

This document was created to provide you with information that can help you better understand dementia, what to expect as the disease progresses and what treatments and resources are available to support you through the course of the disease. It is recommended that you contact a health care professional for any further clarification as well as support.

### WHAT IS DEMENTIA?

Dementia is a progressive condition affecting the brain. It worsens over time and eventually affects all aspects of one's life: how you think, feel and act. Everyone is affected differently. It is difficult to predict which symptoms a person may have, the order in which they will appear, and the speed of progression. The most common form of dementia is Alzheimer's disease (AD), which accounts for 60 per cent of dementia cases. There are also other types of dementia including Lewy Body, Frontotemporal, Vascular and Hydrocephalus. For more information contact the Alzheimer Society of Toronto- see contact information the back of this page.

### WHAT TO EXPECT ALONG THE WAY

Dementia progresses slowly and worsens over time. During this time you may feel confused and may not be able to do things that you now find easy. You will see changes in the way you feel and sometimes you may find that you are upset with yourself and with the people around you. If you have Alzheimer disease, you will typically follow certain stages: *early, middle, late*. In most cases, the disease progresses slowly over seven to 10 years. Each stage is characterized by symptoms, described below:

**Early stage:** Memory loss becomes noticeable. Complex tasks such as banking, following conversation, daily family and work duties may become challenging and complicated. However, most people retain many of their abilities and require very little assistance. Tips to make things easier: reduce clutter, use labels, calendars, timers and pill dispensers. Ask people to speak slowly and reduce distractions during conversation. Tell a trusted friend/family member about the diagnosis if possible, so you have some emotional support.

**Use this stage to learn as much as you can about the disease. Make decisions and plan for later stages. Maintain a healthy lifestyle; what is good for the body is also good for the brain.**

**Middle stage:** You will experience a substantial decline in your ability to function in daily activities. Thinking and memory problems increase and you may need assistance with many of your daily activities. Restlessness, sleep disturbance and hallucinations may also occur. Family and caregiver involvement increases dramatically and additional home assistance or moving to a care facility may be required. See resources available at the back of this page to support you and your family during the course of the disease.

**Late stage:** In this stage, there is a further decline in abilities and 24-hour care is often required. The focus at this stage is to ensure the highest quality of life possible.

## TREATMENT

Currently there is no treatment that will cure dementia, but there are new drugs and medications that help delay and manage the symptoms of the disease. The most common drugs prescribed in dementia are cholinesterase inhibitors. These drugs help to slow down the breakdown of acetylcholine, a chemical messenger that assists memory, thought and judgment. Increased concentrations of acetylcholine in the brain leads to increased communication between nerve cells and may temporarily improve or stabilize the symptoms. Ask your family doctor to explain more about these drugs. Many efforts are made through research to develop treatments that may delay or halt the disease. These treatments are currently under investigation/clinical trials.

## WHO IS OUT THERE TO SUPPORT YOU?

**Alzheimer Society of Toronto** – Provides support for Alzheimer’s and other dementia diseases. The Alzheimer Society of Toronto provides counseling, information, training and lectures, as well as up-to-date information about dementia research. The Alzheimer Society also organizes events, support groups, educational sessions and provides counseling services by professional social workers to support you and your family. Ask your doctor to refer you or contact the Alzheimer Society First Link program at **T: 416-322-6560, Fax: 416-322-6566** or [www.alzheimertoronto.ca](http://www.alzheimertoronto.ca).

**Community Navigation and Access Program (CNAP)** – A network of over 30 non-profit organizations providing the following services: Meals on Wheels, adult day programs, transportation, home help, counseling and support, caregiver services, shopping help, group dining, home maintenance, foot care, friendly visiting, personal care and social worker services. A CNAP social worker will help by advising you about the different service options that best accommodate your needs. You will then be referred to the different agencies upon your consent. Contact CNAP at 1-877-540-6565 or learn more at [www.cnap.ca](http://www.cnap.ca).

**Community Care Access Centre (CCAC)** – This organization provides specialized care services such as nursing, physiotherapy, occupational therapy and social work services, in addition to personal care (dressing, bathing, etc.) and long-term care application. CCAC will assign you a care coordinator that **will come to your home, assess your needs and make referrals** on your behalf, with your consent. The CCAC case coordinator will also follow your case over time. To check for your eligibility for CCAC services contact CCAC at **416-506-9888** or learn more at <http://www.ccac-ont.ca> or ask your family doctor to make a referral.

**Advocacy Centre For the Elderly (ACE)** – This organization will provide you with information about legal and financial rights. Becoming informed about legal rights at an early stage can help you and your family make decisions for the future. Contact ACE at **T: 416-598 2656, F: 416-598 7924**. Learn more at [www.advocacycentreelderly.org](http://www.advocacycentreelderly.org)

**Ontario Seniors’ Secretariat** – For information about federal and provincial financial programs and eligibility for tax returns contact the **Senior Info Line at 1888-910-1999, [infoseniors@ontario.ca](mailto:infoseniors@ontario.ca) or <http://www.seniors.gov.on.ca/en/imdex.php>**

### **Useful websites for information about dementia and related services:**

- **Toronto Dementia Network:** <http://www.dementiatoronto.org/> (Dementia services and information)
- **C-SMHAS:** <http://www.csmhas.com/> (Find services by postal code)