

Aging

People with IDD are living longer than ever before. This is wonderful news!

But, for many people, living longer comes with some unique challenges.

For people with intellectual and developmental disabilities (IDD), aging is likely to begin at a younger age. This means that a person with IDD who is in their 50s may present with some similarities in their mind and body to a person without IDD who is in their 80s. As we age, every organ system changes. This is normal. The difference between healthy aging and *disease* associated with aging can be challenging to distinguish.

Let's go over some of the common diseases associated with aging, and then review how you can support your family member.



Brain health

- **Dementia:** Aging is associated with an increased risk of dementia. The most common cause of dementia is Alzheimer's disease. Symptoms of dementia include short term memory loss (forgetfulness) and having 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 that come with aging, which may include forgetfulness but won't have the same impact on function.

In IDD:

In people with Down syndrome, the risk of dementia is generally increased and presents earlier in age. The decline, though still gradual, may occur more quickly. When people with IDD develop dementia, they will have a noticeable decline in skills, and changes in brain function (behaviour, language, organization, navigating spaces, memory etc.). Because the level of ability before dementia may have included a level of help, the key is to **look for and monitor any changes**. For more on dementia and IDD, please see the dementia section of this toolkit.

- **Depression:** Older adults are also at increased risk of depression. 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 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. Depression can be very treatable, so a doctor should be informed if you suspect that your family member has depression.
- **Delirium:** While dementia is associated with a long term, gradual decrease in memory, delirium happens suddenly. Delirium is an acute 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 blood work is usually needed to assess for the underlying cause of delirium. A nurse or doctor should always be informed if you think your family member has delirium. **Signs to look for:**
 - ☑ sudden change;
 - ☑ fluctuating level of alertness;
 - ☑ unable to focus and maintain attention;
 - ☑ person is disorganized and not making sense, or they are very sleepy and hard to wake up—which is a change from their usual behaviour.

Muscles and bone health

- **Falls:** Older adults have a higher risk of falling. Since people with IDD are already at a higher risk of falling, as they grow older, they are even more vulnerable. 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 fall. Risk factors include taking too many medications (especially drugs that make them 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 has repeat falls, a thorough assessment is needed to prevent the risk of future falls.



What are some ways you can keep your family member safe from falls?

- ☐ An Occupational Therapy (OT) home safety assessment is a good place to start. Contact your local Home Care Coordinator (in Ontario, this is through the Local Health Integration Network). An OT may be able to come to the home and make suggestions about ways to make the home safer, or recommend equipment like a walker or wheelchair.
- ☐ 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. There are also things that can go into the bathroom to make it safer like bars to hold on to, a stool to sit on in the shower or bath, and a raised toilet seat.
- ☐ If there are stairs or steps, help to make sure all steps are clearly visible (adding reflective treads).
- ☐ Have handrails on both sides of the stairs, if possible.
- ☐ Make sure spaces are bright and well lit. Use night-lights or motion sensor lights for the bedroom and hallways.
- ☐ Look at a person's shoes – do they look loose or floppy? Or, are they too tight and uncomfortable? Do the treads on the bottom still work?
- ☐ Stay home in icy weather.
- ☐ Ensure walkways and driveways are cleared of snow in a timely manner.
- ☐ Check a person's feet. If there are long toenails, sores or blisters etc., this is likely to cause a person to walk differently, which could throw off their balance. Be extra vigilant if someone has diabetes, since they are at an increased risk of foot ulcers. For more information, visit www.findingbalanceontario.ca.
- **Osteoporosis and fracture:** Related to falls 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 also at higher risk of osteoporosis. People who take certain medications like anticonvulsants (medications for seizures) are at greater risk. 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. Vitamin D is a useful supplement. There are medications to prevent bone loss and fractures.
- **Frailty:** This is a term that describes a state of vulnerability, where the body is less able to handle an environmental or physical stressor. Aging is associated with increasing frailty, but not all older people become frail. Adults who exercise frequently and function like a younger person are robust - the opposite of frail. When an older person develops multiple illnesses leading to loss of independence, they are frail. Unfortunately, many people with IDD become frail the older they get. H-CARDD research suggests that adults with IDD are likely to be frail as young as 50 whereas adults without IDD show signs of frailty around age 80.

Sensory changes

- **Eyes:** Aging is associated with development of cataracts and other eye diseases. Other common changes are decreased peripheral vision, reduced nighttime vision, dry eyes, and challenges distinguishing shades of colours. Regular eye examinations are needed. If prescription glasses are available, they should be worn during the day. And don't forget to ensure 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) can help promote respectful communication with older adults. If a change seems sudden, ask to have their ears checked—wax can build up 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 the person 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. When looking for signs of pain, it’s important to contrast with their usual presentation.
- See the Non-Verbal Pain Scale for Intellectual Disabilities (link can be found in the Pain Assessment tool in this toolkit).
- Regular exercise, walking or range of motion activities can help prevent joint pain. If there’s low mood, treatment of depression (e.g. with therapy and/or medications) can help reduce pain as well.

**As a person ages, their abilities may change.
It is crucial that efforts are made to find a
person’s strengths and abilities, so that their
quality of life is as best as it can be.**

Impacts of Aging on People with IDD

Vision

- Glaucoma = cloudy looking eyes
- Macular Degeneration = blotchy circles in the middle of eye; these can cause headaches, pain and nausea—look for signs.
- Decreased peripheral vision
- Decreased night time vision
- Eyes can become more dry and itchy.

Brain Changes

- Dementia: gradual personality changes, forgetfulness, mixing up people, losing abilities, language loss.
- Delirium: sudden change; risks are higher.
- Depression: rates are higher.

Lungs

- Swallowing difficulties lead to high rates of aspiration (when food/saliva/vomit gets caught in the lungs).
- Diseases in the lungs are a common cause of death.
- Lung capacity and function decreases, making it harder to do activities.
- More rest may be needed.

Bones & Joints

- Bones become more brittle, increasing the risk of fracture.
- If people have previous fractures, they may have pain.
- Arthritis is common as joints lose lubrication.
- Balance troubles are common.



Hearing

- Wax build up is more common.
- May have harder time locating noises.









Bowels & Bladder

- Harder to hold urine for longer periods of time.
- As metabolism slows, constipation increases.
- May lose control of bladder and bowels more easily.

Feet

- It can be harder to clean and care for feet. Skin can also become more dry.
- Aside from being painful, any blisters, sharp toe nails, or wounds to the feet can cause a person to walk off balance. This increases the risk for a fall.

Aging: Changes and Interventions

Aging change:	How you can help:
 Brain Changes	<ul style="list-style-type: none"> • Track the person's baseline cognitive and functional abilities using a tool specific to IDD, i.e. National Task Group Early Detection Screen for Dementia (NTG-EDSD). • If something changes suddenly, it could be 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	<ul style="list-style-type: none"> • Encourage regular eye exams (generally covered by ODSP every two years). • 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 coloured tape to help mark stairs/surfaces. • Make sure spaces are bright and well lit. Close blinds in the evening to reduce shadows. This is especially helpful for people with dementia who experience sundowning (i.e. increased confusion as the evening sets in).
 Bones & Joints	<ul style="list-style-type: none"> • Review fall prevention strategies. www.findingbalanceontario.ca is a good resource. • Ask the doctor if there are supplements or vitamins to keep bones strong. • Monitor pain: look for wincing, grimaces, moaning. Share your impressions with a health care provider. Using an observational pain scale can help structure your findings. • If there have been repeated falls, ask a health care provider if a comprehensive geriatric assessment would help.
 Medication	<ul style="list-style-type: none"> • 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, it could be because of their medications. • Request a medication review once a year.
 Hearing	<ul style="list-style-type: none"> • Annual hearing assessment is recommended. • Ask doctor to check ears for wax build up. • Use hearing aids (and check the battery regularly). If hearing aids are too hard, try a Pocket 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.
 Feet	<ul style="list-style-type: none"> • Seek out regular foot care (from chiropodist, foot care nurse). Monitor feet for any blisters, or long toe nails. • Ensure shoes are form-fitting and treads intact. • If someone has diabetes, be sure to check their feet more regularly.
 Sleep	<ul style="list-style-type: none"> • Sleep disturbances and changes are common. People may need less sleep than before. • Minimize caffeine after lunch. Discourage napping during the day. • Use the 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 a health care provider.
 Bowels & Bladder	<ul style="list-style-type: none"> • People may require more support to maintain bowel and bladder control. • Support the person to use the bathroom before and after meals, and before bed. • Keep track of bowel movements. Speak with the doctor or pharmacist about a bowel routine if constipation is an issue.

Aging: Syndrome-Specific Information

Every person will age in a unique way. For people with specific genetic conditions or syndromes, the following are things to be mindful of, as they may occur with greater frequency.



Down Syndrome

- Higher prevalence of Alzheimer's disease.
- Higher prevalence of late-onset seizure disorders.
- May develop eye disorders earlier than the general population (cataracts, keratoconus).
- Rates of osteoporosis increase risk of fractures, falls, dental problems, pains.
- Rates of sleep apnea increase with age (can lead to poor sleep, behaviour changes, impacts on heart function).
- Thyroid dysfunction—can cause cognitive changes (but this is treatable!).

Fragile-X

- Associated tremor ataxia syndrome (FXTAS) is a rare neurodegenerative disorder that can affect a small number of people with Fragile-X. It can cause changes in cognition (memory loss, planning difficulties) and movement (tremors, balance and coordination problems).

Cerebral Palsy

- Chronic immobility results in increased musculoskeletal problems: decreased bone health, increased fracture rate, increased incidence of arthritis, contractures (tightened muscles or joints), spasticity (ongoing muscle tightening, resulting in altered movements).
- Already impaired muscle function may deteriorate further due to aging process.
- Risks of swallowing difficulty (aspiration pneumonia) increases.

Autism Spectrum Disorder

- Lifespan outcomes with autism may be unpredictable: some improve, some stay the same, some lose skills.
- There is an increased risk of seizures, accidental deaths (drowning, suffocation), earlier death from heart disease, aspiration pneumonia.
- Ritualistic, compulsive or self-injurious behaviours tend to lessen with age.

Seizures

- Some people experience cognitive decline and brain aging because of their seizures.
- Anti-epileptic medication may cause side effects that increase with age.
- If seizures limited a person's activity while younger, this creates heart health risks as they age.
- Frequent falls during seizures may cause fractures that seriously impact a person's mobility as he/she ages.

Prader-Willi

- Biggest factor: morbid obesity (if weight is uncontrolled) can lead to type 2 diabetes, hypertension, joint and lung problems.
- Premature aging with age related physical morbidity and functional decline.
- Increased cardiovascular disease – frequently right sided heart failure.
- Increased incidence of knee and hip problems (often require joint replacements).
- Increased incidence of dermatological problems.

For more information, check out the: Aging and Intellectual Disability pages of the United States' Resources for Integrated Care, www.resourcesforintegratedcare.com/webinar/series/individuals-with-idd. The above information is from the specific talk, *Growing Older*, by L. Anderson and J. Dorsi (2014).