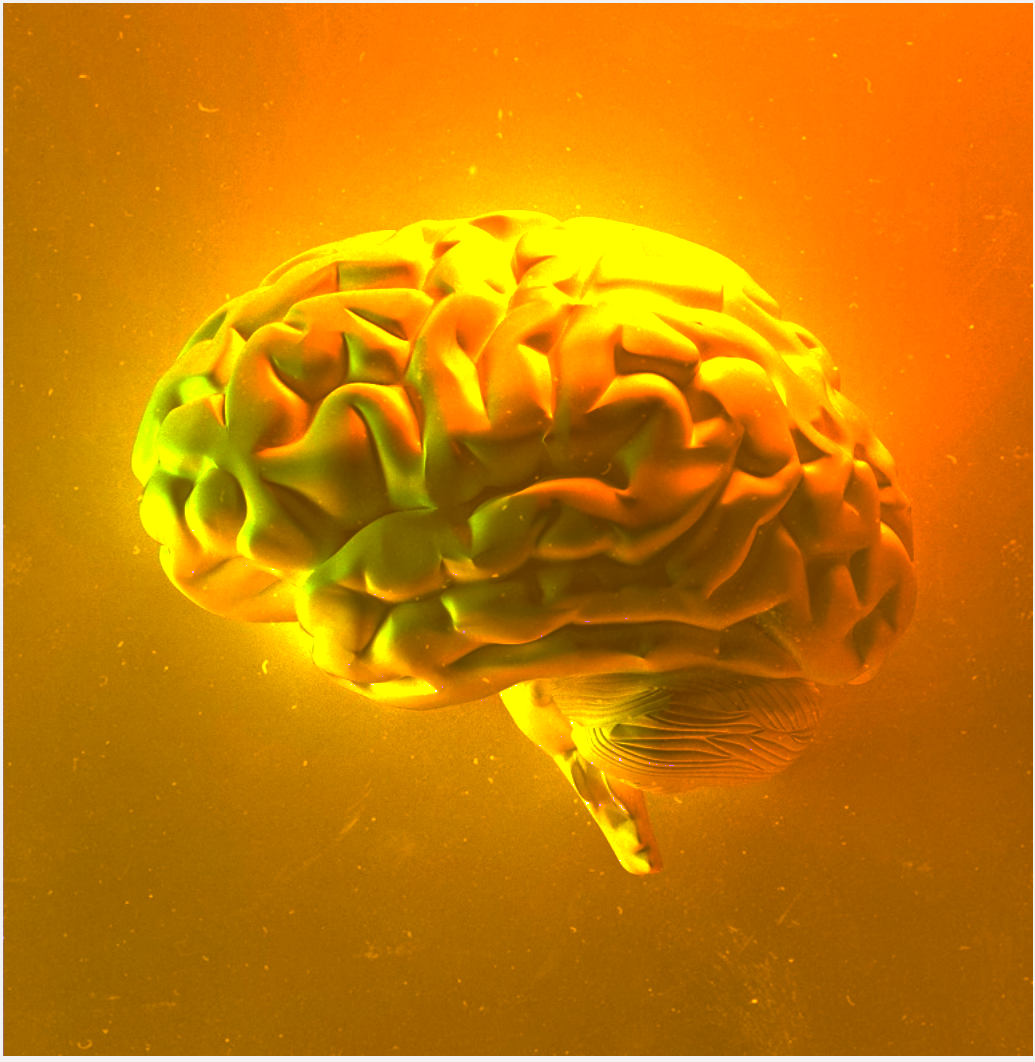


MIND MATTERS:
COGNITIVE DECLINE

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MINIBOOK PROJECT

About Us

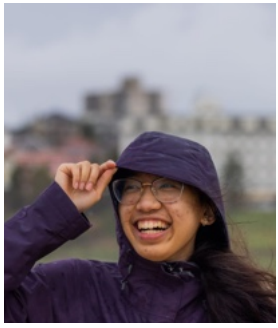
Chapters for Change is a non-profit organization dedicated to advancing health literacy in Toronto, founded by students at the University of Toronto. We recognize that there is a significant gap in access to scientific material on two fronts: cost and comprehension. We aim to improve the situation by providing free access to well-written and well-researched books that are easy to understand. Our books are written by students at the University of Toronto, under the guidance of medical researchers. We hope that you find pleasure in our work and an improved understanding of the topic.

MEET THE AUTHORS



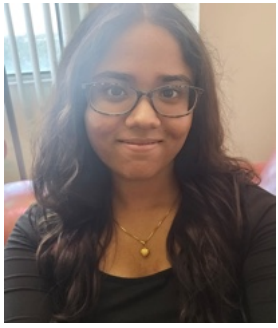
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1

SECTION

Understanding Cognitive Decline

WHAT IS COGNITIVE DECLINE?

Cognitive decline is the gradual impairment of cognitive abilities such as memory, decision making, planning and reasoning (Dhakal & Bobrin, 2023).

STAGES OF COGNITIVE DECLINE	
Subjective Cognitive Decline (SCD) *a.k.a. Subjective Cognitive Impairment (SCI)*	• Self-experienced decline in thinking and/or memory not due to an injury • When thinking and memory is tested they are **within normal ranges** • Individuals are still capable of being independent (Jessen et al., 2021)
Mild Cognitive Impairment (MCI)	• Self-experienced decline in thinking and/or memory not due to an injury • When thinking and memory is tested there are **some impairments** • Individuals are still capable of being independent (Jessen et al., 2021)

WHAT ARE IADLS AND ADLS?

IADLs stands for instrumental activities of daily living, which are activities that allow for an individual to live independently in a community (Guo & Sapra, 2022).

Examples:

- Cooking
- Cleaning

- Using transportation
- Managing finances (Edemekong et al., 2025)

ADLs stands for activities of daily living, which are activities that allow for an individual to care for themselves.

Examples:

- Eating
- Bathing
- Going to the washroom
- Dressing (Edemekong et al., 2025)

The inability to perform IADLs and ADLs strongly indicates cognitive decline (Edemekong et al., 2025; Guo & Sapra, 2022).



KNOWLEDGE CHECK

Which of the following are IADLs?
a. Cooking and managing finances
b. Bathing and dressing

NORMAL AGING OR DEMENTIA

WHAT IS DEMENTIA?

It is an umbrella term for several diseases that affect thinking abilities and behaviours that interfere with a person's lifestyle such as Alzheimer's (World Health Organization, 2017). Dementia is not a part of the normal aging process (Goldman, 2022; "Myths and Realities", n.d.).

As someone gets older, their cognitive function may become slower, requiring more time to recall memories and longer to learn tasks; not typically interfering with function in their daily life (National Institute of Aging [NIA], 2023).

NORMAL AGING	DEMENTIA
Occasionally making poor judgments and decisions	**Often** making poor judgements and decision
Missing a monthly payment	Difficulty managing monthly bill
Forgetting which day it is and remembering it later	Losing track of the date or time
Sometimes forgetting which word to use	Has difficulty conversing
Occasionally losing things	**Often** misplaces items and is unable to find them (NIA, 2023)

If your family member or yourself have any concerns about this please contact your doctor.

WARNING SIGNS OF DEMENTIA

- Not taking care of themselves
  - Eating poorly
  - Not bathing
  - Behaving unsafely
- Difficulty following directions (NIA, 2023)
- Getting lost in places they/you know well
- Becoming more confused about time, people, and places
- Asking the same question repeatedly

CAUSES OF COGNITIVE DECLINE

There are many potential causes of cognitive decline.

Consult your doctor if you or a family member is concerned about your thinking abilities and/or memory.

- Not taking care of themselves
  - Eating poorly
  - Not bathing
  - Behaving unsafely
- Difficulty following directions (NIA, 2023)
- Getting lost in places they/you know well
- Becoming more confused about time, people, and places
- Asking the same question repeatedly

CAUSES OF SUBJECTIVE COGNITIVE DECLINE (SCD)

This list does not include all causes of cognitive decline:

- Mental health & mental disorders
  - Depression
  - Anxiety
  - Sleep disorders
- Substance misuse
- Drugs
  - Sedatives
  - Opioids (pain relief medication)
- Natural aging process
  - Normal to develop subjective cognitive decline
- Medical conditions
  - High blood pressure, Heart disease
  - Liver disease
  - Infectious disease
  - Diabetes, Hormonal dysfunction, Metabolic diseases (disorders that disrupt the process of converting food into energy)
  - Nutritional deficiencies
  - Anaemia (low level of healthy red blood cells) (Jessen et al., 2021)

MYTH

There are no treatments for SCD or MCI.

FACT

Treating current medical and mental conditions can treat some cases of SCD or MCI. Additionally, opting for more brain healthy activities such as regular exercise, eating a plant-based diet, managing stress levels, having high quality sleep, regular social interactions, and regularly challenging your brain can help alleviate cognitive decline (Jessen et al., 2021; Harvard Health, 2024)

MOST AT RISK IN TORONTO

Those most at risk in Toronto are minority groups in Toronto, specifically women, and racialized groups.

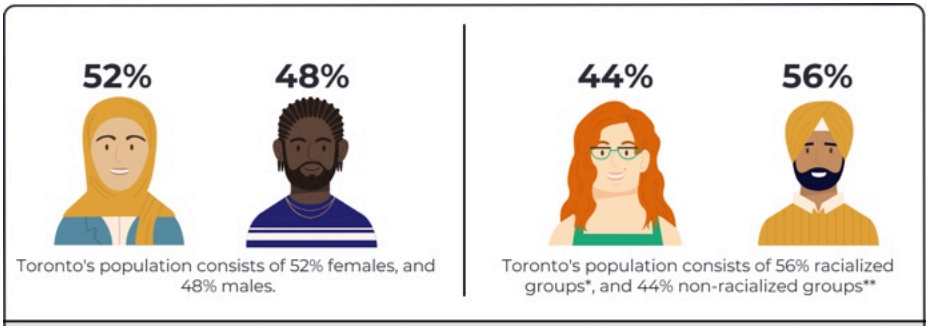


Figure 1: Toronto's Demographic, percentage of men and women (right), and percentage of racialized and non-racialized group (left)

Data Source: Toronto Public Health, 2023

Notes: *Racialized groups refers to those that belong to ethnic minorities that are not White
**Non-racialized groups refers to those that are White

Minorities are most at risk in Toronto because they account for 56% of the population (Figure 1) and often encounter more barriers to accessing healthcare and are often overlooked (Pandey et al., 2021).

Women are most at risk in Toronto because they account for 52% of Toronto's population (Figure 1) and because their brains have a greater ability to offset damage, once diagnosed with cognitive

decline, the brain is no longer able to offset the damage and cognition declines rapidly (Gamble et al., 2025; Levine et al., 2021). Indicating that early preventative measures such as engaging in brain healthy activities need to be put in place even before symptoms arise.

MEMORY & CULTURE

LANGUAGE ACCESSIBLE SERVICES:

CLINIC/HOSPITAL	DETAILS
Toronto General Hospital	Interpreter services to patients in 180+ languages. For more information call 416-340-4800, or email InterpretationServices@uhn.ca or TranslationServices@uhn.ca or visit the website https://www.uhn.ca/PatientsFamilies/Patient_Services/Pages/language_services.aspx
Sinai Health Hospitals and Clinics	Interpreter services to patients in 65 languages at no additional cost. For more information call 416-461-8252 extension # 2121, or email interpreter@sinaihealth.ca. or visit the website www.sinaihealth.ca/patients-and-visitors/interpreter-services
West Hill Medical Center	Staff and doctors that are able to serve patients in Hindi, Urdu, Tamil, Farsi, Tagalog, and Arabic. For more information call 416-283-4111, or email contact@westhillmedical.ca or visit the website www.westhillmedical.ca

MYTH

SCD and MCI will always lead to dementia

FACT

Those with SCD and MCI are at higher risk of developing dementia than those without SCD and MCI, not everyone with SCD and MCI will develop dementia (Mitchell et al., 2014; Roberts et al., 2014).

2

SECTION

PREVENTION AND DETECTION

Age-related cognitive changes — particularly cognitive health decline — in the current aging global population is becoming a major public health concern (Yi et al., 2025). By learning to recognize early warning signs, individuals and their families can take the necessary steps to seek help, make healthy changes and plan for the future.

SPOTTING EARLY SIGNS OF COGNITIVE DECLINE

Understanding cognitive decline starts with paying attention to the earliest changes in cognitive health. Early indicators include changes in mood or behaviour, even before symptoms become obvious. Researchers call this **subjective cognitive decline:** when a person notices a drop in their mental sharpness compared to their own past abilities, but standard memory tests cannot identify any clear-cut problems (Hudon et al., 2020).

Non-memory related changes, such as depression, anxiety, apathy (loss of motivation), irritability or high stress levels in middle-aged and older adults, have also been shown to lead to a greater likelihood of developing mild cognitive impairment (MCI) or dementia later in life (Hudon et al., 2020).



KNOWLEDGE CHECK

Subjective Cognitive Decline (SCD) is detected by:

a. Personal noticing of decline

b. Standard memory tests

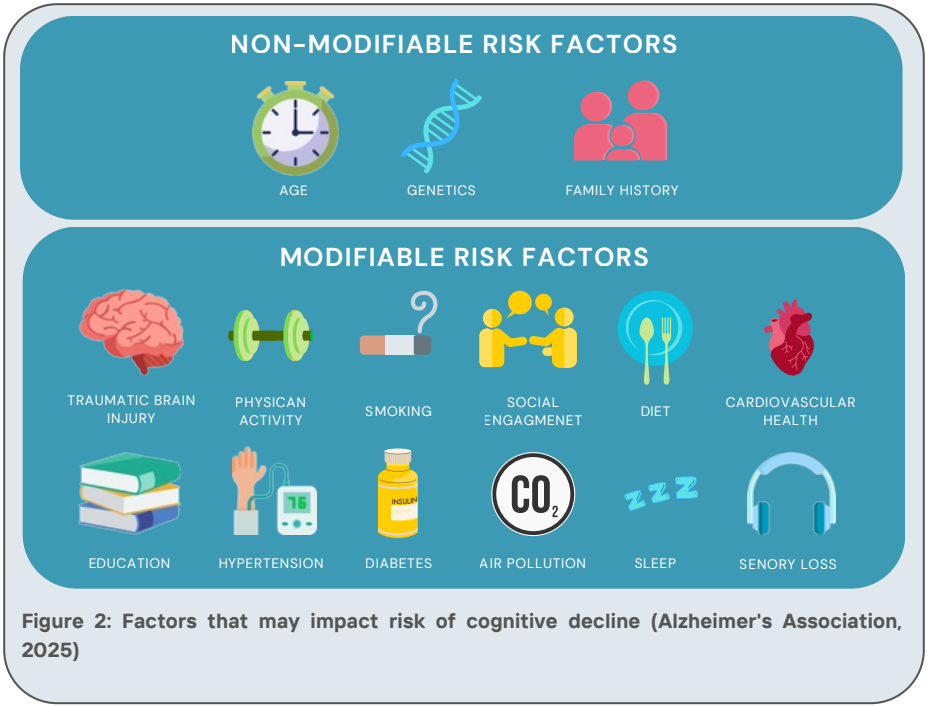


Figure 2: Factors that may impact risk of cognitive decline (Alzheimer's Association, 2025)

WHY DOES EARLY DETECTION MATTER?

Detecting cognitive changes early gives individuals the best chance to slow decline, treat underlying causes and maintain quality of life. An individual with MCI may face measurable changes in one or more thinking skills such as memory or language, but they are able to perform daily activities such as cooking or managing finances without needing major support from others (Hudon et al., 2020).

However, the risk of progression is serious: older adults with MCI, especially those whose memory is affected, are 8-15 times more likely to develop Alzheimer's disease or other dementias compared to older adults without MCI (Hudon et al., 2020). Certain symptoms, such as depression, anxiety, apathy, irritability or perceived stress, can signal an even higher risk of decline.

WHAT ARE THE KEY SYMPTOMS TO LOOK OUT FOR?

MCI is often considered a middle stage between normal aging and more severe forms of cognitive decline, but not everyone with MCI faces progression — some people's symptoms remain stable for years, and a few can even improve (Mayo Clinic, 2024).

Symptoms of MCI can include trouble with memory, language and judgment, which are more serious than the memory issues expected as people get older. However, these symptoms do not affect daily life significantly, and can include:

- An increase in forgetfulness (e.g., missing appointments or social events)
- Losing your train of thought, being unable or having trouble following storylines or conversations
- Finding it hard to make decisions, finish a task or follow instructions
- Trouble finding their way around places they know well
- Poor judgment

MCI can also include symptoms of depression, anxiety, short flares in temper and aggression and a lack of interest (Mayo Clinic, 2024).

STRENGTHENING YOUR BRAIN THROUGH HEALTHY HABITS

Everything in our lifestyle, from what we eat to how we move, sleep and socialize, is connected to our brain health. Healthy habits ensure our ability to delay or prevent negative changes in the body and keep our minds sharper for a long time.

THE GUT BRAIN AXIS

Key Definitions:

1. **Gut Microbiota:** A term that represents all the trillions of microorganisms, including bacteria, fungi and viruses, living in the gut.
2. **Microbiome:** The combined genetic material of the entire gut microbiota.
3. **Gut dysbiosis:** An imbalance in the gut microbiota composition, leading to negative health consequences

The gut-brain axis is a two-way communication system between your brain (which is part of the central nervous system) and your digestive system (which is part of the enteric nervous system). The system uses the gut microbiota, which is the collective term for all the microorganisms located in your gut, to send signals to your brain and influence your behaviour, thinking and memory (Zhang et al., 2025).

Healthy Gut Microbiota can help:

- Regulate inflammation in the body
- Produce neurotransmitters that can affect your mood and memory
- Protect the blood-brain barrier's durability

As we age, the balance of your gut microbiota can change, which can lead to gut dysbiosis. This can cause inflammation, weaken the blood-brain barrier (the brain's protective barrier) and increase the risk of cognitive decline (Olejnik et al., 2025).

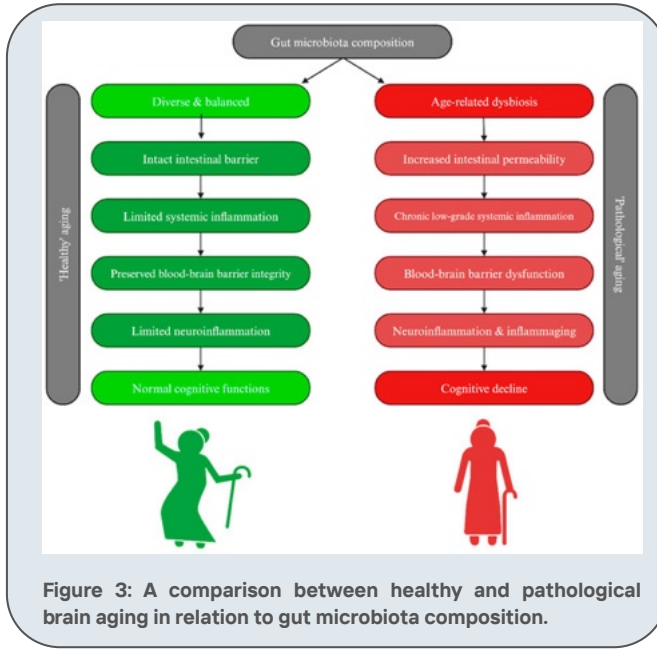


Figure 3: A comparison between healthy and pathological brain aging in relation to gut microbiota composition.

HEALTHY AGING

Balanced gut microbiota → strong blood-brain barrier → preserved cognitive function

PATHOGENIC AGING

Gut dysbiosis → leaky gut → inflammation → cognitive decline (Olejnik et al., 2025)

THE IMPORTANCE OF THE "RIGHT" TYPE OF NUTRITION

Anything we put in our bodies can strongly influence brain health. Research shows that certain diets, such as the Mediterranean diet, plant-based diets, and low-carbohydrate diets, can help protect cognitive function (Zhang et al., 2025). These diets are rich in:

- Antioxidants — substances that help protect cells from damage caused by unstable molecules called free radicals
- Anti-inflammatory agents — substances that reduce or counteract inflammation in the body
- Neuroprotective nutrients — substances that help protect brain cells from damage, disease or death

DIETARY STRATEGIES TO IMPROVE COGNITIVE HEALTH:

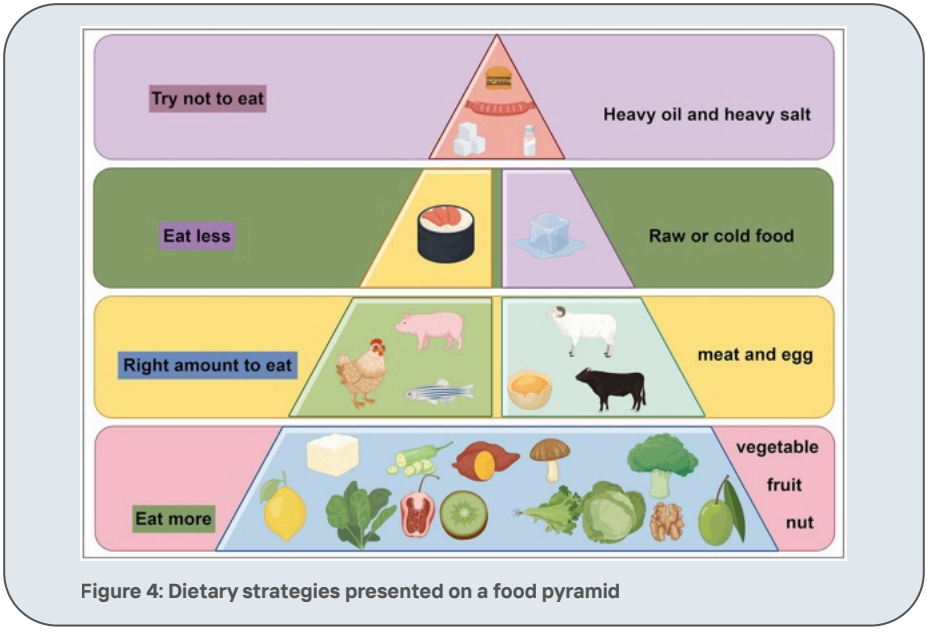


Figure 4: Dietary strategies presented on a food pyramid

Eating more fruits, vegetables, whole grains, healthy fats, legumes, nuts and seeds, while reducing high-carbohydrate foods such as sugar, bread and pasta, and moderating fish and meat intake, can help slow cognitive decline and lower the risk of neurodegenerative diseases (Zhang et al., 2025).

COMMUNITY NUTRITIONAL AIDS

Having access to healthy meals is crucial, especially for older adults who face mobility challenges, social isolation or difficulty cooking. Programs like the Meals on Wheels at Circle of Care (Sinai Health) provide meals tailored to age-related dietary needs and chronic health conditions, helping seniors stay well-nourished to supplement good cognitive health (An, 2025).

Program Website: https://www.mealsonwheels.ca/

SLEEP AND STRESS

Sleep and stress are closely connected to brain health, and surprisingly, the gut plays a significant role in this relationship. Recall the gut-brain axis, the communication system between your digestive system and the brain; this system also influences mood, stress, memory and overall brain function (Lin et al., 2024).

SLEEP AND GUT HEALTH

Sleep is not only vital for resting after a long day, it's also a key player in regulating your gut. Research shows a two-way relationship: poor sleep can negatively affect or upset the gut microbiome and having an unhealthy gut microbiome can, in turn, affect sleep habits negatively (Lin et al., 2024). When sleep becomes disrupted, gut bacteria rhythms are disrupted too. This imbalance, called gut dysbiosis, has been linked to inflammation, heart disease and even brain-related ailments. A healthy gut, however, will aid in regulating good sleep by producing natural chemicals that influence healthy sleep patterns, control inflammation and maintain immunological balance.

STRESS AND THE GUT-BRAIN AXIS

When the body undergoes stress responses, both the mind and gut are affected. Excess stress weakens the gut lining, which is often referred to as a "leaky gut," letting harmful bacteria into the bloodstream, and hence the body. This can trigger inflammation and interfere with brain activity and signalling (Foster et al., 2017).

Gut bacteria also influences the amygdala, which is the part of the brain that helps control stress and emotional responses. A healthy gut balance leads to calmer moods, better emotional control and stress resilience. However, an imbalance in the gut does the opposite, and can increase the risk of developing anxiety and depression over time (Foster et al., 2017).

In addition, research also shows that gut bacteria is essential for normal brian development and function into adulthood; early-life stress, like trauma, can alter brain circuit development, making an individual more vulnerable to stress-related disorders over their lifetime (Foster et al., 2017).

A potential solution to these issues is improving gut health, namely through diet, probiotics or prebiotics (special dietary fibers that help healthy bacteria grow), which may reduce stress and promote emotional well-being (Foster et al., 2017).

KEY TAKEAWAYS

- Better sleep strengthens the gut microbiome, which then improves mood, lowers stress, and supports long-term brain health.

- Chronic stress and poor sleep both disrupt the gut-brain connection, which can lead to mood changes, anxiety, memory problems, and even physical illnesses.
- Supporting gut health may improve both sleep quality and stress response.



KNOWLEDGE CHECK

Which of these statements are true?

a. Poor sleep can disrupt the gut microbiome.
b. Stress only affects mental health, not the gut.
c. A healthy gut can help regulate good sleep patterns.
d. a & c

THE IMPORTANCE OF SOCIAL INTERACTIONS

Having good company and staying socially connected directly affect how well our brains age. Research shows that socially isolated older adults or those experiencing loneliness have a higher risk of developing cognitive decline (Cardona & Andrés, 2023).

Social isolation means having fewer social interactions or contacts, while loneliness is the feeling of being alone, even when you are surrounded by people. Both have their own individual effects on brain health:

- **Social isolation** reduces cognitive stimulation (mental engagement that keep the brain active), which is vital for maintaining memory and thinking skills
- **Loneliness** mainly affects emotional well-being, which can also be harmful to cognitive health over time

Studies suggest social isolation may have a stronger impact than loneliness in terms of speeding up cognitive decline, while main-

taining strong social connections has a positive effect on cognition by preserving brain function and building something called cognitive reserve, which is the brain's ability to adapt and cope with different types of changes as we age (Cardona & Andrés, 2023).

PHYSICAL ACTIVITY COMES IN MANY FORMS

Many older adults tend to spend a lot of time sitting, often without realizing. Too much sitting, known as sedentary behaviour, affects physical health, but also increases risk of heart disease, diabetes, some forms of cancer, and dementia. In fact, older adults who sit for 10 or more hours a day have a higher chance of developing all-cause dementia than those who are more active in their daily life (Lauretani et al., 2025). Any type of movement can combat these issues; the good news is you don't need to run any marathons. Simple and light activities, including gardening, walking your pets, yoga or even dancing around the living room can all make a tangible difference. Taking regular breaks from sitting helps restore metabolic balance in the body and promotes brain and heart health as well (Lauretani et al., 2025).

Doctors also use a valuable clinical tool called a syndrome, which is a collection of recognizable traits or abnormalities that usually occur together and are associated with a specific disease, to spot early warning signs of cognitive decline that can lead to dementia and other cognitive diseases. The specific syndrome is called Motoric Cognitive Risk (MCR) Syndrome, and it is a combination of two things:

- Slowed walking speed (measured with a short walk test)
- Self-reported memory complaints (noticing you forget things more often)

Individuals with MCR — which is about 1 in 10 older adults — are three times higher at risk of developing dementia compared to others their age (Lauretani et al., 2025). However, detecting these early warning signs early allows for timely intervention in lifestyle changes to prevent progression, such as performing more physical activity. Social life can also directly influence physical activity. Being socially engaged can help you keep up with exercise habits, while boosting mood, motivation and self-confidence, benefitting your long-term health.

COGNITIVE EXCERCISE

Similar to how physical movement keeps the body strong, mental activity strengthens the brain. This idea is called the cognitive reserve hypothesis, and proposes that the more we challenge our brains throughout our life, the more "backup" resources and experience we continuously build to protect against cognitive decline (Brown et al., 2023).

Mental exercise doesn't have to be expensive or complicated. Reading, writing, knitting or learning a new skill all count. Engaging in creative activities, such as music, dance, theatre or journaling, has been shown to improve memory, self-esteem and confidence, reduce stress and encourage building social connections (National Institute on Aging, 2019, 2024).

Puzzle games such as Sudoku, chess and crosswords, are also all fun ways to challenge your brain and keep it active. A research study also found consistent evidence that playing more analog games (e.g., board games or card games) is associated with significantly less relative cognitive decline from age 11 to age 70, and also less cognitive decline from age 70 to age 79 (Altschul & Deary, 2020). The social aspect of these games — spending time

with friends or family while playing — also plays a big role in their benefits.

OVERALL TAKEAWAYS

Our brain health is shaped by many parts of daily life that are all connected. Staying active, keeping the mind engaged, sleeping well, and managing stress all work together. Regular movement supports better sleep, good sleep strengthens memory, mental exercises keep the brain sharp, and social or creative activities help reduce stress. Small, everyday choices like taking a walk, playing a game, enjoying music, or practicing relaxation can add up over time to keep the brain resilient and improve overall quality of life!

STAYING CONNECTED TO YOUR COMMUNITY

WHY COMMUNITY MATTERS

Staying socially active isn't just about having fun, it is a crucial aspect of maintaining cognitive health. Incorporating frequent social interactions into daily life can help slow memory decline and protect cognitive function, especially in older adults.

PROGRAMS YOU CAN JOIN

There are many free or low-cost ways to stay involved in Toronto:

- **TNG Active Seniors Program**
  - A free program that offers classes for cooking, fitness, technology, and wellness, as well as day trips around the city and hosting celebrations for seniors

- **The Active Minds Club – Alzheimer Society of Toronto Program**
  - Provides a welcoming, age-friendly space for social connection, mental engagement, and recreation
- **City of Toronto Senior Services**
  - Provides recreation centres, clubs and programming across the city, including fitness, dance, and hobbies
- **Circle of Care Volunteer Program**
  - A volunteering program at Sinai Health with a variety of interest-based opportunities
- **Ontario Senior Active Living Centers (SALCs)**
  - Offers a variety of programs for older adults that promote health, well-being and social connections, including:
    - Arts and culture programs
    - Health and wellness services
    - Lifelong learning classes
    - Multicultural social groups/clubs
    - Recreation and leisure activities
    - Special events/travel

HOW TO FIND WHAT'S NEAR YOU

1. Use the Toronto Service Directory: torontoservicedirectory.ca
2. Call 211: Tell them your language, postal code, and needs
3. Ask your doctor or a nearby public library: They often know about local community events



QUICK TIP

If large groups feel overwhelming, start with attending a small club or volunteering. A simple weekly activity can help build habits that support long-term brain health!

MEMORY CHECKS: GETTING SCREENED IN TORONTO

HOW TO FIND WHAT'S NEAR YOU

A memory screening is a simple way to see how well your brain is functioning. It can include short tests, called cognitive tests, that check memory, language, attention and thinking skills; these tests are safe, non-invasive tests that can help detect any potential issues early, and do not diagnose any specific diseases (Cleveland Clinic, 2022). If you notice changes in memory or thinking in yourself or a loved one, these checks can serve as a helpful first step.

A STEP-BY-STEP GUIDE + WHAT TO EXPECT

1. **Talk to your family doctor:** They will ask you a couple of questions and may perform a basic in-office test. Get referred
2. **Get Referred:** If needed, your doctor may refer you to a specialist memory clinic for a more thorough or detailed assessment.
3. **Attend the appointment:** You will meet with healthcare professionals who conduct the memory tests, ask questions and may order brain scans or bloodwork.

Memory screening may include tests like the Montreal Cognitive Assessment (MoCA) or Mini-Mental State Exam (MMSE) (Alzheimer Society, 2024). You may also be asked about medications, daily habits, or mood. Appointments often take 1–2 hours and may involve follow-ups.

WHAT TO BRING

- Health Card (OHIP) or another valid form of health insurance
- List of medications (if any) and/or any medical aids (hearing aids, reading glasses, etc.,)
- Medical history
- A trusted family member or friend

WHERE TO GO IN TORONTO

- Toronto Memory Program: Free OHIP-covered assessments with referrals provided (torontomemoryprogram.com).
- UHN Krembil Memory Clinic: Detailed multi-day cognitive and medical evaluations (https://www.uhn.ca/Krembil/Clinics/Memory_Clinic).
- Bloor Hearing Institute: Offers cognitive screening using validated tools (https://bloorhearing.ca/service/cognitive-screening-tests-for-dementia/).
- Toronto Brain Health: Provides memory and aging assessments (torontobrainhealth.com).

OVERCOMING LANGUAGE AND TECHNOLOGY BARRIERS

WHY THESE BARRIERS MATTER

Many older adults in Toronto face language or technology challenges that make it harder to find the support they need. These issues can delay diagnosis or prevent people from using services that are meant to help them. Language barriers are serious as they can lead to miscommunication between patients and their healthcare providers, resulting in a lower standard of care. Research shows that patients who experience language

barriers may experience delayed assessment and treatment, misdiagnoses or incomplete instructions regarding their care (Al Shamsi et al., 2020).

LANGUAGE-FRIENDLY SCREENING

- Most hospitals and clinics in Toronto offer interpreter services, often with no associated cost.
  - Let your doctor know you need an interpreter before your appointment.



QUICK TIP: ACCESSING LANGUAGE SUPPORT

1. Call 211 to ask for services in your preferred language
2. Bring a trusted family member if an interpreter isn't available

TECHNOLOGICAL BARRIER SUPPORT

Technology has the ability to help with memory support, communication and social connection, but only if it is fully accessible.

Many individuals may struggle to operate devices such as smartphones, tablets or websites, which can impair their ability to gain access to important resources. If you have an interest in developing technology skills, the following budget-friendly aids can help:

- Simple tablets with voice commands
- Captioned phones
- Medication reminder apps with large text
- Community-run device loan programs

WHERE TO GET HELP

- Public Libraries: Offer free tech workshops and computer access
- Ask your community health centre if they provide device training
- Use the Toronto Service Directory to find digital literacy programs

FINDING CULTURALLY INCLUSIVE SUPPORT

Accessing health care that reflects your identity, values and culture is essential for compassionate, truly supportive service.

WHAT IS INCLUSIVE CARE AND WHY IS IT IMPORTANT?

Inclusive care means getting help from a place that respects your language, culture, beliefs and family values. It is about feeling completely understood and seen, not just treated.

WHAT CAN INCLUSIVE CARE LOOK LIKE?

- A doctor that can speak your first language
- Care teams that respect religious traditions or family roles
- Programs that include familiar or cultural foods, holidays and healing
- Clinics that offer services in multiple languages, alongside accessibility options

INCLUSIVE CARE SHOULD:

- Use respectful, culturally appropriate language
- Post clear signs in multiple languages
- Communicate in ways that work for you (not just forms and tech)
- Include people like you in programs and studies where possible
- Commit to learning about new cultures
- Involve staff and patients in building inclusive care together

WHERE CAN YOU LOOK FOR INCLUSIVE CARE?

There are many ways to access inclusive care in Toronto, including:

1. Ask your family doctor to refer you to clinics that serve your cultural/language needs
2. Explore your local community health centers; many offer programs designed for specific cultural groups
3. Call 211 Ontario to ask for help, resources or support in your own language

3

SECTION

LIVING WITH MEMORY CHANGES

LIVING WITH DIGNITY

Living with dignity is a lot more than just receiving medical care, it includes feeling respected, acknowledged, and appreciated for who you are. For many older adults living with cognitive decline, dignity means being able to make decisions on their own and having agency in whatever decision. The decisions can be small ones we make everyday such as what to eat and wear, or bigger more impactful ones such as financial or end of life decisions.

Just as Maya Angelou, an American poet said: “People may forget what you did, but they never forget how you made them feel.”. This quote represents what living with dignity means—the fact that a person with cognitive decline is still human, alive and should be treated thoughtfully. This reminds us that emotional experiences and connections are just as important as proper medical treatment.

PERSONAL REFLECTION FROM A NEWMARKET HOSPICE

“Losing someone you love never gets easier. I lost both my grandmothers to Alzheimer's within 6 months and it was the hardest thing. After taking care of both of them at home with family, being primarily caregivers, 24/7, when they were called home, I felt lost and incomplete. Now almost a year later, watching my grandmother-in-law deteriorate has brought up so many emotions. We make time to be with them and love them and help them remember all the good times. We don’t want them

in pain, we don't want them to suffer. We want them to be comfortable and happy and go with all good memories. My heart goes out to all those who feel like they are losing their best friend. It will get easier, it has to."

Cognitive decline involves memory loss and many family members forgetting the 'fond memories' and in some cases, the name and faces of their loved ones. Living with dignity means getting the assistance you need in order to remember such memories.

SHORT CONVERSATION BETWEEN A RESIDENT AND A WORKER: (WOOD, 24).

"I sit down to talk with my friend. 'How are you doing?' I ask her. I haven't seen her in a while. 'Oh, about the same. Same thing every day,' my friend says. We fill the air with some more conversation. My friend loves to talk. She enjoys sharing stories of her life. She has many to share.

'Y'know, I survived the great fire of 36' she tells me. She has short-term memory loss and she knows it.
I have heard her stories before. I don't mind hearing them again. Someday, I will miss hearing them and treasure each time that I did" (Wood, 24).

Although memory fades, the individual always remains. As we choose to listen without correcting or interrupting, we understand that a resident's history, no matter how many times it is repeated, is still important. The worker has heard the stories many times, but since she is aware of the resident's condition, she respects that forgetting is a natural part of her life.



KNOWLEDGE CHECK: REFLECT

Think about the older adults in your life or those you've interacted with who may experience memory loss or cognitive decline.

1. How can you honor their dignity and sense of self beyond attending to their physical or medical needs?
2. Reflect on a time when someone made you feel truly respected and seen. How could that experience guide how you support others?

CARING FOR THE CAREGIVER

Caring for someone with cognitive decline or any health-related issue is a deeply human and respected act of service. But caregiving, especially for longer periods of time or provided informally by loved ones, can take a significant toll on the provider. Millions of caregivers around the world report feeling emotionally and physically drained, with over 60% of caregivers experiencing burnout—a state of mental and physical exhaustion which can in turn affect the health and well-being of the caregiver (Cleveland Clinic, 2023).

WHO IS A CAREGIVER

A caregiver is an individual who provides physical and/or emotional support to those who are having challenges with providing and caring for themselves. Reaching this state in life can come from age, declining health, trauma, or many other medical conditions. The support of a caregiver, however, can involve assisting with eating, bathing, dressing, taking medications, transportation, or simply having a person to talk to. Caregivers can be family, friends, or paid professionals, but caregivers who are loved ones are given the name: informal caregivers. Most informal caregivers are women, often adult

spouses or daughters due to cultural expectations (Sharma et al., 2016).

WHAT IS CAREGIVER BURNOUT?

Caregiver burn out is a state of severe physical, mental, and emotional fatigue that results from prolonged caregiving without sufficient rest and support (Cleveland Clinic, 2023).

You may not notice it for months or years, however, this state of burnout is bound to hit you if time isn't taken to rest and recharge.

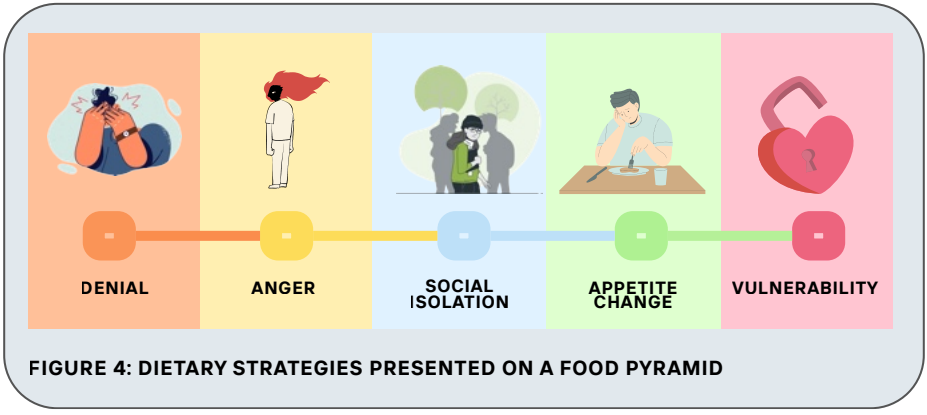


FIGURE 4: DIETARY STRATEGIES PRESENTED ON A FOOD PYRAMID

Common Signs of Burnout

Denial - minimizing or ignoring the amount of caregiving one needs
Anger - feelings of frustration or anger from the repetitive demands of caregiving
Social isolation - avoiding activities, friends and family - things you once enjoyed
Appetite/weight changes - eating too much or too little
Vulnerability - feeling helpless, falling sick more often, feeling weaker mentally/physically

(Alzheimer Society of Canada, 2022).

EDUCATION MATTERS

Caregivers who are well educated on the condition of their loved one/client/resident are less likely to experience burnout. Educated caregivers tend to cope better and feel more confident about the situation. A study published in 2021 regarding geriatrics proved that caregivers that have specialized knowledge and support around cognitive and functional decline are better able to manage care tasks, reducing stress and burnout (Chan et al., 2021).

HELP AT HOME

Caring for those who are experiencing cognitive decline can be demanding and a large commitment, but you do not have to do it alone. In Ontario there are many home and public services that ease the burden on caregivers and improve the caregiving for the recipient.

WHAT IS A PSW?

A Personal Support Worker (PSW) is a professional care provider that assists with daily activities whenever a specific condition makes it hard for someone to live and provide for themselves independently. PSW's are located in many settings such as homes, long term care, and hospice care (Ontario Personal Support Workers Association, 2018).



KNOWLEDGE CHECK: REFLECT

1. How could involving professionals like a Personal Support Worker (PSW) change the way care is delivered? How might it affect your own stress and well-being?
2. Caregiving is a commitment, but no one has to do it alone. What strategies could you use to balance providing care while also taking care of yourself?

PSW IN TORONTO

- Circle of Care Sinai Health - offers over 1.2 million hours of personal home care per year in and around the GTA
- WoodGreen Community Services - this service provides PSW care for specifically adults 55 and older to allow for independent living which is covered by the government and non profits
- PSW's are proven to prevent hospital and clinic visits among care recipients and also give caregivers a much-needed break to prevent burnout (Atoyebi et al., 2022).

MEALS ON WHEELS: NUTRITION/WELLNESS IN TORONTO

Good nutrition is essential for those going through cognitive decline, supporting brain health through a sustaining diet.. Some nutrition services in Toronto not only deliver food, but allow for additional social connections and health monitoring. Consistent and nutritious meals reduce all forms of food insecurity and promote independence among adults who are trying to age in a healthy manner and prevent hospital and clinic visits.

- Circle of Care - Meals on Wheels: Serves over 280,000 meals annually, meeting a variety of dietary needs (kosher, vegetarian, diabetic) and offering wellness check-ins during delivery.
- West Neighbourhood Service - Offers 6 days a week food service that are cost-friendly and have wellness visitors

RIDES FOR SENIORS IN TORONTO

As those with cognitive decline may require more help with mobility, or opt not to drive, there comes a risk of missing important medical appointments or becoming socially isolated due to lack of transportation. There are many ride services available around Toronto to keep seniors connected.

- Circle of Care - iRIDE: Performs over 20,000 rides per year to groceries, appointments, or social events
- This allows seniors to stay connected, reach appointments, and stay up to date with groceries which all contributes to bettering their mental and physical health

THINKING ABOUT LONG TERM CARE

Long term care includes medical, personal, and social services that are specifically designed for those who need constant 24/7 support with their daily lives due to cognitive decline, disability or serious health condition (National Institute on Aging, 2023).

There are many types of LTC that are customized to fit an individual's needs. Institutional care is care that is provided in a nursing home with 24/7 staff support. Palliative and hospice care focuses on end of life care and living until you die. Palliative care focuses on comfort and dignity, improving the quality of life of those with serious medical conditions (National Institute on Aging, 2023).

DO YOU QUALIFY FOR LTC IN CANADA? (ONTARIO HEALTH ATHOME, 2023)

To be eligible for LTC in Ontario you must:

1. Be 18 years or older
2. Possess a Valid Ontario Health Card
3. Have needs that cannot be satisfied at home, even with support
4. Have care needs that can be supported in a LTC

Referrals and eligibility requirements can be further accessed through Ontario Health AtHome (Ontario Health atHome, ca. 2021).

CULTURALLY INCLUSIVE LTC AND WHY IT MATTERS:

Culture is a huge part of comfort, health and well being, especially during the most vulnerable times of one's life.
Whenever you are visiting or researching about a new facility make sure to ask:

1. Do the staff speak your languages?
2. Does the facility cover all culturally appropriate meals such as kosher, halal, etc.
3. Is there space for prayer, worship, and private meditation?
4. Are the other residents also culturally similar to you? What about the staff?
5. Cultural activities and holidays?

CHANGING THE CONVERSATION

Aging is a natural and inevitable part of life yet society often views it as a decline rather than a transition into dignity and wisdom. Many individuals living with cognitive decline or similar conditions face stigma—negative stereotypes and unjust treatment—due to their age or state of mind.

WHAT IS STIGMA?

Stigma is a negative assumption or label that is placed on a group of individuals due to a specific reason that does not apply to everyone in that group. In the context of aging and cognitive decline, stigma can appear in many forms such as:

1. Family and friends may stop inviting older adults to social gatherings, assuming they'll forget, feel out of place, or not be present in the gathering.

2. Especially in the public, people often speak to the caregiver instead of the care recipient assuming that the individual may not be able to comprehend any information.
3. People behave without acknowledging the person, acting as if the individual is not present and is not "there".

This is a type of discrimination called ageism, specifically based on one's age. Often, ageism can lead to social isolation, lower self-esteem, and fear of judgement among the elderly population (World Health Organization, 2021).

THE REALITY OF AGEISM:

According to the (World Health Organization, 2021).

- 1 in 2 people worldwide hold ageist beliefs.
- 6.3 million cases of depression are linked to ageism.
- 12% of adults over 65 experience social isolation. (Canada Network for the Prevention of Elder Abuse & National Institute on Ageing, 2022).

A Government of Canada survey (55+ adults, 2,920 respondents) demonstrated that:

- 46.4% witnessed ageism first-hand
- 33.1% knew someone affected
- 20.5% were unaware of any ageism

(Employment and Social Development Canada, 2023).

Where Ageism Happens Most: (Employment and Social Development Canada, 2023).

- Public places – 39.9%
- Workplaces – 39.7%
- Healthcare – 35%
- Home/social settings – 33.1%
- Long-term care/group housing – 29%
- Media/social media – 26.6%

HOW TO REDUCE STIGMA?

Changing the conversation about aging and cognitive decline is a huge task but we can all work together by starting by ourselves.



FIGURE 6: STEPS TOWARDS REDUCING STIGMA

AGING ACROSS DIFFERENT CULTURES:

Aging in your culture may be different as compared to other cultures around the world. However, the truth of the matter is that we all age and what matters is how we are valued, supported, and respected in the process. While traditions may vary, the universal need for love, dignity, and connection remains the same.

Research shows that views on aging vary drastically across cultures yet certain patterns are still universal. In a specific study involving 3,435 college students from 26 different cultures in the world, students were asked to speak on how different aspects of life may change with age (Löckenhoff et al., 2009). The participants reported that physical attractiveness and the ability to learn and perform new tasks decreases with age, while wisdom, knowledge, and respect tends to increase (Löckenhoff et al., 2009). Although aging may be related with physical changes, the findings emphasize that many cultures associate aging with gaining respect, wisdom, and a sense of value from society. This reinforces the idea that aging is not about declining but rather guiding the next generation and should not be associated with any stigma.

TORONTO RESOURCE GUIDE

Toronto has many resources that support seniors, caregivers, and those living with cognitive decline around the GTA. The programs offer connection, care, and guidance and allow you to stay present within the community.

GENERAL SUPPORT:

Toronto Seniors Helpline: 416 217 2077 | 24/7 | 100 + languages

- Offer a free phone line for seniors, caregivers, or those undergoing memory loss by providing emotional support, guidance and information on programs and services, and assistance with the healthcare system

Ontario Health AtHome: 310-2222

- Can connect adults 55+ to senior homes, long term care or to other home services like nursing and rehabilitation

211 Toronto: 211 | 24/7 | Multilingual Support

- A city wide dispensary that can link you to community programs, social services, or dementia support

MEMORY CLINICS AND COGNITIVE CARE

Toronto Memory Program: 416-386-9761

- Free memory assessments, early diagnosis, and treatment plans for dementia and mild cognitive impairment.

Mount Sinai Hospital: 416-596-4200

- Mount Sinai offers family education about cognitive decline, cognitive testing, and care plans to assist patients and family members

REFERENCES



SCAN THE QR CODE TO VIEW OUR REFERENCES!

Acknowledgements

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"ALTHOUGH MEMORY FADES, THE INDIVIDUAL ALWAYS REMAINS."

This book offers a compassionate and practical look at how aging and memory loss affect individuals, families, and communities. With clarity and care, it explains the stages of cognitive decline, early warning signs, and ways to build healthier habits that protect brain health.

The book also addresses the unique needs of caregivers, the importance of culturally inclusive services, and the resources available in Toronto to support dignity, connection, and quality of life

Give us any Feedback

Take a short quiz about the book

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