

Journey through Dementia



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Foreword

In 2015 it was estimated that there were 850,000 people living with dementia in the UK, mainly being cared for in the community. The national financial cost due to dementia care is £26 billion; however care provided by family members save the UK approximately £11 billion a year (Alzheimer's Society 2015). In a society which has seen structural changes in family types, and an increase in geographical movement of family members, the question could be asked "Who supports the carers?"

In looking at dementia care, the whole family needs to be considered, as well as the prime carer(s) and the person living with dementia. Talk to any member of a support group and comments like "without these discussions, I don't know where I would be..." are frequent. It is therefore vital to have in place a supportive community for both the carer and person living with dementia.

Dementia friendly communities and groups such as Dementia Friendly Keighley are playing a vital role in the creating such a supportive community. This document along with the regular information sessions they provide help in signposting people to relevant agencies and services.

One of the biggest messages passed on at the sessions is that people can live well with dementia. In recent times examples of people living well with dementia have been highlighted in the media, thanks to celebrities such as Sir Terry Pratchett, Timothy West and Prunella Scales speaking openly about dementia whilst continuing to create great television and literature.

Another person who is open about her diagnosis is Christine Bryden, a lady who has not only found love and married since diagnosis, but also completed a degree. To conclude this forward I will end with a quote from Christine Bryden "as we walk this roller-coaster of life together. We are adjusting our dance steps to the changing melody of dementia" (Bryden 2005)

Helen Coates, DFK Volunteer

Bryden C., (2005), Dancing with dementia: My story of living positively with Dementia, Jessica Kingsley Publisher.

Introduction

Dementia Friendly Keighley (DFK) has provided this Journey Through Dementia document to support people with dementia and their carers, families and friends to read about people's experiences of their journey through dementia.

Each journey is unique to the individual and depends on many factors such as type of dementia, age at onset and other health issues. DFK has captured the stages of the journey through dementia and provided a diagram which illustrates each stage (see page 5). This document will break down each of the 7 stages (A-G) by providing more detail, illustrated by people's experiences. Individuals may not pass through each stage in the order listed in the diagram nor pass through all of them. Each stage can vary considerably in length from weeks to decades, therefore the diagram may not illustrate your experiences in the order they occur.

As you work through this document you will see that at each individual stage the diagrams include Stage G: Coping with Change and Grieving. The reason for this is that coping with change and grieving occurs at different stages for people with dementia, their carers, families and friends, so it is mentioned at each stage.

DFK have also produced a directory of local dementia services, activities and organisations that provide support. DFK would encourage you to have a look through the directory to see what additional support is out there for you and if you would like a copy please contact DFK on info@dementiafriendlykeighley.org.uk or 07452 773 788.

**The next section (p6-7) looks at:
Stage A - First Suspicions and Early Signs.**

Journey through Dementia

Coping with change / grieving
(Stage G)

First suspicions/early signs
(Stage A)

Medical Services/diagnosis
(Stage B)

**Living well with dementia
in the community**
(Stage C)

Formal professional care
(Stage D)

Care away from own home
(Stage E)

**End of life for person with dementia
and moving on for the carer**
(Stage F)

Stage A

First Suspicions and Early Signs

Coping with change / grieving (Stage G)

- No external indication to any one although the disease may have begun its development
- First suspicions that there may be something more seriously wrong with memory
- Possible denial by individual living with dementia and/or family/friends
- Growing awareness that the possibility of dementia needs to be taken seriously
- Discussion with family/friends about the topic
- Acceptance of need to seek professional advice

The diagram above summarises some of the steps that may be experienced during this stage of first suspicions and early signs. The following page illustrates stories from people describing their experiences during this stage.

Rod about Mary: “I realised with hindsight that a professional may notice signs long before it becomes apparent to the individual or their family. I have recently been told that Mary told someone she was worried she had dementia about eight years before it became obvious.”

Joan about Roland: “I first noticed the memory loss when he left the car in the car park, and could not find it. We went to the surgery and that’s when he was diagnosed with vascular dementia.”

Barbara about Brian: “We noticed that when driving Brian was forgetting to change gear, not noticing the way we were going and passing the road end.”

Eileen about Norman: “When we look back we first noticed something wrong when driving. He had driven all his life and had a garage in Shipley. He’d take a wrong turn when he was driving, or forget to change gear, but you don’t associate it at the time until he had a bump and he wouldn’t admit that it was his fault.”

Denise about Brenda: “I used to think others might think what’s wrong with my mum and I said I think she is just having a bad day. However you can see changes in character such as my mum never swears but she said ‘do you know I can’t make my effing porridge this morning’.”

Barbara about Brian: “Sometimes the sequence of things gets muddled as Brian started putting two shirts on and getting up at 2 am, getting dressed and demanding that it was morning and then I had to get up with him”.

Denise about Brenda: “She will have a sandwich and yoghurt for lunch and eat the yoghurt first and then the sandwich.”

However, often the individual is reluctant to admit the fact or seek a firm diagnosis.

Rod said “Mary resisted any attempt to discuss this with doctors or anybody” **and Barbara said** “the hardest thing was Brian wouldn’t let me tell the family or friends. It was shut inside of me and I couldn’t talk to anyone.”

Even when changes are acknowledged it is not easy, as **Eileen stated:** “The family couldn’t understand why granddad had changed.”

**The next section which follows Stage A (p-8-9) looks at:
Stage B - Medical Services and Diagnosis.**

Stage B Medical Services and Diagnosis

Coping with change / grieving (Stage G)

- Initial appointment with family doctor (GP)
- Simple tests
- Referral to consultant
- Possible memory clinic tests
- Consultant appointment
- Confirmation of a diagnosis of dementia: there being over a 100 types. The most common being Alzheimer's Disease (70%), then Vascular Dementia (20%).
- Medication prescribed to help control symptoms

The diagram above summarises some of the tests, appointments and diagnosis that may be experienced during this stage of medical services and diagnosis. The following page provides a sequence of events that are likely to be followed at this stage, although it may be different for different people.

1. A person's GP will check and offer treatment for any physical causes; for example, a low thyroid level or an infection would affect how someone can present cognitively. They will then make the referral to the Memory Clinic or a Consultant.
2. The Consultant Psychiatrist will see the person for an initial assessment.
3. The psychiatrist can request a CT head scan if felt necessary at this stage.
4. Diagnosis of Dementia is made by a Consultant Psychiatrist.
5. There will be a follow up visit at their home by a member of Memory Clinic Team, which are colleagues from the Community Mental Health Team and will be either a Community Mental Health Nurse, or Occupational Therapist, depending on what will best suit the person's needs. This visit is mostly a sharing of information and signposting on to other services such as Alzheimer's Society, Social Services and other voluntary agencies that may provide a home visit.

This visit is usually a one off visit, but if it is felt at this point that the person requires more input, then the case is transferred to the Community Mental Health Team for further support until such time the person can be discharged back to their GP.
6. The Community Mental Health Team will be involved for some people with Dementia, but not all and on occasions there may be hospital admission to Lynfield Mount (specialist hospital for people with dementia)

If it is looking likely to be a diagnosis of Alzheimer's disease then dementia medication can be prescribed to help some of the symptoms, but usually given after the consultant has requested further tests and is happy with these results. If medication is required, the initial prescription is usually by the psychiatrist and the GP will supply repeat prescriptions.

There are a number of different staff who may help with treatment and provide support such as an Occupational Therapist, Speech Therapist and Psychologist.

**The next section which follows Stage B (p-10-11) looks at:
Stage C - Living Well with Dementia in the Community.**

Stage C

Living Well with Dementia in the Community

Coping with change / grieving (Stage G)

- Informal support from family and friends
- Contact with organisations that offer support and activities to attend
- Attendance at cafes, and social groups set up to cater for those living with dementia
- Registration of main carer
- Commence Power of Attorney process (not needed straight away but useful to have ready for when it becomes essential)
- Consideration to continue to being able to drive

The diagram above summaries some of the steps that may be considered at this stage of living well with dementia in the community. Despite the devastation of a confirmed diagnosis, it is possible to live well with dementia and for some this stage can last a long time. Don't forget as mentioned on page 4 the directory of local services put together by DFK may help you to find out about what is available locally. The following page illustrates stories from people describing their experiences during this stage.

Joan discussed "Roland and I moved home and came up to be near our son, which helps provide extra support."

Denise said about Brenda: "She can go to the fish shop with a note. That is as far as she can go. I wouldn't send her anywhere that I thought was putting her at risk. She can manage the newsagent without a note. She knows to ask for a T & A and she goes with her 60p or a £1."

Joan describes: "There can be times when life continues peacefully, as long as Roland's with me, he's quite happy, wherever we are".

Barbara about Brian: "He reads, but usually only the big print. He can see the pictures and the big headlines in the paper"

Rikky explains: "It is possible for people to continue with things they have always liked, Rene can watch Emmerdale, but she can't watch the Street".

Barbara told us how they helped Brian with his memories: "we have got a folder we have made with photos; and the photos I have put in go right from him being born to the grandchildren... He is thrilled with those".

Barbara described how: "Brian was able to enjoy things from the past and our niece took him some books, they were his brothers that were bought when he was little. It was way back".

Eileen agrees: "looking back is often helpful, we started with the earliest memories that they had, babyhood, then school days and older, right up to getting married."

Denise describes how: "Friends of Mum's have what they call a roll up session just for the bit of exercise on the bowling green. We just do a few ends and she feels as though she is joining in."

Joan shared a story about Roland: "He did go missing and the police were called and they came and they were extremely helpful and I was amazed. They got all the history recorded; they wanted to know what he was wearing; things like where we had lived years ago. The police found Roland in Keighley, he'd gone back many years to where we had lived before. I was amazed the police were taking details from me then suddenly the door opened and about six more police officers came in. What they do is go out in groups to various places, I thought they were excellent."

The next section which follows Stage C (p-12-13) looks at Stage D - Formal Professional Care

Stage D Formal Professional Care

Coping with change / grieving (Stage G)

- Acceptance that level of support required is changing
- Day Centre attendance
- Domiciliary help
- Sitting service - either statutory, informal or privately funded
- Mobility issues - blue badge registration
- Check statutory entitlements
- Day Care provision increases
- Respite care
- Assessment for permanent care by Local Authority
- Personal decision to arrange permanent care
- Consideration to financial aspects

The diagram above summaries some of the steps that may be considered at this stage of accessing formal professional care. The following page illustrates stories from people describing their experiences during this stage.

Eileen commented: "They sent a female to care for Norman on the first appointment and he wanted a male. They sent a male for the second appointment who was very nice and he was someone who knew the garage and he was quite happy with him, he'd let him shower him and they talked about the garage. It was easier then."

Rod wrote: "Domiciliary help can be useful but it has its drawbacks. An 08:00 appointment to get Mary up can actually arrive any time from about 07.40 through to gone 09:00. This is understandable; however it meant I had to be up dressed and ready by 07.30 every morning seven days a week. We tried varying the time according to the day of the week but that proved too difficult for the caring service rotas."

Rod described: "When the time comes for assessment for possible residential care there is a whole mix of emotions - you are worn out physically and emotionally yet you wonder could you hold on a little longer".

However an individual may become upset and react badly not because of a bad service but because they see a person coming to help as "being on their territory".

It was discussed by many of the carers the need to understand the jargon. "The reference to OPR meant Older Persons Rate and the local term 'flexibed' is used to refer to a bed in a care home where the individual was carefully monitored and assessed over a five to six week period as to whether they met the criteria.

Mary worried about what the neighbours might think being picked up to attend day care services and asked that Rod tell them she was helping out at the day centre.

Respite care can be useful but consideration and planning has to be given to the timing of this service.

The range of services available from local authorities needs to be checked, some will entail costs for the carer or the person living with dementia.

**The next section which follows Stage D (p-14-15) looks at:
Stage E - Care Away from Home**

Stage E Care Away from Home

Coping with change / grieving (Stage G)

- Care Plan
- Choice of care home to be made
- Permanent care home
- Possible changes in behaviour
- Increasing dependence on others
- Loss of functionality
- Nursing care
- Hospital care

The diagram above summaries some of the choices and type of care available to people through care options away from home. Always ask for support from professionals when making these decisions and visit such care options to see how they feel and if they are suitable. The following page illustrates stories from people who have had to make these decisions and additional information for you to consider.

Rod when looking for a care home for Mary: “firstly visit unannounced, as if you were you are just passing, secondly check the smell; there is a difference between fresh smells which are unavoidable and stale ones and thirdly look at the way residents interact with each other.”

There is a Butterfly Scheme at Airedale General Hospital which uses a discrete butterfly symbol to attach to the notes of a patient living with dementia. This helps hospital staff to offer appropriate care for the individual.

Continued support from family and friends is vital even when in a residential care home. Outings and attendance at other clubs can still be possible during the day to allow as much of their accustomed routine to continue with familiar places and people to relate to. It is only gradually that these may become less easy due to impaired mobility or changes in behaviour.

Residential or care homes can be general or specialist ones that specifically cater for dementia. Some will have minimum age limits such as 65 years , an important point when looking for care for those with early onset dementia. There are a number of practical factors about location and your preference for the size of establishment.

Nursing homes will have 24 hour nursing support and their funding allows for nursing needs assessment to be made.

There will be changes in behaviour: **Rod said he noticed that Mary** went through denial - anger - paranoia - anger - bewilderment - acceptance - sadness - contentedness over a period of three years from first suspicions to being settled in a residential home.

Some of these changes may be helped by altering medication.

Sometimes a person can become agitated or upset away from home but **Margaret found that** there was a wonderful team looking after Bob in his respite placement who were happy to let him talk to her on the phone three or four times a day which calmed him down.

Care plans need to be discussed when considering care away from home: these need to be personalised to the individual as each journey is different. It is basically a support plan that covers all aspects of daily living so that any one reading it would know how the individual would wish to be cared for and communicated with. It covers risk assessments that seek to minimize any accidents. One aspect is understanding that there can be deprivations of liberty, such as a locked door to the premises, however this may be necessary because of the need to keep those in residential settings safe. This is particularly the case if mental capacity is reduced. However the over-riding approach is that it is person centered.

**The next section which follows Stage E (p-16-17) looks at:
Stage F - End of Life for Person with Dementia and Moving on for the Carer**

Stage F

End of Life for Person with Dementia and Moving on for the Carer

Coping with change / grieving (Stage G)

- Advanced care plan
- End of life
- Legal and other formal arrangements to be put into place
- Funeral
- Re-adjustment

The diagram above summaries some of the arrangements and consideration for end of life and for the carer when moving on. The following page illustrates stories from people who have had experience of this stage.

This stage is especially difficult and the support of others is vital.

Rikky says "I think the time will come when I ask for help but I'm not looking forward to that, I'm not wanting that so I am delaying it as long as ever I can. Married 60 years next year."

Eileen said about Norman: "My children said they lost their dad many months before he died."

Margaret said "as we knew what was going to happen we spent all our money while Bob could still enjoy and appreciate the travel. I have no regrets about doing this as I now have wonderful memories such as our two winter months in the Canaries."

Some people manage to get "extra care housing" so they can remain with their partner. **Margaret thought** it an ideal way for her and Bob as they had been married for 57 years. "Sadly we only had seven weeks there before he died. Readjustment after death can be very slow, getting on for one year on, the tears return but I calm down and pick myself up but I can't bottle up the feelings for someone whom you have known for 64 years." "His funeral was the worst day of my life and I didn't want anything to do with anybody. But I know he's with me and a better feeling comes all over me."

An advanced care plan is a summary of what the person living with dementia wants in place as they approach the end of life. This covers where they would wish to be cared for, whom is involved and whether they want to be as conscious as possible or as pain free as possible. It will also cover the individuals views on DNAR (do not attempt resuscitation). These plans should be ideally be reviewed on a regular basis, always attempting to reflect the known wishes of the person living with dementia.

The NHS has produced a guide to this; www.endoflifecareforadults.nhs.uk

Sadly, for some living with dementia, they may not be able to be fully involved in making decisions. Deprivation of Liberty safeguarding (DOLS) arrangements may be needed and people appointed to act in the best interests of those whose mental capacity is reduced.

**The next section which follows Stage F (p-18-19) looks at:
Stage G - Coping with Change and Grieving**

Stage G

Coping with Change and Grieving

- This section is shown as existing throughout the journey.
- There is a constant change in circumstance and the need to re-adjust what is possible both for the individual living with dementia and the carer.
- It is possible that the personality of the individual living with dementia will change and sometimes in upsetting ways.
- Support will be needed from family, friends, faith groups and social networks: not just for the practical issues but also for moral and emotional help.
- While new drugs give hope for slowing down the progression of Alzheimer's Disease in mild and moderate cases - there will be still be an inevitable change in ability and functioning as an independent person for those living with dementia.
- Throughout the process there is continual readjustment and the need to accept that your life has changed. A once independent person gradually, often over a longer period, becomes increasingly dependent upon others.

The diagram above summaries some of the arrangements and considerations for coping with change and grieving. The following page illustrates stories from people who have had experience of this stage.

For Rikky: "I never in my dreams believed it would be so hard to think for two people or do things, simple things like getting up in the morning. Having to think what Rene is going to put on, what she's going to wear and it goes on the whole time."

"**Rene** will read a letter, put it down, comment on all the varying bits then start again. Yes I find that quite frustrating".

"I couldn't leave Brian, **Barbara said**, even to go in to the kitchen and prepare the veggies and things like that." "It takes their lives and yours life, you find you cannot go anywhere". "The guilt even now is bad."

Eileen: "He'd blamed me all the time. I found it very frustrating. He would argue with me wherever we were, no matter what I did or said, in company or alone. I was frightened to leave him because he would put a pan on and forget about it. I felt it was my place to look after him and didn't want to put him into respite care." "He couldn't stop eating, but he would tell everybody that I was starving him. He went from 14 stone up to 21 stone."

"Dealing with negatives from others is painful and the existence of local support is essential to help address the balance ...but she has still got feelings and she knows people are not as nice as they ought to be" **Denise** continued to say " her Mum's friend is aggrieved that her friends do not bother with her anymore since her dementia diagnosis. They don't seem to want to know". "It's strange. People are afraid of it, think they might catch it. She would do anything for anyone and now her friends seem to have abandoned her."

"**Rod** felt guilty when Mary went into residential care, within eighteen months of diagnosis, but realises that each person's needs and situations are different and the level of support available from family or others will vary enormously."

Each journey is unique as **Barbara says** "It amazes me how different everyone is. Some are very slow in the way the disease develops, others a lot quicker. Each individual affected has to tackle the journey in their own way".

Despite the relentless advance of the disease, **Rod said** "there can be moments when a glimpse of what was there still can be seen. In the middle of a her usual incoherent sentences, Mary who has difficulty focusing on things and often appears disconnected from the real world, looked at me straight on and said I still love you."

Acknowledgements and thanks

The stories included here come from individuals who shared their thoughts, their fears and their triumphs in September 2014. These were: Joan who cares for her husband Roland; Denise who cared for her Mum Brenda with Edna who is Brenda's friend; Rikky who cares for his wife Rene; Barbara who cares for her husband Brian and Eileen who looked after Norman, her husband. I have included some of my own recollections of caring for Mary as well as general observations from being with other carers at various events and gatherings over the last four years since my wife's diagnosis.

Thanks are due to a number of people who helped with the preparation of this document. Helen Coates and Andrea Peakall kindly assisted in the recording of individual stories which were transcribed by Sandra Kelly. Help with the preparation of the actual documents was provided by Hannah Lindsey of Keighley Healthy Living.

Originally the document was going to a single A3 sheet with a flow diagram and arrows linking to bubbles with the various services. As the work progressed it was realised that it is not a simple straightforward journey and one size does not fit all. This booklet is the result but hopefully it illustrates a "typical" journey in which many will recognise parts of their own experience.

I have also received, as this booklet was being finalised, some helpful comments from Margaret who cared for her late husband Bob. Comments have also been gratefully received from Rebecca Regan, Alzheimer's Society staff and Vicky Thompson of Regency Court.

Rod Tickner,
DFK Committee Member.

Dementia Friendly Keighley (DFK)

DFK is a voluntary organisation (registered charity number 1171003) working to change the way communities in Keighley, think, talk and act about dementia.

DFK provide:

- Information on dementia through Information Stands and Leaflets
- Events about dementia
- Dementia Friends sessions for those who want to learn more about dementia
- Support for local businesses to become more dementia friendly
- Support for local services for those living with dementia and their carers
- Volunteering opportunities for local people
- Free membership for anyone interested in Dementia Friendly Keighley and/or would like to get involved
- Free newsletters to keep up to date with local projects, services and events

If you would like to know more about DFK or if you would like to get involved with helping Keighley become more dementia friendly please contact us on the details overleaf

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Notes

Notes

Please contact DFK if:

- If you would like more copies of the Journey through Dementia or the Directory of Services
- If you are aware of other activities, services or organisations we could add to the Directory of Services
- Or if you would like to get involved or become a dementia friend

DFK can be contacted on:

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