Canadian Down Syndrome Society | Société canadienne de la trisomie 21

Today & Tomorrow

A GUIDE TO AGING WITH DOWN SYNDROME

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A GUIDE TO AGING WITH DOWN SYNDROME

Introduction & Thank Yous

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Introduction to Aging

This is such an exciting time for people with Down syndrome and their families. People with Down syndrome are now living longer than ever before. New possibilities are emerging from research in the area of aging to help people with Down syndrome live longer, more fulfilling lives. Adults with Down syndrome can enjoy a future that includes education, employment, recreational activities, and meaningful relationships.

This resource has been designed to help families, friends, caregivers, and self-advocates learn more about the aging process and to plan and prepare for the future of those with Down syndrome. It includes the most up-to-date information regarding aging, but as more research and support is made available, ideas and best practice may change. By being proactive and learning about issues that may lie ahead you can look forward to a positive aging experience for all.

The life expectancy for people with Down syndrome continues to rise — the median lifespan is now 58 years”

Skotko, 2017, https://www.statnews.com/2017/01/04/down-syndrome-population-aging/

Through this resource you will learn about:

- Potential health concerns associated with aging
- Behavioural and mental health concerns associated with aging
- Recognizing and dealing with an Alzheimer's disease diagnosis
- How to talk about and prepare for death
- Housing options

We are happy to help you navigate through this next stage of life with your loved one and hope this resource provides useful information as well as comfort. We want this experience to be as positive as possible for everyone. As always, please know you are not alone on this journey. There are many people who are experiencing or have experienced the same things that you may find yourself preparing for or going through now. We have included stories from parents, siblings, friends, and self-advocates about their own experiences, hopes, and concerns. We hope that these stories will help you connect and provide a sense of community and support.

Why is it so important to understand the aging process for a person with Down syndrome?

Adults with Down syndrome experience “accelerated aging,” meaning they will age faster than the general population. It is expected that adults with Down syndrome will show physical, medical, and cognitive signs of aging much earlier than what is expected for their age. These signs and symptoms can include difficulties with vision, hearing, lack of energy, and other health concerns.

For a person with Down syndrome, these general signs of aging may start to appear as early as 40 years of age. It is important to be aware of this acceleration in aging for your loved one to understand what to expect and what is normal.

Aging & Well-Being

As anyone begins to age, it is important to keep them active, involved in their community, and positive. Ensuring the well-being of people with disabilities as they transition into old age includes continuing to have positive support networks and being involved in meaningful activities.

Throughout their retirement years, people with Down syndrome may start to slow down and lose interest in some of the activities they previously enjoyed. If this happens, attempt to find other activities that may spark their interest as their abilities change over time.

Remember that your loved one is still a valued person in both your family and the community, even in their older years. Continued involvement in outings and activities such as going to movies, sporting events, or art classes are important to maintain healthy social connections.

“Hi, My name is Jean and my sister Mary Frances has Down syndrome, and this is her story...”

Mary Frances has always been an important part of our closely knit family and small community in Cape Breton. My sister is very active and has been involved in our community her whole life. The people in our town know Mary Frances well as she has stayed active in many ways throughout the years, including bowling, painting, and college classes... to name a few. Throughout her lifetime she has accomplished many things. She held a seat on VATTA with CDSS for 10 years, volunteered within her community, has a strong love for travel, and has travelled to many places.

My sister lived with our mother until she passed away. Luckily for us, my mother had prepared Mary Frances for her death, so my sister had a good understanding of death and why it happens. While the time after my mother passed away was difficult for Mary Frances and she struggled with the grieving process, I believe the foundation my mother provided to Mary Frances on death allowed her to move through the stages of grief with ease. Mary Frances has had other family members close to her pass away in the years since and each one has come with its own difficulty and grieving process. But Mary Frances has found comfort in the knowledge of death that my mother shared with her prior to her passing.

I have since moved into our mother’s home to live with Mary Frances. This was a difficult transition, but certainly worthwhile now that Mary Frances and I have settled into living together. Mary Frances and I share many of the same hobbies, like staying active, travelling, and shopping.

I am aware of some of the health concerns Mary Frances may face as she ages. Recently, I have noticed that Mary Frances has lost interest in some activities, like reading the newspaper and practicing the fiddle, things she has always enjoyed. This caught my attention and I knew I needed to keep her active and find new activities in the community. I found rhythmic gymnastics through the Special Olympics and she tried it out. Gymnastics was a great fit for Mary Frances; she loves this new activity and has made many new friends who are her age in the program as well.

I am grateful for this opportunity and friendship I have with my sister, and I hope it continues for many years to come.

Mary Frances continues to be a happy soul — she goes to bed smiling and wakes up smiling.

How lucky am I?

– Jean
Sister

Overview of Health Concerns for Adults with Down Syndrome

Adults with Down syndrome generally face many of the same health concerns as everyone else. However, there are a few health concerns that can be more common as a person with Down syndrome ages that are important to be aware of.

It is important to discuss all of the following health concerns with your primary health care professional first, as they will have the most up-to-date information and be able to provide input on treatments and screening tests. Each individual is different and they may encounter health concerns not listed below; ALWAYS discuss with your health care professional first.

ALZHEIMER'S DISEASE:

Your loved one may have a higher risk of developing Alzheimer's disease as they age. Alzheimer's disease is more prevalent in people with Down syndrome and may present 20 years earlier than it would for the general population. Alzheimer's disease may primarily impact memory, decision-making abilities, communication, and personality, this does not mean every person with Down syndrome will develop Alzheimer's disease. However, everyone has a different journey but it is important to be aware of potential signs for early detection.

Refer to page 27 for more information on Alzheimer's disease.

GENERAL AGING:

People with Down syndrome age in the same way that everyone else does, but they may develop signs of aging sooner. These aging signs should not be feared as they are completely normal, but it is important that you understand they may present at an earlier age for your loved one.

General aging signs may include:

- Decreased muscle mass
- Weight gain
- Difficulties with vision & hearing
- Generally slowing down and becoming less active

Your loved one may not tell you directly that they are in pain or that something is wrong. Instead, pain or general feelings of being unwell can present themselves as behavioural changes.

HEARING:

There may be many reasons your loved one may be having hearing difficulties. These issues can be permanent or temporary and treatable. In temporary cases, hearing loss can be due to fluid buildup behind the ear drum or a buildup of ear wax. For permanent hearing loss, hearing aids are available to help improve hearing difficulties.

Try these tips to help communicate if your loved one is showing signs of hearing difficulties:

- Talk in quiet areas if possible
- Face-to–face communication
- Gestures
- Sign language

STOMACH, MOUTH, AND THROAT

For people with Down syndrome, a common throat issue is gastroesophageal reflux (GERD). GERD causes acid from the stomach to enter the throat or lungs where it can cause irritation and/or a chronic cough.

It is important to be aware of aspiration at any age for people with Down syndrome. Aspiration occurs when food or fluid is breathed into the lungs. Aspiration can often lead to pneumonia, an infection in the lungs.

People with Down syndrome are also more likely to have gum disease like gingivitis and periodontitis. Keeping up with dentist appointments and dental hygiene can be key in preventing gum disease.

VISION

In young adulthood to middle age, your loved one may start to have vision difficulties. Try to book regular eye exams to check for any vision changes to assess if they need glasses or a change in prescription.

Discuss the following conditions that are more common for adults with Down syndrome with your healthcare professional:

- **Keratoconus:** Keratoconus is the thinning of the clear lens on the front of the eye. This causes it to push out slightly and results in vision impairment.
- **Cataracts:** Cataracts can often appear as a cloudy grey spot on part of the eyeball. This spot leads to an obstruction of vision and can present at any age.
- **Glaucoma:** Glaucoma occurs when there is an increase in pressure in the eyeball that damages the optic nerve. This can lead to gradual vision loss.

HYPOTHYROIDISM

Hypothyroidism is the most common thyroid issue for people with Down syndrome and can emerge later in life. With hypothyroidism, the body sees the thyroid as an enemy and attempts to work against it. Symptoms to watch out for may include fatigue, slow or slurred speech, weight gain, and memory issues. Talk to your health care professional about having thyroid level checks regularly.

“I have always tried to do research on many of the risks for people with Down syndrome as they age. Thyroid issues are often a concern, so lately I have been working on my health and fitness. Eating properly and eating the right amount always helps me stay on track. I also try to be as independent as possible, so that I can handle things by myself. But I know when I’m older I might not be able to do everything independently. I have a close circle of family and friends I know I can lean on and I can ask them for help if I need it.”

– Matt
Self-advocate

OSTEOARTHRITIS

Osteoarthritis occurs at the end of bones where the cartilage wears away in a joint. This can result in discomfort in the joints as there is less protection where the bones move together. Your loved one may start to show signs of pain in the joint by compensating with other movements to avoid using that area.

OSTEOPOROSIS

Osteoporosis develops as the bones in the body start to become thinner and more fragile and can lead to fractures. Try to keep your loved one active with weight-bearing activities and include a diet with vitamin D and calcium to promote bone strength.

ATLANTOAXIAL INSTABILITY

Atlantoaxial instability happens when the bones in the neck are prone to slipping and compressing the spinal cord. There may or may not be symptoms associated with atlantoaxial instability. It is important to get tested by an x-ray image if the individual is engaging in high-risk activities to prevent any potential damage. Consult with your health care professional on testing.

SPINAL STENOSIS

Spinal stenosis is a compression of the spinal cord that runs through the bones in the back (vertebrae). If your loved one already has a diagnosis of arthritis this can cause the bones along the spinal cord to grow or thicken. The growth in the bones causes the spinal cord path to shrink and may apply pressure on the spinal cord.

SLEEP APNEA

Sleep apnea occurs when the body has long pauses between breaths due to an obstruction in the airway when sleeping, which causes less oxygen to circulate in the blood. This can disrupt sleep and may cause the person to have symptoms such as sleeping during the day, fatigue, weight gain, and subtle changes in behaviour such as irritability. A sleep study is commonly recommended.

DIABETES

Diabetes mellitus Type 1 is more common for people with Down syndrome (insulin dependent), and most often diagnosed in childhood. Type 2 can also be present but is not as common. Inform your doctor if you start to notice symptoms that could indicate signs of diabetes, such as weight changes, thirst, fatigue, etc.

Recommended Health Testing & Screening

There are routine tests that a person with Down syndrome should receive throughout their life. Most of the tests are the same as for anyone else but there are some additional ones that may need to be considered at a different age than what is typical to keep your loved one healthy.

General screening tests that should occur annually include:

- Blood tests
- Blood pressure
- Body measurements
- Thyroid levels

Hearing and vision tests should be completed every 2 years. It is recommended that individuals be tested for celiac disease every 3-5 years and have an echocardiogram every 5 years if there is a history of surgery or ongoing heart issues. Other general tests that should be considered if the individual is at high risk are tuberculosis, cervical spine x-rays every 10 years, and pneumococcus after 50 years of age. Discuss these tests with your health care professional.

WOMEN:

For a woman with Down syndrome, once she reaches 21 years of age she should book pap smears and pelvic exams every 3 years if she is not sexually active. If she is sexually active, the tests should occur annually for 2 years and then once every 3 years.

Mammography and breast examinations should be booked annually after 40 years of age. If there is a high incidence of breast cancer in the family, breast exams and tests should be done prior to the recommended 40 years of age as recommended by your health care professional.

Menopause may occur sooner for a woman with Down syndrome. For women with Down syndrome the average age is 42, but it may occur sooner or later than the average. Each person is different. Once the individual has reached menopause a DEXA scan is recommended to be completed every two years to test for bone density.

MEN:

Men with Down syndrome may have lower incidences of prostate and colon issues. Examinations for the prostate and colon should be determined by and discussed with your health care professional.

A DEXA scan (bone density test) can be considered for men if they take medications that can make them more prone to osteoporosis or if they have celiac disease. Testicular exams should be completed annually.

ALWAYS discuss routine tests with your health care professional to decide what is necessary or if there are other tests that are not included here.

"I have worked with Lynn for the past 30 years at Tri City Value Drug Mart in Cold Lake, Alberta. I am proud to say that Lynn did meaningful work that was important and needed to be done for all those 30 years. She was a very important part of our team.

Employing Lynn was good for everyone. My other employees learned from her, I learned from her, and our customers knew her as a permanent presence in the store. Lynn had the most excellent customer service skills. Often when training new employees I would tell them "if you want to be good at this job watch Lynn, she has got it figured out!"

Routine was important to Lynn while she worked at the store. The other staff learned how important Lynn's routine was to her and I think in turn made us all a little more efficient.

Over the last 30 years Lynn became an important asset to our store. When it became time to talk about her retirement, we knew it was time, but also knew we would never find someone as hard working and loyal as Lynn. We miss Lynn in the store, but we are happy that she will be able to enjoy her retirement. She still comes to visit us at the store often and for that we are grateful.

"I am happy we were able to show the rest of the community how important inclusion is and that while there were challenges like there is with any employee, Lynn truly added value to our company!"

– Bob
Owner of Tri City Value Drug Mart

"As Bob has already mentioned, Lynn was employed for 30 years by Tri City Value Drug Mart in Cold Lake.

Both Lynn and I are so grateful to Bob for this employment opportunity and for being patient and creative in making it a great partnership for everyone. Bob even

commented at times that when Lynn was not in the store the morale among his other staff was not as good. As a mom I had comfort knowing Lynn was appreciated and valued for the 30 years she was employed there.

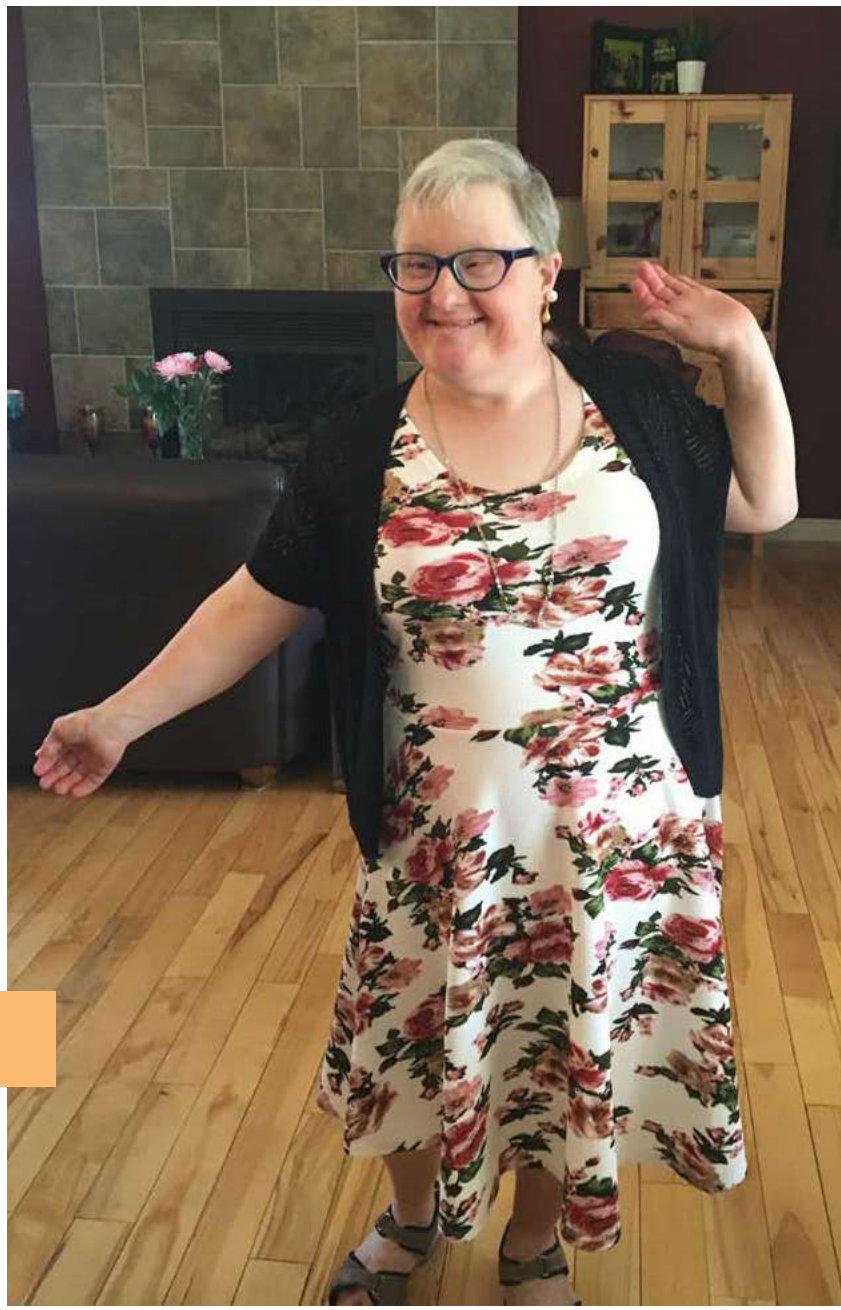
Lynn is now experiencing some short term memory loss. It was important to both Bob and Lynn that she make it to the 30 year mark at the store, and with a party as the end goal, Lynn made it.

Lynn has always been very caring and is well known in our community of Cold Lake. Now in her retirement Lynn is still very active in the community. She participates in swimming, skiing, hiking, bike riding, bowling and bocce.

Lynn attends a day program. The staff in this program are excellent and are always finding new activities to keep her busy and stimulated during the day. At home we try to do many of the same things to keep her active.

We are very proud of Lynn and her accomplishments. We are also very thankful to Bob for the opportunity and putting such trust in Lynn to be a valued employee."

– Heather
Parent



Life & Behaviour Changes in Adulthood

MENTAL HEALTH, BEHAVIOUR, AND AGING

Behaviour is a form of communication for everyone but especially for people with Down syndrome. If there has been a sudden or gradual change in your loved one's behaviour this may indicate they are experiencing the initial signs of aging.

For all mental health/behavioural concerns that are not resolved or become worse, contact your health care professional

Take into consideration that these behaviours can sometimes appear for unrelated reasons, such as signs of mental health concerns or external causes like the individual experiencing body pain or being teased at work. Behavioural changes can appear for many reasons so it is important to document and explore all possible options first with your health care professional.

Someone with Down syndrome may exhibit a variety of challenging behaviours as they age. These behaviours can involve inappropriate sexual behaviour, stealing, lying, aggression, and oppositional deviant disorder (uncooperative with authority figures). For behaviours like stealing and lying, it is possible that the individual is not aware that what they are doing is wrong. It's important through discussion to make sure they understand those universal rules that we may take for granted. For behaviours like aggression, it is wise to look for an underlying issue or cause, especially if it is a reoccurring issue that is not normal for the individual.

TRANSITIONS & LIFE EVENTS

People with Down syndrome may struggle with change in the same way all adults do, but the way they handle each situation may be different. If lifestyle changes happen suddenly and without warning, your loved one may find these situations difficult to accept and process, or they may not even acknowledge the change.

A seemingly small milestone may impact your loved one greatly and they may have difficulty accepting the change whether it is good or bad. It may also take time for the individual to process the event, and behavioural or mental health changes may not be noticeable until a few weeks or months after the transition.

These include transitions such as:

- A sibling moving out
- The marriage of a friend
- Losing a loved one
- Children
- Moving out or moving homes
- Parents becoming ill
- Family or friends moving away
- Change in jobs
- Break-ups
- Divorce
- Change in care or support workers

When dealing with a difficult behaviour, a doctor may be able to write a referral for your loved one which can help them to get into centres such as the Arnika Centre in Calgary, which provides supports for adults with disabilities with mental health concerns.

Some of these situations may cause stress, anxiety or depression for a person with Down syndrome, especially if they feel like they will not get to experience the same opportunities as their siblings or peers like marriage and children.

Situations such as the ones mentioned in the list above may also trigger a type of grieving process for the person even in the case where no one has died. Listen to your loved one's concerns and validate their feelings in these situations. Provide support and focus on the positives that are in the future.

Preparing for changes in advance can be helpful for the future. If you are aware of major transitions approaching for your loved one, try to let them know in advance and prepare for those changes.

Adult regression is a less common disorder that is currently being researched. Regression may present itself as a decrease in daily living skills involving movements, language and communication. Regression is not common for people with Down syndrome but may possibly present when your loved one is placed in transitional and stressful situations. Liaise with your health care professional if you have concerns, and discuss a plan with your loved one.

Some of these behaviours may be due to your loved one aging, or are just natural responses to what is happening.

Strategies to help with change:

- Stay positive
- Talk about the future
- Prepare and talk about events in advance
- Don’t hide information from the individual to try and protect them
- Provide visuals to remind them of upcoming changes
- Modify tasks if needed
- Don’t force a grieving process; everyone grieves in different ways
- Don’t dismiss their depth of feelings

Alzheimer’s disease

Alzheimer’s disease can be more common for people with Down syndrome than the general population due to the presence of extra genetic material on the 21st chromosome. The 21st chromosome is associated with producing a specific protein that is connected to the production of plaques in the brain. The extra genetic material increases the production of that protein to trigger the events that may lead to Alzheimer’s disease. Tangles or plaques in the brain stop the cells in the brain from communicating with each other. Over time, more and more cells are unable to communicate, causing the disease to progress.

On average, Alzheimer’s disease can present itself 20 years earlier for people with Down syndrome than it would for the general population. Symptoms of Alzhiemer’s disease may start to appear around the mid-50s for people with Down syndrome. Remember not every person with Down syndrome will experience Alzheimer’s disease, but the risk may increase with age.

Signs and symptoms of Alzheimer's disease may occur over a long period of time or they can happen rapidly; every person's journey is different. In the beginning, symptoms may be subtle and present as behaviour or personality changes. If you start to notice behaviours and patterns outside of the norm for your loved one, try to keep a log of these behaviours and/or incidents to help your health care professional with a diagnosis. You can also ask your loved one if they notice any changes in themselves or have any concerns.

Alzheimer's disease falls under the term dementia; dementia is the general term that covers a group of symptoms that impacts cognitive tasks like memory and reasoning for an individual.

As more research develops, statistics and information on Alzheimer's disease may vary.

A log of behaviours or concerning events can help your health care professional with a diagnosis, as Alzheimer's disease can commonly be misdiagnosed.

Note that common conditions could be causing symptoms similar to Alzheimer's disease. The following should be considered and ruled out by your health care professional:

- Hearing/vision difficulties
- Dehydration
- Infection
- Stress & fatigue
- Mental health
- Pain
- Thyroid conditions
- General aging signs

To learn more about these general health concerns refer to the Health Concerns section on page 14.

More than 75% of people with Down syndrome aged 65 and older are living with Alzheimer's disease, about 6 times the number of people in the greater population in the same age group.

(Alzheimer's Society)

HOW DO WE GET A DIAGNOSIS?

At this point in time, there is no definitive test for diagnosing Alzheimer's disease. The standardized tools for diagnosing Alzheimer's disease may not be suitable for a person with Down syndrome as they will not take into consideration the individual's intellectual and communication abilities prior to Alzheimer's disease. Talk to your health care professional about tests that are better suited for people with disabilities in determining a diagnosis.

EARLY STAGES OF ALZHEIMER'S DISEASE:

In the early stages of Alzheimer's disease there may be an inability to focus and complete tasks that are typically part of one's daily routine. Caregivers may need to provide cues and encouragement throughout the day for the individual to complete tasks and stay focused. There also may be signs of depression and other mental health issues that can arise.

The early signs of Alzheimer's disease can include the following:

- Becoming uninterested in past enjoyed activities and socializing
- Changes in walking patterns and/or coordination
- An increase in obsessive compulsive behaviour such as repetitive actions, hoarding, and strict routines
- Change in sleeping and eating patterns
- Behaviour and emotional fluctuations — increased anxiety, frustration, sadness, fearfulness, decrease in impulse control, short term memory loss, disorientated in familiar settings, and reduced communication skills

It is important to be aware that a person with Down syndrome may be more likely to have seizures when they have Alzheimer's disease.

These symptoms may differ from person to person and in each stage; some behaviours may not be present while others will.

TIPS FOR DEALING WITH CHALLENGING BEHAVIOUR:

- Check to see if the behaviour is being caused by something else, such as hunger, thirst, pain, bathroom needs, lack of sleep, skin irritations, boredom, or environmental factors
- Don't ignore the behaviour; move the individual to a comfortable space and try to understand what is causing their behaviour
- Redirect to a new enjoyable activity if possible
- Avoid starting arguments, strive for win/win outcomes

"I'm familiar with Alzheimer's disease because my Grandma has developed the disease. I know there are times when you are lucid, and it means you remember the past, and then other times you don't remember everything. I know Alzheimer's disease can come with having Down syndrome and most of the time it comes with old age.

I have talked about it with my family and I still have questions, but I am continuing to learn more about it each day to help prepare myself for the future. It is still hard for me to accept and I would feel really scared if I wasn't able to remember my friends, family, and co-workers. But I know I would have my family to support me just like how we support my Grandma. We spend as much time as we can with her and surround her with love and support to remind her that we will always be there for her.

My advice to others going through this with a loved one is to remind them that you love them and will be with them every step of the way."

- Alana

Self-advocate

Remember not to take your loved one's behaviours personally; their behaviours can be symptoms of their disease and not meant to be directed at you as a caregiver or friend.

ALZHEIMER'S DISEASE AND MEMORY LOSS:

The main concern with Alzheimer's disease in its later stages is the individual's memory loss and ability to complete daily activities independently. Your loved one may start to become confused with what the time or place is, struggle with communicating, and misplace common items.

Include the person in decision making for as long as possible. If there are choices to be made about potential treatment plans or living situations in the future, ask the individual what their wishes are, if possible, before they are unable to make informed choices for themselves.

Personal directives and decision making options are discussed on page 56.

TIPS FOR ALZHEIMER'S DISEASE AS IT PROGRESSES:

- Challenge the individual to remain active. Each day might differ in what your loved one is able to do independently or what task they can complete that day
- Ensure you are able to adjust the level of difficulty with each activity and provide help when needed. Too difficult of an activity could cause challenging behaviour; set realistic goals to avoid disappointment
- Try to stay in familiar environments
- Be aware of potential hazards in the house. As your loved one's memory and cognitive abilities start to decline, some items may need to be removed in the house or supervision may need to be provided to keep the individual safe
- Attach notes to household items to remind them what it is or what they need to do
- Stick to a routine as much as possible
- Reminisce and use old photos to remind them of their past and family/friends
- Play music that was popular during the lifetime of the individual

TREATMENT:

Currently there is no cure for Alzheimer's disease. Depending on your health care professional's advice, medication may be provided to help manage symptoms. Always ask your health care professional for the most up-to-date information and the best treatment approach.

"My Opa just recently died. I was volunteering in his nursing home up until he died and it was nice to spend time with him. My Opa lived with dementia in the end. He was still the same amazing person inside, he just needed to have people around him who were able to understand his needs. But I know he is in a better place now. I'm aware there is a chance that I may get Alzheimer's disease but I know that we will deal with it the same way we dealt with Opa's dementia. With lots of love."

– Matt
Self-Advocate

Include the individual in treatment plans or living options for as long as possible.

Establish a plan for the future with your loved one.

SELF-CARE AS THE CAREGIVER:

Caring for a person who has both Down syndrome and Alzheimer's disease can create stress and burnout. Remember that as a caregiver you also need support and time to care for yourself. If it is available, make sure you have respite.

Respite is when either a facility or support worker is able to assist in caring for an individual for a few hours a week or even a few days to relieve stress and caregiving duties for the main caregiver. Remember it is important to have time for yourself. This will help improve the support you are able to provide to your loved one.

If the person you are caring for is not already involved in activities outside of their home, look for adult day programs in your community. These programs can be useful for sharing the caregiving responsibilities or provide respite that gives you time in the day to complete other tasks. Other resources such as support groups or talking to family and friends can help with your well-being; remember you do not have to deal with this alone.

Your loved one's care is important, but they cannot be cared for unless you are caring for yourself as well.

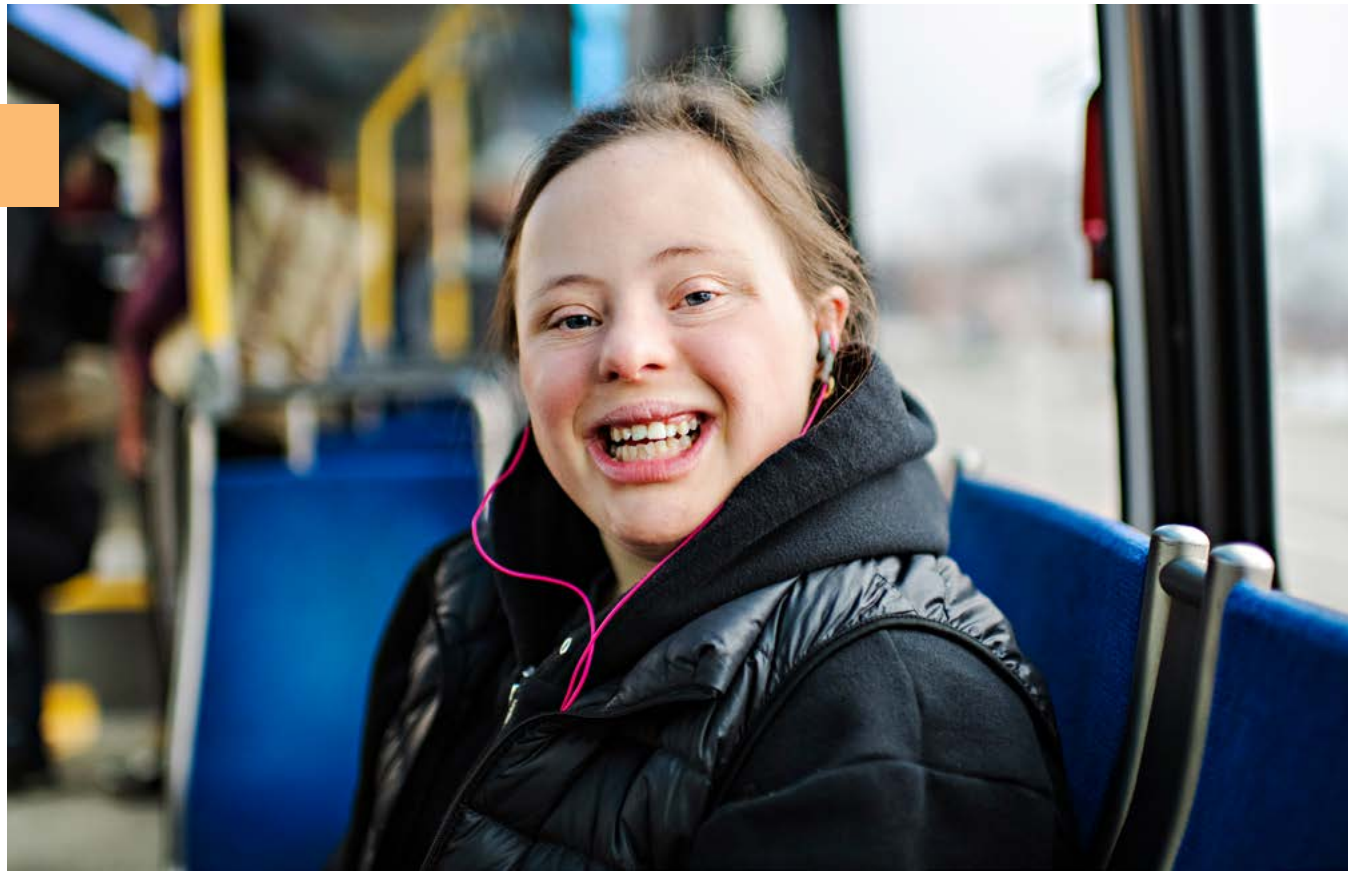
“My sister Vicki has Down syndrome and currently lives with me and my husband.

Vicki is now in her 53rd year. Vicki is independent in that she takes care of herself very well and has always made her own breakfast for which she is proud.

Recently, we have noticed some beginning signs of Alzheimer’s disease. Where Vicki could easily vocalize, she is beginning to have word-finding difficulty and trouble identifying items, not too much, but enough that we acknowledge what is beginning to happen. She is experiencing some irritability, a personality trait she has never had. Her obsessive compulsive behaviours have also stepped up a notch.

Vicki receives funding for which we are very grateful. The funds are used for respite and a wonderful support worker who Vicki adores, and we do too! We decided that we simply could not place Vicki into a home at this point, she has always been with family and is happy. Vicki loves her bedroom and privacy.”

- Elizabeth Ramage
  Sister



Talking About Death:
A Parent's Guide

When a close family member, friend, co-worker, or pet dies, some form of grieving will occur. We all grieve in a different way and in our own time, and so do people with Down syndrome. It is important to talk about death and examples of death, preferably before a death occurs so the individual is prepared. Ensure the individual understands what death is, and that it's a normal part of life, and that feeling sad or frustrated is okay. The more the individual and family talk about death and understand the process — especially if it is something that is expected in the future for someone — the less scary it will be when the time comes, and they will have the skills and knowledge to cope.

"I have had family members pass away that were very close to me. These were hard times in my life and it was hard at first to let them go but I know they are always with me in my heart. I try to focus on remembering the happy moments that I had with them."

– Julia
Self-advocate

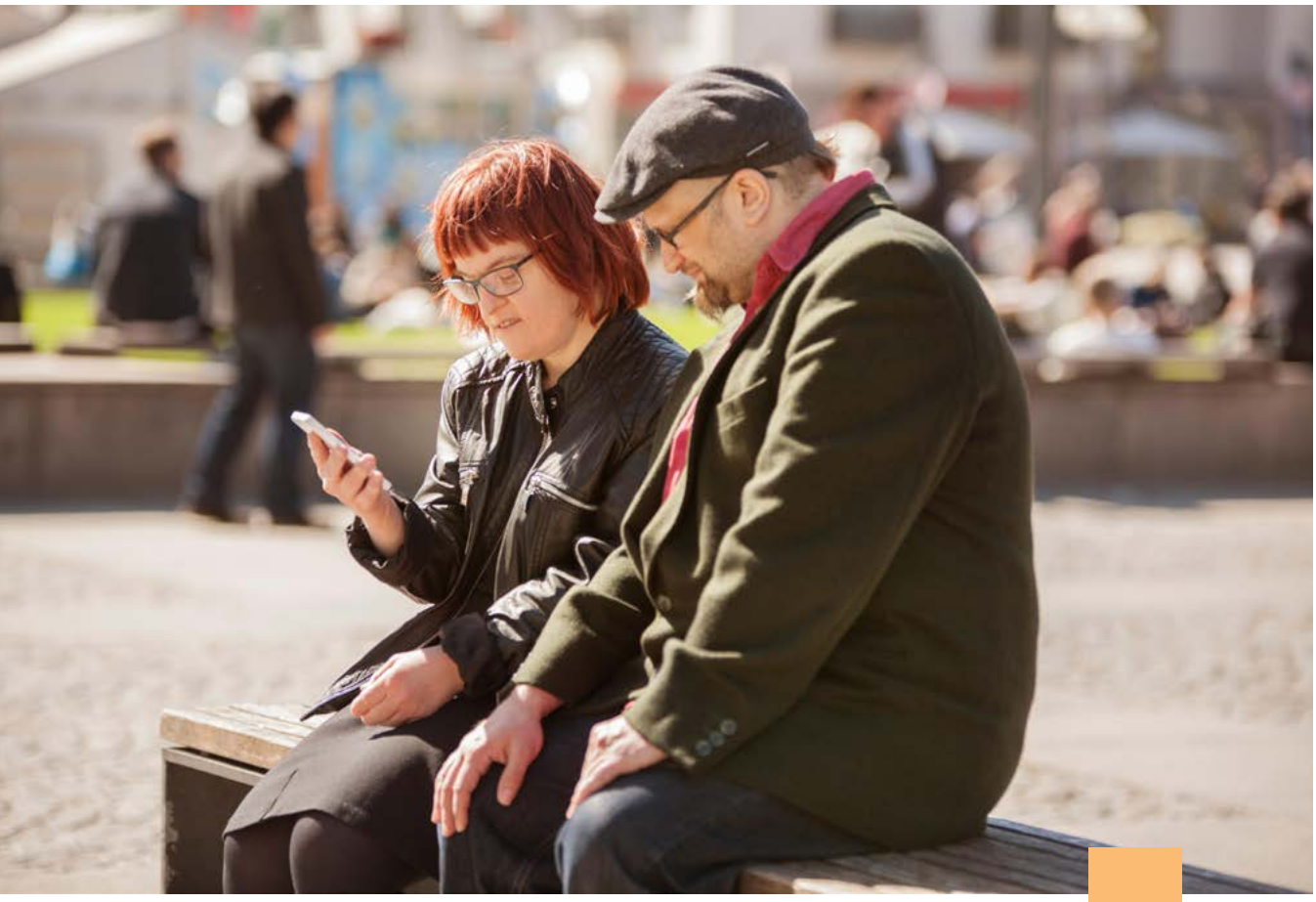
Although it may be hard and awkward to bring up, if you are the parent/guardian of an adult with Down syndrome, you should talk about how you as the parent may die before they do. This can be done over a period of time, by slowly and consistently bringing up the topic. This involves not only discussing death but discussing funeral options, wills, and your own personal wishes.

If you don't talk about death and try to avoid it, it can make the situation much harder for everyone. Talking about death can be done by using examples, such as on TV, famous celebrities that pass away, an animal that has died, etc. It is also valuable to talk about cemetaries and funerals. If you pass by one, take a moment to acknowledge it and discuss it with the person. Even if they don't reply, or reply with something irrelevant, continue to bring it up and discuss different aspects of it in hopes that they are processing the information even if they may not want to discuss it just yet.

Discuss death, wills, funerals, cemeteries, and all aspects surrounding death and what to be prepared for.

TIPS FOR TALKING ABOUT DEATH:

- Don't generalize; be specific about what happens
- Generalizing may cause more confusion
- Avoid saying things like "they are in a better place" or "they won't wake up." This can cause confusion or be misinterpreted
- Use phrases like "they died" to make it clear
- Allow time for the person to process this new information and concepts
- The use of pictures and other supplemental tools can help explain
- Have a plan in place for who will take over being the main support if a parent or caregiver dies
- People with Down syndrome have a great memory; try to remind them of the positive times with the person or animal through pictures or conversation



GRIEF

Depending on the individual, there may be a delayed grieving process for your loved one. It may take months or even years for the individual to talk about a death or show signs of grieving. This may be because they do not know how to handle the situation and deal with their grief, and/or a misconception of time and when events happened.

Try not to force the individual to talk about the situation if they are not cooperative. Instead, wait for the time when they bring it up themselves to discuss it. This may take a while, but take the time to talk through it with them even if it has been a long time. Grief groups are not generally recommended as the individual may not want to discuss it at the specific time that the group meets, and this can cause more harm than help. However, some may find comfort in grief groups, so find what works best for your loved one.

“It is hard to talk about things like getting old or dying ....but it feels good to share and plan with your family and friends”

– Janet
Self-advocate

Housing Options

When the time comes for your loved one to move away from the family home or change living arrangements, there are many options. Each option will allow for different levels of support for adults. Ensure that you are involving your loved one in the choices about their living arrangements, as this can help to identify preferences and support needed.

The following are some potential housing options for an adult with Down syndrome. Depending on the individual's abilities and preferences, not all may apply.

INDEPENDENT LIVING:

People with Down syndrome may be capable of living independently. It is completely up to the individual and their needs if they wish to do so. Some people with Down syndrome may be able to live by themselves with some support from friends and family, depending on the person and their wishes.

SUPPORTIVE ROOMMATE:

A common choice among people with Down syndrome is to choose to live independently but with a roommate. The roommate can be classified as a "supportive roommate." A supportive roommate helps the individual with tasks and planning for the week as well as community support. The roommate's level of support is dependent on how much assistance the individual needs. Generally, supportive roommates are hired and paid for their help. The supportive roommate may have another job or could be a student, so they may not be around 24/7, but should be flexible to be around when the individual needs them.

Another option similar to a supportive roommate is more like a supportive family. Couples or families may open up their homes to accommodate an individual to live with them, the individual will pay rent and in return the homeowner provides accommodation and a certain level of support to the individual. Every situation is different, find a plan that works for everyone's needs.

GROUP HOMES:

Group homes consist of multiple individuals with a disability living in one home. Typically, qualified care staff are present to help residents with their individual care needs and daily activities. Group homes can be a good fit if the individual likes to be social and participate in group activities and needs support from a caregiver throughout the day and night.

Independence can be an important issue for people with Down syndrome as they get older. Often, people with Down syndrome can live on their own or with a supportive roommate; there is a wide spectrum, from no support, to support once a week, to full-time support. There are services in place to help families with this transition as well.

http://cdss.ca/down-syndrome-answers/can-a-person-with-down-syndrome-live-on-their-own/

“When Paul was about 25 years old he saw his younger sister move out on her own and thought that he would like to do that as well.

We told him that was fine with us, but there were certain things that he had to be able to do on his own, before we could help him to do that. We sat down and made a list.

The first thing he had to do was have a job. Working gave him the money he needed to pay the rent and buy groceries. Prior to this, I don’t think that he really saw the importance of working. He had had several jobs but hadn’t really tried hard to keep them. Once he connected working to moving out, he really changed his attitude.

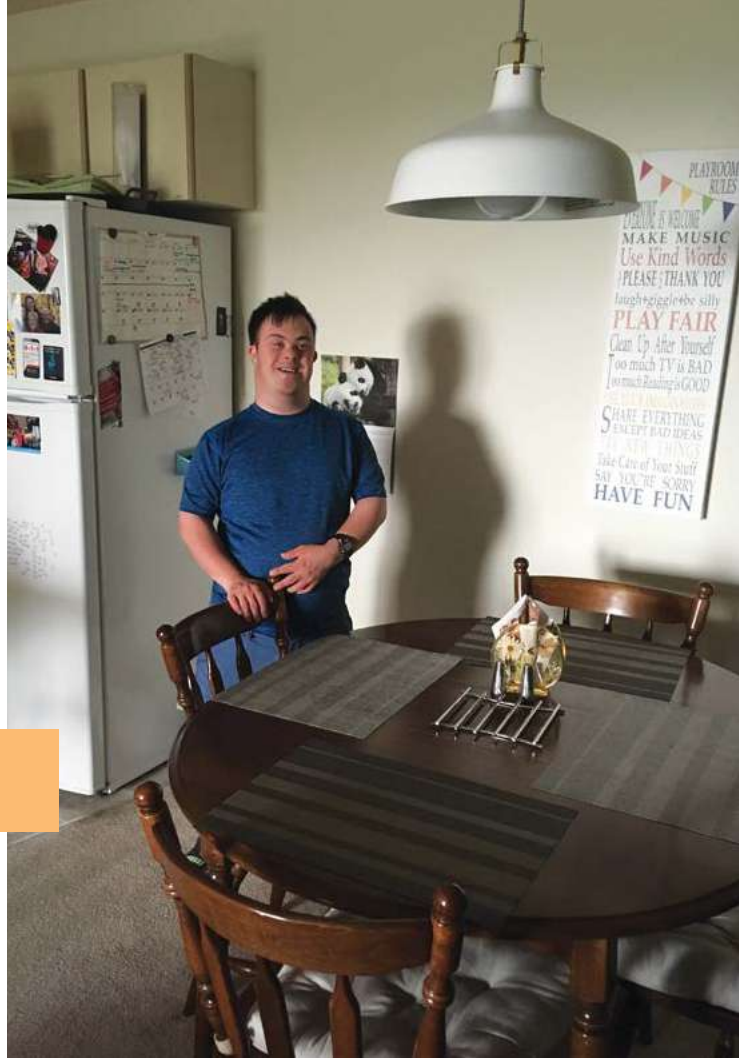
As we checked items off the list we realized that he was going to be ready soon. The hard part now was going to be finding an appropriate apartment and even more difficult, the appropriate supportive roommate.

Paul did that part on his own. We were interviewing a young lady to be a facilitator with Paul and left the two of them alone to get to know each other over coffee. When we got back Paul had told her all about how he was looking for a roommate and thought she would be perfect for the job. As it turned out, she thought so too!

By renting the apartment ourselves, when the roommates’ situation changes and it is time for them to move on, Paul doesn’t have to move. He stays where he is, and a new roommate moves in. That way his living situation remains pretty settled.

Paul is very proud to be living on his own (with a supportive roommate) and doesn’t even like to come home much anymore. We have to work hard to get him to come home for a sleep over every once in a while. This experience has been wonderful for Paul’s sense of independence and it has freed us up to be able to travel and also be independent from him. Paul’s next step? He wants to own his own place! Another milestone that we’ll have to figure out together.”

– Susan Sawka
Parent



LONG TERM CARE:

Long-term care homes have different levels of care depending on the individual's needs. Some have full-time staff, and some only have part-time or limited medical care staff at certain hours. Long-term care is a good option if the person is in their later years and needs some level of 24-hour care or care that is beyond the ability of other living situations. It may also be considered if wandering becomes an issue with the diagnosis of Alzheimer's disease and they need a secure area, such as a locked building or unit, to prevent them from becoming lost.

FAMILY HOME:

There is always the option for your loved one to stay at home. This is the option that many families choose so their loved one can stay in a familiar environment and be with their families. Since some people with Down syndrome are outliving their parents, families need to make sure that they have sufficient health and physical ability to stay as the primary caregiver. Check in with yourself and your family if there needs to be extra help in the home or options regarding moving into a supported living situation. See respite 34.

“I am trying to be more independent. I used to live with my parents but when they moved out of town I moved in with my brother and his family, and now I am preparing to live with a roommate. I also try to stay in good shape and eat healthy so that my body is in good health. When my parents moved away I felt sad and I missed them. I would call, text or FaceTime them when I missed them — it was hard but I relied on my other family members for help. My support worker also helps me out with things my parents used to help me with.”

– Natalie Olson
Self-advocate

“Margaret was born in Calgary in 1954 with Down syndrome.

Her parents were told to put Margaret in an institution but they declined and she was raised at home with her older sister Mary. Margaret had a great life and lived with her parents until they passed away when she was 20 years old. Not knowing where would be best for Margaret to live, Margaret and Mary moved in together and became roommates. This was just the start of a very special living arrangement and relationship between Margaret and Mary.

Over the next couple of years Mary invited two other friends who were also teachers like Mary to live with them. Both Margaret and Mary relished in having more people living with them. It was great for Margaret as the roommates challenged her to do many things. As all the roommates were teachers, they ensured Margaret was capable to be as independent as possible. This created a very special bond and friendship between the women. Margaret was always included in the house and was expected to pitch in and help with household chores like everyone else.

Eventually the roommates decided they needed to give Margaret her own space in the house to allow her to have more independence and privacy. They renovated the home to give Margaret her own bedroom and space so she could have more independence and a place to do her artwork.

As time passed, the roommates spent much of their time together and even occasionally travelled together. Eventually one of the roommates passed away, which was difficult for Margaret as she had grown close to all of them. As Margaret got older, her sister Mary and her other roommate noticed she would often become frustrated easily and was becoming more forgetful. Mary had always planned for Margaret to live at home with her for the rest of her life, but as her needs increased and Mary’s health began to fail as well, it became apparent that Margaret needed to move to an alternative living arrangement that would work best for both Margaret and Mary. Mary supported Margaret as long as she could, but eventually recognized it was no longer safe for either of them to remain living together.

The sisters remained close even while not living together. Both credit their independence and health to the strong friendships and skills they learned living together with their roommates.”

- Family friend of Margaret and Mary

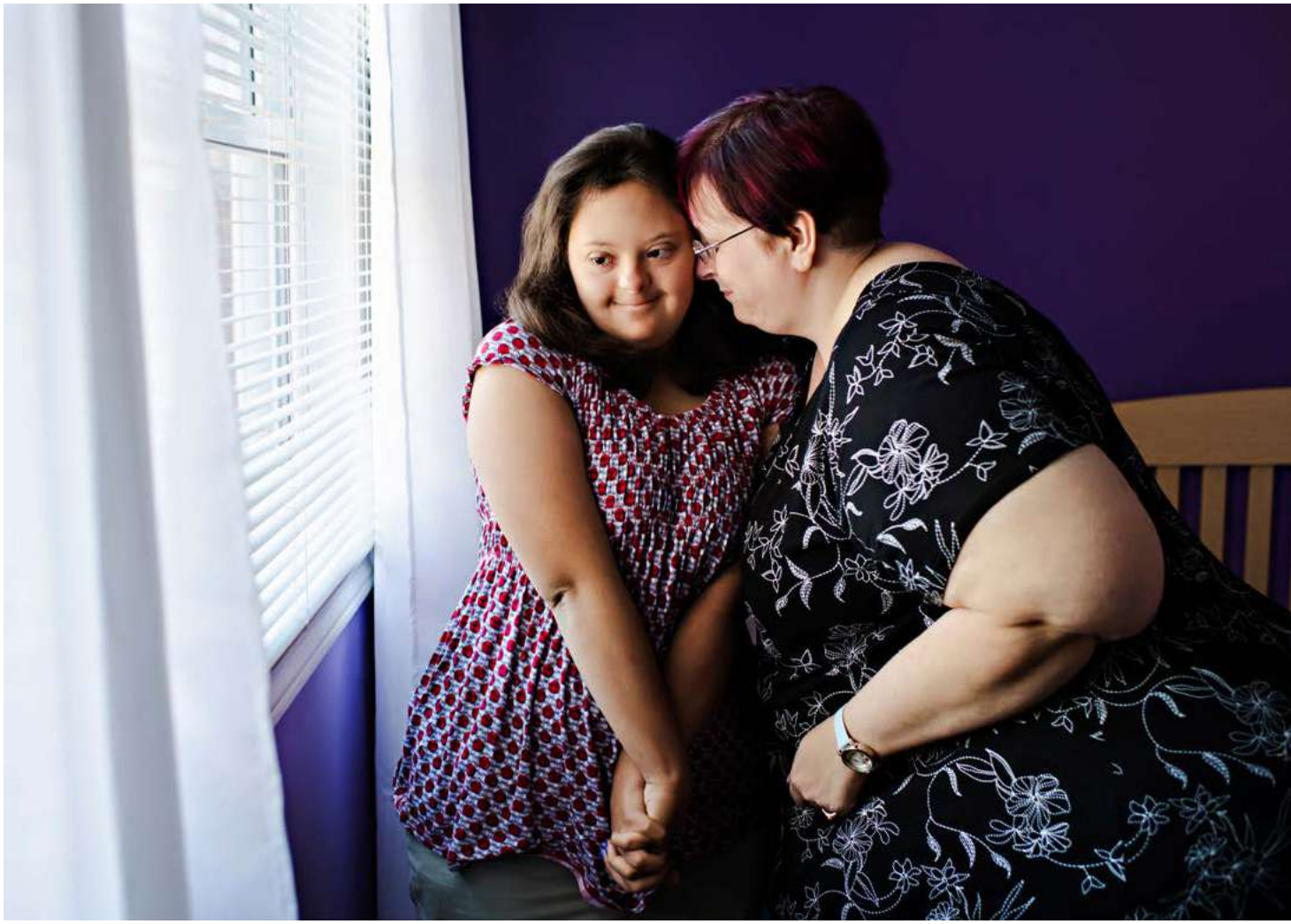
TRANSITIONING BETWEEN HOUSING OPTIONS:

Moving houses can be a stressful event for anyone. When transitioning between different living arrangements, try to prepare as much as possible before the move actually happens. The concept of moving and potentially moving in with different people or strangers may cause some behaviour issues and challenges even if the move is a positive change.

To help prepare with moving, consider the following tips:

- Remind the individual in advance about the change coming by the use of a calendar
- Talk about the change frequently and answer any questions
- If possible, visit the new living place multiple times to make it familiar

Remember that as people age their needs may change and the decision about where they live may need to be revisited. This can also apply if circumstances change within the home.



Financial Supports

Province Specific

In each province there will be different types and ranges of financial supports for people with disabilities. For now, we have specified the supports that are currently available in Alberta through the Government of Alberta website. No private supports are listed below.

Check back as we continue to update financial supports for each province.

Alberta

PERSONS WITH DEVELOPMENTAL DISABILITIES (PDD)

PDD is an Alberta based program that covers the cost of services from agencies for those who are eligible for funding. Their primary goal is to involve individuals in their community and promote independence for those with developmental disabilities. All agencies connected with PDD are designed to create an individualized service plan. They offer four types of support based on the individual's identified needs, which include:

- **Community Living Support**: This support is provided in the home and involves help with activities of daily living.
- **Employment Support:** This support is for educating individuals about jobs that are available and providing the tools to maintain a job.
- **Community Access Supports:** This support provides assistance with activities outside of the home such as sports, shopping, and volunteering.
- **Specialized Community Supports:** This support is for a short-term period in the community when an individual may need more support than what is typical for them.

Some of PDD's eligibility criteria include:

- The individual must be 18 years or older
- Have an IQ of 70 or below
- Must need help with 6 or more activities of daily living out of a tested 24
- Must have had two of the listed criteria prior to turning 18

Once approved for PDD, staff will work with the family and the individual to come up with goals and appropriate services that can be utilized. If the individual's needs have changed the PDD staff and/or family can adjust the goals and services to better optimize your loved ones needs and supports.

To find out more information on eligibility and the application process go to the Government of Alberta website.

ASSURED INCOME FOR THE SEVERELY HANDICAPPED (AISH)

AISH is an Alberta-based program that provides support for those who have a disability and are unable to support themselves financially. With AISH, individuals may be entitled to a monthly living allowance, monthly child benefit, health benefits, and personal benefits.

Some of the general criteria for eligibility include:

- Must be 18 years or older
- Must have a permanent disability
- Have an inability to earn a higher income due to their disability
- Be an Alberta resident

AISH promotes the individual to continue working or volunteering even if they are receiving funds from AISH.

It takes around 4 months to set this process up, and there is no fee associated.

To find out more information on eligibility and the application process go to the Government of Alberta website.

The AISH benefits admin program is a voluntary program that you can cancel at any time. It is a free program that helps people who are receiving AISH to budget and pay bills. It only helps in managing AISH money; other money such as income or gifts cannot be discussed.

Instead of AISH benefits being delivered to the person directly it will go to the office of the public guardian or trustee. From there it goes into an account they have set up for the individual. Bills also get sent directly to them and they pay them for the individual with the AISH money received. The money still belongs to the individual and the individual must tell employees how they want to budget their money and the staff will comply.

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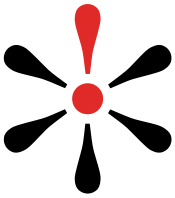

Canadian
Down Syndrome
Society

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trisomie 21

Today & Tomorrow

A GUIDE TO AGING WITH DOWN SYNDROME