

Sharing a new dementia diagnosis with patients and caregivers

Disclosing a diagnosis of dementia is never an easy task for physicians. This can be life-altering for patients and their families, and there are a variety of reactions that can result from the disclosure of this diagnosis including disbelief, denial, shock or anger. Some patients are aware of the implications associated with a diagnosis of dementia, while others rely on their physician to educate them about the course of the illness, the inevitable decline and the lack of any definitive treatment. For most patients, having a conversation regarding dementia at the earliest possible opportunity can help them to better understand and manage the disease. Here are a few suggestions to help you better support your patients who have been diagnosed with dementia:

In preparation, make sure to:

1. Encourage patients to have a family member or friend with them.
2. Have the results of the testing in front of you
3. Have the Quick Resource Guide with you.

General guidelines for the conversation:

1. Remind the patient why testing was undertaken. Remind the patient about things they have said are causing them difficulty or concern (e.g., “You told me your memory is not good. These tests have confirmed that, and I think I have an explanation for why”).
2. **Test Results:** “The test results have come back and I would like to share them with you. They confirm our concerns about your memory.” Go through the results in detail if you think the patient would like to hear them (take into account what information would be most critical for the patient to hear).
3. **PROVIDE DIAGNOSIS:** “According to the test results you have dementia” (state the type of dementia if possible). Ask if the patient would like to talk about this today or at your next meeting. This helps patients have a greater sense of control.
4. **When the discussion happens, consider using the following language:** “Dementia is a disease of the brain that slowly progresses and worsens. Sometimes the disease can take years and during this time you will find yourself confused and you may not be able to do things that you now find easy. You and your family will see changes in the way you feel and you may occasionally feel upset with yourself and with the people around you. There are medications that may help your symptoms from worsening, and there are many community resources to help you and your family over the next few years. I would also like to see you regularly so I can help you manage this effectively”.
5. **PROVIDE TOOLS:** Provide the patient and caregiver/family member with information sheets and resources. Patients and families often don’t take the next step of calling these organizations for help. It is important to follow up to see if they have done so. It would be helpful to share with them the various resources they can find through the Alzheimer’s society (e.g., valuable information, support groups and counseling services are available).
6. **REFERRAL:** Make a referral to **Alzheimer Society of Toronto First Link**
Referral form: <http://www.alzheimertoronto.org/firstLinkReferralFormOnline.htm>
T: 416-322-6560, Fax: 416-322-6566, www.alzheimertoronto.org

Key messages:

1. Acknowledge the patient’s feelings e.g. “*I understand that this is difficult to digest*” or “*I can see you are confused/ upset/ shaken*”
2. Suggest that the patient and their family take time to absorb the diagnosis and come back at a later date for more information. Many people will be shocked at the stage of initial diagnosis and will not be able to ask or absorb information properly.
3. It is important to consider both the caregiver and the patient when addressing feelings.
4. Let the patient and his/her family members know that they are not alone. Emphasis should be given to the progressive nature of the disease and the importance of connecting with the appropriate resources and planning ahead.

Dementia Diagnosis Disclosure Guide Short Form

Early diagnosis = Early access to resources and early preparation

PREPARE

- Gather all information
- Gather resources
- Ask the client to come with his/her significant other/friend

WHAT?

- Test results
- Diagnosis
- Information
- Resources
- Referrals

HOW

- Acknowledge feelings
- Give time
- Be approachable for further discussion
- Discuss supports and early preparation

** Acknowledgment to David Ryan Ph.D. C.Psych. - Director of Education & Knowledge Processes Regional Geriatric Program of Toronto Assistant Professor, Faculty of Medicine, University of Toronto Consulting Psychologist , Sunnybrook Health Sciences Center for his input in developing this tool.

Copyright ©2012. Mount Sinai Hospital, Toronto, Canada. All Rights Reserved.

Disclaimer: Permission to use, copy, modify, and distribute this material for educational, research, and not-for-profit purposes, without fee and without a signed licensing agreement, is hereby granted, provided that the above copyright notice, this paragraph and the following paragraphs appear in all copies, modifications, and distributions.