

DEMENTIA INFORMATION SHEET FOR THE FAMILY MEMBER /SIGNIFICANT OTHER

You have received this sheet because your family member or significant other has been diagnosed with dementia. Receiving a diagnosis of dementia can be devastating not only for the person with the disease but also for their family and people around them. As the disease progresses, your role in supporting and caring for the person with dementia will change and increase over time.

This sheet is meant to provide you with information about what to expect along the way and to let you know that you are not alone. There are many resources and support services available for you and your loved one to help and guide you along the way.

WHAT IS DEMENTIA?

Dementia is a progressive condition affecting the brain. It worsens over time and eventually affects all aspects of a person's life - how they think, feel and act. Everyone is affected by the disease 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 approximately 60 per cent of dementia cases. There are also other forms 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 the person with dementia may be confused and may not be able to do things that he/she now finds easy. You will see changes in the way the person feels and you may also find they are upset with themselves and with the people around them. If the person you are caring for has Alzheimer disease, they will typically follow certain stages: *early*, *middle*, *late*. In most cases, the disease progresses slowly over seven to 10 years. Each stage is defined by certain symptoms, discussed below:

Early stage: Memory loss is noticeable to the person who has the disease, as well as those around them. Tasks like banking, following conversation, daily family and work duties may become challenging and complex. However, most people at this stage retain many of their abilities and require very little assistance. Tips to make things easier: reduce clutter, use labels, calendars, timers and pill dispensers. Encourage the person with dementia to participate and be independent in accordance to their abilities and interests. Speak slowly and reduce distractions during conversation. Discuss their wishes for the future so they may partake in decision-making. Encourage them to maintain a healthy lifestyle. What is good for the body is also good for the brain; doing it together will keep you healthy too! For more tips contact the Alzheimer Society of Toronto.

Middle stage: Thinking and memory problems increase, with a decline in ability to do daily activities. Restlessness, sleep disturbance and hallucinations may occur. Family/caregiver involvement increases dramatically; additional home assistance or moving to a care facility may be required. Note that all behaviours express communication - try to understand what the person is trying to convey. Use visual cues and gestures to help the person understand. For additional coping strategies and support contact the CARERS program at Mount Sinai Hospital or see more resources at the back of this page.

Late stage: There is further decline in the person's ability to complete daily activities; 24-hour care will be required. The focus at this stage is to ensure the highest quality of life possible. Tailor activities to strengths, abilities and fields of interest. Though the person may not have the capacity to understand and respond as in the past, they are still likely to feel affection and will benefit from reassurance.

Caring for a person with dementia can introduce many challenges and responsibilities that may add to stress among caregivers or family members. It is highly recommended that you seek assistance at the initial stage of the disease to help you and your loved one plan for the future and to help put supports in place as early as possible.

WHO IS OUT THERE TO SUPPORT YOU?

Alzheimer Society of Toronto – Provides support for Alzheimer's and other dementia diseases. Provide **counseling support, information, training and lectures**, as well as **up-to-date information about dementia research**. They organize events, support groups, educational sessions and provide counseling services by professional social workers to support you and your family members. 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.

The Reitman Centre CARERS Program at Mount Sinai Hospital – This is a program created for family carers and offers skill-based tools and emotional support to provide care at home to family members. A concurrent arts-based program for cognitive and interpersonal stimulation is provided for the person with dementia. Services are offered at no cost to you. Ask your family physician to refer you or contact the CARERS program at: **T: 416-586-4800 ext. 5192**. Read more at www.caregiverMSH.com.

Community Navigation and Access Program (CNAP) – A network of over 30 non-profit agencies 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**. Use these services as a respite option to relieve you of your duties and to allow yourself some quality time. When you call CNAP, a social worker will assess your needs and refer you to the different agencies upon your consent. Contact CNAP at **1-877-540-6565** or learn more at www.cnap.ca.

Community Care Access Centre (CCAC) – This organization provides specialized care services such as nursing, physiotherapy, occupational therapy, and social workers, in addition to personal care (dressing, bathing) and long term care application. CCAC will assign you a care coordinator that **will come to your home, assess your needs and will make referrals to the different services as needed** on your behalf with your consent, and will follow your case over time. To check for your eligibility for CCAC services contact CCAC at **416-506-9888** /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. Being informed about legal rights at an early stage can help you and the person with dementia make decisions for the future. Contact ACE at **T: 416-598-2656, F: 416-598-7924**. Learn more at www.advocacycentreelderly.org.

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)