

**Dementia Canterbury:**  
**Carers Education Meeting for Adult Relatives of People with Dementia.**

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These notes add to some of our discussion from our meeting, focussing on some common questions and issues that face us when a parent (or close relative) develops a dementia.

- **What is dementia?**

Dementia is a syndrome of impairment in some core functions of the brain severe enough to lead to problems in everyday living, caused by a degenerative disease of the brain. Core functions include abilities such as understanding, reasoning, remembering, communicating, and forming reasonable plans of action. (Neuro)degenerative diseases are caused by various illnesses that damage brain cells and how they function. Because the underlying illnesses are unfortunately usually incurable using current medical treatments, dementia is therefore usually progressive. Dementia most commonly occurs with older people but can occur at younger ages.

- **Differences of opinion within the family.**

There's nothing like stress to bring these out, including, sadly, disagreement over money matters. Dementia certainly causes stress for all concerned.

What can we do when conflict threatens?

- Seek an outside opinion, such as from the family doctor, the hospital's services, good friends, your church or other religious group, or other agencies such as Dementia Canterbury. The right outsider can bring clarity when emotions are running high and may help the different people involved to start talking constructively again.
- Try to understand other people's perspectives. People do not behave randomly - there are always reasons. A good starting point is to assume that everyone is doing the best that they can under the circumstances, even if this "best" is not very good. Grief and stress affect people in very different ways and sometimes people behave badly when they mean well.
- Try to achieve openness about important decisions right from the beginning, especially if there is a history of difficulty between family members.
- Decision-making about our parents or other relatives with dementia is not the time or the situation to be settling old scores or trying to change our family members' behaviour. Keep the focus on the person living with dementia and what they need - don't get distracted.
- We are not responsible for others' actions or beliefs. Sometimes we just have to agree to disagree. Obviously, if we really think that some serious harm is going to come to a person living with dementia because of the actions of others, we must raise the alarm, but this doesn't happen often.
- When things get sticky, don't forget to ask the person with dementia what they think - but not with the intention of getting them to be the referee. Maybe they hold a key to the solution (they may have been managing conflict in the family for years after all).
- Not all conflict is bad, even if it scares us. In particular, sometimes our opinion is wrong. It may be possible that changing our mind is the right thing to do. Gracefully.
- Just because a challenging family member expresses an idea in a challenging way doesn't mean it was a bad idea.

- **Is dementia inherited?**

Our genes are inherited from our parents – half of them from each one. Our final genetic make-up is very complicated: the exact genes and other DNA that we will get from each parent is randomly determined; DNA can occasionally change due to mutations as we grow; every gene can come in several different forms; the genes we have all affect each other; and genes are greatly affected by the environment so that their effects are different in different people at different times in our lives, even in identical twins! That's why there's no such thing as a single gene for being tall or a single gene that causes high blood pressure – it's also why there's no-one else on the planet just like you. Most illnesses happen because of a complex mix of lots of different genes adding together with lifestyle factors and other environmental factors (many of which are unknown). However, there are some genes that are so powerful that they can cause illnesses all by themselves if they occur in the wrong form.

Most illnesses that underlie dementia are of the complex sort – complex patterns of genes are part of the reason but not the whole story about why a particular illness occurs. Having specific forms of certain genes passing through our family raises our risk of developing a dementia but does not cause the dementia as such (other genes protect us).

On the other hand, the dementia illnesses that are caused by single genes usually occur well before old age and they are all rare. These illnesses pass strongly through families and usually cause dementia before the age of 55. Some of them can be detected by blood tests, but blood samples would usually need to be gained from three generations from the same family to be sure.

So for the majority of illnesses that cause dementia, the real question is “how much does our risk increase if a parent develops dementia in old age”? It is true that our risk is increased compared to someone with two parents who died in old age without dementia, but this is not a “life sentence” for us or the start of a “family curse”. Our true chance of developing dementia depends on our lifestyle, other environmental factors, ‘luck’ and also our personal likelihood that we will live into old age so that the illness has a chance to develop in the first place. Because of this relatively complex contribution to our personal risk from having a parent with dementia, and because there is nothing we can do about our genes with current medical knowledge, the best advice is to concentrate on the things we can change.

Every human being has some chance of developing a dementia – perhaps we should focus on the things we can do to look after our brains. What can we do, starting now?

- stop smoking as soon as possible.
- eat a varied, healthy diet that is particularly rich in fresh, colourful fruit and vegetables, not high in red meat, and includes fish, nuts and olive oil.
- if we drink alcohol, make sure that it is not every day and hardly ever causes intoxication.
- exercise for half an hour or so, several times each week, hard enough to raise a sweat.
- from mid-life onwards, see a doctor for a health check regularly to measure blood pressure, weight, general health and review any medications we are taking – your GP can advise how often this should be.
- know your cholesterol level and get advice to lower it if it is too high.
- keep mentally active, especially by staying socially active, and by challenging ourselves with new things every year or so.
- ensure that we plan for retirement so that our activities and social contacts do not drop away to nothing when we stop paid work.

Perhaps it all boils down to “everything in moderation” and “if you don't use it you lose it”. Some people choose to take various medicines in the hope that these will prevent dementia, such as multivitamins, Ginkgo Biloba, vitamins, Aspirin, fish oils or omega-3 fatty acids, hormone replacement therapy for women, anti-inflammatory drugs, turmeric, coconut oils and so on. There's no hard evidence at this stage any of this will help you and some of it may even harm some people. Let the buyer beware!

- **Role changes when a close relative has a dementia.**

We can find ourselves taking on all kinds of new roles when a parent or other close relative develops a dementia, such as acting as a driver, cleaner, nurse, social worker, police officer, accountant or lawyer! Sometimes this is very unwelcome, sometimes this can crowd out our role as son or daughter (or other relative or friend), and sometimes this can have a large impact on our other roles unrelated to the person with dementia, such as reducing our ability to be a husband, wife, parent, employee, boss or friend. Sometimes we don't actually have the resources to take on the new dementia-related roles due to insufficient time, energy, skill, motivation, health or money.

Be alert to the dangers of over-commitment. It may be helpful to list all the important people and groups you deal with and write down all the roles you fulfil. You might end up with a very big page of relationships and roles. This can help you weigh up what is happening when roles change, discuss it with others and actively decide what to do next rather than just let events follow their own course. We cannot keep adding more – something will 'give'. Do we want to choose what that is, or let it happen because we drop the ball or burn out?

Options might include:

- re-balancing things so that you add the new roles as well as maintaining all the old ones, but with different emphases.
- dropping some of the old roles or relationships (we do this all the time in other circumstances).
- sharing the new roles or some of the old ones with other people, such as redistributing the bread-winner or parenting roles with our partner.
- sometimes we can ask or pay social agencies to take on some of the roles, such as organising day care for our parent with dementia, or for our children.

Notice that this widens our options from just thinking in a simple way about "I have to take on looking after Dad on top of everything else".

There may come a time when the right thing to do is to relinquish the caring role almost entirely to professional people that are paid to do it. This can free you up to 'just be a son or daughter' (or other relative) again. This might be unexpectedly good for you and for the person living with dementia.

Don't forget that none of this is set in concrete, so decisions should always be made as current 'working plans' only. Circumstances will change, and not just the dementia-related circumstances of the person you care about. This year's plan may not work for them or for you next year. Such flexibility also gives you the freedom to notice when 'Plan A' isn't working for someone in your network of relationships, not least yourself. There is always a 'Plan B'.

Another thing that it is important to remember is that you don't need to make all of these role decisions yourself. There are usually other people in the family to help decide and social agencies can help by providing a sounding board for you. Never forget that the voice and views of the person with dementia are actually at the heart of all this. They may well have some very good advice for you. Do they even need you to be taking on all the roles you are worrying about, right this minute, in the way you envisage?

Finally, remember that role transitions may be a very good thing. Taking on a carer role may be extremely satisfying for both of you, reinforcing your mutual love in a new way as the person with dementia's development enters a new phase. In some societies dementia is not seen as an illness but as a developmental stage. Perhaps we have something to learn from that?

- **Legal issues.**

My advice is that every adult needs a Will that matches their current situation, Enduring Powers of Attorney set up for Property and for Health and Welfare, and open discussions with their families about their attitudes towards serious illness, death and dying

This last part is called Advanced Care Planning. I encourage you to write these advanced care planning thoughts down in a formal document with your GP. Ask them how this can be done. Other legal documents such as an “Advanced Directive” can be drawn up with a solicitor but my opinion is that hard and fast rules about serious illness and dying are not nearly as useful as general guidelines and attitudes.

Start with yourselves on all these legal issues and then ask other relatives to do so too – or do it together!

If your relative with a dementia has not set up Enduring Powers of Attorney (EPOAs) or a Will, it is important to be sure that they have enough understanding to go through with this before seeing a solicitor. This is called “capacity” or “competency”. Your relative’s doctor is the person to advise you regarding this if you are not sure, and they can provide you with a supporting letter for your solicitor if required. Occasionally they will refer to a specialist for a second opinion when the issue is unclear.

Once Enduring Powers of Attorney are set up, they are not automatically set in action. As an ‘attorney’ you usually have no power to do anything unless the person with dementia voluntarily gives it to you (such as “signing rights” at the bank) or when a qualified health professional advises that the subject person no longer has the capacity to manage their own affairs. This is called ‘activating’ the EPOA and requires a medical letter, usually from the person’s GP. Capacity can change (getting better or worse depending on all kinds of factors) and it can also be sufficient for some things but not others, so the whole situation is quite complicated. Having said all this, EPOAs generally work well to protect your relatives with dementia as well as yourself.

Setting up EPOAs has a cost attached because a solicitor must be involved (a separate solicitor for the person setting them up from your own solicitor, if you are to be the person named in the EPOA). They generally cost a minimum of \$300 for each of the two EPOA documents.

- **Any questions?**

Dementia Canterbury has a great deal of information and experience in dealing with these issues and questions, and knows how to get more in-depth answers from legal or health care experts if required. Don’t hesitate to ring them up if you want to know anything else.