The Dementia Edition

One of the challenges with dementia is the often slow imperceptible onset: A misplaced item; a forgotten word; a missed appointment.

This earliest stage, when onset is just being detected is a burdensome moment for the individual affected, their partner and indeed the entire family.

Not only is there the dread of the diagnosis, but the cognitive symptoms are frequently met with a sense of fear, shame and/or embarrassment. Concern for the loss of dignity also looms as does fear for the future, one’s care and the impact on those nearest to us.

This information package discusses the personal and social issues of coming to terms with dementia and managing on a personal and interpersonal basis.

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Coming to Grips as the Memory Fades

It starts so innocuously; a misplaced set of keys, a lost wallet, a burned dinner. Any one event is so easily dismissed, but taken cumulatively you quietly begin to question your own mind or that of your partner or parent or friend.

Despite the finesse with which the issue is raised, the comment or concern may cut like a knife and the thought of perishing inside one’s own mind terrifies.

Very often, awareness of one’s own deficits is limited. One doesn’t see what one cannot remember. The gaps are filled in with one’s own beliefs that seemingly make sense to the one affected, but bears no resemblance to the reality of the others. Conflict, mistrust, confusion, anger, depression, loss, anxiety pervade.

Coming to grips as the memory fades is a process over time and a journey for not only the affected but also for those whose lives intersect. A new normal sets in. It is not a static new normal but one that rests on shifting sands.

How does one talk about these changes, these challenges, the implications, the choices? How does one cope whether the affected, the caregiver, the family or the friend? What should be said or left unsaid… and when?
While you may be scared, upset and fearful for the future, talking about your concerns can not only ease the emotional burden, but lead to new skills to manage your situation more effectively.

Living with dementia, coming to grips as the memory fades will be so different from one person to another. The right way of one isn’t necessarily the path of another. What is considered right will also be a function of where one is over the course of one’s journey. There can be so much to talk about, yet when and how can be the issues one has to figure out.

If you or a loved one is concerned about or coping with dementia, apart from the wonderful services available through different community groups and resources there is a much more private and particular path and events and discussions that need be determined, that need be had.

When seeking to cope amidst the fear of a life affected with dementia, include Counselling.

Counselling is for the person affected with dementia as well as for the partner, the family and even friends.

Counselling is aimed at facilitating emotional adjustment, healing relationships if necessary and facilitating care planning. Counselling can also help people manage the delicate conversations they would much rather avoid, but where avoidance makes matters more difficult.

As painful the thought and reality of dementia, the isolation and feeling stuck and upset for conversations not had can be even more tragic. Life is less about what it throws at us than how we can cope individually and together.

We may find meaning, greater peace and more support the result of Counselling.

Counselling may be available through a local community agency, community support groups, through your doctor’s office, employee benefits or through private counselling services.

Explore what resources are available to you and seek to attend.

Counselling may help what feels insufferable, feel meaningful. It may help you better manage the shifting sands, finding strategies to cope and better manage from one stage to the next. It is well worth considering when coming to grips as the memory fades.

After all, there will be so much to talk about and discuss.

Just as the individual and loved ones may be coming to terms with the onset and diagnosis of dementia, ones concerns may turn to the challenges resulting from deepening cognitive deficits.

At this stage of dementia, counselling is better directed to helping the partner, caregiver, family and friends cope by learning specific management strategies.
Understanding and Dealing with Three Cognitive Issues that can Create Havoc

While most people immediately go to memory loss as a primary deficit of dementia, there are other issues which can create havoc for coping be it for the affected person or support persons. Chief among those other issues are anosognosia, confabulation and disinhibition.

Anosognosia is the condition of the person lacking awareness of their own deficit. This is quite different from denial.

Denial is seen as a psychological defense mechanism to distance oneself from the emotional challenge of accepting one’s issues. In denial, the person does have an awareness of the deficit, but hasn’t come to accept it.

Anosognosia is truly the absence of awareness of the issue or deficit.

When applied to the issue of memory loss, the person in denial will likely become angry or agitated when confronted by others about losing an object. The person may even become agitated or angry with him or herself.

As for the person with anosognosia, if confronted on the issue of memory loss, this person may be apt to not even understand the problem as originating with themselves, but may more believe someone is playing a mean trick on them. This person is apt to be less defensive about it because they literally don’t get it.

Confabulation may be best understood as the mind filling in the gaps for not perceiving things as they really are.

Given dementia, the person may not be aware of their own deficits. They may make things up to fill in the blanks, which feels real to themselves. This creates a challenge for those around them.

With confabulation a person may be seen as accusatory, blaming others on the basis of misunderstandings or simply making things up in order to make sense of their distorted view of personal experiences.

For instance, a person may accuse their partner of having an affair when they try to put together broken elements of their perception, knowing the other is out, not knowing where and perhaps catching a piece of a message about a meeting. While the story of an affair seems to make sense to the affected person, it strays far from the reality of the situation where the other person may have simply been out shopping with a friend.

Confabulation is often combined with anosognosia. Not realizing what one may miss, one constructs a distorted view that only makes sense to that person. Arguing and counselling are typically not of value to the affected person, but again, counselling can be of particular value to those who support the affected person.

Disinhibition is when the brakes fail to control our normal impulses.

Skills in managing behaviour associated with cognitive deficits can facilitate adjustment as well as promote and maintain the dignity of the affected person. These skills can be learned by family and friends.
While everyone has had the experience of wanting to say or do something that may be deemed inappropriate, we have a set of internal controls that keep us from doing so. The disinhibited person has a faulty set of those internal controls and as such may say or do things inappropriate to the situation. These persons appear to lack social judgment and their behavior or comments may be inappropriately humorous to rude to hurtful to harmful or dangerous.

Taken together, anosognosia, confabulation and disinhibition can create havoc in the life of the person with dementia and those who provide for their support or care as well as other family and friends.

Counselling the affected person about these issues will have little to no impact and may actually create more turmoil and upset for everyone.

Rather than counselling the affected person, it is the support or caring persons, very often the family members and friends who require counselling and education. Sometimes called psycho-education, this form of counselling is best directed to explaining these conditions and offering strategies for management.

Strategies include learning:
1. When not to argue;
2. How to redirect to more socially acceptable conversation and behavior;
3. How to convey this information to other caregivers, family and friends who interact with the affected person.

These can be challenging strategies to learn and role play may be helpful with instruction.

Many family and friends are upset not only for the management challenges but also for the compromised dignity of the affected person. They may feel shame or embarrassment for the affected person or themselves.

It is important to address those feeling as well as learn effective management strategies so that the dignity of the affected person may be better protected by loved ones and friends. Protecting one’s dignity begins by acknowledging the dementia so that problems arising are not seen as a reflection of the affected person, but can be viewed compassionately as an outcome of a disease process.

Counselling and education for loved ones and friends are often the best way to help the person with dementia at this stage.

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Gary Direnfeld is a social worker. Gary has been helping individuals and families manage cognitive issues ever since he developed and operated Canada’s largest private brain injury rehabilitation centre in Canada during the 1990’s. In addition to his appreciation of cognitive issues and the interplay with psycho-social issues, Gary is also a recognized expert in marital and family therapy by Courts in Ontario. Gary provides a range of services for people in distress and managing behaviour for persons of all ages. He speaks at conferences and workshops throughout Canada and the US and is frequently quoted in the media. Please call directly for information about services.