagement not available in typical LTC settings).

A significant problem with the Olmstead decision is that it is an unfunded mandate. Among newly admitted residents with schizophrenia, those younger than 65 years account for 60.3% of admissions and have lower rates of medical illness, suggesting a lack of clinical indications for skilled nursing care.[34] Regardless of the Olmstead decision, there are insufficient community resources to enable discharge of those with cognitive problems who are unable to care for themselves owing to mental illness and lack of social support, especially for those with cognitive decline who need supervision.

Another problem of caring for the mentally ill in LTC relates to prescribing. OBRA guidelines for psychoactive medications are for geriatric residents, and mostly for treating behavioral symptoms of dementia. Treating mental illness in younger residents often requires higher doses and may even require deviating from the guidelines (e.g., more than one antipsychotic, PRN antipsychotics, different approaches to medication reductions). Use of psychotropic drugs in elderly persons with dementia or in mental illness is controversial and beyond the scope of this tool kit. Nevertheless, it is important for clinicians working with younger adults to have some latitude in the management of psychotropic medications and nonpharmacologic strategies in treating mental illness. Physicians should have some familiarity with these conditions among this population. On-site psychiatric assistance is ideal, but, lacking that, outside consultation may be necessary. In this case, the facility should familiarize the psychiatrist with the regulations and needs of the facility. Psychiatrists see residents on an outpatient basis and make assessments based on brief interactions, whereas LTC facility staff have the advantage of daily exposure to the resident, and it is important that their observations are conveyed to the psychiatrist. A psychologist can also assist in caring for residents like Mina.

It is important that the facility document mental illness diagnoses as indications for antipsychotics. If correctly coded, this ensures that Mina will not trigger on the MDS as a case of unjustified antipsychotic use. Medication monitoring and reduction strategies may require more skill, but can fit in with other facility policies. For example, chronic delusions or hallucinations are often less amenable to medication management, but delusions associated with negative affect (disturbances in mood) or hallucinations that cause distress or induce anger or aggressive or self-harm behaviors are better targets for antipsychotics. Behavioral activation programs that involve residents in facility activities to improve their mood and well-being should be sought, offered, encouraged, and documented. Working with these residents may involve working with conservators, and it is important to understand the various legal ramifications of conservatorship in your state (e.g., some of those on mental health conservatorship retain rights to make medical decisions; others do not). Obtaining informed consent for psychotropic medications may be more challenging with some types of conservators. For advance care planning (e.g., code status), it may be necessary to submit court affidavits by the physician justifying the intensity of treatment recommendations and to obtain a court order for “comfort care” or “no CPR.” Adherence issues may be problematic, even with conservatorships. A conservator may have the right to decide but staff may not be able to force eating, care, lab tests, exams, oral medications, or other recommended treatments.

One LTC facility reported one resident who refused all exams, vital-sign monitoring, immunizations, and lab tests for the duration of her stay—if staff approached, she became violent. Those with mental illness may be receiving more involuntary medications or treatments, which can be uncomfortable for staff and may require education and training to maintain safety and dignity. It is important to document the overlying cognitive issues of mental illness because it is usually cognitive issues that inform the LTC placement and result in lack of motivation, apathy, withdrawal, and poor social engagement. (For further discussion of cognitive screening, see Box 1, page 17.)

Repetitive documentation of attempts to engage a resident with different strategies can be helpful in caring for those who are self-isolating or nonadherent. Off-site psychiatric visits may be necessary. Alternatively, video calls or verbal consults may be helpful. If this cannot be done, carefully document the reason as well as the justification for the chosen course of action. Involve Mina with recovery meetings, if possible, because the tenets of 12-step programs may be understandable and helpful even to people with significant impairment. Alternatives like SMART Recovery may be beneficial (telephone and online meetings are available in addition to in-person meetings on or off campus; see the case study in this section on alcohol and drugs).[35]

Staff need training on mental illness because many do not understand it well. Staff need to understand that delusions are often fixed and not amenable to medication management or “convincing.” A mentally ill resident may be stable but retain a delusion for years. Strategies to deal with delusions can be similar to those used to deal with advanced dementia and confusion: don’t argue, try to identify and validate the underlying feeling, and try to engage the resident in something else. Staff should not play along with the delusion or lie, but to build trust it may be necessary to acknowledge their reality: “Oh, that sounds frightening. Would you feel safer in your room or out here with other people?” Sometimes those with mental illness have aggression for which it is difficult to identify the triggers (e.g., response to internal stimuli). Thus, it is important that staff are aware of changes in mood and affect, which may indicate a change in the quality of the delusions or hallucinations. Staff need someone to whom they can report subtle changes in residents’ behavior or mood, such as a social worker, nurse, psychiatrist, psychologist, or physician.

Mentally ill residents may benefit from medication reductions if their illness is stable and their routine is structured, but staff must watch for changes. Often with long term use of these medications, tapers are more effective if they are accomplished slowly, with weeks or months between reductions to assess response and avoid overreacting to small behavioral changes. Documenting that the antipsychotic medication is targeting the delusion or hallucinations that lead to aggression, or that a sleeping pill addresses the irritation that leads to aggression, or that the antidepressant or mood stabilizer reduces the propensity of depression, anxiety, or irritability leading to triggers for aggression can be helpful and may be a good target to monitor in the case of medication reduction trials.

CASE #2

case #2: Frank is a long term stayer with Possible Personality disorder

Frank is a 62-year-old male who was admitted to the rehab unit 4 years ago for ongoing care of his extensive leg wounds. It was expected that he would leave the facility and return home, but he continues to have recurrent cellulitis owing to poor self-care, is unable to manage his diabetes, and cannot walk well, requiring increased help with ADLs. Once his rehab was completed, he was moved to a LTC unit. His comorbidities include type 2 diabetes mellitus, chronic lymphedema, chronic renal disease, morbid obesity, and depression with anxiety. Prior to his hospitalizations, he had lived independently and had a 29-year work history. He was noted to have poor interpersonal skills and made insulting comments to peers. He sometimes asks female caregivers to touch him sexually and calls them “bitches” *if they refuse. He only wants to watch TV and smoke, refusing the recommendation to quit smoking in order to promote wound healing. He says he has no one who cares about him and has always been a loner. He complains about staff and the activities, and it is difficult to persuade him to do anything.*

Younger residents may be more likely to stay a long time in LTC. In a study of eight Texas LTC facilities, 82% of the 136 residents aged 18 to 64 years were not projected to have a short stay at the facility.[17] Younger residents also often have a higher degree of cognitive awareness, and thus have unique problems in forming long term relationships with staff and peers and in finding stimulating and engaging activities. The problems are not always attributable to the LTC environment. Some residents have long-standing interpersonal anxieties, difficulties with coping skills and anger management, and personality challenges. Others experience a personality change related to the tragic loss of their body image, independence, and sense of self-worth. Some have depression and others have ongoing apathy or abulia with less interest in activities—a kind of passivity or giving up. In the case described above, finding something that engages Frank is key. Just offering a menu of activities is unlikely to work. Persson and Ostwald[17] found that the majority of younger residents with physical and mental health deficiencies spent most of their time alone or watching television but wanted more relevant and meaningful recreational activities and meaningful relationships with family, staff, and other residents. These younger residents have significant unmet psychosocial and recreational needs.

The first step may be to get to know Frank better. Find out what he used to like to do, what he is interested in, and what he is thinking. Then, facilitate the development of a relationship with another resident or a staff member (e.g., certified nursing assistant, nurse, social worker, psychologist, volunteer). This could be accomplished by consistent staff assignments or careful attention to roommate and seating arrangements. Finding something for Frank to do that has some meaning (e.g., helping others) can also be a way to improve his mood and behavior. Anecdotal evidence and the results of our survey suggest that art and music programs can be particularly helpful for these residents. Fine art programs, wheelchair sports, poker, evening and late-night events, and computer technology have been popular and serve to provide social support as well as a tangible outcome.

Residents with depression may respond to behavioral activation,[36] whereby those around a person seek to notice and respond positively to healthy behaviors such as participation in activities, and reduce reinforcers, such as sympathy or allowing escape from responsibilities. With behavioral activation, the resident identifies goals in major life areas (e.g., relationships, education, hobbies, recreation) and then is highly encouraged to participate in activities to achieve those goals, which can address anhedonia. One way to determine whether a resident has interests useful for a behavioral activation approach when they can't or won't tell you is to discover whether there is something they look forward to doing, are motivated to continue, and miss when not engaged in it. In Frank's case, he developed a relationship with a man who shared his interest in music and would play music for the other residents. For more ideas, see the case study in this section on managing boredom.

Frank is likely to spend the rest of his days in your facility, and no one wants those days to be full of conflict and misery. Expending the energy and resources needed to improve the problem is important. It is also important to choose your battles. Which battle? Focus on the issues that affect others before those that affect only the individual. That is, in this case, Frank's negative and borderline abusive treatment of staff and peers should be addressed as a priority and will likely enhance quality of life far more than lecturing him about blood glucose control and smoking cessation. In fact, addressing the psychosocial issues may be the best way to enhance compliance in other areas. As Frank begins to like his life, trust the staff, and feel accepted, it is likely that he will be more likely to accept influence in other areas. Because he is so alert and so "mean," staff had adopted the belief that he was in control of his behavior and that he needed firm limits; however, this strategy was unsuccessful. It made staff feel ineffectual and put them in an antagonistic position, resulting in Frank being angrier, less engaged, and less compliant. Once staff understood that Frank's difficult personality was a disorder and not fully under his control, they were able to feel more empathetic. They were then able to model empathy and compassion and to develop a healing relationship.

Managing personality disorders in LTC is extremely challenging and works best with a compassionate team approach.[37] Residents with personality disorders can cause chaos and frustration with their behaviors and attitudes and often incite strong feelings in their caregivers, including revulsion, anger, hate, and a desire to put the individual in his or her place.[38] These residents engage in black-and-white thinking in which individuals are randomly deified or scorned, resulting in conflict and splitting staff, often causing staff to become angry, frustrated, and less effective.

Interventions that may be successful in a case such as Frank's include trying to engage the resident with empathy and understanding. Identify unmet needs for love or control and try to find alternative avenues to meet those needs. Identify underlying emotions such as fear of abandonment and provide reassurance that you are committed to the resident. Focus on small approximations of the desired behavior rather than the ways that the behavior is still unacceptable. Develop a structured routine with clear limits. Assign staff who are consistent, strong, compassionate, and able to follow the care plan and suppress their negative feelings about the resident. Choose staff who are experienced and who take pride in working with challenging people. Reward both caregivers and the resident for any positive behaviors and for following the care plan. Establish a strong physician role in dealing with certified nursing assistant issues; this justifies assistants when they say "We cannot do this—doctor's orders." This also ensures that the physician is not involved in splitting and, when hearing complaints about nursing or other staff, will support the team rather than siding with the resident and promoting splitting.

For residents like Frank, the following interventions have been identified as **not** being helpful:

- Repeated conversations or team meetings outlining the negative behaviors that have to stop and consequences that are hard to enforce.
- Use of agency staff or rotating staff. New staff can more readily be manipulated and their use makes it less likely that rules will be followed. In addition, frequent change and lack of routine play into Frank's fears of abandonment and prevent him from developing healing relationships.
- Psychoactive medications are not very effective for personality disorders.
- Psychiatric consultation; in Frank's case, he walked out.
- Pressure for the resident to use psychotropic drugs; in Frank's case, he refused.
- Increased opioid use, which aggravates irritability and drug-seeking behaviors.
- Attempts at discharge—there may be no other options for care.

In this case, the staff required quarterly retraining, at which times the plan of care was reviewed and staff were allowed to vent; this reduced staff splitting and refusing to care for Frank. Staff splitting is a common problem with younger residents, but proactive policies and procedures, staff training, behavioral management plans, and good use of team meetings can reduce it. In this case, staff were encouraged to focus on Frank's positive attributes (e.g., his ability to hold a job for 29 years, his talent for music). Frank was recognized for his musical talent and for sharing his gift with the facility "family."

CASE #3

case #3: Jackie Has Huntington's disease

Jackie is 27 years old. She suffered the untimely death of her mother when she was just a toddler and was raised by her aunt. She came from a lower-income family, and decided at an early age that she did not want to remain "at the mercy of the system." She looked forward to marrying, raising a family, and having a good job; however, starting in high school, she began to experience some changes in her personality and some abnormal movements. She entered college but had to drop out for "financial reasons." She had multiple jobs, but despite her intelligence, couldn't keep them very long. She was recently in a single-vehicle auto accident and suffered a concussion and limb fractures. Hospital staff noted that she was impulsive and kept trying to get out of bed and walk, was occasionally incontinent, had some speech and swallowing issues, and had rather dramatic movements. She was diagnosed with Huntington's disease. Because she was unable to care for herself she was sent to a LTC facility. She became increasingly depressed and angry at caregivers, eschewed help, and self-isolated in her room.

Best known for its choretic movements, HD is a hereditary and relentless disease that usually begins in middle age and results in progressive decline over approximately 20 years. There is no way to predict exactly when LTC services will be needed. Although many HD patients are treated for years in an outpatient setting, as the disease progresses and family resources wane, institutionalization is not uncommon. Although symptoms usually appear between the ages of 30 and 50 years, the disease can strike those as young as two or as old as 80 years, and the progression of symptoms is different for each individual. Over time, symptoms typically include declines in physical functions such as eating, swallowing and walking; reduced cognition that affects the ability to learn and reason; and emotional instability or difficulty controlling behavior.[39] These residents are difficult to place and need a higher staffing level for what is likely to be a lifetime of care. In a series of 52 residents cared for over 8 years in one California LTC facility, residents averaged 48 years of age at admission and stayed an average of 11 years (until discharge or death). Age at death ranged from 29 to 78 years.[40]

Planning and preparation are essential before accepting a resident with HD. Edgemoor, a distinct part of the San Diego County Psychiatric Hospital that has become a referral site for HD patients, offers the following care strategies for facilities to consider (for more information, see Ferrini et al, 2009[40]):

- Stagger the admissions of residents with HD to allow time for assessment and adjustment.
- Have staff committed to developing relationships with HD residents.
- Adaptive equipment (e.g., walkers, canes) is generally not useful for residents with HD; try letting residents with severe ataxia walk as long as possible.
- Use a Broda chair (Broda Seating, Detroit, MI) for residents in the later stages of walking and to reduce choretic movements. There are two kinds: a pedal Broda that is like a wheelchair and can be mobilized with feet and hands, and a lounge-style chair with a padded foot box that is better for the later stages with severe chorea. Both can use a y-leg strap to hold the choretic limbs in place and allow comfortable positioning for eating or activities; the strap is not considered a restraint if the resident permits it. It is used to prevent falling from chorea, not to keep the resident from getting up (release on request).
- Carefoam chairs can be useful for the later stages of the illness (www.carefoam.com. Accessed 02/04/13).
- Place padding or mattresses around the bed, place mats on the floor, and pad the corners of furniture. Pad sharp corners in the room and the resident's elbows, knees, and shins.
- Make food available day and night; a snack is often more effective than psychotropic medication to treat agitation.
- Use consistent assignments.
- Find ways to create meaning in Jackie's life through activities and relationships.
- Consider private-duty nursing (one-to-one monitoring) for severe impulsivity, high fall risk, sexual acting out, and aggression.
- Manage aggression with a combination of medications (e.g., off-label antipsychotics, benzodiazepines, antidepressants, mood stabilizers), resident approaches (e.g., leaving the resident alone when frustrated), and managing the environment to reduce triggers.

Train staff to understand HD and the way it may affect care. One source of training are the webinars at the "Caregivers Corner" on the Huntington's Disease Society of America website (http://www.hdsa.org/living-with-huntingtons/family-care/caregivercorner/index.html. Accessed 01/29/13).[41] Another good resource is a printable handout explaining what Huntington's Disease is in layman's terms (available at: http://www.lundbeck.com/global/brain-disorders/disease-areas/huntingtons-disease [Accessed 02/27/13]). Involvement in a Huntington's foundation by staff, resident, and family can provide information and support.

CASE #4

case #4: Hank Has a criminal History

You admit Hank from the local hospital after a stroke. At the time of admission, he has limited speech and mobility. After rehab, he is able to walk with a cane and to speak, but as he gets stronger, he becomes irritable and unfriendly. One day the sheriff comes to the facility. You find out that Hank is on parole and that he is a registered sex offender.

LTC facilities fear residents like Hank—what LTC facility wants to be known for having a parolee? Referring hospitals may not know and do not have to report Hank's history. Staff may wonder, "What crime did he commit?" "Am I in danger?" "How do I protect the other residents?" Few people who work in LTC know much about sex offenders, the criminal justice system, or how to deal with those whose violent tendencies may be informed by something other than the impulsivity of dementia. Younger residents are stronger, more mobile, and unpredictably dangerous. A registered sex offender often puts the facility's address on the sex offender registry website.

Data gathered by the organization A Perfect Cause show that the number of registered sex offenders living in the nation's LTC facilities more than doubled between 2004 and 2005.[42] In a 2006 study by the U.S. Government Accountability Office (GAO) that identified sex offenders by using the FBI's National Sex Offender Registry (a compilation of sex offender registries submitted by all states), most offenders were male, under age 65, and living in LTC facilities. Sex offenders represented 0.05% of the 1.5 million residents of LTC facilities and intermediate care facilities. Furthermore, about 3% of LTC facilities and 0.7% of intermediate care facilities housed at least one identified sex offender during 2005.[43] Not only registered sex offenders find their way into LTC. Prompted by rising health care costs and increasing numbers of chronically ill inmates, California and other states have initiated efforts to shift medically impaired (and therefore costly) prisoners from their correctional systems to community LTC facilities (AMDA Policy Resolution E11. Addressing an Expected Increase in Long Term Care Continuum (LTCC) Residents With Criminal/Correctional Histories. Available at: http://www.amda.com/governance/resolutions/E11.cfm. Accessed 02/04/13.)

Most LTC facilities do not routinely impose different supervision or separation requirements on residents who are known offenders or who have prior convictions. Often, prior convictions are not known. Facility staff may have little knowledge or experience in this area and may not even understand the difference between jail, prison, parole, and probation, or what the charges mean. Moreover, only four states have laws specifying that LTC facilities be notified when registered sex offenders become residents. In May 2006, Illinois became the first state to require criminal background checks on all current and incoming LTC facility residents.[44]

How can facilities address the risk involved in admitting a person with a criminal or violent history? First, examine your facility's admissions policies. It is a good idea to know which sex offender database your state uses and to check every new admission there. For example, the Dru Sjodin National Sex Offender Public Website coordinated by the U.S. Department of Justice is available at www.nsopw.gov/Core/Portal.aspx (Accessed 01/29/13). This is public information, and there is no reason for facilities not to use it. A known sex offender won't necessarily be denied admission, but the facility can consider questions such as, "Do we want to take a chance, knowing that discharge options may be limited?" "Does this person have the potential to be aggressive and the physical capability to create difficulty?" Also, knowledge of the criminal behavior may assist in risk assessment, care planning, and protecting other residents.

Second, develop a policy that all visitors to the facility be notified of the potential for aggressive, unpredictable, or antisocial behavior in residents. (See the sample online.[a])

[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

You have admitted Hank. Now what? First, get as much information as possible. Ask Hank questions and watch his response. Use screening questions such as the following:

- Have you ever had trouble with the law?
- What did you do? When?
- Did you spend any time in jail or prison?
- Are you on probation or parole?
- Do you have to register for anything?

Find out what the parole agent knows and will tell you. Talk to staff about what they have observed in Hank's daily habits and tendencies and whether there are any red flags. When the assessment is complete, make a care plan to address specific concerns (e.g., can Hank do his annual registration himself or does he need help? Should you keep him away from intergenerational programs where children are present? Are his victims generally male, female, or both? How physically capable is he?). Care plan interventions should focus on reducing opportunities for trouble and access to potential victims. Interventions may include placing potential victims in areas away from a potential offender and monitoring residents' times up in chairs and in common areas to ensure that potential victims are not left unsupervised. Carefully planning seating arrangements, separating nonmobile residents from those who are mobile, and other ways of reducing access to victims may be helpful. The facility can limit times up and locations to hours and spaces where there is adequate supervision or less access to potential victims (e.g., remove wheelchair from room at night). Consideration of restricting the use of power wheelchairs for those who are sex offenders or who may otherwise use their mobility to harm others may be warranted and justified for the safety of other residents. Sometimes a wheelchair can be outfitted with a high bar in the back that keeps the potential offender in or out of an area. Alarms or tracking devices can be of some assistance, but are expensive and difficult to install. Some medications such as progesterone or estrogen hormones, antipsychotics, or antidepressants have been prescribed off label to reduce sex drive and may lower risk in some situations. Staff must report any unusual behaviors such as differing patterns of activity or staring or sitting near those who are unable to consent. Vigilance can often prevent a potential problem.

Donna Cohen, a researcher at the University of South Florida's Louis de la Parte Florida Mental Health Institute, has received a grant from the American Association of Retired Persons to study the presence of potentially violent and dangerous residents, including sexual predators, in the nation's LTC facilities. "Our nearly three million elders living in nursing homes and assisted-living facilities are among our most vulnerable citizens," concluded Cohen. "It is our hope that this study will not only emphasize the urgent need for awareness of the issue but will also encourage states and care facility administrators to engage their resources to protect the vulnerable."[44] AMDA also has committed to exploring the projected needs of the criminal justices system's growing population of aging inmates, including ways to balance the rights of post-prison residents with the rights and safety of other (nonconvict) residents in the facility (AMDA Policy Resolution E11). Finally, although it is important to use available data on past criminal behavior to assess risk and plan for safety, criminal conduct may occur absent any of these indicators. As criminality in LTC settings receives greater attention, the view that harmful behavior is somehow not serious because it is done by elderly, disabled, demented, or otherwise impaired persons will be challenged as seen in the enactment of the Elder Justice Act (EJA). The EJA requires reporting of suspected criminal acts to law enforcement, something many caregivers and facilities have been hesitant to do in the past.

CASE #5

case #5: Barney Has multiple sclerosis

Barney is a 49-year-old man with MS and related paraplegia. As a result of his MS, he has impulsive behaviors, irritability, and significantly impaired short term memory. He forgets daily that he agreed to placement at the facility, that he no longer has an apartment, and that he cannot walk. Barney makes frequent attempts to elope and has frequent angry outbursts that include throwing objects at the staff and threatening to hit them. His family is unable to manage his care at home. He was irritable at home but not to this extent. His forgetfulness makes it unsafe to leave him alone. He has accused the staff of holding him against his will. One day he will be OK with living in the facility, but the next day he will be angry and accusatory. He is alert and appears intelligent and articulate, so his concerns seem reasonable and he appears to have decision-making capacity on superficial examination. He can express his goals and plan for discharge but he is totally unrealistic about what he can do.

According to estimates from the National Multiple Sclerosis Society, about 10%of persons with MS will enter a nursing facility or assisted-living center at some point in their lives.[45] As reported by Buchanan et al[46] in an analysis of MDS data, LTC residents with MS are distinctly younger than the regular LTC population, with an average age of about 58 years on admission. Residents with MS differ from the "usual" LTC population in other ways as well. They are more physically dependent and have more difficulties with range of motion and loss of voluntary movement. The symptoms of MS can include fatigue, spasticity, balance and gait problems, sensory disturbances, visual impairment, cognitive deficits, bowel and bladder dysfunction, tremor, numbness, pain, swallowing problems, and even complete paralysis.[45] Although some of the symptoms of MS may be familiar to caregivers, the severity and clustering of MS symptoms, as well as daily and long term fluctuations in symptoms, present unique challenges to staff.

Buchanan et al[46] reported that one in three residents with MS has impaired cognitive function and over one-third have depression, but only about 12% have been evaluated by a licensed mental health specialist. The cognitive dysfunction in MS can be insidious and can affect only one of two cognitive domains, as is the case with Barney.

Capacity Assessment

The nature of some of the cognitive decline is that the resident may not be aware of it. With preserved verbal fluency and vocabulary, the resident can appear more intact than he or she actually is, and the cognitive deficits may be affecting the resident's ability to make his or her own choices. When conflict arises between a resident's wishes and societal norms, medical advice, or family opinions (as in Barney's unrealistic plans for discharge), clinicians should assess decision-making capacity.

A practical framework for assessing capacity can be referred to by the acronym U-CARE, as shown in the box below[47]:

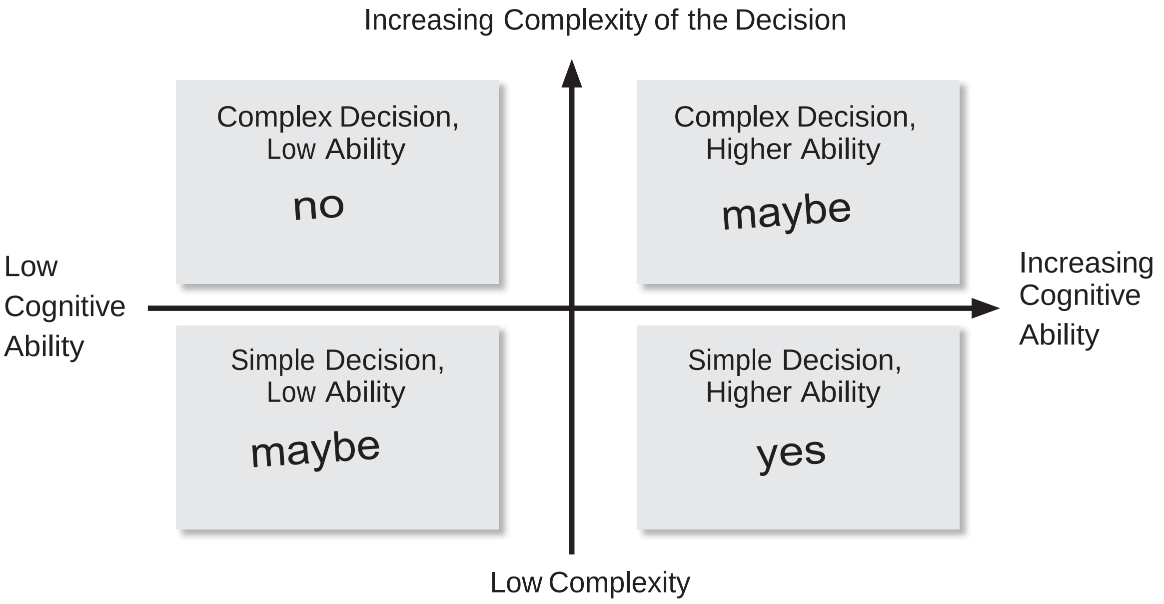
BOX 4. Capacity to Decide (U-CARE)

- — Understanding of the relevant information
- — Consistent responses over time when questions are asked different ways and by different people
- — Appreciation of the significance of information as it applies to the person’s situation
- — The ability to Reason with relevant information, logically weighing options
- — The ability to Express a choice

Adapted from Grisso and Appelbaum 1998[48]

Decision-making capacity can fluctuate with the resident’s condition and the particulars of the decision being made. As the complexity and risk of a decision increase, cognitive ability must also increase to sustain decision-making ability (Figure 1).

Figure 1. Relation Between Complexity of the Decision and Cognitive Ability



In borderline cases, multiple observations are necessary. Cognitive decline makes people anxious and fearful and creates a sense of loss of control, autonomy, and self. Therefore, it is important to preserve the resident's sense of self. Discuss the situation by using the resident's own words and find areas of agreement. Developing relationships is key. (For further discussion of developing relationships, see the section 2. *Best Practices: Facilitate Appropriate Relationships Between Residents and Staff*, page 13.) For further discussion of assessing decision-making capacity, see the article by Gibson and Ferrini in Annals of Long Term Care.[47]

Caregivers need to understand various types of cognitive decline and should meet frequently to support each other and share strategies for reducing residents' anger and fear. In Barney's case, the staff talked about the movie "Groundhog Day" to help them to understand what was happening to Barney's memory. Everything he had done in a day was lost to his memory by the next day. The staff working with him needed a lot of support and encouragement, and it helped them to have professional contacts (e.g., social worker, rehab staff, licensed nurse) to validate their feelings. Education about a particular disease such as MS can be a source of support for staff. In one facility in Toronto, Canada, the Multiple Sclerosis Society provided education for both staff and residents on the care needs of those with MS.[9]

In Barney's case, the staff used redirection of his behaviors rather than resisting behaviors or scolding or arguing with him, even if he was totally unreasonable. In some cases, it is best to play along a little. Talk with the resident about going home someday and about how what you are doing now may help. For example, "We have to get you stronger. Do you want to do some biceps curls while I pull up these pants for you?" Allowing the resident to plan for discharge rather than forcing him to face the reality of his situation can be kind if words are chosen carefully and do not constitute lies.

Physical exercise can mitigate this anxiety and fear, as can social stimulation. Finding a buddy in a peer can help, as can providing an opportunity to talk with others about MS, such as joining an MS society. In Barney's case, ample documentation was done by multiple members of the team, and Barney worked with an ombudsman to have an impartial third party witness the statements and advocate for him. Cognitive testing, if available, is recommended to validate staff observations. Less-helpful approaches include trying to reason with the resident, giving him too many options, or reminding him of his disability and agreement to stay in the LTC facility.

Over time, with constant reinforcement and a routine, more and more of Barney's knowledge about his condition and disabilities sank into his long term memory. But it took a long time, patience, and the development of a trusting relationship with staff.

Planning for LTC placement, including financial planning, is complex and laden with emotional issues. Staff can direct families to the National Multiple Sclerosis Society for helpful information on the LTC facility admission process and on financial planning for chronic diseases (Available at: http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/index.aspx [Accessed 01/29/13]).

CASE #6

case #6: maureen is a Bariatric Resident

Maureen is a 52-year-old Native American with MS that has resulted in near total paralysis. She can use a power wheelchair, but needs assistance with all other ADLs. She is more than 250 pounds, but refuses to be weighed. In fact, she has not been weighed for 2 years. Talking about her weight upsets her. If she is weighed, she wishes it to be private and not written in her record. She prefers junk food to what the facility serves and drinks a 6-pack of sweetened soda daily. She prefers to be nearly constantly snacking between meals. She requires staff to feed her. She has to be moved very carefully owing to her chronic pain and high risk of spontaneous fracture because of chronic daily prednisone use. Maintaining her skin integrity requires a complex regimen of placing dressings and powders between her skin folds and replacing them once or twice a day.

The epidemic of obesity in the United States affects all segments of the population, including LTC, and many obese LTC residents are young adults. In one study of U.S. LTC facilities over a 10-year period, the percentage of newly admitted residents who were obese rose from 15% in 1992 to more than 25% in 2002, and nearly one-third of these were aged less than 65 years.[49] Younger adults who are chronically institutionalized and have high rates of dependence may also become obese in the LTC facility. For example, many younger quadriplegic residents who do not modify their caloric intake to match their reduced energy requirements can become overweight or obese.

Admissions of obese residents to facilities not prepared or designed to accommodate them result in numerous challenges and barriers to care, such as inadequate staffing levels, the need for additional training and specialized equipment, and alterations in the physical environment.[50] Skilled nursing facility staff are generally unfamiliar with weight loss medications (prescribed or over-the-counter), prescribed weight loss diets, or bariatric surgery options. Specific aspects of bariatric care will require additional staff education, including sensitivity to obese residents' needs and rights, skin care, hygiene and wound care, mobilization complicated by excessive weight, and promotion of self-care.[51-54]

Feeding issues are complicated and ethically challenging in the obese, as are resident rights and staff responsibilities. Many bariatric residents are malnourished despite their excessive weight, and many are unable to exercise to lose weight. In Maureen's case, her right to refuse treatment extends to her rights to refuse a modified dietary regimen and to lose weight; however, when staff care for and feed Maureen, then Maureen's rights are mitigated. Finding the balance is tricky and should be somewhat collaborative, trying to meet the underlying needs and preferences of the resident in a person-centered environment while also promoting the health and safety of both the resident and the staff. A facility may limit unhealthy foodstuff "risk" in a number of ways. The facility can develop policies regarding storage and feeding of outside food to dependent residents (i.e., family or friends would have to purchase, store, and feed them junk food because facility policy may not permit staff to do this). Nutritional counseling, psychologic counseling, support groups (e.g., Overeaters Anonymous [OA]), and surgical intervention (gastric bypass) can all be considered. The facility may permit refusal of care (e.g., weighing) but also can refuse to place a resident in a power wheelchair unless there is confirmation that the resident's weight is not over the weight limit for safety. The use of the power wheelchairs can be a powerful motivator, because these chairs can be hard to get and critical to independence. Facilities can establish a weight limit for the chair and refuse to accommodate a resident who is over that limit (for further discussion of power wheelchair policies, see the subsection *Power Struggles: Use of Power Wheelchairs in Long Term Care,* page 23).

Skin issues are a constant concern with bariatric residents, with frequent intertrigo, fungal infection, and moisture in skin folds. Skin needs to be inspected more frequently for rashes and redness, and moisture must be managed. Interdry dressing or abdominal pads can be placed in skin folds. Antifungal creams and powders may be required long term. Air overlay mattresses may be used long term to prevent pressure and to promote comfort.

Facilities may refuse to admit some residents on the basis of weight, justifying the decision by increased risk of staff injuries from resident care activities such as turning or lifting; requirement to purchase or rent bariatric-type beds, chairs, and lifts; or concern about unreimbursed higher care needs. Some also note psychologic issues associated with morbid obesity. Experience suggests that these concerns are valid and that properly caring for this population takes preparation, expertise, training, and specialized equipment and supplies. In a model for caring for obese residents developed by one large LTC provider, several strategies and environmental modifications were adopted to promote resident safety and to prevent or reduce work-related injuries.[50] These included providing extra space for staff to maneuver; training staff in proper body mechanics and ergonomics; adjusting the environment by expanding doorways, hallways, and toileting and bathing areas; installing ceiling lifts and sturdier support bars; and purchasing bariatric equipment. Even with equipment, however, most facilities find that moving and repositioning obese residents takes more time and more staff. Proper equipment for caring for obese residents can include bariatric beds, reinforced bed trapezes, appropriate bedside lift and transfer equipment, extra-wide wheelchairs and walkers, and reinforced toilets designed to accommodate obese individuals.[50] Tables and seating accommodations for obese residents can be made available. Commonly used supplies will be needed in larger sizes, such as oversize gowns, bed linens to accommodate unusual bed size, and incontinence supplies.

CASE #7

case #7: gretchen Has developmental disabilities But is Able to state Her wishes

Gretchen is a 20-year-old resident with cerebral palsy, spastic quadriplegia, and developmental disabilities who develops worsening dysphagia. She often refuses the modified diet from facility caregivers, while accepting regular-consistency food from family members. She has experienced a 26-lb weight loss in 1 year, and consistently states that she does not want a feeding tube. She witnessed an unsuccessful resuscitation of a friend and indicated that she never wants "that." Her mother, her legal guardian, supports this choice, but her case manager doesn't agree and has enlisted the out-of-town father as an ally. The care team has expressed concerns about state and federal developmental disability requirements, guidelines, and agency involvement.

This case highlights complex issues regarding capacity and decision making, familial conflicts, resident rights to take risks within a LTC facility, and the role of the staff in assisting residents who wish to forego recommended care. LTC professionals are skilled at dealing with residents with limited capacity and with conflicts between impaired but opinionated residents and their family members or among family members; however, most of these situations involve an adult who has lost capacity rather than someone who always lacked it. Addressing this case begins with assessing the resident's capacity and her wishes regarding feeding. The Medical Orders for Life-Sustaining Treatment (Physician Orders for Life-Sustaining Treatment paradigm) checklists and guidance can provide a clear process (Available at: http://www.compassionandsupport.org/index.php/for_professionals [Accessed 01/29/13]). (See also *Box 4. Capacity to Decide (U-CARE),* page 54.)

If Gretchen is convinced of her capacity to make this decision, difficulties remain. When dealing with developmental disability, there are often unique family dynamics from protracted childhood illness and dependence. In addition, our society looks at the situation differently. A developmentally disabled and stably cognitively impaired individual is expected to be tube fed, for example, unlike a person with a similar level of disability from a massive head injury, advancing dementia, or stroke in whom it is more acceptable either not to start or to discontinue tube feeding. Adding to the complexity is that state and federal agencies advocating for the rights of the developmentally disabled often believe that "no code" or discontinuation of life-prolonging therapy is not acceptable and may even be cause to remove parental or legally authorized representative rights.

Exercise of autonomy and assumption of risk are also at issue. Can the LTC facility permit an individual to engage in risky behaviors? What role should the institution play to educate its residents about risky behaviors and prevent them within the facility? Is Gretchen's refusal to accept tube feeding or modified diet a refusal of treatment under resident rights statues? Could accommodating her also be interpreted as helping her to harm herself by preparing and offering a diet known to be unsafe, or by asking staff to feed the diet to her when the outcome could be choking aspiration or death? Sometimes the diagnosis affects the ethical evaluation (e.g., letting an individual with progressive dementia or advanced cancer eat whatever she wants seems different from doing the same with someone who is chronically ill or developmentally delayed, in whom life expectancy is longer).

Successful interventions in these circumstances include use of the interdisciplinary team and shared decision making via "risk-sharing conversations." The facility may try the new diet preference only under supervision, for a defined trial period, or with some other safety measures to balance facility safety obligations with resident autonomy. Other possible interventions include the following:

- Ethics committee[b] consult with interdisciplinary team. The committee might consist of physician, nurse practitioner, social worker, chaplain, nursing staff, and administrator to define the feeding issue (i.e., resident rights, quality of life, best practice).
- Speech therapy consult to review with staff the safest diet that is palatable for the resident and to promote the healthiest preparation and feeding methods if the resident is to be allowed more autonomy in deciding what to eat.
- Palliative care consult to provide assistance with symptom management.

[b] AMDA. Starting & Maintaining a Long Term Care Ethics Committee. Available at: http://www.amda.com/resources/print.cfm#ETHTK13.

- Hospice consult can be considered if weight loss continues.
- Use of pictures appropriate to the developmental disability level to explain differences in diets and tube-feeding procedures and to allow her to demonstrate her feelings and choices.

CASE #8

case #8: Robert Has Profound developmental disability

Robert is a 37-year-old white male with cerebral palsy. He had been on a Hospice benefit, but because of his continued health, he is no longer eligible. Robert is bed-bound; he requires total care with a percutaneous endoscopic gastrostomy tube and sleeps 22 or more hours a day. He has been diagnosed with schizophrenia and "self-harm" and takes multiple antipsychotics as well as multiple medications for seizures and muscle spasms. His exhausted mother is frightened of changes, but doesn't really know the reasons he is taking so many medications. She longs for a better life for him and has devoted her life to his case, resulting in the loss of her job, marriage, and even relationships with his siblings.

This case highlights something often seen among younger adults in the developmentally delayed population: a person with multiple diagnoses and many medications who appears sedated. Psychoactive medications are often used for behaviors, but often those behaviors are not observable or do not really fit the model of a mental illness like schizophrenia and are more like the behavioral disturbances of dementia with perseveration, child-like tantrums, or unusual sounds. When questioned about the need for these medications and the symptoms being targeted, legally authorized representatives can often provide little information except an impression that the medications are necessary and cannot be stopped. Often when legally authorized representatives are provided reassurance and careful explanation of risks and benefits, staff can attempt step-wise gradual titration, and these residents can often be removed from many of their medications so that they are more awake and have enhanced quality of life. Staff need to be aware that some behaviors may emerge (e.g., vocalization, masturbation, grabbing), but that nonpharmacologic treatments are more effective. Explain to staff that the psychotropics were not treating a particular symptom but rather were sedating the resident much like a chemical restraint. Many of these residents improve when removed from antispasmodic and benzodiazepine medications. They often have more problems with fixed contractures and some spasm with movement rather than actual muscle spasm.

In Robert's case, he was slowly tapered off multiple sedative medications (Benadryl, baclofen, Phenobarbital, Ativan, valium) with the consent of his legally authorized representative. He became alert and started to sing most of the day, sounding like a whale. As he awakened, he was reevaluated by a speech therapist and was found able to swallow. He was permitted to eat, first with oral gratification only, and then gradually advanced as his strength increased to three meals and snacks daily. He was placed in a customized wheelchair, allowing him to be upright, which further enhanced his ability to eat and to interact with others. Although he could not talk, he appeared to enjoy being with others and watching movies and activities. He loved pizza and ice cream, foods he had never tasted. He had been on multiple seizure medications for years with no change and no seizures. When tapered off most seizure medications, he never seized. His mother was overjoyed to see his progress and was able to confront her guilt about her caregiving and forgive herself as she saw how much he was able to enjoy his life. In a way, the treatment of the son, which enhanced his quality of life, was also a way of treating his family.

cases #9–11: sexuality in the ltc environment

case #9

The supervisor was called to the nursing unit by the charge nurse one evening. One of the staff nurses had been passing by a resident room with an open door. The curtain was drawn around the bed, but the nurse could see that the ceiling lift was being pulled along the track with jerking movements. She knocked on the open door and called out the resident's name. When no one answered, she became alarmed and pulled the curtain aside to make sure the resident was all right. The resident is a woman with quadriplegia and moderate cognitive deficits. Her boyfriend, a resident with hemiparesis from a cerebrovascular accident, was using the lift to support himself while they were engaged in sexual activity.

Sexuality is always a difficult subject in the LTC facility—among adults of any age—and many of the same issues are relevant to younger and older adults. Sexuality raises issues of consent and capacity, the role of staff in facilitating expressions of sexuality, privacy, and dignity. It is important that the facility establish and communicate policies to the staff for uniform enforcement that promote a balance among privacy, free expression, dignity, and safety for all involved.

Staff should be vigilant to identify potential liaisons and intervene openly and honestly with education and frank discussions to prevent risky situations. In this case, if the staff had identified the developing relationship, they could have proactively (and during business hours) interviewed each party to discuss the situation, ensure the necessary capacity and consent, and make plans for safety.

Once a potential or actual liaison is discovered, it is critical to maintain dignity while assessing the situation for adequate capacity and consent. A risky situation may exist when one partner has a higher cognitive capability than the other. In this case, the female resident's cognitive disability raised the question of whether she had consented to sexual relations or the boyfriend was forcing himself on her. To ascertain this, it is important to interview the residents separately and document that they both understand the risks, benefits, alternatives, and potential hazards of the activity and are willing to continue. In this case, although the resident did not have the executive reasoning skills necessary to make difficult health care decisions without assistance, she was able to make decisions about what she liked and did not like to do with her boyfriend and maintained a basic right of privacy.

It sounds paternalistic, but sex between two LTC residents needs planning and prior approval. Residents interested in any type of liaisons should be told clearly that sex in LTC facilities requires advance approval and planning. Individuals with the desire and ability to engage in sexual acts with others must be informed that other residents they may perceive as potential partners within the LTC facility may appear more capable than they are. They must understand that any potential partner needs to be reviewed with the staff in advance; if not, they may be accused of abuse or a sex-related crime with serious penalties. Errors can often be made when one resident perceives consent from another and engages in a sexual act, but it is later found that the partner was unable to understand or consent. Unplanned liaisons carry a real risk of being reportable as aggression, manipulation, or sexual abuse.

Planning for sex involves identifying a private space and time and planning for the safety of both residents. Does the facility have a private room for the occasion? Is there a larger bed? What are the sizes and disabilities of the involved parties? Is contraception needed, and do they need assistance with that? In planning for sexual expression, the facility will need to determine what staff will and will not do to help. For example, the facility may state that those who can engage in sexual activities without staff help may do so, but may stop short of assisting residents in sexual acts (e.g., placing a condom, positioning, placing one resident in the bed of another with a mechanical lift). A facility may offer to lift both residents into the same bed if that appears safe or to offer a safer environment for intimacy (e.g., an area in the rehab gym that has a wide mat, ceiling lift, and screens for privacy).

Discussion of risks and benefits becomes more complicated if the facility or caregivers know something about the risks that those involved do not. The facility may know that a person has a sexually transmitted infection (e.g., AIDS or hepatitis C), or that one person is married or even that one person is trying to get pregnant. Ideally, the facility would obtain permission from the individuals to share any information or, if that is not possible, educate both to ask and disclose.

If facility equipment is to be used, there are real concerns for liability and safety. For example, if facility policy is to have staff members present when a lift is used, then residents using a lift by themselves would violate this policy and perhaps the safety guidelines of the lift. In this case, the charge nurse identified that the male resident was using a lift without training, alone, and in a way that was unsafe. The male resident had looped one arm through the lift and used the motorized lift to pull himself to standing, which put him at high risk for a fall. Some facilities have a program whereby staff volunteer and are trained to physically assist disabled couples to have intimate relations, but this is not required to meet the test of accommodation of needs.

The reactions of staff, peers, and families to sexuality pose another difficulty. If residents are capable of making their own decisions, then ideally no one else is informed except staff involved in those residents' care. The situation is more challenging, however, if capacity isn't straightforward or if family members are very involved in other aspects of care and expect to be involved with this issue. In this case, the staff may ask whether they need to contact the mother who is next of kin and activated health care proxy for medical decisions. Most observers will say "no" unless permission is given to disclose. Facilities will need to address staff mores and prejudices about sexuality and sexual practices. In this case, the staff were observed talking among themselves about the incident, and some were appalled by the behavior. Leadership staff should take these conversations to private areas and educate staff about rights and facility policies. It is important that residents feel that the situation is private, even if staff plan and communicate about it. In addition, staff need an opportunity to discuss their own feelings and reactions behind closed doors and to have these concerns addressed, because these issues can leak and potentially result in violations of privacy, inappropriate conversations, or even reprisals. In some cases, staff with serious objections may need to be removed from assignments that impact their values.

Ideally, prior to this incident, when the two residents developed a relationship, the social worker should have interviewed the female resident to determine if she was comfortable with the male resident's sexual overtures. Although we're talking about the female resident in this particular case, both partners in the liaison must be comfortable with advances and capable of making decisions about them. In this case, the social worker was satisfied that the female resident was able to understand the sexual advances and to accept or reject them. She also made certain that the female resident knew that she could come to the social worker to discuss the relationship if it became uncomfortable for her. She was provided information about contraception and sexually transmitted diseases. The facility even stocked condoms, and she was given one to keep (she could not apply it herself, however; neither could he…). As people change their minds and risks and benefits change with time, assessment and documentation must occur on an ongoing basis. As liaisons do occur during hours when social workers are not present, nursing staff should be comfortable talking to residents about plans to have sex or about sexual practices. Often, these conversations cannot wait until the next day when the social worker is there. The nurse needs to be comfortable asking the kinds of questions or making observations that will determine if the residents involved are consenting each and every time.

> In their own words:
>
> "I would like to see staff help couples be together intimately without talking about it to anyone.''

case #10

A 31-year-old man is a quadriplegic but has intact sensation. He cannot masturbate and has purchased a sleeve device that goes over the penis. He asks for staff help to apply it. Should they consent?

The safest answer to his request is clearly "no." The staff's job involves providing basic nursing care; this falls outside their training and experience and has a high potential to go wrong. Ideally, this is something a friend assists with, and not staff; however, staff may feel very sympathetic toward the resident and may want to help to enhance his quality of life, autonomy, and satisfaction. Sometimes we do things a little differently for those under our care to provide the best quality of life.

In this case, if a staff member volunteered to help and could set appropriate boundaries and comply with all the rules, then perhaps this could be permitted. This arrangement would need careful oversight, however, and require honest discussion between the facility and resident about the risks and benefits. Staff would never be required to assist, because this may violate reasonable personal standards, and a facility could well refuse owing to risk of complaints or perceived boundary violations.

case #11

A 28-year-old was found using her personal computer to take videos of herself topless to post online.

On the one hand, this is her body, her room, and her right. On the other hand, this is facility property and the facility does not want illicit activities taking place. Furthermore, she is a dependent adult and the facility wants to ensure that she is not being exploited. In this case, the facility could limit belongings or access to services the facility is providing (e.g., the Internet). The facility can also enforce polices about pornography, especially as they relate to ensuring that the work environment for the staff is free from harassment. If the resident agrees to not engage in this activity with staff present, however, the facility's options may be limited. Educate the resident on the dangers of this activity, ensure that she has privacy, suggest counseling, and suggest alternative ways of self-expression and earning money.

Any discussion of electronics in LTC in relation to younger adults should include the benefits these items can have for some residents' quality of life. In some cases, the facility investment in obtaining and assisting with use of a computer can be a life changer for the impaired resident. In these cases, staff will often feel very protective of the computer and will not balk at anything it takes to keep it running because they realize that the computer improves both the resident and staff quality of life. Some facilities work with charities to obtain donated computers and may choose to lend them to residents, with an agreement in place, and determine if their use enhances quality of life.

CASE #12

case #12: Allyn Has too much stuff

Allyn has been at the facility for 2 years. He has a power wheelchair and a second one that is broken, but he may want to fix it. He shops on Craigslist and has purchased a laptop, desktop, large old-fashioned TV, and stereo system. He has his own coffee pot (he doesn't like decaf) and a large bottled water dispenser. He requests that staff purchase the water and put the five-gallon bottle on the dispenser. He has a large collection of sock monkeys. He is quadriplegic and uses a Hoyer lift. He refuses to part with anything, has a big "do not enter" sign on his door, and only lets certain staff he trusts touch his things.

One challenge in caring for younger residents is the amount of stuff they have. Many times these individuals consider the LTC facility their home and have nowhere else to go or to keep their belongings. Many have bulky items like power wheelchairs, stereos, and TVs and electronics such as curling irons, hairdryers, toaster ovens, microwaves, water dispensers, coffee makers, and blenders. Facilities can establish policies concerning belongings, but these can be challenging to enforce, and staff are constantly asking where to draw the line. It is common for some rooms to be singled out as cluttered while others with a similar amount of stuff are not. Younger residents are more likely to be aware of these differences and will resist change, stating that "So-and-so has more stuff than I do." Individuals may have great psychologic attachment to their things, many of which they see as essential to their quality of life. Managing clutter can be fraught with conflict and staff splitting can occur.

Clutter can interfere with movement of staff in the room and care, especially the use of mechanical lifts, and can shift valuable staff time from care responsibilities to "stuff management." Many residents who want to have a lot of stuff are unable to manage it themselves. Therefore, they want staff to make the toast, heat up their hair iron, water their plants, fold and put away their clothing, load the 50-pound water bottle onto the dispenser, and track and charge their electronics. In addition, staff are often held responsible if these items are lost or damaged; thus, the facility accumulates more risk and liability by permitting more belongings. Disposing of resident's belongings without permission can expose the facility to complaints about rights. Use of some belongings can affect others (e.g., large, loud stereo systems; pornographic or explicit decorations or possessions, which can constitute sexual harassment of staff or other residents). Housekeeping is stymied by the need to move and carefully replace or clean so many items.

Clutter can also hide contraband or restricted items that can be safety hazards. The unsecured water dispenser can topple over. A portable toaster, coffeemaker, or hair iron can cause a burn that may very well be blamed on the facility, and many facilities prohibit these items in resident rooms or without supervision. Food storage can lead to bugs or spoilage, and may require nursing assistants to prepare, monitor, and feed food that is potentially unsafe.

Ideally, clutter policies and enforcement balance safety with homelike atmosphere and right to belongings. A staff member who reports a problem should not be solely responsible for resolving it. This kind of "punishment for reporting" results in less reporting. Remind residents that the facility has a right to limit storage and the items allowed in the facility (i.e., you aren't confiscating their property, just declining to permit its storage or use in the facility). Inform residents and families about what items are restricted and why. Policies on restricted items or contraband should also highlight differences between items restricted for all (e.g., guns) and those restricted for some (e.g., some residents with assessments can have medications at the bedside). In addition, policies may state that residents who can care for their own belongings and need less staff assistance can have more belongings than those who are unable and require more assistance. Enforcement should be uniform while allowing for differences on the basis of care needs. If belongings are removed, the resident or a representative should be present to minimize the risk of complaints of theft or damage. If family members are involved, they may wish to keep some of the belongings (e.g., off-season clothes). (Sample policies and notification letters for excessive clutter are available online.[a])

[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

CASE #13

case #13: the smiths are married

The Smiths were both residents in their early 30s with significant physical limitations who decided to get married. They didn't tell facility staff they were married until months after they had done so. They initially wanted to share a room, but once relocated, they kept getting into fights with yelling, name calling, and threatening. The staff heard their yelling and wanted to know whether to leave them alone, stand by as witnesses (who were often asked to take sides), or to call and report this as abuse. The facility at first assigned the two to the same caregiver, but later to different ones. The Smiths would want information shared between them one day and then would change their minds a day later. They would request information about obtaining restraining orders against each other and filing for divorce one week and be reconciled the next. Mrs. Smith has an IUD, but requests its removal because she wants to get pregnant. The facility medical director is not comfortable removing the IUD. Mr. Smith is later discharged, but the volatility of the relationship doesn't change.

The issue of couples in LTC is not unique to younger residents, but some of the problems that younger residents face in relationships (e.g., sexuality, risk of pregnancy, presence of minor children) are unique. Although none of our experts has experienced dealing with a pregnant resident, it has been reported. One LTC facility reported that a schizophrenic resident's pregnancy was not noted for 5.5 months, during which time she received no prenatal care, lost the opportunity for termination, and continued psychotropic medications that may be unsafe for a developing fetus. It was reported that the facility failed to recognize pregnancy as a possible explanation for an enlarging abdomen in a woman of reproductive age.[55] Pregnancy can result from consensual or nonconsensual sexual acts. Given the proximity of women of reproductive age to men, this concern is bound to arise in LTC just as it has in psychiatric hospitals, jails, and prisons.

Dealing with the problems of interpersonal conflicts from a love relationship can be time consuming and fraught with ethical challenges. Key challenges are maintaining appropriate boundaries between staff and residents and remaining professional at all times. Staff are reminded not to take sides between spouses. Staff are also reminded that relationships between disabled, often mentally challenged residents may look different from what they are accustomed to. Staff need a private place to vent their own feelings on the issue. Counseling of the couple may improve the relationship dynamics.

Practical concerns include appropriately maintaining residents' legal status, appropriately permitting and limiting visitors, and sharing medical information on the basis of constantly changing resident preferences. In this case, the facility is probably best served by not providing information to one spouse without first checking with the other each time, except in cases of emergency. In addition, setting appropriate limits on behavior is important. Remind these residents that behavior that may be acceptable in the privacy of their home is not permitted in the communal setting of a LTC facility. Specifically, arguments should not disturb other residents and should occur in private areas. Residents and staff need to know that a relationship does not justify abusive behavior. Any abusive behavior observed or reported between domestic partners who are dependent adults must be treated as abuse and reported to the authorities in compliance with state and federal regulations.

LTC facilities should address pregnancy risk and prevention with at-risk residents. Women of reproductive age who are at risk of pregnancy should consider birth control. Options such as the Depo-Provera shot and oral contraceptives are sometimes used for menses regulation. Women of reproductive age also need routine health maintenance including pap smears, breast exams, and sexually transmitted disease screening, which can be done inside the facility or sent out for referral. Challenges exist in performing some of these examinations on women with disabilities. Before referral, it is important to identify whether the consultant has the authority to transfer a resident, whether the resident would be safe on an examination table, and whether the procedure can be accomplished. Practitioners should determine whether a woman is or may be sexually active and have some knowledge of birth control methods. Facilities should have a few condoms available in the nurse's cart, just in case. Requests for them are signals that further conversations may be required regarding capacity and risk evaluation (See Cases 9–11: Sexuality in the LTC Environment, page 60). For a compendium of birth control methods, refer to publications from the U.S. Department of Health and Human Services Office on Women's Health (available at: http://womenshealth.gov/publications/our-publications/fact-sheet/birth-control-methods.cfm [Accessed 01/30/13]) or Planned Parenthood (available at: http://www.plannedparenthood.org/health-topics/birth-control-4211.htm [Accessed 01/29/13]).

If a resident becomes pregnant, options must be explored. It is important to determine whether a crime was committed (e.g., rape, molestation) and to identify the father. Facilities need to be alert to pregnancy as a possibility for women of reproductive age, and should track menstrual periods and recognize signs of pregnancy. Staff need to be aware of pregnancy and refer for pregnancy counseling early enough that termination can be considered. Staff should be educated on pregnancy-related risks, prenatal care requirements, and emergency planning. A medication review is necessary as many medications commonly taken by LTC residents may be teratogenic and are often withheld during pregnancy, which can result in other complications. A LTC facility that is unable to care for a pregnant resident must find a suitable discharge location. The parents must be informed that the infant cannot be cared for in the facility, although challenges in visitation may arise if the mother wishes long term visits from the infant and asks staff for assistance in caring for the infant. Consideration of options such as alternative family members to raise the child, adoption plans, or foster care may be necessary.

Some younger residents may already have dependent children. These children may be cared for by relatives or may have been fostered or adopted. Children in LTC facilities can bring joy to residents, but there are risks to the children that require mitigation. Children need supervision in the LTC setting, and the dependent adult resident cannot provide it (i.e., children must be accompanied by another responsible adult). Children must be supervised at all times and protected from residents who may frighten or harm them and from inappropriate situations (e.g., nudity, masturbation, profanity). Ideally, visiting areas are contained. Children should not be used as translators, and minor children cannot be decision makers. Visits can be improved with services offered to the children to explain the illness and what to expect. This is particularly challenging in the case of HD, where children are observing a parent with a condition they have a 50% risk of acquiring themselves. These children often have difficult relationships with the institutionalized parent owing to previous drug or alcohol abuse, mental illness, brain injury, or other conditions. The possibility of overnight visits can be challenging. Does the facility permit a child to stay overnight without an accompanying adult? If so, who is responsible for the child? Some facilities have playgrounds for visiting children; however, these have liability and safety issues as well.

CASE #14

Case #14: Dealing With Technology in Long Term Care

- *Toby uses the facility's Internet service to access pornographic websites and shows them to other residents—for a price.*
- *Shakira's iPod is lost again; she wants it replaced.*
- *Dylan has limited use of his upper extremities—he needs staff to help him to set up the computer, to get him positioned, and to load software for him.*
- *Portia posts information about the facility on her blog and takes photos of staff in her room without their knowledge.*
- *Sandra has asked her nursing assistant to be her Facebook friend. Sandra has her nursing assistant's cell phone number and texts her if she is out when Sandra wants to communicate.*

These cases illustrate a trend that may initially be more common in younger adults but will eventually affect all LTC residents: technology. Devices are becoming more powerful, cheaper, and smaller all the time, and more and more facility residents own them. Such devices have tremendous benefits in reducing isolation, enhancing safety (taking a cell phone on outings), maintaining connections, and providing easy access to a wide variety of activities (e.g., games, social media, news, movies); however, there are problems, too. Younger adults have a far different relationship from that of older adults with social media, photography, and video recording devices, and different expectations for public and private connections. They do not think it odd that their family, friends, and staff are all Facebook friends. They may tweet personal (i.e., protected) information about other residents. They may surreptitiously record staff to prove poor care, or families may want to install "nanny cams" to see what is really going on.

These devices are often small, and thus are easily misplaced, caught in bedding, broken, secreted, or stolen. They can be expensive. They require care—programming, charging, repair—which often cannot be performed by the resident owing to cognitive or physical limitations, leading to yet another service expected of certified nursing assistants, who may not be trained to provide it. Residents are often far more sophisticated than staff about these devices. The devices use electricity, which is an added cost. Does the facility charge for access to its Internet service? Who can use it and for what purpose? Can the facility regulate its use (e.g., to restrict pornography)? Some residents with impaired cognition or executive function may be like children, whose use of the Internet should be supervised because they are vulnerable to exploitation; how can this be done practically?

In their own words:
What services would you like to see offered?

“Individual computer for each person.’’

“[Have] computers available. Want to have e-mail.”

Facilities can require computer use agreements in which residents agree in advance to certain restrictions and that violations of the agreement can result in loss of computer privileges (a more proactive approach). Facilities may provide basic computer training to staff to enhance their job skills, quality of life, and enable them to assist residents. Handouts can be devised with simple instructions on Internet access or sending e-mail; however, once residents get e-mail addresses and accounts, be prepared to receive e-mails from them. Computer use agreements can address dos and don’ts about eating and drinking while using the computer, amount of time permitted when people are waiting, downloading music or other harmful files, computer hygiene, and pornography. Facilities may require a basic computer skills assessment before permitting access. Facilities may make computers and the Internet available in public areas, but should invest in some assistive technology and virus software as well as periodic cleanups and oversight to ensure that these machines continue to operate. A skilled and interested resident may “police” the computers for downloads that contain malware or viruses. Collaborations with local high schools can be helpful to get manpower to fix computers and to teach residents to use them.

Technology is changing very quickly. Facilities can develop plans to manage technology and to clarify what staff can and should be doing. Policies should cover what kinds of e-mails can be sent to residents and when. When can residents be photographed and what can be done with those photographs? How are cell phones, iPods, tablets, and computers charged and maintained? Who is responsible for damages, and what computer-related tasks are the responsibility of the caregiver? Even if facility policy states that staff cannot be Facebook friends with a resident, staff may have relatively public profiles that allow residents to stalk them online and learn about their private lives, so establish policies and train staff to make their online profiles more private. Even with well-written polices, most of these decisions are based on the judgment of the staff member enforcing the policy.

CASE #15

cAse # 15: Pain management and drug seeking in long term care

Todd has a history of polysubstance abuse including intravenous drug use. He has a spinal abscess and was admitted on sustained-release oxycodone 30 mg twice daily using all breakthrough doses. He continually insisted that his pain was a 10/10 no matter what and wanted hydromorphone as a PRN because it was "the only thing that works." He spends the day in bed and is irritable, demanding, and unfriendly. Todd continually triggers the MDS by describing his pain as 10/10 "all the time," which he states interferes with sleep and activities.

An in-depth discussion of pain management is far beyond the scope of this guideline, although good resources include the following:

- AMDA's Clinical Practice Guideline *Pain Management*.[c]
- US Department of Veterans Affairs, Management of Opioid Therapy for Chronic Pain (2010). Available at: http://www.healthquality.va.gov/Chronic_Opioid_Therapy_COT.asp (Accessed 02/05/13).
- Practice guidelines for chronic pain management. An updated report by the American Society of Anesthesiologists Task Force on Chronic Pain Management and the American Society of Regional Anesthesia and Pain Medicine. Available at: http://www.guidelines.gov/content.aspx?id=23845 (Accessed 02/05/13).
- American Academy of Family Physicians. Pain: Chronic. Available at: http://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleId=61 (Accessed 02/05/13).
- Pain Treatment Topics. Available at: http://pain-topics.org/ (Accessed 02/05/13).

It is important for those caring for younger residents to have some familiarity with the special needs and concerns of this age group. Many physicians feel more comfortable prescribing opioids to older ladies with arthritis and a reduced life expectancy than to a young male with a history of drug abuse and a nonspecific pain syndrome for whom they have more difficulty determining true need versus drug-seeking behavior and who may require opioids for years. Chronic pain is a common concern for residents with decreased mobility, paralysis, and musculoskeletal disease. Persons with a history of substance abuse generally receive poor pain control.[56] Helping staff to understand important pain concepts such as end-of-dose failure (when the therapeutic effects of a medication diminish before the anticipated time), tolerance (diminished reaction to a drug, requiring higher dosages), and physical dependence (experience of withdrawal symptoms such as irritability, increased blood pressure, and tachycardia with drug removal) is necessary to ensure adequate pain relief. Suggestions for pain management in younger adults include the following:

- Narcotic agreements with goal setting, monitoring, and aligning expectations (see sample online[a]).
- Setting clear goals regarding functional status and engagement in activities in conjunction with prescribing opioids. Rather than a pain number, the goal may be that the resident has enough pain relief to get up daily and participate in at least one activity.

[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

[c] AMDA. Pain Management. Clinical Practice Guideline. Ordering information available at http://www.amda.com/tools/guidelines.cfm.

- Adding nonpharmacologic interventions such as behavioral activation, engagement, fulfilling activities, warm and cool packs, exercise, range of motion, massage, touch, and relationships.
- Teaching the resident to use guided imagery, visualization, and relaxation techniques to assist with pain management.
- Trial adjuvants: there are so many non-opioid pain management modalities that using these alone or in combination can significantly reduce or eliminate the need for opioid medications. These include but are not limited to topical agents such as topical lidocaine, analgesic balm preparations, capsaicin, oral and topical nonsteroidal anti-inflammatory drugs (NSAIDS), systemic agents such as desipramine and imipramine, anticonvulsants, acetaminophen, muscle relaxants, and steroids.
- Trials off and on opioids at varying doses to determine whether opioids are indicated and effective as measured by functional goals, recognizing that much pain can be opioid resistant and that opioids have many negative side effects including tolerance, gastrointestinal side effects, and hyperalgesia. Use stepwise trials to see if increasing or decreasing opioid medications results in either a change in the pain scale or a difference in quality of life. For example:
  - Todd may be approached in this way: “Your pain is a concern to me. I take it seriously. I will increase your pain medications, and you keep a diary about what works and what activities you are able to do.”
  - When following up, check the diary. If the pain is improving and his activity level improves, he may be a person who benefits from opioid and adjuvant therapy.
  - If, however, he continues to complain just as vehemently despite increases of 100% to 200%, then it is a good idea to try lowering the opioids and tapering them off with the diagnosis of opioid-resistant pain.
  - Adjuvants with less risk of tolerance and hyperalgesia can be selected and titrated.

  In the authors’ experience, pain and quality of life frequently improve when opioids are tapered. Monitor carefully selected behaviors with and without opioids and on varying doses and determine if there is any correlation between behavior and functional status and opioid prescription. Some LTC specialists dealing especially with younger residents note that despite the (often difficult) initial period of downward titration of opioids, elimination of opioids has made dramatic improvements in quality of life, functional status, interactions with others, and future ability to discharge to the community.
- If the resident is operating a power wheelchair, using drugs or alcohol, or experiencing side effects, special precautions are necessary before prescribing opioids.
- Nursing staff should be aware that residents on pain medications or methadone are likely to become anxious and demanding about receiving their medications on time. It works better to give them their medications early in the med pass rather than to “punish” them for acting-out behavior by making them wait. Waiting will only increase their anxiety and acting out.

CASE #16

Case #16: Gay, Lesbian, Bisexual, and Transgender Residents

Christine is in her 50s and is a transgender individual with HIV/AIDS. She has had breast augmentation, but has not had genital surgery. When admitted, she clearly defines herself as a female, and facility staff attend to her beauty needs with makeup, hairstyle, and dress, but as her physical health declines, she elects to let her facial hair grow, refuses to be shaved, and at times does not respond to the name "Christine" but does respond to "Christopher." Staff feel uncomfortable and often use the wrong pronoun. Some residents laugh or call her names. She has no friends visiting and had reported estrangement from family, who are not involved owing to unresolved conflict.

There is increasing sensitivity to the needs of lesbian, gay, bisexual, and transgender (LGBT) individuals in the LTC facility; however, surveys still find evidence of discrimination in admissions and care. One survey of more than 700 volunteers reported the following problems[57]:

- Fear of being "out" and vulnerable,
- Verbal or physical harassment by residents,
- Verbal or physical harassment by staff,
- Refusal to accept medical power of attorney,
- Staff refusal to refer to or use preferred name,
- Staff refusal to provide basic services or care,
- Failure to provide proper medical care, and
- Abrupt or attempted discharge; refusal to admit or re-admit.

Facilities may fear accepting these residents as a result of a lack of education and experience or fear of negative publicity. Those with experience caring for these individuals note that it is important to be sensitive to the manner in which the resident identifies him- or herself, to identify by preferred name and gender, and to protect confidentiality and dignity. Private rooms may be preferable if possible, especially in cases such as Christine's, if some ambiguity exists about the gender assignment with advancing illness. For many LGBT individuals, there may be different family dynamics—perhaps simply a domestic partner of the same gender—or perhaps conflict within the family of origin or among current friends that needs sorting out when the resident is alert and able to communicate. For example, a resident may need assistance to complete the appropriate legal documentation for a long term partner to be the legally authorized representative rather than the out-of-state family who has not been involved in the resident's life. Staff need a private place to ask their questions and sort through their feelings about caring for these residents. Only staff who feel they can provide sensitive and compassionate care should be assigned. Staff need to be aware of the environment and protect these residents from harassment as much as possible and may also have to educate peers about the situation. One training resource is the film "Gen Silent," which follows the lives of six older LGBT adults in the LTC system over the course of a year (Available at: http://stumaddux.com/GEN_SILENT.html [Accessed 01/29/13]).

This case presents a transgender adult having cognitive decline and an identity crisis, and who now isn't answering to the female name she originally requested. This individual benefited from a private room. Staff were instructed to meet her where she was at the time—referring to her by her name of choice at any time, providing both types of clothing (women's and men's), and offering to shave her but permitting her to refuse.

CASE #17

case #17: Hernandez is Bored

Hernandez is bored. He has been here for years and feels that a plan to ever get out is hopeless. His friends are not visiting as much as they used to. He thinks the same old activities are boring. He just wants to stay in his room and sleep.

LTC facilities were never designed for long term stays for younger residents, and boredom is a common complaint among this population, especially among those with more cognitive abilities. This tool kit covers various options for alleviating boredom—work, school, assisting others, computers, cell phones, and activities (See Table 6). Sometimes, however, the complaint of boredom persists, regardless of what is offered. Sometimes boredom can be a sign of depression with loss of interest in activities that were previously engaging. In this case, a behavioral activation plan can be implemented—residents undergo an assessment of what they used to like, choose something that they may consider trying now, and are rewarded for engaging in the activity. Many times when people begin to engage in activities, even if they were initially reluctant, they develop relationships and satisfaction that is self-reinforcing and serves to engage them in the community. Boredom can be reduced by setting and achieving goals. For example, a resident set a goal to complete a 3-mile wheelchair race 6 months in the future and then worked over that time period with increasing distances traveled until the race day. Having outsiders from a community reintegration program come to the facility and talk to residents about the possibility of returning to the community has been very effective in some facilities, even for those who are unlikely to leave.

TABLE 6. Activities shown to Engage Younger Adults in Long Term Care

- Outings outside the facility: zoo, powwow at a local Native American reservation, museums, festivals
- Community walk to local grocery or fast food stores
- Laundromat trips
- Entering something in the county fair and attending
- Attending school or adult education in the community
- Music making, drum circles, choral group
- Music therapy
- Book clubs, reading aloud to other residents, storytelling
- Intergenerational activities with children
- AA, Narcotics Anonymous (NA), OA meetings (invite the community in)
- Religious assistance from the community—offering services in the facility and facilitating resident attendance or young adult groups outside the facility
- Start a small business (e.g., make photographic cards or art cards to sell)
- Encourage residents to blog or write about their experiences and assist them in getting published

(continued)

TABLE 6. (Continued)
Activities shown to Engage Younger Adults in Long Term Care

- Involve residents in quality improvement teams in the organization, invite them to meetings, have them review policies, have them assist with the newsletter, publicly honor their contributions
- Have residents do something for charity—respond to a disaster, send cards to homeless children, make toys for shelter dogs
- Internet café where residents learn and share computer skills
- Local community college/adult education—some have programs that may be appropriate for younger residents
- Makeover programs where hair is styled, nails done, makeup applied (with consideration of infection control issues)
- Contests and tournaments: dominoes, Texas hold 'em poker where someone wins and the contest can last several days; contests where staff and residents work together, such as a scarecrow-making contest
- Gardening programs
- Giving residents candy to give to local children and offer in facility "Trick or Treat" program for Halloween
- Nature trips (hikes) to wheelchair-accessible beaches, parks, lakes, or trails
- Holiday lights excursions
- Local high-school sporting events
- Follow a sports team: parties with special food and near-beer
- Dress-up activities (e.g., formal dance, prom, crowning a wheelchair princess)
- Train for and compete in a wheelchair race
- Wheelchair regatta; community boating event
- Fine arts programs (healing HeARTS) where residents work in group projects on a single canvas with residents of varying abilities and also small classes with higher-functioning residents working on individual projects
- Longer term group art project that takes weeks and results in product to display: large crepe paper student heart made for Mother's day and displayed in lobby or tree with leaves each imprinted with staff and resident THANKFULness statement
- Concerts with "younger" music: can be held outside on summer evenings so the music doesn't disturb others; invite local teen garage bands
- Happy hours with alcohol or "mocktails" and nonalcoholic beer with an adult atmosphere
- "Adult" entertainment such as exotic dancers of either gender
- Mentor new residents or other younger residents to help them to integrate into the facility or adjust to their illness; adopt-a-resident program in which one resident serves as a special friend to another resident to care and assist with activities and sometimes advocacy
- Men's or women's groups facilitated to discuss particular issues relevant to that group
- Educational seminars on topics of interest: sexuality in the disabled, cyber safety, photography, getting back to the community, stress management, dealing with difficult people
- Cooking programs where residents plan, shop for, prepare, and eat a meal together
- Monthly resident-choice meals where residents create a menu that the kitchen executes
- Late-night movies, themed movie series with discussion for higher-functioning residents
- Modified sports programs (wheelchair hockey, soccer, or basketball); use softer balls and more staff who are excited to work on small goals
- Pet therapy
- Computer gaming; facility can purchase games for residents to borrow
- Wii games are surprisingly simple for residents to perform and are also enjoyable for those watching

CASE #18

case #18: substance Abuse—Alcohol and drugs

Trent is 42 and has a long history of substance abuse. He is at the facility after suffering an epidural abscess resulting in pain and bilateral lower extremity weakness complicated by endocarditis. He has a long history of tobacco abuse, alcoholism, and polysubstance abuse but has not used for the 45 days he was in the hospital. He is weaker and needs help with ADLs and seems a little confused at times. His friends who come by from time to time are tattooed and often homeless and like to hang out at the facility. They often eat off his food tray or ask other residents to share. Trent asks for a prescription for medical marijuana. His mother, from whom he was previously estranged, is happy he is finally somewhere safe and wants to make sure he gets the help he needs for this long term problem.

This case brings up multiple issues for which LTC facilities are often completely unprepared, such as risk of active substance abuse, unsavory visitors, pain management in residents at risk for substance abuse, and the need for treatment. There may be discharge difficulties for these residents, unrecognized cognitive impairment from substance abuse, and sequelae that cause increased disability and frailty at younger ages from years of hard living. There are also difficulties in dealing with familial and psychosocial issues in a resident with long term substance abuse problems. Care plans for these residents should deal with current and potential problems. In this case, the resident has polysubstance dependence/abuse in institutional remission. He has suffered substance-abuse complications in multiple body systems (e.g., cognitive, immune, functional, cardiac). Right now, he is too sick to use the substances and lacks access, but as he gets well, the desire to use may resurface. You would like to offer him some kind of treatment, but most nursing facilities have little experience and few resources in this area. Information is available from the World Health Organization (Available at: http://whqlibdoc.who.int/hq/2001/who_msd_msb_01.6b.pdf [Accessed 01/29/13]). Options may include self-help recovery programs such as AA, NA, or SMART Recovery that the resident can attend inside or outside the facility.[35] Cognitive impairment may render this unhelpful or even counterproductive, because it may "remind" the resident of drug or alcohol use. In traditional 12-step approaches, coping skills are not taught. In approaches like SMART Recovery, although coping skills are taught, cognitive impairment may prevent learning and use of those skills. If a resident is referred to any form of treatment, he or she should be monitored to assess the effect. A type of straightforward psychotherapeutic intervention called "Brief Interventions" can be taught to social workers and can be effective at addressing substance abuse issues. Motivational interviewing principles may help the resident to develop a plan for abstinence.[58]

This medical complication could be severe enough to finally end Trent's substance abuse problem—the proverbial wake-up call. If so, it is also often the case that the individual is functionally impaired to such a degree that he may not be able to live his previous lifestyle and may need substantial resources to reintegrate into the community. Alternatively, he may elect to stay at the facility long term. In this case, substance abuse problems can resurface and new risks arise, such as drug use in the facility or outside, his inducing others to join him or selling drugs to make money, and unsafe behavior in or out of the facility as a result of drugs or alcohol. If the facility is concerned about active substance abuse, urine or blood toxicology screens could be ordered, or a breathalyzer may be purchased and used by the facility (e.g., prior to administering narcotic painkillers). With evidence of use, searches can be made of his person and room and any drugs or alcohol removed. If illegal drugs are found, law enforcement can be called (although in some states, law enforcement is not interested in arresting LTC residents for substance possession).

Many facilities are reluctant to admit residents who are addicted for two primary reasons: the resident's behavior and the risk of diversion. For those with active addiction, careful screening is needed to ensure that the individual is committed to the program and understands the rules of the facility, and that visitors do not bring illegal drugs into the facility. Care plans have to be thorough, and there should be a contingency for overdose (e.g., frequent monitoring, doors open, Narcan in the emergency kit) and a plan for management of acute intoxication or withdrawal symptoms. Because few facilities will accept these residents and some have private-pay insurance, there is revenue potential in caring for them. A facility that admits and successfully manages an addict may develop a niche in the industry.

A particular difficulty has been identified with residents taking methadone as part of a maintenance program for substance abuse transitioning from a hospital to a LTC facility. Prescribing methadone for drug addiction requires special training and expertise and is highly regulated. Most skilled nursing facility physicians cannot and will not do it.[59]

Residents must be transported daily to the clinic providing their methadone, because it normally cannot be available within the facility. Alternatively, an arrangement may be made with a clinic to dispense the medication within the facility, but the medication must be prescribed and monitored by a physician with expertise. For more information, see the sample policy online.[a] Sometimes, in an effort to make these patients more acceptable for admission to LTC, the hospital staff switches them from methadone to another opioid or indicates that the methadone is prescribed for pain rather than drug treatment. Neither option is ideal from a substance abuse treatment perspective, and without careful admission screenings may even go unrecognized. In individuals with severe disabilities (e.g., massive stroke, accident) who no longer have the ability to engage in illicit behavior, this could be more effective in inducing institutional remission than in a resident with more functional and cognitive ability to continue with long term habits.

For facilities with larger numbers of younger residents, conducting substance abuse training for staff and having staff or volunteers who can run ongoing groups are also very useful. For example, one facility has a SATS program (substance abuse treatment services) that comprises individual assessments and counseling, assistance with care planning, and facilitating resident groups and staff trainings.

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[a] Clinical Corner: Younger Adults. Available at: http://www.amda.com/YA.

CASE #19

cAse #19: Family dynamics in the care of Younger Adults

Susan's ability to speak is limited as the result of a stroke she suffered at age 36 from using methamphetamine. Her 55-year-old mother often speaks for her. They sometimes spend the entire care planning conference introducing a list of complaints that take time, investigation, and tact to resolve. You notice that Susan's care needs are not that great and that she seems content, but when her mother comes, the tension rises. The demanding and criticizing of staff seem overwhelming, and they tend to avoid contact because of the tension. Nothing they do is "ever" right.

Family concerns are salient in LTC residents of all ages, but there are particular issues in play for younger adults. The dynamics of parents helping younger LTC residents are quite different from those of children helping parental LTC residents. In some cases, the family is the clinical unit and we cannot fully help the resident without consideration of the family members.

Staff may lament and react to the mother's involvement, but it is likely that she is there to stay and dealing with her issues will be key to a successful placement. The same concepts discussed earlier are important here. We need to understand the perspective of the mother. She may feel hopeless, guilty, or devastated emotionally, not only because of the severe medical outcome, but also because of the drug use preceding it. She may desperately want to "do something" and may not know what else to do. She may consider her complaints to be "advocacy" and a way to protect her daughter from further trouble. Connecting with her begins with seeing her point of view, validating her feelings, and finding another way to meet her needs.

Facilities have had success with inviting these families to family councils, involving them in quality-improvement initiatives, or finding volunteer opportunities for them within the facility. Providing a single contact for complaints who has strengths in dealing with challenging people can be helpful and protects the other staff from the mother's negativity. This can help to preserve therapeutic relationships. Reminding the mother that the daughter depends on the caregivers and needs to develop trusting relationships can help her to see that mistrust and fear are not in her daughter's interest. Validating her feelings of loss, regret, being out of control, and isolation can also be important.

Ill from Birth

When younger adults have been cared for at home by parents since birth, family dynamics have been in place much longer than in the typical family in which the adolescent seeks and is eventually able to achieve independence. The reaction of the family to placement can vary considerably. An example of openness are the mother and daughter who were both admitted because the aging mother's health problems left her unable to care for her severely disabled daughter. Upon seeing how thrilled her daughter was to be among others and attending activities, the mother commented, "I thought keeping her home was doing the best thing for her, but she loves it here." The two made plans for the daughter to stay after the mother was well enough to return home.

In some ideal cases, aging parents recognize that they need to provide alternative arrangements for their ill adult children and work with the team to make the transition to LTC as smooth as possible. More often, however, we see families who have difficulty giving up the role of primary caregiver after years of parental sacrifice. In these cases, the admission of the young adult is often sudden rather than premeditated and could be the result of a downturn in health of either the resident or the caretaker.

In some situations, the primary caregiver has died, leaving the secondary caregiver the spoken or unspoken mandate to care for the young adult, often without the necessary physical, emotional, or financial means. It is particularly important in these cases for the team to be sensitive to the specific dynamics and form an alliance with the family rather than an "us versus them" mentality. Ways of creating an alliance include empathizing with the life changes that have brought them to the point of seeking a facility, acknowledging and respecting their efforts as caretakers in the community, and continuing to seek their advice as knowledgeable team members for their loved one.

Younger Adult Reactions to Parent Involvement **(Ill from Birth)**

It is also important to be aware of the reaction of the young adult to placement in terms of family dynamics. For example, the resident may be happy to have some relative freedom from parental control. The staff may observe some acting-out behavior similar in nature to a first-year college student who is away from home for the first time. On the other hand, the younger resident may be invested in continuing the longstanding parent-child roles, particularly if the parent is having difficulty detaching. Sometimes this is caused by the child "helping" the parent who has minimal interests aside from caretaking of the child by continuing to need care. The team can intervene by offering ways parents can remain involved in care but allow their adult children the opportunity to expand their horizons. For example, they may encourage parents to become involved in advocacy or peer support on a local or national level for their child's illness, to become involved in the family council meetings, or to assist other parents placing their adult children in LTC. The team can involve the young adult resident in activities that can be shared with their concerned parent, such as recreational activities with a performance that can be observed by the parent or a rehabilitation graduation certificate or ceremony.

Staff should be aware that for young adults who have been living under their parents' care since birth, LTC placement is likely the first time the resident has been part of a social group other than the family. It is likely that they have no idea how this new society works, especially if their parents haven't set reasonable consequences for acting-out behavior. Although they are not adolescents, it may be helpful to conceptualize the work of the team as guiding the young adult into society, even if they are in their 30s, 40s, or 50s. Clear guidelines via pre-established policies and procedures that are calmly explained and consistently enforced can facilitate the transition. If the placement has occurred owing to the death of the caretaking parent, it's important for the team to expect and allow for a period of grief. In all cases, an early referral to the mental health staff (psychologist, psychiatrist, social worker, or chaplain) provides a forum for young adult residents to address their concerns as confidentially as possible and for the treatment team to get feedback from the mental health professional about which approaches will work best for particular family dynamics.

Siblings and other relatives **(Ill from Birth)**

The role of the healthy sibling in a family where one person has been ill from birth can vary considerably. If there were reasonable expectations for all children regardless of physical health, relationships are likely to be psychologically healthy and mutually supportive. If children were treated differently by parents because one child was healthy and another ill, relationships between siblings are likely strained. The healthy sibling may be in a caretaker role or may have distanced him- or herself from the family unit. The healthy sibling may disagree with the way the parents handled the ill sibling, yet be acutely aware that he or she will be responsible once the parents are unable to care for the ill sibling. Regardless of the dynamics, LTC placement is a shift in the family system and an opportunity for the siblings to reconnect or to connect differently. The interdisciplinary team can facilitate this process.

Ill Through Capricious Fate

Residents who have become ill owing to factors largely out of their control such as MS or car accidents have different family dynamics from those who have been ill since birth. In these cases, the young adults generally have been living independently of their parents, with jobs and families of their own. When parents step in as caretakers once again, the team can help them to negotiate their own grief at the loss of their independent child and find ways for them to assist their loved one while still maintaining their own health and lives. Providing information and referral to outside organizations for particular illnesses, such as the MS Society or a stroke support group, can be invaluable. It may also be helpful to discuss ways in which parents can help while allowing their adult children to retain as much control over their lives as possible, understanding that the amount of assistance needed by the parent can change over time.

Younger Adult Reactions to Parent Involvement **(Capricious Fate)**

When younger adult residents have been living independent lives before placement, they may have mixed feelings regarding parental involvement. On the one hand, they are likely to badly need this help, and on the other, they may feel guilty or even angry about it, particularly if they had challenges in separating from their parents initially. The illness of the young adult may have occurred when they were in the middle of raising a family or about to take over some aspects of care for their aging parents. These factors will affect the amount of care needed by the resident and the feelings about parental involvement. Again, the opportunity to discuss these issues with the mental health staff is essential. It is important for the team to discuss with younger adults how involved they would like their parents to be and with what decisions and help them to understand that the level of involvement can change over time. The team can assist residents to find ways of meeting their own needs so that they are less reliant on their parents, such as ordering supplies via the Internet rather than relying on a parent to run errands.

Siblings and other relatives **(Capricious Fate)**

The illness of a family member is a crisis for the family, and the team can help to facilitate family connections and involvement. For example, the team can suggest ways that long-distance siblings can assist the loved one who needs care (such as being the person who orders the supplies over the Internet and has them shipped to the resident or who contacts friends of the resident to reduce isolation) and can assist the family in finding a caretaking balance.

Ill Through Lifestyle Misfortune

Residents whose illness is the result of involvement with drugs, alcohol, gangs, or other dangerous activities are likely to have had challenging relationships with their family members. Sometimes family members have been involved in similar activities; at others, family members have watched their loved ones seemingly inexplicably "go down the wrong path." Family members may have been enabling the substance abuse or dangerous behavior without realizing it and may feel guilty, ashamed, or hopeless. They are likely to need support with their grief and self-blame. If appropriate, the facility can help families by involving the resident or family in substance abuse treatment. Twelve-step programs offer support. Family members can also be encouraged for involvement that enhances resident care, while less-helpful involvement can be minimized or skillfully redirected. Facilities may need to establish or review policies on visitor behavior such as drinking, smoking, or bringing in contraband and explain these to family members upon admission of the resident. Given the likelihood of conflict among family members, the team should make use of the main contact person when discussing care issues. Staff training on the behaviors of substance abusers and the reactions of their family members and others around them will help the team to provide a more unified and effective front.

Younger Adult Reactions to Parental Involvement ***(Lifestyle Misfortune)***

Young adults who enter LTC owing to a misfortune that occurred while engaging in dangerous behavior are likely to have a conflicted relationship with their family members. They may blame their parents or reject their efforts to help (sometimes with good reason), yet need their help because of their illness. Family dynamics are varied and a referral to the psychologist and other mental health professionals is essential to begin to sort through the issues so that residents can accept care from the team and from their parents, if necessary.

Siblings and other relatives ***(Lifestyle Misfortune)***

As with residents who are ill from birth, the siblings of substance-abusing or acting-out residents may have experienced differences in parental behavior and consequences. They may react by becoming caretakers, by distancing themselves from the family drama, or may be substance abusers themselves. During the crisis of LTC admission, the team can help to facilitate appropriate involvement in care and a positive shift in family dynamics. Families may need assistance in balancing the amount of care provided by various members and may benefit from referral to outside support groups. Residents may be able to work through previous conflicts in psychotherapy in order to accept help from siblings or to reject inappropriate assistance.

IV. THE FACILITY'S ROLE IN BEST PRACTICES

Role of the medical director

The F501 defines the role of the nursing facility medical director (42CFR §483.75[i])[13]:

(1) The facility must designate a physician to serve as medical director and
(2) The medical director is responsible for
  (i) Implementation of resident care policies and
  (ii) The coordination of medical care in the facility.

The regulation itself is straightforward, but it is in the details that the proverbial devil resides. The interpretive guidelines delineate the qualifications of the medical director, including knowledge of medicine and standards of practice in LTC coupled with skill at oversight and coordination of clinical practitioners. Each facility is encouraged to empower its medical director with greater responsibility and authority. The medical director may serve as a conflict mediator, investigating and responding to complaints, and collaborating with facility clinical and administrative staff, residents, and families to assure excellence in clinical care. Medical directors may be responsible for evaluating care provided by other practitioners, addressing risk, and evaluating the functioning of systems of care. Nationally accepted statements concerning the roles, responsibilities, and functions of a medical director can be found at the AMDA Web site, http://www.amda.com/about/roles.cfm.

In the case of younger residents, medical directors may have to oversee exceptions. They may be required to adapt AMDA and other practice guidelines to meet the needs of younger people (e.g., guidelines for psychotropic prescribing, Beers list prescribing, decisions about health screenings, intensity of care for various diseases, pregnancy testing, sexuality). Medical directors may be called upon to handle the often-difficult cases of younger adults by nurses, social workers, administrators, and even other physicians. The medical director is expected to have some expertise in special issues affecting younger residents such as mental illness, substance abuse, behavioral management, balancing rights and safety, and risk management. The medical director may be the best candidate for tasks that other physicians may find unusual or complicated, such as overseeing the evaluation of a resident's ability to safely operate a power wheelchair. Given the heightened security expected by regulators and the public in the care of younger residents, concern for their needs must be incorporated into the processes of quality assurance process improvement. Education, information, and communication domains focus on the need for medical directors to be excellent communicators and educators and to model up-to-date clinical practice.

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Role of the Interdisciplinary team

> *Sandra has been doing very well, but when she gets a temporary staff assignment while her regular caregiver is on vacation, she becomes demanding and hostile. She pushes the call light incessantly and her mother tells you that the staff members who respond are not being sensitive to her needs. She gets skin breakdown because the temporary caregiver puts the brief on too tightly across her hips. The doctor's office tells you that they are fielding four complaints a day from her mother and ask what is going on with care at the facility. The social worker is asked to call the mother but feels that she can do little as "all the complaints are about nursing." Sandra has a fall and states that she tried to get out of bed herself because the caregivers didn't come. When her regular caregiver returns, you find out that the caregiver had a daily routine to give her a hand massage and take her outside, and that the routine was not performed by other staff.*

The health conditions that lead to LTC placement create multiple stressors on residents that may affect them physically, mentally, socially, and spiritually. Providing high-quality holistic care for young adults in a LTC environment requires an interdisciplinary team effort that allows the expertise of each discipline to be effectively used to develop an appropriate plan of care. With younger residents in particular, the team may need to expand their notions of treatment and incorporate unorthodox approaches to facilitate residents' adaptation to illness and the LTC facility.

Younger adults, because they are likely to have longer stays and may have a more-difficult adjustment to illness, often need extra psychosocial supports. They may require access to support groups or organizations for their particular illness such as the MS Society or the Amputee Coalition. Recreational needs may be very specific and different from those geared toward older adults, such as Internet access or adaptive technology to play games. Teams can make the most of the interdisciplinary approach by being open to creative ideas no matter where they come from and taking advantage of the different styles and approaches among disciplines. Team members should work together in care planning and in training the staff members who will actually provide the intervention. For example, if the team decides to try using specific music during care, the procedure should be explained in detail to aides and nurses who are involved. Even better, the intervention can be documented so that any staff member can use it.

The issue of communication among team members and between shifts is paramount, because certain younger adults tend to split staff and use the gaps in communication to their advantage. This lack of communication can be seen in the example above where caregiving details weren’t known among floor staff, leading to anxiety and acting out for Sandra and her mother. A lack of communication also becomes apparent when a resident who comes back intoxicated from a Saturday off-campus isn’t met with consequences until the weekday shift arrives on Monday morning. The team can facilitate communication by establishing policies and training staff to enforce them, by care planning as many of a resident’s needs as possible, and by sharing care information among staff who are covering for absences, particularly in cases when it’s likely that the resident and/or their family will be distressed by the absence of the primary caretaker. Teams can also make better use of the change-of-shift report to relay not just medical issues but behavioral changes on the part of residents.

V. Recommendations

We propose the following recommendations for consideration in developing guidelines for the care of the younger adult in LTC:

1. Psychiatric/psychologic support team: Mental health staff, including psychiatrist, psychologist, psychiatric nurses, and social worker should be a routine part of the care team. Residents identified upon admission as having potential mental health issues or problems should be referred immediately.
2. Specialized recreational activities and resources: Younger residents need activities geared toward their interests and involving their peers. When trust has been established, they can run their own groups with staff as helpers. Activities providing a showcase for residents’ talents and expertise are likely to be successful among all age groups and provide an excellent forum for increasing connections among peers.
3. In-facility support groups: Illness-specific support groups can be helpful. Providing space for such community groups allows residents the opportunity to connect positively with peers in the community, reduces isolation, and increases the visibility of the LTC facility.
4. Peer-to-peer support: Residents who are successfully addressing their impairments, disabilities, and/or addictions should be given the opportunity, if they desire, to assist newly admitted disabled peers. One of the most devastating effects of illness and placement on younger people is a feeling of uselessness. Providing peer support diminishes this feeling and creates meaning and purpose out of their experiences.
5. Computers and electronic gadgets: Residents should have access to Internet services and electronic equipment as appropriate. Lack of access increases feelings of isolation, frustration, and confinement. The Internet can be used for education, contact with family and friends, and connection with similarly disabled peers, among other benefits. Computers are essential to the mental health of the younger resident.
6. Younger resident councils: Resident council meetings are an excellent tool for staff education and identification of younger residents’ concerns; they also foster appreciation for the administration when resident concerns are addressed.
7. Staff training: Administration and facility staff require education specific to the needs of the younger resident. Training that focuses on dealing with behav-

ior problems, understanding mental illness, resident-staff communication, and stress management can be conducted by the psychologist, psychiatrist, social workers, and psychiatric nurses. Training can also be accomplished through a panel of younger residents who function at a higher cognitive level and can share their feelings, experiences, and concerns in an interactive educational environment by responding to questions from staff participants.

8. Clear and enforceable policies: Explosive outbursts of behavior among this population pose an imminent threat to residents and others; therefore, facilities should have clear, enforceable policies for dealing with problematic behavior and staff members should know these policies.

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ResoURces

Throughout the toolkit, references are made to supplemental resources that are available online. These online resources can be accessed through AMDA's Clinical Corners page at http://www.amda.com/YA.

Policies and Procedures SAMPLES available:

- Abuse and Criminal Activity
- Acute Problematic Behavior
- Belongings
- Boundaries Social/Sexual Contact
- Complaint Grievance
- Danger to Others
- Decision-Making Capacity
- Leaving the Facility
- Loss Damage Property
- Married Couples
- Methadone for Substance Abuse
- Non-Adherence, Refusal of Care, Non-Compliance
- Personal Appliance Safety Check
- Power Wheelchairs
- Restricted Items (Contraband)
- Smoking of Tobacco Products
- Safety Assessment
- Suicide Prevention Plan
- Visitors

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