



Network Newsletter

LTCSWI Fall Conference

Mark your Calendars!
LTCSWI Fall Conference
Friday, November 8, 2024

The fall conference is scheduled for Friday, November 8, 2024, at Northcrest Community in Ames.

- Dr. Tom Mouser, MD, Chief Medical Officer, EveryStep, will lead us in a seminar on **Palliative Care and Hospice**.
- **Frontotemporal Dementia**, will be covered by Deb Scharper, FTD Support Group Leader, Alzheimer’s Association.
- Cynthia Letsch, JD, Attorney at Letsch Law Firm, will help us learn more about **Medicare**.
- We end the day with a session on **Financial Exploitation of the Elderly**, by Crystal Doig, Director, LifeLong Links/Aging Resources.

6.0 Continuing Education Units

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Brochures and registration will be available in early September

**NEW LOCATION:
Northcrest Community in Ames**

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Social Work CEUs



- Minimum of 27 hours of continuing education required every two years.
- The two year period begins January 1 of each odd-numbered year and ends December 31 of the next even-numbered year. (Current Period: January 1, 2023 - December 31, 2024)
- A minimum of three hours in social work ethics which must meet the *Rules of Conduct* including such things as *informed consent, competence, privacy and confidentiality, access to records, dual relationships and conflicts of interest, and sexual relationships*.
- Those who regularly examine, attend, counsel, or treat dependent adults must complete 2 hours of training within six months of employment or self-employment, unless otherwise specified by federal regulations, and requires one hour of additional training every 3 years.
- Those who serve in a supervisory role must complete 3 hours of continuing education in supervision.
- The licensee should maintain a personal file with all documentation of the continuing credits obtained.

For more information visit:

<https://dial.iowa.gov/licenses/other-professional-licensure/social-work-licensure#laws-amp-rules>



~Submitted by Ceci Johnson

Intellectual Disabilities and Dementia

By Sue Coyle, MSW

Social Work Today: Vol. 24 No. 2 P. 20

When individuals with intellectual disabilities are diagnosed with dementia, both they and their support systems have unique needs.

A dementia diagnosis is challenging for anyone—both the individual who is diagnosed and their family members/caregivers. Dementia is a condition defined by the loss of memory and intellectual functioning, as well as behavior changes and the eventual inability to complete everyday tasks, among other symptoms. Such a diagnosis, when possible, comes with treatment options, resources, and supports but also the knowledge that the individual will lose—whether slowly or quickly—aspects of themselves over time, though Philip McCallion, PhD, a professor and director of the School of Social Work within the College of Public Health at Temple University in Philadelphia, assures, “The person is still there. They are still the individual they always were.”

The needs of every individual with dementia are unique.

Similarly, the needs of every adult with an intellectual disability are unique. A number of diagnoses and a wide range of abilities exist under the umbrella of intellectual disability. The American Psychiatric Association defines intellectual disability as a disability that involves problems with general mental abilities that affect functioning in the following two areas:

- intellectual functioning (such as learning, problem solving, and judgment); and
- adaptive functioning (activities of daily life such as communication and independent living).¹

Individuals with an intellectual disability may be diagnosed with Down syndrome or Fragile X syndrome, for example. Their abilities may range from being able to live independently for some time to needing to live with a full-time caregiver.

When someone with an intellectual disability is diagnosed with dementia, their needs, as well as the needs of their present or potential caregivers, must be addressed with care, taking into account the specific yet unique factors that will affect them moving forward and acknowledging both diagnoses.

Prevalence

Dementia is not an uncommon diagnosis for adults with intellectual disabilities. In fact, research shows that individuals with Down syndrome specifically have a higher risk of developing Alzheimer’s disease. According to the Alzheimer’s Association, approximately 10.9%

of adults older than 65 have Alzheimer’s disease. Comparatively, the National Down Syndrome Society notes that “Estimates show that Alzheimer’s disease affects about 30% of people with Down syndrome in their 50s. By their 60s, this number comes closer to 50%.”²

Alzheimer’s disease is more likely to develop earlier in adults with Down syndrome as well, with signs and symptoms often starting when an individual is in their 40s as opposed to their 60s.

The data is less clear in regard to other forms of dementia, as well as other types of intellectual disabilities. Some studies have shown a higher prevalence of dementia in adults with intellectual disabilities at a younger age while noting that additional factors may influence such rates. For instance, a study published in 2023 found that “Although the prevalence of dementia in people with ID [intellectual disability] without DS [Down syndrome] was found to be higher at a younger age than in the general population, the results of this study suggested that adequate education, prevention of head trauma and stroke, and treatment of hypertension and depression may reduce the risk of dementia.”³

As individuals with intellectual disabilities continue to live longer, it is likely that additional research and data on the risk of dementia will also expand.

Development and Progression

The symptoms of dementia in adults with intellectual disabilities can vary. Generally, memory loss is considered the hallmark sign, and while that can be one of the early symptoms, it’s not necessarily the first indication that an individual with an intellectual disability is developing dementia.

Kristin Rains, MSW, director of Dementia Care Partners in San Francisco, California, notes that the signs that an individual with an intellectual disability has dementia can be similar to those seen in the general population but can also be different. “I certainly have known individuals who have shown short-term memory loss. However, for some of our individuals, especially those who are nonverbal, you are not going to see those signs.” She explains that it’s more likely that behaviors will change. The individual may withdraw from their favorite activities or show increased agitation or confusion. For example, she says, “You might notice that they’ll start to use different words. Instead of using your name, they’ll say, ‘Hey, you!’”

Monica Moreno, the senior director of care and support for the Alzheimer’s Association, agrees, adding, “There are other warning

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signs that can signal cognitive decline, including altered judgment, mood changes, challenges in decision making, and planning and carrying out daily tasks. Identifying these signs in people living with intellectual disabilities can be more challenging since symptoms associated with some intellectual disabilities may closely align with those of early cognitive decline.”

When signs begin to appear, attaining an appropriate diagnosis is an important next step. However, this can be challenging. “The assessment instruments that we use don’t really work for many people with intellectual disabilities,” McCallion says. “The existing instruments make it look like everyone [with an intellectual disability] has dementia, and that’s not the case.”

Assessments designed for adults with intellectual disabilities exist, though not necessarily as diagnostic tools. For example, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) released the NTG-Early Detection Screen for Dementia, which was designed “not [as] an assessment or diagnostic instrument but [as] an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the cognitive impairment assessment.”⁴

Tools such as this allow for family members, caregivers, and practitioners to establish a foundational and documented understanding of an individual’s well-being and abilities. This foundation is vital not only in enabling an accurate and timely diagnosis of dementia should it occur but also in monitoring the progression of the disease. It provides a baseline that, Rains says, indicates what an individual’s abilities, such as carrying on a conversation, were at their highest level of functioning.

“If you go to a doctor and they don’t know what the individual’s baseline is, they’re not going to be able to know what the changes [in cognitive functioning] are,” she explains.

It’s also important to note in what context the changes are occurring, Rains says. “Are these symptoms coming on very quickly? It’s probably not a brain change. Has something else changed in their



life? Have they lost a job or lost a friend?” Getting a picture of the whole person allows caregivers to provide the most accurate information and practitioners to make the most accurate diagnosis.

Individual Support

Once a dementia diagnosis has been given, the individual with intellectual disabilities will need support—likely an extension and evolution of the support that’s already being provided. One of the key components of that support is communication to the degree possible about the diagnosis and how that may affect the individual.

There are numerous resources available for family members and caregivers from organizations like NTG, the Alzheimer’s Association, and the National Down Syndrome Society. These resources can be used to help explain the disease, with the caveat that the information given should be communicated in a way that’s most effective for the individual receiving it.

“In communicating disease-related information to a person with intellectual disabilities, caregivers should stick to proven communication strategies that have been successful in the past,” Moreno says. “Since Alzheimer’s and other dementia gradually diminish a person’s ability to communicate, it is important for caregivers to reassess and adopt new communication strategies as needed.”

Additional support will vary depending on the individual, how the disease progresses, and the supports already in place, including who the caregiver(s) is or will be as independence diminishes.

“It can be very different from the general population,” Rains says. “Most don’t have spouses. There’s not a husband or a wife or children to care for you. The most likely person you’ve got in your life is a paid caregiver or it’s your parents who are maybe in their 80s now. They may be experiencing their own brain changes. It can be very complicated.”

Caregiver Support

Those complications can make it difficult not just for the individual with dementia but for their caregivers as well. It’s equally as important that the caregiver receives support, services, and resources throughout.

“Caring for a person with Alzheimer’s takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves,” Moreno says. “Caring for someone living with intellectual disabilities facing Alzheimer’s or another dementia can be even more challenging as caregivers are most likely adding additional responsibilities to those already provided.”

It’s not only the additional responsibilities but also the shift in the goal of caregiving. “When we think about caregiving for people with intellectual disabilities, our goal is always that each year they become more independent,”

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McCallion says. However, with dementia, “You reach this point where people are not going to become more independent. In fact, they’re going to lose some of their independence. All of the work that [the caregivers have] done, they’re going to watch it disappear over time.” Not only knowing this but also experiencing it as a caregiver can be overwhelming and bring up a great deal of complicated emotions. Additionally, depending on how the disease progresses in the individual and to what degree the caregivers can continue caring for their family member, there may be layers of guilt adding to the emotional weight of caregiving.

Marianne Iversen, BSW, director of mental health and aging support at the Down Syndrome Connection of the Bay Area, notes that both parents and siblings of individuals with intellectual disabilities and dementia struggle with decisions about care and respite because of promises they made to themselves or others. “If they’re siblings, so many have made promises to their parents on their deathbed [about caring for their sibling]. They’re carrying this guilt around.”

Iversen offers a monthly support group for caregivers of adults with Down syndrome and dementia. The support group is unique in its population and offers a community to caregivers during what can be a very isolating experience.

In addition to emotional support, caregivers need access to education about dementia and how it may progress, as well as resources such as respite or daytime care.

Community Support and Changes

Unfortunately, many of these resources for both the individual with dementia and the caregivers are not readily available or are not designed to meet the needs of adults with intellectual disabilities, particularly those who are not yet in the older adult age group. “Dementia can hit early,” Iversen reiterates. “Those senior programs that maybe could accept someone with dementia can’t [accept a younger person].” They’re also likely not prepared or properly trained to accept a person with an intellectual disability.

Rains adds that even when programs are designed for individuals with intellectual disabilities, they may not be prepared for changes in the level of care they need. This can be particularly evident and jarring when it comes to housing. According to the Residential Information Systems Project, approximately 16% of individuals with

intellectual or developmental disabilities lived in group homes in 2019.

Speaking specifically of California, Rains notes that many housing programs are based on a static diagnosis. “You’ve had this lifelong intellectual disability, and you can’t work, you can’t keep a job, so we’ll make sure you get housing, and you go to a day program,” she explains. “But that’s assuming that nothing changes. If you need a higher level of care, you’re going to have to move to a different home. Some of our individuals move from home to home to home. It is tragic that just at a time that they are struggling, they’re removed from their home, then moved again.”

Social Work’s Role

More care and thought need to be allocated to making communities and community programs such as housing and day and respite programs accessible to individuals with intellectual disabilities who have dementia. Without such resources, the individuals and the caregivers suffer. This is where social workers particularly can come into play, though they are needed at every stage of a dementia diagnosis.

Social workers can advocate for the population as a whole and for their individual clients within their community to create more accessibility and opportunity. They can also work to find the resources that already exist that may not be as readily known.

“As a social worker, look around, look beyond to see what else is in the community. Look for whatever can be done to make sure that you’re addressing the whole family, not just the individual with the brain change. What do the carers need?” Rains says. “Make sure that doctors are really addressing the brain change and the impact that it’s having on the whole person and not just masking the symptoms. And make sure you are doing everything you can to uplift the person, allowing them to live the best quality of life with the skills that remain.”

-Sue Coyle, MSW, is a freelance writer and social worker in the Philadelphia suburbs.

References

1. What is intellectual disability? American Psychiatric Association website. <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>. Updated March 2024.
2. National Down Syndrome Society. Aging and Down syndrome. https://ndss.org/sites/default/files/2022-06/Aging-and-Down-Syndrome_0.pdf. Published 2013.
3. Takenoshita S, Terada S, Inoue T, et. al. Prevalence and modifiable risk factors for persons with intellectual disabilities. *Alzheimers Res Ther*. 2023;15(1):125.
4. National Task Group on Intellectual Disabilities and Dementia Practices. NTG-EDSD. https://www.the-ntg.org/files/ugd/8c1d0a_f969e085d5a64bc79f80fa1332c0ac50.pdf. Published 2022.



Residents' Rights Month: The Power of My Voice

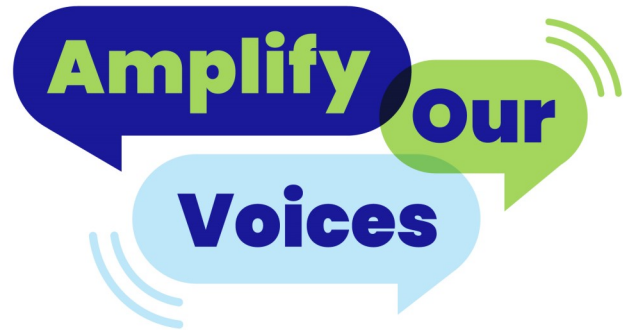
October is Residents' Rights Month, an annual event designated by Consumer Voice to honor residents living in all long-term care facilities and those receiving care in their home or community. It is an opportunity to focus on and celebrate the dignity and rights of every individual receiving long-term services and supports.

Residents have the right to self-determination and to use their voice to make their own choices. This year's Residents' Rights Month theme, **The Power of My Voice**, emphasizes self-empowerment and recognizes the power of residents being vocal about their interests, personal growth, and right to live full, enriching lives."

For More Information and Resources:

<https://theconsumervoice.org/events/2024-residents-rights-month>

~ Submitted by Ceci Johnson



National Consumer Voice for Quality Long-Term Care

Reasons Facilities Should Participate in Residents Rights' Month

1. Educate staff on residents' rights (annual requirement).
2. Build relationships with residents, families, and staff.
3. Promote community involvement in long-term care.
4. Increase community awareness of residents' rights.
5. Highlight the facility's dedication to promote residents' rights and person-centered care.



Psychiatry for Non-Psychiatrists will be held in person at Des Moines University Medicine and Health Sciences in Des Moines, IA, and streamed live via Zoom. The cost to attend is the same for both options. During the registration process, you will select your preferred attendance option.

Cost

Registration Fee (In person): \$99

Registration Fee (Online): \$99

Audience

All healthcare professionals are invited to attend.

Purpose

The robust demand for mental health services has grown steadily and outpaced the supply of psychiatrists. Non-psychiatric clinicians are increasingly filling that void and providing vital mental health care in many settings, including primary care clinics, hospitals, and community health centers. This conference will provide additional support to these clinicians so that they are better prepared to meet the mental health needs of their patient populations.

For More Information: <https://cme.dmu.edu/PNP-2024>

It is not your job to save everyone. Some people are not even ready to be helped. Focus on being of service to those who are, and be wise and humble enough to know when the best service you can offer is to guide them toward help in another direction.

— Anna Taylor, award-winning New Zealand fiction author



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The Long Term Care Social Workers of Iowa is a statewide organization, promoting the professional status of social work in long term care facilities. Our purpose is to facilitate your professional growth in long term care, offer continuing education opportunities for you, and provide the means with which you can enrich the lives of long term care residents and their families. Anyone who works in long term care is welcome to join!

Member Benefits

- ◆ Conference Discounts
- ◆ Quarterly Newsletter
- ◆ Membership Directory
- ◆ Discussion Forum

Application Form Available: ltcswi.com

Fall Conference Preview Friday, November 8, 2024 Northcrest Community, Ames

- ***Palliative Care and Hospice***
- ***Frontotemporal Dementia***
- ***Medicare***
- ***Financial Exploitation of the Elderly***

Continuing Education Credits:
6.0 Contact Hours

Conference Brochures will be out in
early September

See you at the Fall Conference!

