

Chapter 3 part 1

1.1 Chapter 3

1.2 introduction

Hello, and welcome again to our programme on coping skills for families and carers. This is chapter 3: maintaining relationships, Part 1: diagnosis.

1.3 Diagnosis: the carers' experience

You often hear about the advantages of diagnosis, and the changes it can bring, but getting to that point can be a complex process, from the point of view of the families with dementia and of the clinicians.

Please click on the video to hear carers talk of their experience of diagnosis.

1.4 Diagnosis: the clinician's experience

Clinicians also reflect on the complexity of making a diagnosis. Click on the video to hear more.

1.5 Diagnosis: 3 families

When it comes to diagnosis, the difference in experiences amongst families is seldom discussed. Yet family situations vary in terms of who knows about the diagnosis, how they found out, and who they tell about the diagnosis. Here, We will present to you 3 scenarios:

In the first case, a family is concerned that their loved one has dementia, but they don't know how to approach the subject with he person. Does the family address the issue with the person themselves, or should they consult with their GP?

In the second case, the family had received the diagnosis, but the person with dementia hasn't. In this case, the family is faced with a dilemma: do they tell their loved one of their diagnosis, and if they do, what is the best way to do this?

In the third case, the person with dementia themselves has received the diagnosis of dementia, but they are unsure as to how to tell their family.

Please click on the scenario closest to your situation to find out more.

1.6 Scenario 1

1.7 Scenario 2

1.8 Scenario 3

1.9 Diagnosis: benefits

Seeking a diagnosis can bring about both benefits and challenges. We will first discuss the potential benefits:

Anxiety and depression are both very common in the early stages of dementia, when the person is aware that something is changing, but they can't tell what it is. A formal diagnosis can help make sense of the strange changes that have been happening, and can help reduce anxiety and depression. It is important to treat the person with dementia with dignity and respect; they may have a diagnosis of dementia, but dementia does not define the person. The person doesn't BECOME dementia, they are the same person that have always been, but now they HAVE dementia. This is a very important distinction.

Once a diagnosis of dementia is known by the person with dementia, their family, friends, and the wider community, it can make the dementia journey less of a burden for all involved. On a practical note, the family can tap into the appropriate services right away, with the assistance of

the medical or caring professions. They can get in touch with the HSE, the Alzheimers Society of Ireland, the Carers Association, and Alzheimer cafes.

Following a diagnosis, families can understand and plan the caring role, friends can be informed and taught to understand the signs and symptoms of dementia, and local communities can gather together to offer moral and practical support once they understand the illness and its symptoms.

Local shops, post offices, banks and community groups such as the GAA, Active Retirement, bridge clubs and bingo halls will be much better equipped to interact with the person with dementia if they are aware of their diagnosis.

1.10 Diagnosis: challenges

The "one" relationship that you had before the diagnosis of dementia now becomes "many" relationships. Whereas you and the person with dementia had your own unique relationship, you may now find yourself surrounded by others: family members want to understand everything that's going on so that they can help, but also medical professionals: GPs, consultants, geriatricians, neurologists, and the caring professions: home care, occupational therapists, home help, social workers, Public Health Nurses. The relationship that was once one special relationship has now become crowded with well meaning others, and it can feel as if dementia has taken over and that the relationship becomes secondary. This can be difficult to recognise and accept, but if you still can and for as long as you can, you should continue to do the things you always enjoyed doing as a couple and as a family.

1.11 Overcoming challenges

How can we overcome the challenges of receiving a diagnosis?

First of all, make the person with dementia aware of the diagnosis, as well as family, friends and the local community. This is key in allowing the individual couple and the family to be active in their own environment for as long as possible.

- Seek support from family and friends

For example, if as a couple you liked to go somewhere on the bus but you can't take public transport any more, ask for a lift from a family member, friend or neighbour.

- Accept help whenever it's offered. Be specific in what you need and S.P.E.L.L. it out!

For example, ask "Can you do the shopping for me on Monday at 11?! or "Can you take me to an appointment in the hospital on Tuesday at 2?" or " Can you give me 2 hours on Thursday afternoon so that I can go out?"

- Stay active and involved in your local community

For example, go dancing, go singing, go to mass, go to the match, go for coffee, take someone along for support if needs be.

- Continue to be the couple you were for as long as you can

If you are husband and wife, or in a loving relationship, maintain physical intimacy for as long as you wish: hold hands, share the same bed, kiss, cuddle, be tender and loving, say I love you, reminisce. It can be helpful to remember that the person beside us HAS dementia but is not defined by the disease, they are still the person they have always been.

- As a carer, try to do the things that you would like your spouse to do for you if the roles were reversed.

For as long as you wish, be the individual, couple and family that you have always been, Seek whatever support is available to help you, and remember that these moments are precious.

1.12 For more information




Building Dementia Skills Capacity

Coping Skills for Families and Carers

**You have finished: Part 1: Diagnosis
in Chapter 3: Maintaining Relationships**

**You can now go to
Part 2: Living with losses**

for more information, go to
[Dementia Elevator](#)