



TODAY AND TOMORROW

A Guide to Aging with Down Syndrome





WELCOME



Welcome to your guide to aging with Down syndrome! The information, stories, and resources shared in this booklet can help adults with Down syndrome and their caregivers navigate important topics such as **mental and physical health, life changes, relationships, grief, and more.**

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TABLE OF CONTENTS



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.

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.

| | | |
|---|--|--|
|  | Introduction to Aging | 06 |
|  | Health and Wellness Overview | 08 |
| |  HEALTH CONCERNS AND THEIR SYMPTOMS |  EXERCISE AND FITNESS |
| |  HEALTH TESTING AND SCREENING RECOMMENDATIONS |  MENOPAUSE |
|  | Alzheimer's Disease | 32 |
|  | Down Syndrome Regression Disorder | 44 |
|  | Life and Behaviour Changes in Adulthood | 60 |
| |  MENTAL HEALTH ADVICE AND SUPPORT |  RELATIONSHIPS |
| | |  GRIEF |

INTRODUCTION TO AGING



People with Down syndrome are now living longer than ever before thanks largely to advances in medical diagnostics and treatment. The average life expectancy of a person with Down syndrome has more than doubled in the past 40 years.

People with Down syndrome are living into their 50's, 60's, and beyond. More possibilities are emerging from research in the area of aging to help people with Down syndrome live even longer, more fulfilling lives.



INTRODUCTION TO AGING



With more adults with Down syndrome outliving their parents and primary caregivers, the need to proactively plan for the future has never been more important.

Adults and seniors with Down syndrome can enjoy a future that includes education, employment, recreational activities, and meaningful relationships.

Life expectancy of people with Down syndrome has more than doubled over the past 40 years – from 25 years in 1983 to around 60 years of age today.

– **GLOBAL DOWN SYNDROME FOUNDATION**

By being proactive and learning about issues that may lie ahead you can look forward to a positive aging experience for all. 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 older 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 a valued person in both your family and the community, even in their older years.

Continued involvement in outings and loved activities such as going to movies, sporting events, or art classes are important to maintain healthy social connections.




HEALTH AND WELLNESS OVERVIEW



People with Down syndrome age in the same way that everyone else does, but they may develop signs of aging earlier than those in the general population. It is common that adults with Down syndrome will show physical, medical, and cognitive signs of aging earlier than what is expected for their actual age.

However, it is not predictable. Any sudden or dramatic change should be investigated. For a person with Down syndrome, general signs of aging may appear in their 40's. Signs of aging are completely normal, but it is important that you understand they may present at an earlier age for your loved one so you know what to expect.

GENERAL AGING SIGNS MAY INCLUDE:

-  Generally slowing down and becoming less active
-  Weight gain
-  Difficulties with vision and development of hearing loss



CAREGIVER TIP:

It is important to discuss any health concerns with your primary health care professional, as they will be able to provide input on screening tests and necessary treatments.

RECOMMENDED HEALTH TESTING AND 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 they may need to be administered at a different age than what is typical for the health of your loved one.

CAREGIVER TIP:

Always discuss routine tests with your health care professional to decide what is necessary or if there are other tests that are not included on this chart.



GENERAL SCREENING TESTS



Blood tests (annually)



Blood pressure (annually)



Body measurements (annually)



Thyroid levels (annually)



Hearing and vision tests (every 2 years)



Tested for Celiac disease (every 3-5 years)



Echocardiogram (every 5 years if there is a history of surgery or heart issues)



Tuberculosis (if the individual is at high risk)



Cervical spine x-rays (every 10 years)






Pneumococcus (50+ years of age)

RECOMMENDED HEALTH TESTING AND SCREENING



FEMALES




-  Pap smears and pelvic exams (every 2-3 years)
-  Mammography and breast examinations (usually after 40 years of age)
-  DEXA scan for bone density (every 2 years, discuss risk with your doctor)

CAREGIVER TIP:

If you have a family history of breast cancer, speak to your health care professional about what age they recommend exams and tests should begin.



MALES

-  Testicular exams (annually)
-  Prostate and colon examinations (discuss with your healthcare professional)
-  DEXA scan for bone density (every 2 years, discuss risk with your doctor)

HEALTH CONCERNS AND COMMON SYMPTOMS



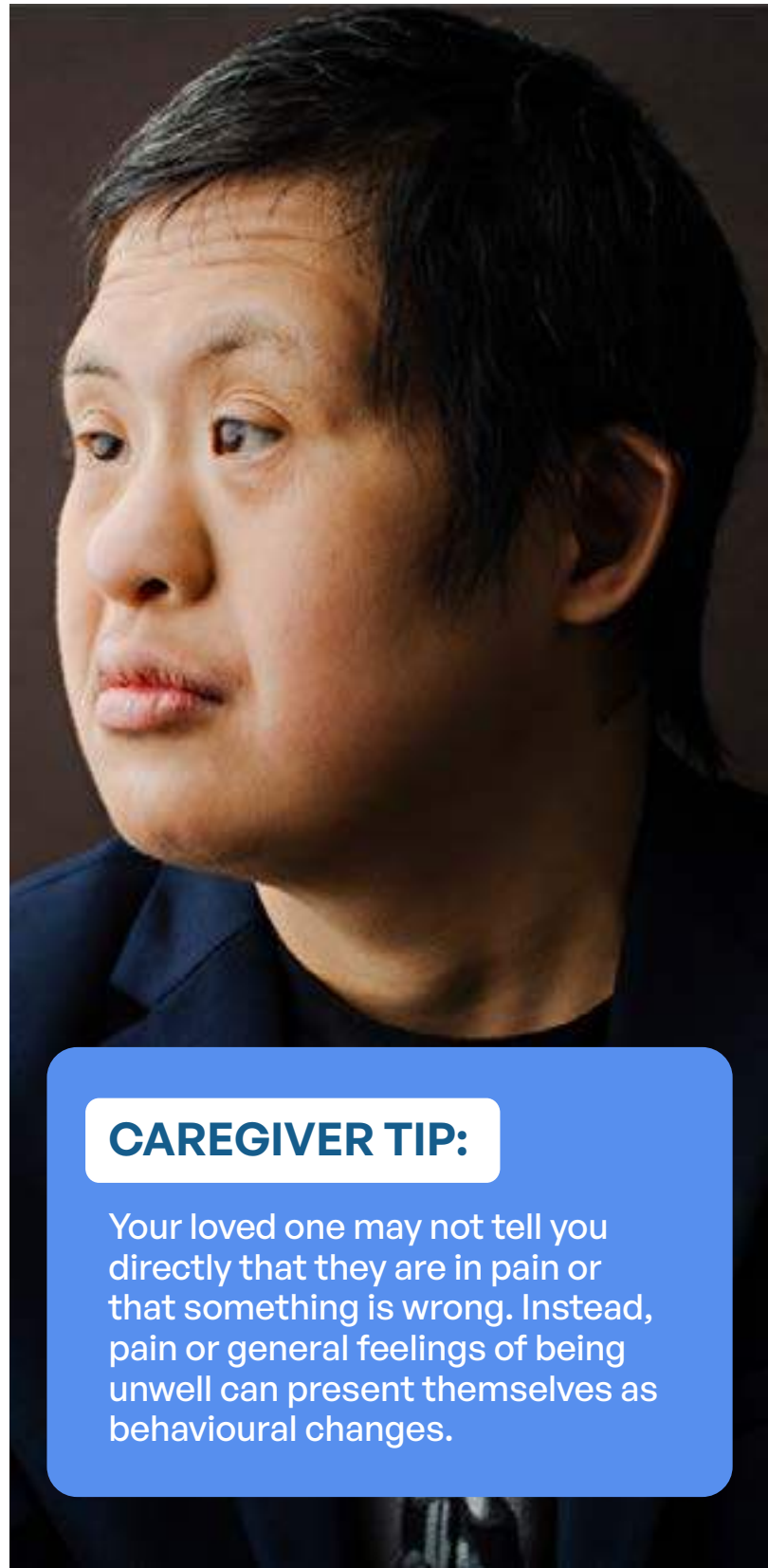
Throughout this resource, we will provide guidance on supporting your loved one's well-being and helping them to maintain a healthy lifestyle as they age. While adults with Down syndrome often experience many of the same health concerns as the general population, there are some conditions that may be more common.

It's important to be aware of these conditions and watch for any changes or symptoms so that care can be provided as early as possible.

Medical problems in individuals with Down syndrome may go undetected or undiagnosed until much later in life.

The following pages offer an introductory overview of health concerns to keep in mind if you notice any symptoms or changes in your loved one with Down syndrome as they age.

Remember that each individual is different, and they may encounter health issues not listed below.



CAREGIVER TIP:

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.

HEALTH CONCERNS AND COMMON SYMPTOMS



VISION PROBLEMS

Early cataracts, glaucoma, and keratoconus can all cause vision impairment.

Recommendations: Try to book regular eye exams to check for any vision changes.

HEARING LOSS

Ear wax impaction can cause hearing loss.

Recommendations: Routine exam for impactions and screening to assess any hearing loss over time. For permanent hearing loss, hearing aids are available to help improve hearing difficulties.



ALZHEIMER'S DISEASE

Alzheimer's disease is more prevalent in people with Down syndrome and may present 20 years earlier than it would for the general population. It primarily impacts memory, decision-making abilities, communication, and personality.

Recommendations: Please visit page 32 of this resource for more information about Alzheimer's disease and Down syndrome.

HEALTH CONCERNS AND COMMON SYMPTOMS



OBESITY/OVERWEIGHT

Increased risk due to slower metabolism and barriers to regular activity causing many other issues.

Recommendations: Tracking weight. Guidance for a healthy diet and increasing activity.



THYROID DYSFUNCTION

The thyroid controls many metabolic processes. Symptoms to watch out for may include fatigue, sluggishness, weight gain and constipation.

Recommendations: Talk to your health care professional about having thyroid level checks regularly. Medication may be required.

DIABETES

Mellitus Type-2. As managing weight later in life can be an issue, diabetes is a common concern for adults as it is often connected to being overweight.

Recommendations: Inform your doctor if you start to notice symptoms that could indicate signs of diabetes, such as weight changes, thirst, and fatigue. Sometimes medication is recommended along with healthy dietary changes and exercise for prevention.

HEALTH CONCERNS AND COMMON SYMPTOMS



CELIAC DISEASE

A condition where one's body can't digest wheat gluten and wheat-containing products causing a response that damages the lining of the small intestine and prevents absorption of certain nutrients. Symptoms could include fatigue, irritability, anemia, stomach issues or even an increase in unusual behaviours.

Recommendations: Diagnosis by blood test and biopsy. Your Primary Care Physician (PCP) may recommend a consultation with a gastroenterology specialist to make the diagnosis. Restrictive changes to the diet usually relieve the symptoms.

GERD

GERD (gastroesophageal reflux disease) causes acid from the stomach to enter the throat or lungs where it can cause irritation and/or a chronic cough. Aspiration occurs when food or fluid is breathed into the lungs. Aspiration can often lead to pneumonia, an infection of the lungs.

Recommendations: It is important to be aware of aspiration at any age for people with Down syndrome.

GUM DISEASE

People with Down syndrome are more likely to have dental disease including gingivitis and periodontitis.

Recommendations: Good consistent home-care routines along with keeping up with dentist and dental hygienist appointments can be key in preventing dental disease.

HEALTH CONCERNS AND COMMON SYMPTOMS



OSTEOARTHRITIS

Adults with Down syndrome can be extra flexible. With time this can aggravate large joints leading to pain and stiffness. Look for non-verbal signs of pain, compensation to avoid using that area, or decreased mobility.

Recommendations: This is often under-reported. Speak to your healthcare professional about treatments and lifestyle modifications for osteoarthritis.

OSTEOPOROSIS

Osteoporosis develops as the bones in the body start to become thinner and more fragile and can lead to fractures. Adults with family history and those experiencing early menopause or taking certain medications may be at risk.

Recommendations: A thorough review of health and all medications. Speak to your healthcare professional about treatments and lifestyle modifications.

ATLANTOAXIAL INSTABILITY

This 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. This can happen at any time in life even if previous tests were negative.

Recommendations: Consult with your health care professional on testing. X-rays may be required. Degenerative changes and the development of arthritis over time can affect the spinal cord, changing one's coordination, gross motor function and incontinence.

HEALTH CONCERNS AND COMMON SYMPTOMS



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.

Recommendations: Speak to your healthcare professional about treatments and lifestyle modifications for spinal stenosis.

OBSTRUCTIVE SLEEP APNEA

This sleep disorder occurs when the body has long pauses between breaths leading to poor quality sleep. It can strain the heart and lungs and cause high blood pressure.

This person may have symptoms such as sleeping during the day, fatigue, weight gain, irritability and behaviour changes.

Recommendations: A sleep study is commonly recommended.



“I have always tried to do research on many of the risks for people with Down syndrome as they age.

I am still doing my research and learning a lot about things I did not know. Thyroid issues are often a concern, so I have been working on my health and fitness. Eating properly and eating the right amount always helps me stay on track.

A lot of food you eat has a lot of health benefits like Brazil nuts, eggs, seaweed, and fruit.

Remember to ask a professional and your parent what’s best for you and to believe in yourself and make yourself proud.

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



EXERCISE AND FITNESS



Regular physical activity plays an important role in maintaining the health of adults with Down syndrome as they age.

Exercise can help your loved one maintain mobility, improve heart health, support bone strength, and enhance overall well-being. It can also contribute to improved mood, energy levels, and quality of sleep.

Recent research has shown that consistent physical activity can also have cognitive benefits for individuals with Down syndrome.

[*The Mindsets Study*](#), conducted by Dr. Dan Gordon at Anglia Ruskin University in partnership with the Canadian Down Syndrome Society, found that walking for 30 minutes three times per week can improve information processing and attention after just eight weeks.

These findings reinforce the importance of incorporating regular movement into daily routines and habits.



EXERCISE AND FITNESS








Despite the many benefits of regular exercise, many adults with Down syndrome do not have a fitness routine established.

[A study analyzing data from the 2011–2012 National Core Indicators Adult Consumer Survey](#) found that only 13.5% of adults with intellectual disabilities in the United States met the recommended physical activity guidelines, compared to 30.8% of the general population.

Your loved one may find exercise challenging, and aging can bring new physical and mental changes that make regular activity more difficult.

COMMON CHALLENGES INCLUDE:

-  Joint pain or mobility concerns
-  Fatigue or lack of energy
-  Low motivation or lack of social support
-  Limited access to inclusive fitness programs
-  Lack of transportation



Understanding these barriers can help you find solutions that encourage movement in ways that feel enjoyable and achievable. As part of their support system, your role is essential — many fitness opportunities aren't easily accessible without advocacy and encouragement.

Adults with intellectual disabilities spend, on average, more than 60% of their day in sedentary behaviour, which has been linked to increased health risks.

EXERCISE AND FITNESS



ENCOURAGING PHYSICAL ACTIVITY

Helping your loved one stay active doesn't have to mean structured workouts. Look for activities that match their interests and abilities and develop a routine that works for them. Even small amounts of regular movement can make a difference in your loved one's overall health.

Talk to your loved one's healthcare provider about safe and appropriate activities, and explore local programs that offer accessible fitness options.

Here are some strategies for supporting their movement:

INCORPORATE MOVEMENT IN DAILY LIFE

Gardening, stretching while watching TV, or short walks after meals can all contribute to an active lifestyle.

MAKE IT SOCIAL

Group classes, community walking clubs, or dancing with friends can make exercise more engaging.

FOCUS ON ENJOYMENT

Encourage activities they love, such as swimming, yoga or playing with nieces and nephews. Don't be afraid to keep trying activities until you find the perfect fit!

START SLOW

Start with short, lower-intensity activities and gradually increase to longer, more difficult exercises.

ADAPT AS NEEDED

Consider modified exercises or seated workouts to accommodate mobility changes.

PROVIDE ENCOURAGEMENT

Positive reinforcement and celebrating progress can help maintain motivation.

“I have been a Special Olympic athlete since I was 12 years old. I participate in many sports! In the fall/winter, I am in swimming, power lifting, snowshoeing, and skating.

In the spring/summer, I do track and field, bocce, and golf. I have been to a provincial competition twice. Once in swimming and, last year, I competed in snowshoeing at provincials and qualified for nationals in February 2024 in Calgary. I’m very excited and have been training hard. I am, also, a member of the Athlete Input Council and a Special Olympic Health Messenger and I sit on the board of directors of Motionball-Kelowna.

Playing sports has made my life so much better! My sisters both played sports growing up and I always went to cheer them on at competitions. It took a while for me to find a sport that was right fit for me and a coach that was familiar with coaching people with disabilities. Swimming was the first sport I really fell in love with.

My parents put me in private lessons until I was old enough to join Special Olympics. SO is where I met some of my very best friends, we’re like a family. It makes me happy to have found a community who loves and supports me like they do. Being active also inspires me to eat healthier and take care of my mental health. I’ve gotten to travel with my team and next year, I’ll be heading to Calgary to represent BC at Nationals. I have the best home support system too and how they all cheer for me! I will definitely stay active for the rest of my life! I have an active family, which helps. Special Olympics is for all ages so I will get to be part of this community for as long as I want! Can’t wait to keep making memories with my friends.

Taking care of our bodies and health is so important. It helps us prevent disease and also lets me do all the things I want to do! Being active is so important for my mental health too. I feel my best when I move my body often.

– KASSIDY RUTLEDGE, ATHLETE AND SELF-ADVOCATE, BRITISH COLUMBIA



MENOPAUSE



Menopause is a normal aging process in women that marks the end of fertility.

It is characterized by significant hormonal changes that cause menstruation to stop and can result in a variety of symptoms. For most women, these symptoms are minor and can be navigated. *Unfortunately, this topic is rarely discussed and even less so for women with Down syndrome.*

The symptoms of menopause can be confusing, and women often find this transition difficult. Menopause can be more challenging for women with Down syndrome because they may not understand the hormonal changes that are happening in their bodies. During menopause, women with Down syndrome may experience behavioural changes; new behaviours may appear, and existing behaviours may become more noticeable.

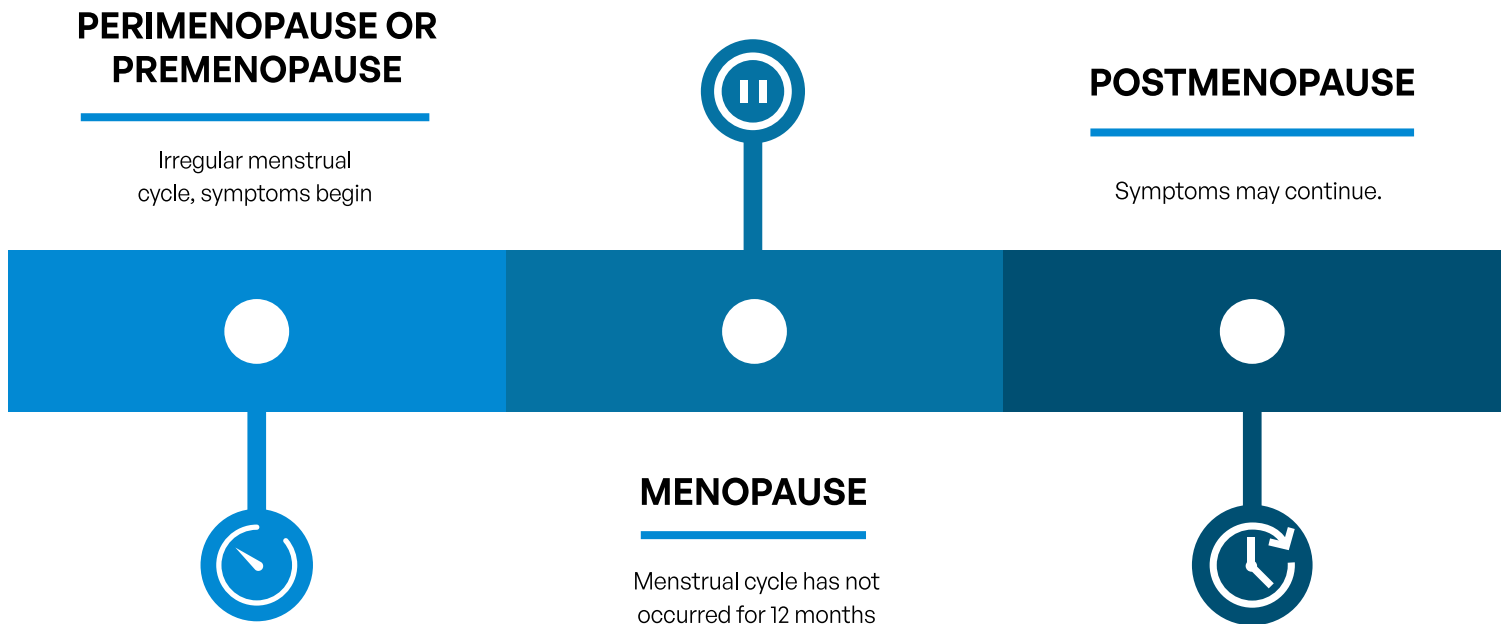
Another potential challenge is diagnostic overshadowing, which occurs when medical professionals attribute symptoms to an existing diagnosis of Down syndrome rather than a possible new condition like menopause. Menopause is confirmed when it has been 12 months since the last menstrual period. It occurs at an average age of 52 in neurotypical women and at a median age of 46 for women with Down syndrome.

However, the symptoms of premenopause can occur 5 to 6 years before menopause begins.





STAGES OF MENOPAUSE



SYMPTOMS



Hair loss



Dry skin, acne



Hot flashes



Weight gain



Altered menstruation



Vaginal dryness and bladder atrophy



Fragility of nails



Joint pain

MENOPAUSE



HOT FLASHES AND NIGHT SWEATS

The most common symptom of perimenopause. Sensations of intense heat starting in the chest and rising to the face, sometimes causing sweat and redness. They often occur at night and are sometimes followed by chills. May persist in perimenopause.

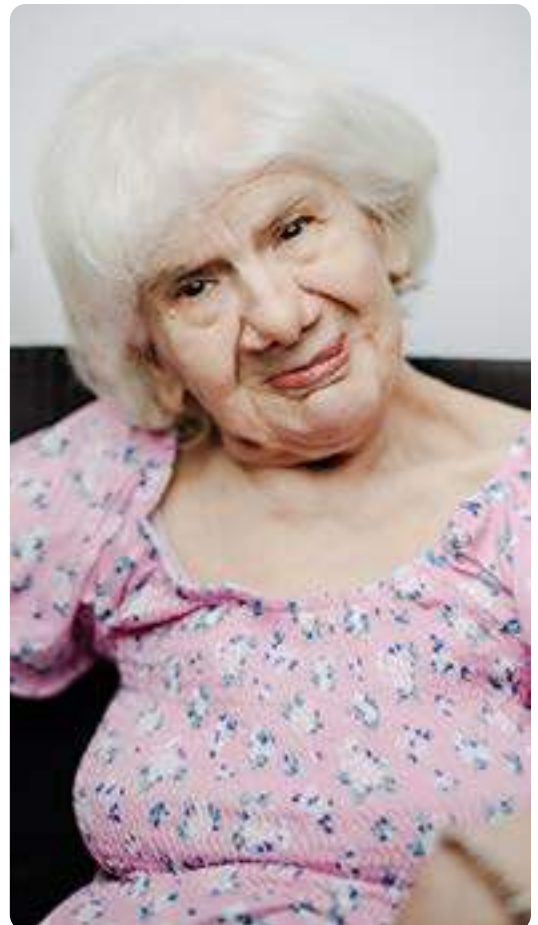
Recommendations: Limit stress, encourage physical activity, reduce the room temperature, have your loved one dress in several layers of clothing, reduce intake of stimulants (ie. caffeine, chocolate, spicy food, sugar, cigarettes, hot drinks, heavy meals), keep a logbook to track if elements of your loved one's diet, environment, physical activity, etc. trigger the hot flashes.

MOOD DISORDER

Depressive symptoms may be experienced due to fluctuating hormones in perimenopause. These may include crying more easily, irritability, mood changes, anxiety, and decreased energy and motivation.

While depressive symptoms are common, depression is not. Women who have previously experienced a depressive episode are more likely to experience another during perimenopause.

Recommendations: Stay physically active, eat a balanced diet, have a good sleep hygiene, keep up usual routines, consider any recent life events that may have triggered the symptoms, and if depressive symptoms persist, consult your doctor.



MENOPAUSE



SLEEP DISORDER

One of the most important symptoms as it can impact several other symptoms experienced, like mood disorders, weight gain, and memory loss. Maintaining a good sleep hygiene allows the body to rest.

Recommendations: Have a regular sleep routine, avoid stimulants like caffeine and cigarettes before sleeping, stay physically active during the day; avoid exercise before bedtime, have a lighter dinner earlier in the evening to allow for better digestion, minimize naps during the day, have a sleep-friendly environment (cold, dark, quiet and calm), limit screens 30 minutes before bedtime, do guided meditation before sleeping.

JOINT AND SKIN PAIN

Decrease in estrogen causes a decrease in collagen production. This can create dry skin or a change in skin's appearance and texture. Weight gain can increase joint pain.

Recommendations: Encourage your loved one to do physical activities that strengthen the body and the joints, help your loved one to have a balanced diet, encourage your loved one to use moisturizers that are right for their skin, consult a pharmacist to discuss a joint pain supplement if needed.

WEIGHT GAIN

During perimenopause, the digestive system slows down and muscle mass and bone density decrease. This can cause an increase of fat in the chest, abdomen and hips. On average, women can gain 1.8 to 4 kg, or 4 to 9 lbs. Weight gain can also cause increased joint pain.

Recommendations: Encourage physical activity, change your loved one's diet, help them to consume more fiber, reduce your loved one's food portions to decrease calorie intake.



GENITOURINARY SYSTEM

During menopause, the bladder descends, vaginal secretions decrease, and the walls of the vagina, the labia major and minora, and the urethra thin. This may cause urinary leakage, increased frequency and urgency of urination, urinary tract infections, irritability of the genitourinary system, and vaginal dryness. Vaginal dryness can result in itching, bleeding, pain during intercourse or vaginal infections.

Recommendations: Consult a pelvic physiotherapist to strengthen the pelvic floor, establish a bathroom schedule, encourage your loved one to drink water, have your loved one use lubricant during sexual intercourse, have your loved one describe symptoms to the doctor; estrogen gel may be prescribed to decrease discomfort of vaginal dryness; antibiotics may be prescribed to treat a urinary tract infection or vaginal infection.

DECREASED LIBIDO

A decrease in libido, or sex drive, could be caused by some of the other symptoms experienced.

Recommendations: Identify possible triggers, such as genital discomfort, depressive symptoms, low energy due to lack of sleep, decreased self-esteem, or difficulties in a relationship; if you identify a trigger, it can be addressed with the help of a doctor or physiotherapist.





SHORT-TERM MEMORY LOSS/MENTAL FOG

Perimenopause can affect short-term memory, which can cause a feeling of living in a mental fog. This may include decreased motivation, difficulty concentrating, headaches, difficulty communicating or finding words, confusion, or a feeling of the brain working in slow motion. These symptoms are only present during perimenopause. Unlike Alzheimer's disease, these symptoms do not increase or progress, they remain stable.

Recommendations: Have your loved one name and explain symptoms to a doctor and keep a logbook to track when these symptoms occur; notice if there are any correlations with lifestyle or potential triggers.





NON-HORMONAL TREATMENTS

EXERCISE

Several symptoms of menopause can be relieved with non-hormonal solutions. For example, physical activity can improve almost all the symptoms of menopause and has numerous other health benefits.

Twenty minutes of daily movement with muscular and cardiovascular effort is recommended, but any addition of movement will have a positive impact.

It's important to work at a pace that's comfortable for your loved one and to respect their limits. [Here are a few ideas you can encourage your loved one to try:](#)

-  Get some fresh air before meals
-  Household chores like sweeping, getting mail, or putting away dishes
-  Take the stairs instead of the elevator
-  Swim or go for a walk
-  Participate in group classes like yoga or Zumba
-  Dance to their favourite song

CAREGIVER TIP:

Try non-hormonal options with your loved one before consulting a doctor for hormonal treatments.



MENOPAUSE











DIET

Diet can also impact the symptoms of perimenopause.

Eating habits can be difficult to change, especially if they've been reinforced over many years. Just like with physical activity, the best approach is to make small, gradual changes rather than trying to improve everything all at once. Planning meals each week can help you to establish a healthy menu for your loved one, vary their meals, and help them know what to expect.

Here are a few tips for your loved one's diet:

-  Consult the latest version of [Canada's Food Guide](#)
-  Introduce new foods
-  Plan a healthy menu of meals for the week with your loved one
-  Cook simple and nutritious recipes together
-  Try to find a balance rather than eliminating foods entirely
-  Minimize processed foods
-  Try replacing some foods with healthier alternatives (eg. chocolate hummus instead of hazelnut spread)
-  Enhance recipes by adding healthy foods (eg. adding cauliflower to mashed potatoes)

CAREGIVER TIP:

Try to reduce your loved one's consumption of foods or drinks with caffeine, chocolate, alcohol, or a lot of spices.



MENOPAUSE



HYDRATION

Hydration is often forgotten, but it has many benefits for the body, including supporting the genitourinary, digestive, and cardiovascular systems.







It also promotes skin and joint health and regulates body temperature. All liquids matter, though choices with low sugar content are the most beneficial.

There are also a variety of natural alternatives available to treat some menopause

symptoms. There is no scientific evidence to support these treatments, as few studies are done on non-medicinal alternatives.

It's important to discuss these treatments with your loved one's doctor or pharmacist before trying them to ensure they won't interact in unexpected ways with any other treatments or medical conditions.

Here's how you can help your loved one stay hydrated:

-  Have them keep a bottle of water nearby
-  Drink flavoured or unflavoured sparkling water
-  Drink smoothies or herbal tea
-  Add water flavouring or fruit slices to water
-  Establish a water consumption routine
-  Increase consumption of fruits and vegetables

CAREGIVER TIP:

Make small, gradual changes in areas like diet, exercise, and hydration to help your loved one establish new habits over time.



MENOPAUSE



HORMONE TREATMENTS

Hormone treatments can have many benefits for the symptoms of menopause.

However, it is also possible to experience significant side effects. The effectiveness of this type of treatment often varies from one person to another.





Hormone treatments are usually prescribed when symptoms are persistent and are disrupting your loved one's functioning. They can not be used preventatively.

If your loved one tries a hormone treatment, it's important to follow up with your doctor and discuss any changes in symptoms so they can adjust the dose if needed.

Hormone treatments are recommended for a maximum of five years. With any menopause treatment, remember to take things one day at a time and keep your loved one involved in decision-making and implementation.

Every change, no matter how small, can have a positive impact, and being surrounded by support will help your loved one to experience this life transition more smoothly.

Hormone treatments can be administered in several ways:

-  Vaginal gel
-  Skin patch
-  Skin gel (recommended over oral)
-  Oral

CAREGIVER TIP:

Always discuss the symptoms your loved one is experiencing in detail with a doctor before receiving a prescription for a hormone treatment so that other potential causes can be ruled out.

ALZHEIMER'S DISEASE



People with Down syndrome are at a higher risk of developing Alzheimer's disease, and symptoms often begin earlier than in the general population – sometimes as early as their late 40s or early 50s.

This is because extra genetic material on the 21st chromosome in people with Down syndrome increases the production of a specific protein linked to plaque formation in the brain. These plaques and tangles interfere with communication between brain cells, leading to progressive symptoms over time.

Alzheimer's typically appears about 20 years earlier on average in people with Down syndrome than in the general population. The disease progresses differently for everyone – it may develop slowly over time or come on suddenly.



Over 70% of adults with Down syndrome aged 65+ are living with Alzheimer's.

– ALZHEIMER'S SOCIETY

ALZHEIMER'S DISEASE



PRE-DIAGNOSIS

Even if your loved one doesn't have any symptoms of Alzheimer's, there are steps you can take to promote their well-being and prepare for any possible changes as they age. Maintaining healthy routines for eating, exercising, sleeping, and stimulating the brain may reduce your loved one's risk of Alzheimer's, and taking them for regular medical checkups can help to catch any early signs.

The abilities of adults with Down syndrome vary, so it is important to establish a baseline of what is normal for your loved one. It's helpful to record this information to use as a comparison if their behaviours or abilities start to change. The screening tool offered by the [***National Task Group on Intellectual Disabilities and Dementia Practices, Early Detection and Screen for Dementia \(NTG-EDSD\)***](#) is a great way to record this information. It's most helpful to begin using this screening tool annually when your loved one is in their 30's, before symptoms of dementia are likely to begin.

If the screening tool indicates any significant changes, or if you observe possible symptoms in your loved one, it's important to seek medical attention as soon as possible. Symptoms may be subtle, and they may

come and go. Changes in personality or behaviour such as withdrawal from social activities are sometimes more noticeable early symptoms in adults with Down syndrome than the memory impairment typically observed in the general population.

It may be easy to attribute symptoms to normal aging which can delay a diagnosis. However, even small changes shouldn't be dismissed. Checking in with a health care provider about new or unexplained changes early can help rule out other causes and, if needed, start the process of planning the proper support and care for your loved one.

Accessing services can take time, so acting before your loved one's daily life is significantly disrupted can help ensure they receive timely, effective support.





ALZHEIMER'S DISEASE



GETTING A DIAGNOSIS

Standard Alzheimer's screening tools that are used for the general population aren't always reliable for people with Down syndrome, as they may not account for lifelong differences in learning and memory. Adapted tools that are specific to the intellectual Disability community help provide a more accurate picture by comparing your loved one's current abilities to their own baseline and are important in helping

 Hearing or vision loss

 Pain or infection

 Thyroid issues


 Other hormonal imbalances


medical professionals determine an accurate diagnosis.


Before a diagnosis can be made, your health care professional should explore any other possible causes of dementia-like symptoms:

 Dehydration or malnutrition

 Medication side effects

 Stress, fatigue, or grief

 Depression or other mental health conditions

 Stroke or general signs of aging

CAREGIVER TIP:

Keep a journal of behaviour changes and unusual incidents. Patterns can help doctors make an accurate diagnosis.



ALZHEIMER'S DISEASE



SYMPTOMS AND STAGES OF DEMENTIA

Dementia is a general term for a set of symptoms caused by changes in the brain that affect memory, thinking, communication, and daily functioning. There are different types of dementia, each with its own causes and patterns of progression.

Alzheimer's Disease is the most common cause of dementia. It is a specific brain disease that leads to dementia symptoms and typically progresses through gradual stages. While the following stages describe dementia in general, they can help you understand how Alzheimer's Disease – the most common cause of dementia in adults with Down syndrome – may progress over time.

After a dementia diagnosis, individuals typically move through three stages: **early, middle, and late**. These stages may look different for people with Down syndrome than in the general population, and the symptoms and progression will vary for each individual. The progression isn't always linear. Some people may plateau or show temporary improvements.



ALZHEIMER'S DISEASE



EARLY STAGE

In the early stage of dementia, a person with Down syndrome may still participate in many of their usual activities and maintain a certain amount of independence. They might experience mild changes in memory, mood, or daily functioning.

These changes can appear gradually. Early intervention, consistent routines, and ongoing support can help maintain independence for as long as possible. For some individuals, this stage may last for several years.

These symptoms may differ from person to person, and not all will be present for every individual. They may include:

- A decreased interest in either activities or hobbies
- Difficulty focusing or completing familiar tasks independently
- Changes in walking patterns, coordination, or gait
- Increased obsessive or repetitive behaviours, like hoarding or rigid routines
- Changes in sleeping or eating habits
- Mood and behaviour shifts – including anxiety, frustration, sadness, confusion, or reduced impulse control
- Disorientation, short-term memory loss, or wandering
- Reduced communication skills
- Possible increase in seizure activity

SUPPORTING YOUR LOVED ONE

Try to maintain your loved one's routines and independence as much as possible during this stage while implementing additional supports as needed for their safety and well-being. Here are a few ways you can offer support:

- Provide information to help your loved one understand the changes they are experiencing. Break things down into

manageable pieces and repeat it using familiar language.

- Encourage your loved one to continue participating in activities and hobbies that are meaningful and comforting. This can help to reduce confusion and anxiety. Adjust the activities as need to make them more accessible.

ALZHEIMER'S DISEASE



SUPPORTING YOUR LOVED ONE

- Provide cues, visual supports, and encouragement to help your loved one complete daily tasks.
- Monitor for other health issues that may cause or worsen symptoms, such as pain, vision or hearing loss, thyroid changes or infections.
- Involve your loved one in decision-making while they can still clearly express their preferences to others.

CHALLENGING BEHAVIOUR

Your loved one may become agitated or emotional from the mental and physical changes they are experiencing. It's important to remember these behaviours are symptoms of the disease and not personal attacks.

Here are a few strategies to help manage heightened emotions:

- Look for underlying causes that can be addressed, like hunger, thirst, pain, fatigue, boredom, overstimulation, or other environmental triggers.
- Move to a calm, comfortable space if possible and approach the situation with patience.
- Redirect them to an enjoyable or soothing activity.
- Avoid arguments; aim for solutions that preserve dignity and reduce stress levels.



ALZHEIMER'S DISEASE



PLANNING AHEAD

It's crucial to start planning for the future while your loved one can still express their wishes, particularly because it may take time to get supports in place for the later stages of dementia.

Include your loved one in conversations about possible treatment plans or how their living situation might change as the disease progresses and ask them what their wishes are. Discussing end-of-life care, although it can be a difficult topic, may also be beneficial for future planning.



MIDDLE STAGE

The middle stage of dementia is often shorter in adults with Down syndrome than in the general population.

Supervision and ensuring your loved one is safe should be the priority during this period, and they might need increased support with hygiene, meals, and daily tasks. Symptoms may include:

- Difficulty recognizing familiar people and/or places
- Seizures, mobility issues, or incontinence
- More frequent disorientation and emotional distress
- Further withdrawal from familiar routines and activities
- Reduced language/short-term memory

CAREGIVER TIP:

Consider bringing together a Circle of Support who can share in planning, companionship, and respite. This may include family, friends, support workers, and healthcare providers.

ALZHEIMER'S DISEASE



MIDDLE STAGE (CONT'D)

If possible, encourage your loved one to continue familiar activities they enjoy. Keep in mind that their behaviours and symptoms may change from day to day, and you may need to adjust or try new strategies to continue providing comfort and support.

Here are some ways you can support your loved one during this stage:

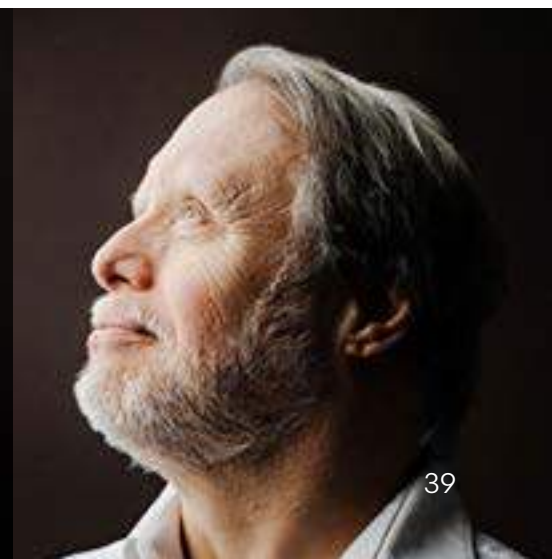
- Switch to softer foods to help avoid choking
- Reduce stress and keep your surroundings soothing
- Manage triggers for reactive behaviours when you are able to
- Stimulate your loved one's memory with stories and photos

COMMUNICATION

It may be beneficial to adjust how you communicate with your loved one, as non-verbal methods of communication can be easier to understand.

These communication tips can help to minimize agitation and confusion.

- Body language and facial expressions are helpful cues
- Try to maintain positive tone and word choice when possible (avoid “no” or “don’t” and gently redirect instead)
- Written notes, visual cues, and/or assistive communication tools may be helpful



ALZHEIMER'S DISEASE



MOBILITY

If mobility becomes a challenge, assistive devices such as a walker or a stair lift can help make daily movement easier and safer. Depending on your loved one's living situation, environmental adjustments such as renovations may also be needed to ensure they can navigate home safely.

For some families, in-home supports may be enough; for others, a transition in housing might eventually be needed.

If relocation or other long-term supports are required, begin planning well in advance, as waitlists are common.

During relocation or other major changes, try to incorporate familiar routines, people, and belongings to help reduce confusion and disorientation.

LATE STAGE

The final stage of dementia is generally shorter than earlier stages.

Your loved one will likely need significantly increased care during this time and require additional supports.

Bodily functions often decline significantly, which can lead to health complications such as infections or other illnesses. Providing comfort, dignity, and palliative care should be the focus as you support your loved one through this stage.

CAREGIVER TIP:

Supports such as counselling and arts-based therapies may be helpful to support your loved one's emotional regulation and mental stimulation.



ALZHEIMER'S DISEASE



LATE STAGE (CONT'D)

Symptoms can include:

- Significant memory loss
- Immobility and risk of falls
- Significantly reduced or absent speech
- Difficulty chewing or swallowing
- Full incontinence
- Increased sleep
- Breathing problems
- Weight loss

NUTRITION & HYDRATION

Ensuring your loved one has a regular intake of nutrients and fluids is important at the beginning of late-stage dementia. It is likely that they will need support to eat and drink and will not remember to do so themselves.

Chewing and swallowing often become challenging, so a swallowing assessment may be needed. Some individuals might need pureed food or a feeding tube to continue receiving nutrients.

The final stage of dementia is often extremely challenging for caregivers. Consider supports for yourself like respite and if you've established a circle of support, don't be afraid to lean on them.

END OF LIFE CARE

It can be challenging to determine when hospice care or palliative care may be beneficial for your loved one. Monitoring for the changes identified above may help you to make that decision.

Support for your loved one during this stage will likely focus on helping them manage physical pain, emotional distress, and other symptoms as much as possible.

Whenever you can, follow your loved one's previously expressed wishes for care, including end of life care.

Although they might have limited or no verbal communication during this stage, your loved one may still find comfort in visits from family and friends. You can support visitors to interact with your loved one in ways that feel reassuring and positive.

CAREGIVER TIP:

Familiar voices, songs, and smells may be calming or uplifting for your loved one.

ALZHEIMER'S DISEASE



Dementia affects each person differently. Your loved one's essence remains even as their abilities shift. Supporting them through this journey can be difficult, but you're not alone.

With the right tools, people, and preparation, it's possible to honour their life, comfort, and dignity every step of the way.

TREATMENT AND RESEARCH

Currently, no medications have been specifically approved by Health Canada or the U.S. Food and Drug Administration (FDA) to treat dementia in individuals with Down syndrome. The effects and safety of many treatments that are used for Alzheimer's Disease in the general population have not yet been specifically studied in people with Down syndrome.

Because people with Down syndrome may metabolize medications differently due to factors like body size, metabolism, and common health concerns (such as thyroid issues or diabetes), caution is advised when using drugs that have not been specifically tested and proven safe for them.

Treatment for Alzheimer's Disease in people with Down syndrome primarily focuses on supportive care and managing symptoms rather than curing the disease. Medications available today tend to modestly ease cognitive symptoms but do not reverse memory loss or halt disease progression.

Addressing coexisting health conditions—like thyroid disorders, depression, or arthritis—can significantly improve quality of life by reducing pain, confusion, and irritability.

Research efforts continue to improve understanding and treatment options for Alzheimer's Disease in people with Down syndrome. Notably, the National Institutes of Health launched a major initiative to identify biomarkers—biological signs in blood or brain—that can help detect and monitor Alzheimer's Disease earlier and more accurately in adults with Down syndrome. Collaborative projects with organizations such as the Alzheimer's Association and the Linda Crnic Institute focus on developing blood tests to identify individuals at high risk.

Pharmaceutical companies and research institutions are also investigating genetic and cellular factors that could inform future therapies. In addition to biomedical research, large international studies like the POINTER and FINGERS projects show that healthy

ALZHEIMER'S DISEASE



TREATMENT AND RESEARCH (CONT'D)

lifestyle habits—such as regular exercise, good nutrition, heart health, and social engagement—can lower dementia risk and support brain health, even later in life. While no definitive treatment exists yet,

ongoing studies and clinical trials offer hope that more effective and tailored therapies will emerge to support individuals with Down syndrome facing Alzheimer's disease.



DOWN SYNDROME REGRESSION DISORDER (DSRD)



Down Syndrome Regression Disorder (DSRD) is a rare and alarming neuropsychiatric condition where a person with Down syndrome, often between ages 10 and 30, exhibits the sudden onset of symptoms and behaviours including but not limited to the loss of previously acquired social, cognitive, language and daily living skills, as well as changes in sleep patterns, behaviour, mood and movement.

Changes may include insomnia, incontinence, mutism, motor difficulties, obsessive/compulsive behaviours, hallucinations, or psychosis.



DOWN SYNDROME REGRESSION DISORDER (DSRD)



Although first described in the mid-20th century, it was only in 2022 that DSRD was officially recognized as a disorder and that experts published the diagnostic criteria and recommended workup. Awareness is growing, research is advancing, and new treatment options are emerging. The publication of the initial Expert Consensus Paper provided comprehensive diagnostic criteria and recommended testing protocols.

With clinical trials currently underway in the U.S., DSRD is now being studied worldwide. Physicians and researchers including Dr. Jonathan Santoro (USA), Dr. Joaquín Espinosa (USA), and Dr. Eileen Quinn (USA), along with teams in France, the UK, and Australia, are leading efforts to:

- Improve diagnostic tools
- Develop targeted treatments
- Explore autoimmune and inflammatory links
- Work toward prevention
- Raise awareness among medical professionals

DSRD is often misdiagnosed as psychiatric illness, autism, or early-onset Alzheimer’s Disease. However, there is growing

evidence that some cases may be driven by autoimmunity and neuroinflammation, offering hope for effective treatments. Increased efforts are needed to spread awareness in the medical community about DSRD and ensure early diagnosis and prompt and easy access to treatments is possible.

The creation of a comprehensive team of informed and motivated care providers for patients and their families can provide the best chance for the fullest recovery and a return to baseline functioning and participation in past activities and interests.

In most cases a number of specialists are involved in the diagnosis and treatment of DSRD, often including neurologists, immunologists, and psychiatrists as well as therapists involved in the eventual rehabilitation efforts.





“Over a period of weeks, these individuals lose their developmental milestones and withdraw into their own world. Families describe it as living with a ghost—the person is there but not really there.”

— Dr. J. Santoro

DOWN SYNDROME REGRESSION DISORDER (DSRD)



WHAT DOES DSRD LOOK LIKE?

Just as all individuals with Down syndrome are unique, the presentation of symptoms of DSRD can also vary from individual to individual. Symptoms may be different and may also present with varying levels of severity. They may appear slowly over time or escalate quickly.

You may notice your loved one is eating more, or eating less, or is suddenly having difficulty falling asleep or sleeping too much.

They may seem more emotional than usual, even laughing or crying for no apparent reason. They may exhibit some changes in memory or other cognitive changes.

Their self-talk or internal preoccupation may increase. They may begin speaking less or speaking in a whisper or not at all.

Physically they may seem to be moving slower or even freezing in place.

Because these symptoms may progress slowly in some cases, they can sometimes be missed or even dismissed.

In other cases, symptoms occur seemingly overnight, and families see their loved ones change rapidly.

CAREGIVER TIP:

Because early diagnosis can lead to more positive treatment outcomes, it is important to be familiar with the signs and symptoms of DSRD and act quickly.

DOWN SYNDROME REGRESSION DISORDER (DSRD)



DSRD can look different in every individual. Symptoms may mimic, overlap with, or be confused with autism, Alzheimer's or psychiatric conditions, which makes accurate diagnosis essential. Common symptoms include:

Mental Health & Emotional Changes:

sudden mood changes, apathy, anxiety, panic attacks, obsessive-compulsive behaviours, hallucinations, delusions, or unexplained fits of laughter/crying.

Speech & Language: mutism, whispered or slowed speech, new stuttering, repeating certain phrases.

Movement & Physical Changes: slowed movement or "freezing" (catatonia), unusual tics or grimacing, changes in gait, and loss of independences in daily tasks like eating, dressing, bathing or toileting.

Sleep & Energy: insomnia, reversed sleep cycles, excessive sleep, sudden low energy.

Thinking & Memory: forgetfulness, confusion, trouble concentrating, getting lost in familiar places.



“My daughter Sara had a full-blown regression 11 years ago. For us, and in my experience in speaking with other families, I think this is common; the total of all those symptoms is that your child is gone.

The child that I knew, who was the light of my life and made me laugh out loud every day, was just different.

I even say it was like Sara died, and I didn't have time to mourn her because I had this belligerent stranger in my midst that I had to deal with.

It can really be a very catastrophic thing to happen to families. I have families that say their life is divided into pre-regression and post-regression eras.”

- DR. E. QUINN, LEADING RESEARCHER/PARENT



DOWN SYNDROME REGRESSION DISORDER (DSRD)



DIAGNOSING DSRD: WHAT MAKES IT DIFFERENT?

Symptoms of DSRD may overlap with other medical-related diagnoses. The effects of Down Syndrome Regression Disorder may be confused with symptoms of Alzheimer's or Autism, which are common diagnoses amongst the Down syndrome community.

Common symptoms that overlap between the three can include:

- Difficulty with communicating through language
- Social withdrawal
- Issues with memory
- Heightened emotional irregularities and dysregulation (including agitation, restlessness, and aggression)

Age at the onset of symptoms is one factor to consider. DSRD symptoms are similar to those of Autism and Alzheimer's Disease.

Autism is usually detected early in childhood, as young as 2 to 3 years old, whereas Alzheimer's Disease is usually diagnosed well into adulthood, often beyond 40 years of age. DSRD is most likely to occur as your loved

one becomes an adolescent/young adult, often around puberty.

DSRD has been diagnosed and responded to treatment in patients younger than 10 and older than 30 years of age, but most commonly it occurs in that age range.

Less commonly, it can occur at other ages. There is now growing recognition that in some patients there is a slower onset, but in the majority, it is rather rapid.

This is another thing that distinguishes DSRD from Alzheimer's besides age. Dementia symptoms usually develop slowly over a much longer period of time.



DOWN SYNDROME REGRESSION DISORDER (DSRD)



DIAGNOSING DSRD (CONT'D)

The [International Expert Concensus \(2022\)](#) outlines eight diagnostic criteria. If six or more are present, DSRD is considered probable:

1. Sudden behavioural changes/altered mental state
2. Cognitive decline
3. Regression in developmental or social milestones
4. Seizures or new neurological symptoms
5. Sleep problems
6. Speech or language
7. Movement disorders including catatonia
8. Psychiatric symptoms

There is currently **no single test** for DSRD. It is a **clinical diagnosis of exclusion**, meaning doctors must rule out other conditions such as thyroid disease, infection, seizure disorder, or psychiatric illness. Recommended tests include:

- Thyroid function including antibodies
- Autoimmune and inflammation screening
- Lumbar puncture, brain MRI, and EEG
- Referrals to neurologists, psychiatrists



DOWN SYNDROME REGRESSION DISORDER (DSRD)



TREATMENT OPTIONS

Because your loved one may be less verbal or less able to tell you how they are feeling, and given the abstract nature of many of the symptoms that can be experienced with DSRD, there can be a number of challenges both with regards to diagnosis as well as testing and treatment.

In some cases, seeking doctors and care providers with experience working with individuals with intellectual disabilities can be especially helpful (such as a Dual Diagnosis Psychiatrist as opposed to a General Psychiatrist).

Treatment is individualized with the most effective approaches focusing on reducing inflammation and stabilizing brain health.

Treatment options may include the following either alone or in combinations:

- **Immunotherapy:** Immunosuppressants such as high dose immunoglobulins given by IV (IVIG). The immune systems of individuals with Down syndrome are prone to dysregulation, including overactivity, which can lead to neuro inflammation. Immunosuppressants calm the immune system and may relieve symptoms.
- **Psychiatric Medications:** Therapies and treatment are individualized
- **Catatonia Treatment:** Benzodiazepines or, in some cases, electroconvulsive therapy (ECT)
- **Supportive Therapies:** Rehabilitation with speech, occupational or physical therapy

Not everyone responds the same way to these treatments. Some regain skills and return to baseline or near baseline functioning.

DOWN SYNDROME REGRESSION DISORDER (DSRD)



SUPPORTING A LOVED ONE

Because individuals with Down syndrome may not always verbalize their struggles, recognizing behavioural changes is critical. Remember you know your loved one best. Families and caregivers can help by:

- **Trusting instincts** – you know when something is wrong
- **Maintaining routines** – to reduce stress
- **Seeking help early** – early treatment leads to better outcomes
- **Involving teachers and support staff** – in monitoring changes
- **Asking for help** – from doctors, friends, etc.

CAREGIVER TIP:

Keep a journal with dates, photos, and videos to track your loved one's changes, symptoms, side effects, and improvements.



DOWN SYNDROME REGRESSION DISORDER (DSRD)



CAREGIVER IMPACT & SELF CARE

The emotional toll of DSRD on families is profound.

[A 2025 caregiver survey](#) found that families of individuals with DSRD report **higher levels of financial strain, sleep disruption, social isolation, and depression** than those caring for loved ones with other neurological issues.

Strategies for caregivers include:

- **Counselling or therapy** – both for the caregiver and the individual with DSRD
- **Including a Social Worker** or complex care coordinator
- **Support groups** – online and in-person, to connect with others on the same journey. Families with experience on the DSRD journey can also provide insights with respect to preparing for meetings and appointments, managing symptoms, advocating for care and treatments.
- **Accepting help** – from family, friends, and social workers to manage appointments and daily needs
- **Self-care** – prioritizing rest, nutrition, and emotional support





“The DSRD journey is a
marathon, not a sprint.
Give yourself grace.
You are not alone.

— Cindy, Parent



GOOD NIGHT, DREAM TIGHT
WISHING IS A GOOD THING TO DO BUT TO MAKE IT A REAL
DREAM A DREAM
A DREAM IS THE YEARNING OF THE HEART
DREAM
A dream is a wish that the brain makes
(There are 7 million wishes being made every second)
KEEP CALM AND DREAM ON
NO DREAM IS TOO SMALL OR TOO BIG
SWEET DREAMS MY LOVE



DOWN SYNDROME REGRESSION DISORDER (DSRD)



You cannot accomplish everything in one day, and the road to recovery will be long and is not linear. There will be lots of ups and downs. You will need help.

And self-care is important.

Wherever possible, accept the help and support of family and friends, particularly during the early stages when symptoms may not be well managed, and when there are multiple appointments and meetings and medical tests required. Families are often juggling these responsibilities along with other familiar obligations. Ask for help and get help when it is offered.

Self-care is difficult during this time, but also crucial. Your loved one with DSRD truly relies on you and you will ultimately be their lifeline as you navigate the requirements that come with this complex diagnosis.

It is important to do all you can as a caregiver to ensure you are eating well, resting well, and finding the emotional support you need.

The emotional toll of this diagnosis on families is significant and cannot be

overstated. Make the preparations needed to get the support you need. For some this may mean making time to speak with a counsellor or therapist. For some a close friend who is a good listener can make a difference.

Online support and counselling are also viable and sometimes a more convenient option. Talking through the challenges and the trauma of this illness can help caregivers process and manage the changes they are facing.

If you are a caregiver and are experiencing a heightened level of distress, anxiety, or depression - please reach out.

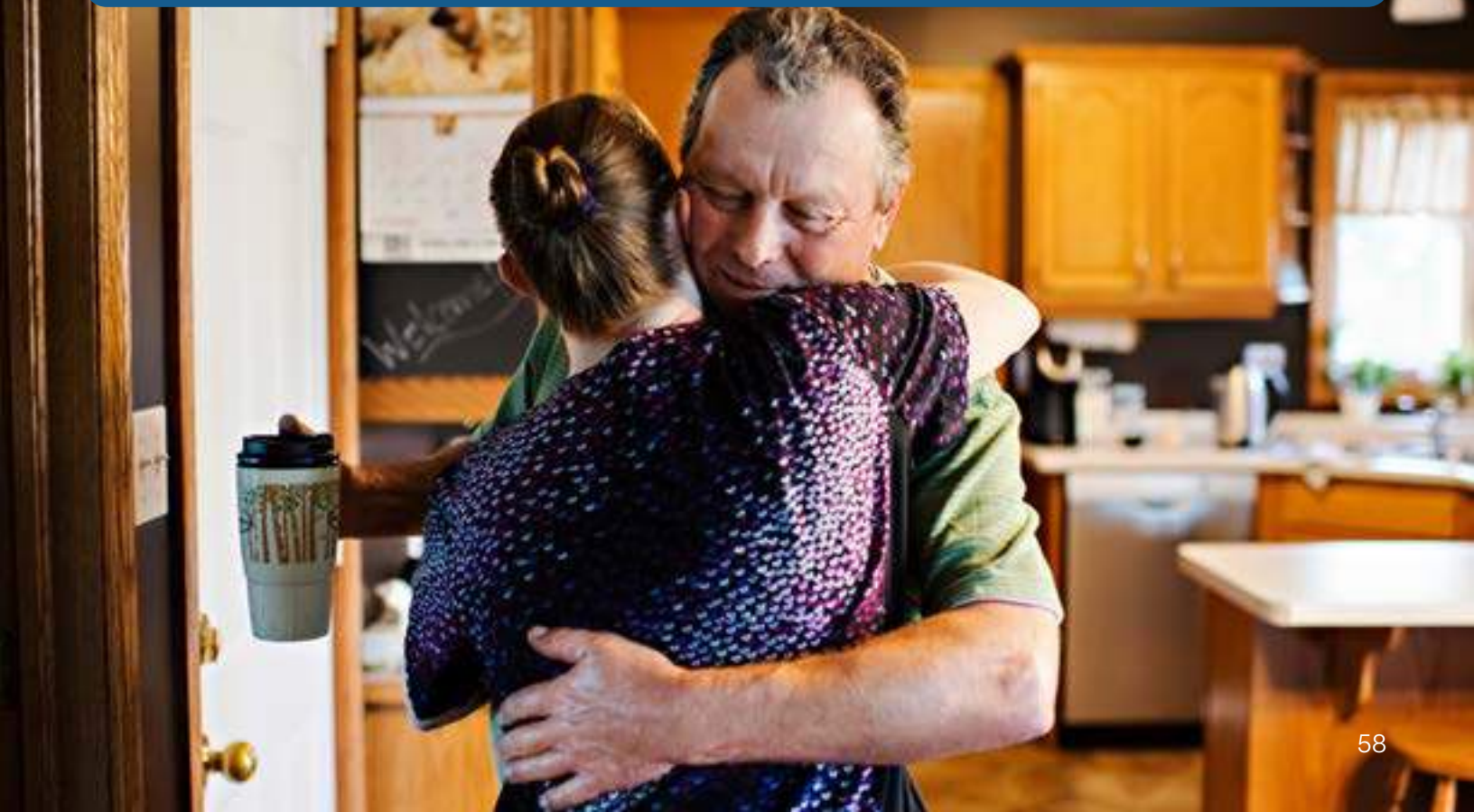
Parents of individuals with DSRD have found themselves in such distress that reaching out to a crisis hot line has been needed.





CAREGIVER TIP:

Keep numbers for various supports on your phone and don't hesitate to reach out when you are feeling overwhelmed.



DOWN SYNDROME REGRESSION DISORDER (DSRD)



Making an effort to understand the symptoms your loved one is experiencing is also important.

While some symptoms may appear to be behavioral, they are out of their control. Gaining an understanding of some of the psychiatric symptoms they are experiencing will help you know how to support them in moments of crisis. Understanding the physical limitations caused by Catatonia will help you care for them with increased patience and compassion.

Be kind to yourself. The grief of seeing your loved one suffer and change before your eyes is devastating. Not every day is going to be perfect. Give yourself some grace and take things one day at a time. Lean on others when you can. Reach out for support. Others have and are currently walking this path. You are not alone.

Dr. Eileen Quinn started an [on-line support group](#) after her own daughter became ill with DSRD. Today this private group has close to 3,000 members who provide each other with support, encouragement, and insights into this difficult journey. Families and caregivers with a loved one with DSRD

(or probably diagnosis) are encouraged to join. Medical professionals treating patients with DSRD are also welcome.

A [Public Information Page](#) was also set up on Facebook where the most valuable information and documents (including webinars) are posted. This is a great resource for families, friends and others wanting to learn more about DSRD.



MENTAL HEALTH



At least half of all people with Down syndrome will face a major mental health concern during their life.

Mental and physical health are closely connected, and it's important to take care of both as your loved one ages.

Even if a person has no history of mental illness, their thoughts and emotions can significantly affect them and impact their wellbeing. Anyone can experience mental

health challenges at any point in time, particularly if there are other major changes happening in their life. Some mental health challenges are temporary while others are more long term.

Either way, there is no shame in struggling with mental health and it is important that you address these issues with the proper support and care, just as you would a physical illness.





BEHAVIOURAL CHANGES

Sudden or gradual changes in behaviour can appear in adults with Down syndrome for many reasons, and behaviour is often a form of communication for individuals who may struggle to communicate verbally what they are experiencing in their mind and body.

New or different behaviour may indicate the initial signs of aging, but it can also stem from physical pain, social distress, or mental health concerns. If you notice a change in your loved one's behaviour, it's important to document it and explore all possible causes with a healthcare professional.

Some challenging behaviours that people with Down syndrome may exhibit as they age include:

- Stealing
- Lying
- Inappropriate sexual behaviour
- Aggression

For behaviours like stealing and lying, it's possible that your loved one doesn't realize what they are doing is wrong, and it's important to have a conversation with them. For behaviours like aggression, looking for an underlying cause can be helpful, especially if it is not typical behaviour and becomes a recurring issue.

Changes in behaviour that may indicate a mental health concern include:

- Losing interest in activities they previously enjoyed
- Becoming very irritable
- Displaying heightened emotional responses
- Avoiding situations that may be stressful



MEDICAL CAUSES

Mental and physical health can cause or worsen the symptoms of the other. If you notice behavioural changes in your loved one, a good first step is to take them to a doctor for a thorough medical examination. The physician can identify if your loved one is experiencing any underlying physical discomfort from issues such as:

- Thyroid function issues
- Anemia
- Sleep disorders
- Vision or hearing problems
- Digestive issues
- Dental pain
- Side effects from medications

Diagnostic overshadowing — where symptoms of a physical health issue are mistaken for a behavioural or mental health concern — is common in people with Down syndrome. Ensuring a thorough medical assessment can help identify the correct cause of behavioural changes.





TRANSITIONS & LIFE EVENTS

Adults with Down syndrome may also exhibit changes in behaviour if they are struggling with life changes, particularly if they happen suddenly.

The way each individual handles transitions varies, and one person may respond to new changes differently throughout their life.

Whether the change is positive or negative, your loved one may find it difficult to process and may not even acknowledge the transition at first. Life events that may trigger behavioural or emotional changes include:

- A sibling moving out
- Family or friends getting married
- Family or friends having children
- Moving homes
- Parents becoming ill
- Family or friends moving away
- Changing jobs
- The ending of a romantic relationship
- Divorce in the family
- Changing caregivers or support workers

These situations may cause stress, anxiety, or depression, especially if your loved one senses that they won't get to experience the same opportunities as their siblings or friends.

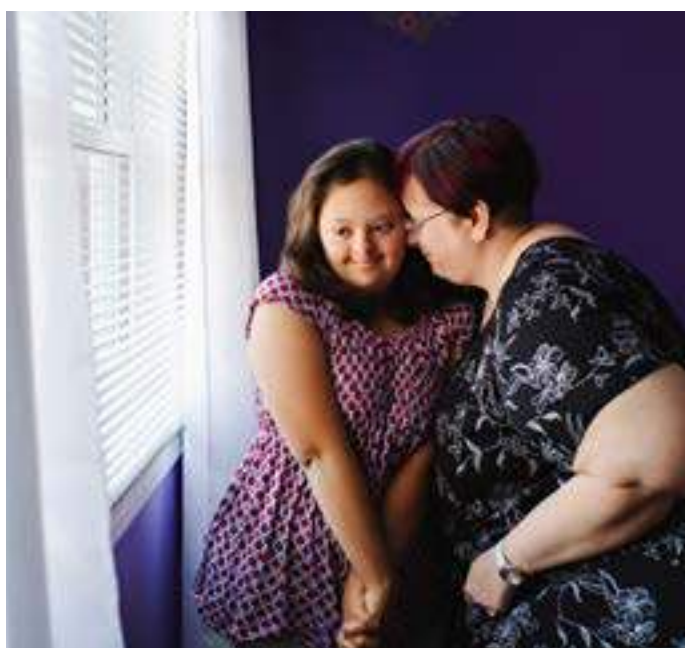




TIPS FOR NAVIGATING LIFE CHANGES

- Prepare for life events in advance if possible and discuss them together
- Listen to your loved one's concerns
- Validate their feelings
- Stay positive
- Talk about the future
- Don't hide information from your loved one to protect them
- Provide visuals to remind them of upcoming changes
- Modify tasks if needed
- Don't dismiss the depth of their feelings

Helping your loved one process the change in their life will allow them to move through difficult emotions in their own time.



MENTAL HEALTH CONDITIONS

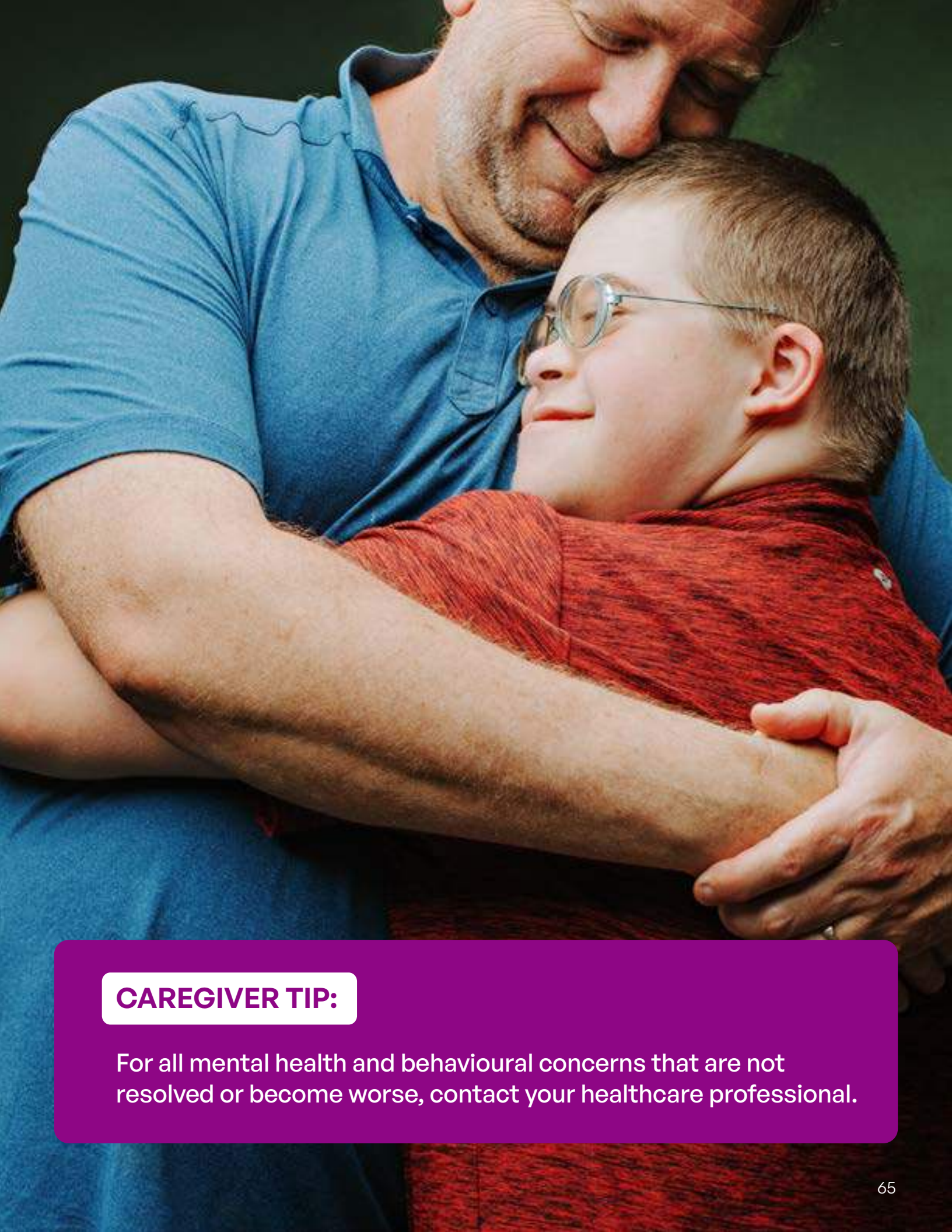
Mental illness is different from situational distress (such as anxiety or depression related to a life event), because it continues over a sustained period of time and negatively impacts daily life.

Family history and traumatic events can contribute to mental health challenges. Symptoms of mental illness often present differently in people with Down syndrome.

Your loved one may not express the thoughts and emotions that are indicators of mental health concerns, instead you may notice changes in behaviour.

People with Down syndrome may experience:

- Generalized anxiety
- Depression
- Obsessive-compulsive disorder (OCD)
- Bipolar disorder
- Hoarding
- Attention-deficit/hyperactivity disorder (ADHD)
- Oppositional Defiant Disorder (more common in children)



CAREGIVER TIP:

For all mental health and behavioural concerns that are not resolved or become worse, contact your healthcare professional.



LIFESTYLE AND ROUTINE

Establishing healthy routines for eating, sleeping, socializing, and exercising can help to improve your loved one's mental health. Other strategies that promote mental wellness include:

- Encouraging independence and involving your loved one in decision-making
- Providing social connections
- Helping your loved one practice mindfulness techniques
- Reducing stress
- Encouraging positive activities

Supporting emotional expression is also important. Encourage your loved one to talk about their feelings, name and describe their emotions, and discuss things that make them feel better.

TREATMENT OPTIONS

If your loved one is struggling with their mental health, it may be helpful to build a team of specialists to provide support.

This may include a psychiatrist, a psychologist, a behaviour specialist, your family doctor, your pharmacist, or your loved one's support network.

COPING MECHANISMS

Self-talk, or when people talk to themselves, can help your loved one to manage difficult emotions, process life events, and solve problems. Many people with Down syndrome also develop a pattern of thoughts or behaviours, referred to as "the groove."

This preference for sameness and repetition can help manage stress, increase independence, and provide structure.

Although you may feel an instinct to prevent these types of behaviours, they can be quite helpful. They only become a concern if the coping mechanism interferes with your loved one's daily functioning or safety, or if they become stuck and cannot shift away from it.

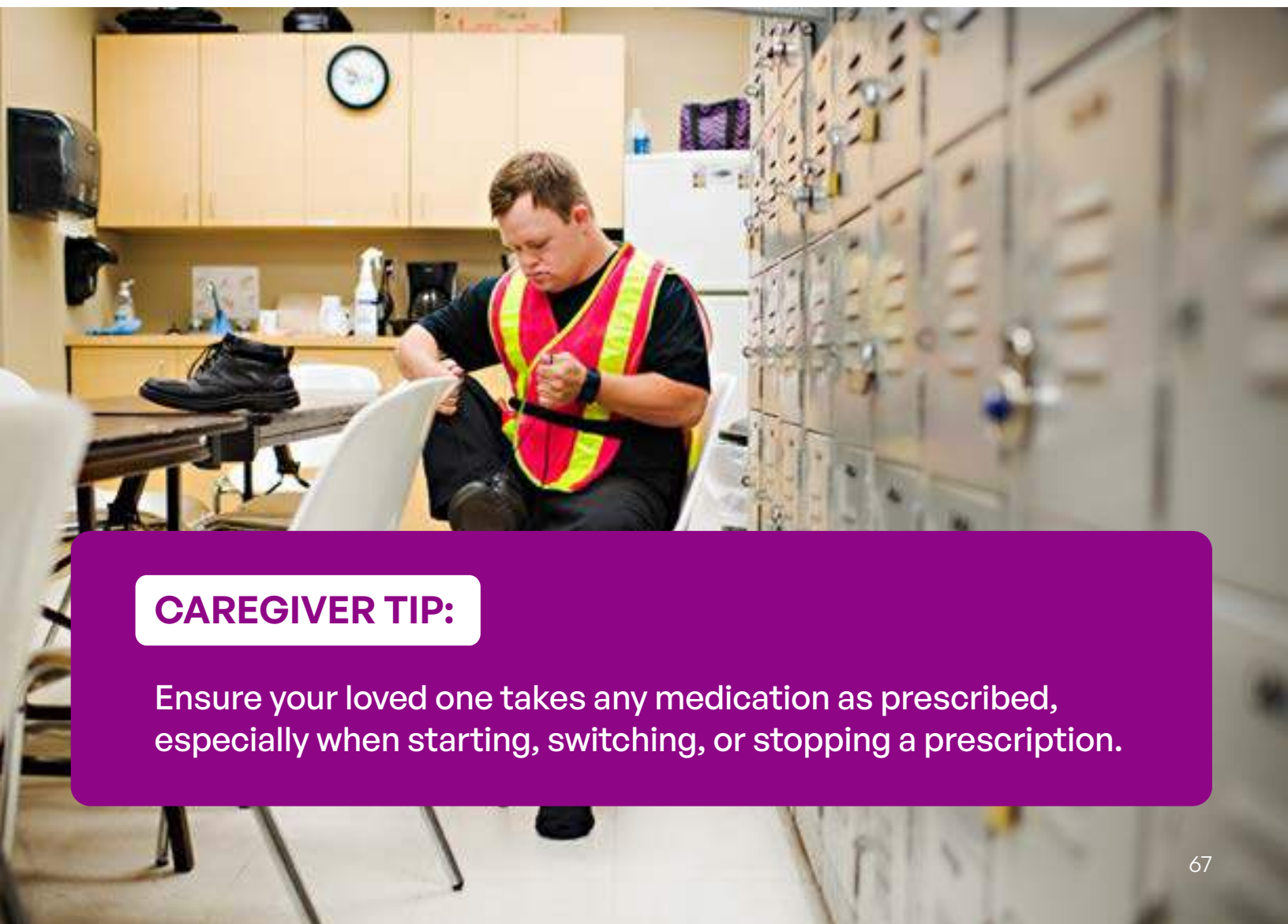




PHARMACEUTICAL TREATMENT

Medications often work well to treat mental illness in people with Down syndrome, but some antidepressants may cause side effects.

Finding the right medication may take some trial and error, and a psychiatrist can help adjust prescriptions as needed. It's important to track how your loved one is feeling and any symptoms they experience as they change medications. Most medication changes happen gradually, and it may take time to determine if the treatment is effective.



CAREGIVER TIP:

Ensure your loved one takes any medication as prescribed, especially when starting, switching, or stopping a prescription.



PSYCHOLOGICAL THERAPY

Traditional talk therapy may be challenging for individuals who have trouble expressing themselves verbally.

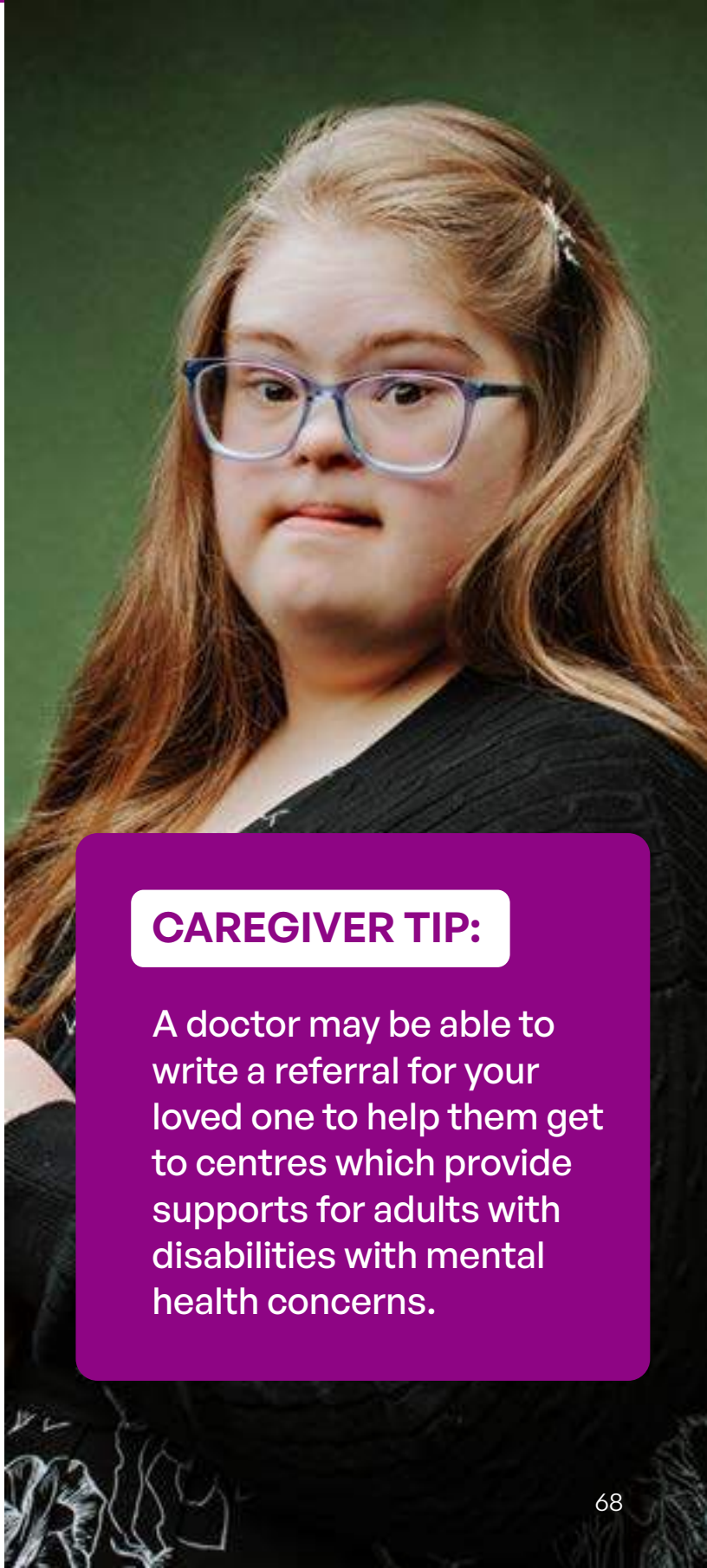
Structured approaches like Cognitive Behavioural Therapy (CBT) can be effective as it focuses on how thoughts, behaviours, and emotions all affect one another.

In people with Down syndrome, there is more focus on changing behaviour to trigger changes in thoughts and feelings than on cognition.

Therapy may take longer for adults with Down syndrome, and caregiver involvement can be beneficial for those who are nonverbal or minimally verbal.

Promoting mental wellness starts with recognizing the signs of mental health concerns, ruling out medical causes, and providing the right support.

With patience, understanding, and a strong support system, you can help your loved one navigate their mental health with confidence.



CAREGIVER TIP:

A doctor may be able to write a referral for your loved one to help them get to centres which provide supports for adults with disabilities with mental health concerns.

“I think that it is very okay to feel sad or angry sometimes. It is up to you if you really want to let the feelings out. One way to get my feelings out is telling people the way that I feel on the inside. I want to know how to unlock all of the feelings that I have or had.

There are so many things that I can do to help me feel better like being able to talk to my own parents. They can help me to feel better about myself. If anyone does not have parents to talk to then you can talk to your roommate or your community support person and they can help you to fully understand your feelings. I have always benefited from seeing my counsellor because I have had a lot of concerns about my past life.

This is why I still go to my new counsellor on a regular basis. I always talk to my counsellor about my relationships and about my own feelings. If you have any problems with anything then you can go to see someone to help you. My own advice for anyone who has a lot of big feelings is to have all kinds of people to really talk to.

If you are feeling sad, mad, frustrated, or angry, you should talk to your loving parents because they can help you to fully understand about the big feelings that you might have.”

– PAUL SAWKA, CDSS AWARENESS LEADER AND SELF-ADVOCATE





RELATIONSHIPS

Social connections are extremely important for aging adults and having an active social life can have a multitude of mental, emotional, and physical health benefits. However, it may become more difficult for your loved one to stay social as they age. There are a number of barriers that can affect their friendships:

- Lack of structured, scheduled activities like school or work
- Losing contact with old friends
- Limited ability to travel independently
- Mental or physical health challenges
- Changes in housing or living arrangements
- Reduced mobility or cognitive function

Only 12-15% of adults with Down syndrome participate in social activities on a weekly basis.



MENTAL HEALTH



It's important to prioritize your loved one's social life as they age. Notice if they show signs of loneliness, boredom, or withdrawal and offer them support in maintaining existing friendships and building new ones. You may need to think creatively to keep them connected with their community. Here are a few strategies that might be helpful:

- See if adjustments can be made to some of their favourite activities to make them more accessible.
- If in-person activities are challenging, support your loved one with virtual opportunities to socialize, like phone calls or video chats.
- Reach out to local supports such as day programs, community centers, or your local Down syndrome group.
- Explore group classes or clubs that are focused on your loved one's interests or start your own group by connecting with like-minded peers.
- Seek out local events or festivals organized by your city or county.
- Coordinate transportation or ride sharing to make it easier for your loved one to attend activities.
- Look for volunteer opportunities that might help your loved one meet new people.
- Maintain existing friendships through structured routines, like a weekly coffee catch up.

A conversation with your loved one about their friendships and interests is a good place to start so that they can choose the activities and people they want in their life.

You may consider social pursuits that are specifically for adults with intellectual disabilities or general community activities that are for everyone.





FAMILY

Alongside friendships, family relationships form the foundation of an adult's social world.

These bonds provide continuity, support, and a strong sense of identity. As adults with Down syndrome age, the nature of family relationships may evolve.

Parents and other primary caregivers enter their senior years, and siblings or other family members may begin to take on more caregiving responsibilities or even become a primary caregiver when their parents are no longer able to do so.

Adults with Down syndrome may also grow into new roles within the family, such as becoming a beloved aunt or uncle.

Maintaining your loved one's engagement in family life is important. You can nurture family bonds in small, everyday ways:

- Involve your loved one in household routines.
- Include them as a key part of family traditions, decisions, or celebrations.
- Adapt family activities so they remain accessible and enjoyable.
- Encourage extended family members and close family friends to stay connected and engaged.

This kind of continuity provides stability and comfort, especially as other areas of life may change with age.

It's important to remember that your loved one not only receives care, they also contribute meaningfully to family life through companionship, emotional support, and shared joy.

Continuing to give them opportunities to contribute will support their independence and mental well-being.

Open, inclusive communication is essential. Checking in regularly, inviting input, and creating space for your loved one to express their preferences helps them feel heard and respected. Everyday interactions—like family meals, shared hobbies, or storytelling—are valuable opportunities to connect.

And, as in any family, disagreements or frustrations may arise; approaching these moments with patience and clear communication helps maintain trust and understanding.



GRIEF

Grief is a natural response to loss. When a close family member, friend, co-worker, or pet dies, your loved one will experience grief, just as anyone else does.

Adults with Down syndrome may also grieve other changes and life transitions. The grieving process will look different for everyone and may take longer than average for some adults with Down syndrome.

Some people experience anticipatory grief even before a loss occurs, such as when a loved one is dying or when they notice changes in themselves due to aging.

TALKING ABOUT DEATH

Talking about death before someone passes away can help to reduce fear and confusion. Although it can be difficult, the more your loved one understands death the more prepared they will feel.

If you don't talk about death and try to avoid it, it can make the situation much harder for everyone.





STRATEGIES FOR HARD CONVERSATIONS

- Be clear and specific. Avoid phrases like “they are in a better place” or “they won’t wake up” that could cause confusion. Use direct language such as “they died.”
- Use examples like fictional characters, celebrities, or animals to explain that death is a normal part of life.
- Repeat conversations over time to give your loved one opportunities to ask questions and process their emotions.
- Use pictures or other non-verbal tools to help with communication
- Validate their feelings. If someone they care about has died, make sure your loved one knows that feeling sad or frustrated is okay.
- Focus on positive memories. After someone passes away, remind your loved one of the special times they spent together.



CAREGIVER TIP:

Let your loved one decide how they want to participate in grieving rituals, such as attending the funeral or keeping a memento.



PLANNING FOR THE FUTURE

Although it is difficult to discuss, one of the most important conversations you can have with your loved one is helping them understand that you may die before they do. This includes discussing funeral options, wills, and plans for who will support them.

Though you may not be able to plan for every aspect of their care in advance, discussing what will happen as a family will ease any anxiety your loved one may have about who will take care of them. You may find it helpful to establish a network of friends and family members who will collaborate on your loved one's future care. Organizations like [Microboards Ontario](#) and [PLAN](#) can support you with this person-centred planning process.

PROCESSING EMOTIONS

Your loved one may need support as they process their feelings. Some adults with Down syndrome have a delayed grieving process and may not talk about a death or become emotional until months or years after it happens.

Let your loved one process things on their own timeline and be there to support them when they're ready.

Give your loved one lots of opportunities to remember the person who has died and reminisce and maintain your loved one's usual routines as much as possible and try to avoid additional big changes at the same time as the loss to reduce stress.

CAREGIVER TIP:

Photos, videos, music, or preparing favourite foods can be great ways to honour a lost loved one for individuals who are non-verbal.



SYMPTOMS OF GRIEF

In addition to strong emotions, your loved one may experience some physical manifestations of grief, particularly if it's difficult for them to express themselves emotionally. The grieving process may possibly include:

- Initial shock or disbelief
- Mood swings and strong emotions
- Trouble concentrating
- Low energy or fatigue
- Physical pain
- Change in appetite
- Shortness of breath
- Change in sleep
- Withdrawal from regular activities

OTHER SUPPORTS

Talking with trusted friends and family members is an important pillar of support for your loved one when they are grieving. They may also need additional supports, such as counselling, art therapy, or grief groups.

There are limited grief resources in Canada specifically designed for adults with intellectual and developmental disabilities, so you may need to adapt general grief supports using visual tools, simple language, and memory-focused activities such as making

a memory box or writing out their favourite story about that person.

The goal of grieving is not to forget, but to reach a place where your loved one can think about the person who has died with more peace than pain — holding on to happy memories and feeling safe moving forward.





“My sister Mary Frances lived with our mother until our mother 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. 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, MARY FRANCES’ SISTER

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