Conversations about care: *are you having a Family Meeting*?

Guidelines to having a successful family meeting following a diagnosis of dementia in the family

Dementia can have a significant emotional and practical impact on the lives of a person diagnosed with it and all family members. Practical issues such as putting care in place and addressing financial and legal arrangements can be challenging, and disagreements within families are common. Families and caregivers are encouraged to meet soon after a loved one is given a diagnosis of dementia in order to discuss some of the issues and challenges that may arise. This guide offers some useful suggestions for having an effective family meeting and offers a number of options for addressing or reducing family conflict.

Before having a family meeting it is often helpful to consider the following:

1) Family roles will affect perspectives on dementia in families. For example:
    - A spouse/partner of a person with dementia, distressed at the illness of their life partner, may have a different perspective on care planning from that of sons/daughters, or extended family.
    - Siblings may have different views for example older siblings may feel pressure to take on responsibility for decisions around care due to earlier family roles; on the other hand younger siblings may feel an unequal involvement in decision making.
2) Family members should acknowledge
    - they have each had different experiences within their families
    - they have different life circumstances and *these may change*
3) The focus should be on the person with dementia
4) Difference of opinion is normal within all families
5) There will be disagreements but all opinions should be respected
6) Understanding different points of view within the family is important
7) Previous family disagreements should be put aside and personal criticism of other family members avoided
8) A written summary / plan of action of each meeting can be helpful

9) An agreement to further meetings will reduce the need to resolve everything in a single meeting, since *care needs are likely to change over time*

Holding Family Meetings

Caring for a loved one with dementia can present families with many challenges. The progression of dementia may not follow a predictable pattern. It may be difficult for families to make care plans for a family member. Callers to our Helpline and attendees of our family carer training courses frequently raise the issue of communication difficulties and disagreements within families when they try to make decisions about care. For example:

"How do you go about getting all the family on the same wavelength?"
"I find the changing relationship between me and family members most challenging"
"How to deal with the blocks put up by family members?"

Dementia affects people differently and the circumstances and capacities of family members to provide support can vary considerably. Therefore it is often helpful for families to meet and discuss care plans for a family member with dementia.

Family Meetings: Information that may help

Common questions asked by family members affected by dementia

Our comments and suggestions are based on feedback from families and our experience in assisting them to plan care for their relatives. It can be difficult to come up with correct answers for many different situations family members encounter. Over time new insights and ideas may emerge.

Should the person with dementia be involved in family meetings?

As far as is possible, a person with dementia should have the opportunity to be involved in all discussions and decisions relating to their care, including their financial and legal matters. This is often best done in the earlier stages of dementia, if possible, taking into account family circumstances, the stage of dementia and the person's ability to participate without distress.

A family meeting that becomes tense could be very difficult for a person with dementia. The person may struggle to concentrate and become distressed if disagreements about their care become tense and may find it difficult to understand the discussion. Therefore it is recommended that efforts are made to avoid this situation and arrange 'carer only' meetings if necessary.

It is always unhelpful to involve someone with dementia in arguments and family conflict.

How can family members who live abroad or long distances away from a relative with dementia participate in care arrangements?

Some family members, due to their personal, family, employment and health circumstances, or location, have difficulties providing direct care for a relative. Those living abroad or far away should be enabled to discuss and comment on care plans for a relative by phone or email. With goodwill and creativity, they may be able to use some weekends or holiday periods to provide help with care, or contribute financially to enable the family to engage professional home carers or arrange respite care. It is not helpful to make plans without consulting them. They should ensure that they do not undermine the efforts of the main carers, living with or near the person, doing their best in their circumstances.

What are the main issues that cause tension and distress in families of people with dementia?

The main issues likely to affect families are:

- A diagnosis of dementia, is likely to affect family members in very different ways including feelings of loss, grief, fear and stress
- Denial of the fact that a relative is unwell despite evidence that something is wrong
- Denial by the person with dementia that there is anything the matter (for many different reasons, the person is often not told the diagnosis, forgets being told, or is unable to deal with the diagnosis)
- Distress about the person's condition and prognosis
- Disagreements over the person's condition and capabilities
- Anger directed at the person with dementia through belief that the person is saying or doing something 'on purpose'
- Distress about differences of opinion about care plans within the family
- Resentment about level of contact or care input of other family members
- Family members perceiving professional/non-family care as their failure rather than opportunity for the person to experience stimulation and friendship from contact with others
- Resentment over family members′ income or contributions towards care costs.
- A main carer excluding other family members from contact or with a relative or not sharing information regarding a relative with dementia.
- A care crisis arising from sudden deterioration in the person's condition, illness of a main carer, lack of backup support, lack of planning
- Lack of support services in the community

What can families do to avoid family conflict when caring for a relative?

*Even in the **best of families** the onset of dementia may precipitate distress and anger. It is helpful if families undertake a number of actions*

- Ensure that all family members have accurate **information** about dementia. This should include children and teenagers who may become confused and distressed if they do not understand what is happening to a relative with dementia

- Follow up all available **sources of help.** Contact the public health nurse for advice about local services- home help, day care and respite care. Contact the *Alzheimer Society of Ireland* and other organisations that might provide help and support
- If possible have **regular family meetings**, or phone/email contact to discuss both short term and longer term care plans

---

Why should families have regular meetings about caring for a relative?

During early discussions families may reach decisions that one individual within the family will take on the caring role. This may arise in many families, but can be more likely to occur where a person is a spouse/partner, or if a family member receives a carer's allowance, or is due to inherit a family property.

Families are advised to consider the changing needs of a person with dementia. In the very early stages of dementia it may be relatively straightforward for one carer to provide simple care and support for the person with dementia. However, as dementia progresses care provision may become too physically and emotionally exhausting for one person and care plans need to be reviewed. This can be done more easily if families recognise the need to review plans.

Regular meetings can-

- Provide the main carer(s) with the opportunity of discussing care issues without feeling that he/she is complaining to others
- Provide an opportunity to family members who are not as closely involved with care to raise concerns and ask questions which they may not want to ask in telephone conversations
- Remove pressure to complete plans/solve all problems during one meeting
- Reduce pressure to assemble all the care support, housing adaptation information and legal and financial information at one or two meetings

How can we avoid having arguments if we have different opinions about caring for a relative?

It may be helpful for family members agree to consider a number of key issues before discussing the care for a relative.

- The decisions made should ensure that the wishes and needs of the person with dementia are met as fully as possible within the constraints of family circumstances. (*Families can feel pressure to comply with the wish of a family member to be cared for at home even when the house layout, lack of suitable adaptations, and lack of family resources necessary to ensure that a family carer is not overwhelmed with care responsibilities are not available)*
- If a large family is involved it may be necessary to agree how decisions will be made e.g. by consensus, by majority
- If the family has had differences of opinion in the past it may be necessary to involve an outsider (**mediator**)

- The care for a person with dementia should **not** (except in the early stages of dementia, or in unusual circumstances) be left to one family member
- Caring can be very stressful and planning discussions should not undermine the efforts of the main caregiver
- Family members should avoid making promises they cannot keep

- Delegation of tasks is very important but families need to accept that their siblings/relatives may do things differently
- In-laws involved in caring should be invited to attend some meetings about care even if they are not involved in legal and financial planning meetings

What happens if we can't agree on care plans?

If, after many attempts, 'family members only' meetings are unsuccessful, involvement of an outside **facilitator/mediator** may make meetings more productive. If, after involving a mediator, families cannot agree on care plans it may be necessary to have the person made a ward of court. Officers of the court will be involved in making financial, legal, and care decisions for the person and although would seek the views of the family would hold ultimate responsibility for making decisions. This legal procedure is likely to change when the Assisted Decision Making (Capacity Act) 2015 comes into effect.

What if a relative has not given power of attorney?

Occasionally, for financial and legal reasons it may be necessary to have a person made a ward of court, even where family members are in agreement on a plan of action. This usually arises where the person has *not* given power of attorney to a trusted relative or friend before he/she becomes unable to make these legal arrangements.

What can be done if a family member cannot, or will not, help with care?

Sometimes, despite all efforts, it may be impossible to involve all family members in the care of a relative. Those who do help may have to get on with caring knowing that, over time, they may feel a sense of satisfaction and achievement about the care and support they have given to a family member with dementia.

There are many reasons why some family members avoid involvement in care arrangements. Some of these reasons cannot be adequately articulated or understood at the time the family members are discussing plans.

- Dementia can profoundly change family relationships. If families learn about the condition and use creative and practical strategies to cope with dementia they can minimise its effects and reduce distress

- It is important to ensure that every possible support available in the community is accessed. Adequate respite, day care, and home care can play an important part in reducing tension and stress
- Family differences of opinion on care are normal and understandable. Debate, even heated debate, on the relative merits of proposals for care can have the positive effect of ensuring that the decisions reached are based on thorough examination of all options.

Conclusion

Dementia makes a significant emotional and practical impact on the lives of a person diagnosed with it and all family members. It helps if families acknowledge their relationships will change as they respond to emerging needs and issues. They need to make every effort to avoid damage to their relationships due to differences of opinion and the pressure of providing care for a relative.

The search for the ‘ideal’ plan or the ‘perfect’ care arrangement for a family member can heighten tension and distress in families. All families can reasonably do is explore a variety of options and agree on plans which suit their unique circumstances, changing plans and arrangements if, and when, necessary.

If families can agree on plans for care and work together they can experience support from each other. They can source their strengths and have the satisfaction of knowing that they did their best in their situation and met the challenge of dementia in their families as well as possible.

Useful Contacts

The Alzheimer Society of Ireland Contact the Alzheimer National Helpline Monday to Friday, 10 am to 4 pm. Saturday, 10 am to 4 pm Freephone 1800 341 341. Email: helpline@alzheimer.ie Visit www.alzheimer.ie	**The Carer's Association.** For services such as home respite, carer training and support groups around Ireland; Call 1800 24 07 24 or visit www.carersireland.ie
The Health Service Executive (HSE) To find out where your local HSE Health Centre is or to ask about services that may be available in your area; Call 1850 24 1850, visit www.hse.ie	**The Legal Aid Board** The board provides legal aid and advice on matters of civil law. There is a means test to access this service. The Family Mediation Service is provided by the Legal Aid Board at 1890 615200 or www.legalaidboard.ie
The Law Society of Ireland For a list of solicitors working in Ireland, call 01 672 4800 or visit www.lawsociety.ie	**FLAC – Free Legal Advice Centres** Voluntary organisation which provides information and referral on legal issues over the phone and at a number of part-time clinics. There is no means test for the service but they do not provide legal representation or undertake legal work. Contact the Information and Referral Line at 1890 350 250.
The Mediators Institute of Ireland (mii) For a list of all available mii accredited mediators you may contact by telephone or email or view the website on **:** **www.themii.ie** The Mill, 35 Fitzwilliam Place, Dublin 2. Tel : 01 – 6099190 Email : infor@themii.ie	