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Supporting People with IDD as they Age

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Debbie is 52 years old. She has been a valued member of the group home where she has lived for the past 12 years. She moved to the group home when her mother passed away. She has a brother, David, who lives a couple of hours away. He comes to visit Debbie for holidays, and special times in between. Debbie has Down syndrome. She takes medication for some health issues with her heart and thyroid. Debbie loves setting the table for everyone at mealtimes. She loves walking to the park down the street, and going to the movies. She likes picking out nice outfits for the day.

Over the past year, staff have noticed some changes in Debbie. Sometimes her outfits aren't as coordinated as they used to be. She still likes to set the table, but sometimes she seems to get 'stuck,' and staff support her to finish the task. Staff have also noticed that, for the most part, she still likes to go out for walks, but it seems to take her longer, and some days she does not want to go at all, which is a big change.

Question: What are some ways the group home can support Debbie?

Background:

People with intellectual and developmental disabilities (IDD) are living longer than ever before. This is wonderful news! But, for many people, living longer (aging) comes with some unique challenges.

Researchers in Ontario have found that people with IDD show signs of frailty and age-related diseases at an earlier age than people without IDD (Martin, Ouellette-Kuntz, McKenzie, & Habash, 2018; Ouellette-Kuntz, Martin, & McKenzie, 2016). They are also more likely to use aging-care services like home care at earlier ages.

The amount of people over 45 with IDD is growing. As a direct care staff, perhaps you have noticed that many of the people you support are aging, and may be developing more health care challenges.

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So, what do we mean by aging, anyway?

Aging is a biological process associated with changes to the mind and body. For people with IDD, aging is likely to begin at a younger age than it does for adults in the general population. This means that a person with IDD who is in their 50's may present with some similarities in their mind and body to a person without IDD who is in their 80's. As we age, every organ system changes. This is normal!

Let's go over some of the common diseases *associated with aging*, and how you can support people during this time.

- **Dementia:** Some people get dementia as they get older. The most common cause of dementia is Alzheimer's disease. Symptoms of dementia include short-term memory loss (forgetfulness) and difficulty organizing one's daily routine (executive dysfunction). Over time, people with dementia lose their language and their ability to function independently, so help will be needed to eat, get washed and dressed, and to walk around safely. This is a key difference from normal brain changes with aging which may include forgetfulness without the impact on function or being able to do the things you like to do.
 - **We now know that people with developmental disabilities are more likely to develop dementia than other adults, and it can happen at a younger age.** This is most notable for people who have Down syndrome, but we now know that this is also an issue for adults with other forms of IDD. The declines, though still gradual, may occur more quickly than they do in other adults. When people with IDD develop dementia, you may see personality changes, or behaviour changes. It might be tricky to notice changes in someone who already requires a fair bit of help. This is why it is very important to know the people you support very well, so you can compare them now to how they were a few months ago or a year ago, rather than just comparing them to other people.
- **Depression:** As one gets older, the risk for developing depression also increases. Signs of depression include things like a low mood (sadness), along with changes in sleep, having a hard time concentrating, poor appetite, and feelings of guilt. A person with depression may also become more irritable or easily bothered. Movements may be slower, and you might see that it is harder for a person to be motivated to do things they used to enjoy. The risk for suicide is higher in older adults than younger adults. Depression is treatable, so a doctor should be informed if you suspect that someone you support has depression.
- **Delirium:** While dementia is associated with a long-term, decrease in memory and skills over time (months to years), delirium happens suddenly (hours to days)! Delirium is an **acute (sudden!) state of confusion**, and it can be a medical emergency. Unfortunately, delirium can often be missed. Older people, especially those with dementia or other brain diseases have a higher risk of developing delirium when there are any changes to their overall health. Even something minor like a medication change or poorly treated pain can lead to delirium. A physical examination and bloodwork is usually needed to assess for the underlying cause of delirium. A nurse or doctor should always be informed if you think a person is showing signs of a sudden change.

Signs to look for: suddenly being very confused, fluctuating or changing level of alertness (for example, knowing who a roommate is early in the day, then not recognizing them after lunch, then knowing who they are again later), being unable to focus and maintain attention, being disorganized and not making sense, or being very sleepy and hard to wake up.

- **Falls:** Older adults have a higher risk of falling. Unfortunately, people with IDD are already at high risk of falling because of issues with balance, walking, and reflexes, making this an even bigger issue among older adults with IDD. Falls may seem minor in younger people, but older adults may suffer serious injury to the skin, muscle, or even break bones because of a simple trip. Things that may make people more likely to experience falls include: taking too many medications (especially drugs that make you drowsy), joint problems (arthritis), weakness of muscles (from stroke or deconditioning), poor balance (from stroke or nerve damage), poor vision (cataracts or macular degeneration), and dementia. When an older person falls more than once, a thorough assessment is needed to prevent the risk of future falls.

How can you keep people safe from falls?

- An Occupational Therapy home safety assessment! Contact your residence's local Home Care Coordinator (in Ontario, this is through the Local Health Integration Network, previously known as the CCAC).
 - Look around the home and see if there are any changes you can make. Remove or secure things a person may trip over – like cords and clutter, mats, and rugs.
 - Make sure floors are dry. Keep close supervision in the bathroom.
 - If there are steps, help to make sure all steps are really visible (e.g., add reflective treads).
 - Have handrails on both sides of the stairs if possible.
 - Have lights on and bright, and night lights or motion sensor lights for the bedrooms and hallways.
 - Look at a person's shoes – do they look too loose or floppy? Or, are they too tight and uncomfortable? Do the treads on the bottom still work?
 - Check a person's feet! If there are long toe nails, sores or blisters, etc., this is likely to cause a person to walk differently, which could throw off their balance. Be extra careful if someone has diabetes, since they are at increased risk of foot ulcers.
Here is a resource that may help: www.findingbalanceontario.ca
- **Osteoporosis and fracture:** Another common problem related to aging is osteoporosis, which is a disease of bone loss. Both older men and women are at risk of osteoporosis, but postmenopausal women are at a higher risk because of the loss of estrogen, which protects bones. Older individuals with little exercise, living an indoor sedentary lifestyle are at higher risk of osteoporosis. So are people who take certain medications for a long time like medications given for seizures. Bone loss leads to fractures, which can severely impact a person's independence. We know that people with IDD have higher rates of fractures when young, so as they age, the risk increases even more. There are medications to prevent bone loss and fractures. Vitamin D and calcium intake through the diet or supplements will help maintain bone health.

- **Eyes:** Aging is associated with development of cataracts and other eye diseases like glaucoma and macular degeneration. Other common changes are decreased peripheral vision, reduced nighttime vision, and challenges distinguishing shades of colours, and dry eyes. It's important that people with IDD get their eyes checked regularly. If prescription glasses are available, they should be worn during the day. And don't forget to make sure a person's glasses are clean and free of smudges!
- **Hearing:** Hearing loss is common with aging. Use of appropriate hearing aids (always check the battery) or a pocket amplifier (like a Pocket Talker or FM system) might make hearing easier. If a change seems sudden, ask to have their ears checked—wax can build up much more quickly as people age.
- **Skin:** Older adults can get dry skin (xerosis). Regular moisturizers should be used to protect the skin. If an older adult is less mobile, pressure ulcers can develop. Proactive positioning and skin protection can help prevent ulcers. If a person is spending a lot of time in bed, or in a chair, it is a good idea to involve a nurse or occupational therapist for an assessment to see how to minimize pressure sores.
- **Pain:** Pain can often be missed. An essential part of care is to figure out if someone is in pain, and if so, where they have pain, so that appropriate treatment can be started. Consider asking people about pain in a way they will understand ("Where does it hurt?" "Any ouches?"), while also using visual aids to help as needed. Also include observational pain assessment tools, in the event a person's language abilities limit their abilities to reliably tell you if they are in pain. We should never assume that someone with IDD can't feel pain—this is false! When looking for signs of pain, it's important to contrast with a person's baseline or usual presentation (so, it is important to have the input of someone who knows the individual well).
 - To learn more about pain, including the different types of pain, and ways that you can help, please see the article, *OUCH! How Understanding Pain can Lead to Gain when it Comes to Supporting Those with Developmental Disabilities*
 - See the Non-Verbal Pain Scale for Intellectual Disabilities or the PAIN-Alzheimer's Disease tool.

As a person ages, their abilities may change, which can impact the roles people play in the home.

It is crucial that efforts are made to find that person's strengths and abilities, so that their quality of life is the best it can be.

Dr. Yona Lunsky shares her thoughts...

I used to think it was so important to keep my sister doing the things she used to do. What will happen if she doesn't go to that activity anymore? But lately, I have started to think about these things differently. Will I want to do exactly the same things when I get older as I am doing right now? If I can change my mind, can't she? If she is aging faster, maybe we need to adapt things faster too. We have to get creative to find new ways for her to be involved in household activities, and feel good about herself.

What you as staff can do:

Depression, Delirium, Dementia

- Track baseline cognitive and functional abilities using a tool specific to IDD (e.g., NTG tool).
- If their thinking or memory changes suddenly, think: delirium? Notify medical personnel.
- Be on the lookout for depression. It could be a recent life event (losing a friend, family member or staff), or something in the past that was triggered, or stays with that person.

Vision

- Encourage yearly eye exams.
- Make sure a person's glasses are on, and clean.
- If they have vision deficits, approach them in a way so they can see you.
- If there are depth issues, tape down contrasting colour tape to help mark stairs/surfaces.
- Make sure spaces are bright and well-lit. Close blinds in the evening to reduce shadows.

Falls Risk and Balance

- Review fall prevention strategies. www.findingbalanceontario.ca is a good resource.
- Ask the Doctor if there are supplements or vitamins that may be helpful for members to take to keep their bones strong.
- Monitor pain: look for wincing, grimaces, moaning. Share your impressions with the medical provider. Using an observational pain scale can help structure your findings.
- If repeat falls, ask MD to refer for a comprehensive Geriatric assessment.

Medications

- If an individual takes more than four medications, this increases their risk of falls, confusion, side effects and interactions. Flag this to the doctor or pharmacist.
- If there is a sudden change, could it be because of their medications? It's never a bad question to ask.

Hearing

- Annual hearing assessment. Ask doctor to check ears for wax buildup.
- Use hearing aids (and check the battery regularly). If hearing aids are too hard, try a Pocker Talker. Otherwise, speak simply, clearly and slowly, and reduce environmental noise (TV, radio off). Write things down if a person is reading. Speak on their better side if they have one.

Foot care

- Seek out regular foot care. Monitor feet for any blisters, or long toenails.
- Ensure shoes are form-fitting and treads intact.
- If someone has diabetes, be sure to check their feet more regularly.

Sleep

- Sleep disturbances and changes are common. People may need less sleep than before.
 - Minimize caffeine after lunch. Discourage napping during the day.
 - Toilet before bed, but keep hallways well-lit in event of getting up at night.
 - Rates of sleep apnea are high. If sleep troubles persist, speak with the doctor.
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Bowel and Bladder

- People may require more support to maintain bowel and bladder control.
- Offer to toilet a person before and after meals, and before bed.
- Use a Bristol Stool Chart to monitor bowel movements. Speak with doctor or pharmacist about a bowel routine if constipation is an issue.

In conclusion:

Thinking back to Debbie, it seems like Debbie is showing several signs of aging. You've probably thought of many things you would like to do to support her. Here are some ideas from our end:

- Completing the NTG tool to obtain a picture of Debbie's skills and abilities now. If an older version was completed, or there is a baseline measure to compare it with, this will be helpful. If not, track what you can now.
 - o If Debbie's mood seems different than usual, we would let the doctor know.
- Dementia: We would bring Debbie to her doctor to share the changes noticed (findings from the NTG; getting more confused with things she used to be able to do on her own – getting dressed, setting the table; more withdrawn and not wanting to engage with the children in the park; walking more slowly, more carefully).
 - o The doctor can help to determine if there are any medical tests to do (bloodwork; review her medications, for example), and if it's a good time for Debbie to be referred to specialty services for further assessment.
- Depression: We would try to learn more about Debbie's mood by asking her if she is: happy? mad? sad? We would look around the home to see if there are subtle changes that may be affecting her. How are the other people doing where she lives? Are any of them sick or unwell, which Debbie may be reacting to? How is her brother doing? Might Debbie be worried about him?
- Delirium: We would monitor Debbie closely for any sudden changes, like if she gets confused or mixed up quickly, and let the doctor know right away.
- Vision: We would take Debbie to the eye doctor to get her vision checked, in case she needs new glasses. Maybe part of the reason her behaviour has changed is because she can't see properly.
- While we are waiting for information on next steps/further assessments, we could try to help Debbie continue to do the things she has always liked to do.
 - o We could help her to pick out her clothes, and then cue her to lay them in the order she usually gets dressed to see if this helps her to get dressed properly.
 - o We could simplify the table setting, by helping her through it one step at a time.
 - If we think Debbie might need some more help than we can manage with the current level of staff, we would ask if Debbie could be seen by her Home Care Coordinator to see if she qualifies for some Personal Support Worker (PSW) hours.
 - o We would invite her brother to come visit more often, if he is able, and see if Debbie enjoys these visits.
 - o We would check Debbie's shoes to make sure they fit her properly, so that walks to the park are comfortable.
 - o We would invite Debbie to watch her favourite movies with others in the home – maybe we could do this a bit more often, if possible. If it seems like she's not paying attention as well, it would be good to have her hearing checked.
 - If there is a FM sytem/Pocket Talker, we could ask her if she would like to try it, in case this helps her hear better.

For more information:

Alzheimer's Society of Ontario: <http://alzheimer.ca/en/on>

- This is a website that provides lots of information about Alzheimer's disease and dementia.

Dementia Screening Tool: National Task Group – Early Detection Screen for Dementia; National Task Group on Intellectual Disabilities and Dementia Practices (2013):
www.aadmd.org/ntg/screening

- This is a screening tool for dementia. The authors of this tool recommend administering yearly, beginning at age 40 for people with Down syndrome, and when there has been a change in function noted for others.

Finding Balance Ontario (Falls Prevention): www.findingbalanceontario.ca

- [This is an Ontario-based website](http://www.findingbalanceontario.ca) that aims to help prevent falls among older adults by providing strategies to use to reduce your risk of falling.

Jenny's Diary: <http://www.learningdisabilityanddementia.org/jennys-diary.html>

- Free booklet and postcards that can be used to support conversations about dementia with people who have IDD.

L'Arche Canada's *Aging and Disability*: <http://www.aging-and-disability.org/en/home>

- This website provides information about different issues related to aging and IDD and tips for things to do to better support someone who is experiencing these challenges.

MAPS (Multidimensional Assessment of Providers and Systems):

<https://www.mapsresearch.ca/projects/aging/>

- This resource provides information about research that is being done in Ontario on aging adults with IDD.

Ontario Partnership on Aging and Developmental Disabilities:

<http://www.reena.org/training/opadd/>

- This webpage provides information about the Ontario Partnership on Aging & Developmental Disabilities (OPADD). This is a partnership of service providers in the continuum of seniors services and developmental disabilities.

Publications and Papers from the International Summit on Intellectual Disability and Dementia (Glasgow, Scotland – October 13-14, 2016):

http://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/summit_publications.pdf

- This includes a summary of different papers on dementia and IDD that were presented at the International Summit on Intellectual Disability and Dementia in Glasgow, Scotland in 2016.

Representing the Underrepresented: Empowering Conversations About Learning Disabilities and Dementia <https://www.elder.org/the-elder/representing-the-underrepresented-empowering-conversations-learning-disabilities-dementia/>

- This interview highlights the challenges of supporting an adult with IDD with dementia and the importance of effective communication and support.

Supporting Derek video: <https://www.youtube.com/watch?v=O3ekO4QdKXU>

- This is a video to be used to train staff working in care homes how to better care for patients who have IDD and dementia.

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