

DEMENTIA

IMPACT ON RELATIONSHIPS



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ABSTRACT

When people receive a diagnosis of dementia, life changes. The journey from pre-diagnosis onwards can be a long road. Life must still be led to the best of an individual's ability. For some, this is a bewildering experience, fraught with uncertainty. This study explores how this affects a couple's relationship and in what way.

The research was carried out by Lynda A Hogg; the report was written by Lynda A Hogg.

As a person with a diagnosis of dementia, I understand what it is like to live with the illness and the impact it can have on relationships. Lynda

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DEMENTIA - IMPACT ON RELATIONSHIPS

There are so many connotations and variables and no two people are alike. The flamboyant extrovert can become quiet and the normally introverted person can become more outgoing and vocal. The one certainty is that change is inevitable.

Introduction

Dementia does not discriminate; people who receive a diagnosis of dementia come from all backgrounds and social levels. Many high profile people over the past few decades have received a diagnosis of Alzheimer's disease or one of the other dementias and have had to come to terms with it. Whether you are a president of a country, prime minister, philosopher, teacher or homemaker, dementia has an inevitable impact on your life and relationships.

Some people have family support networks and others are alone. Everyone reacts differently. If you have a partner dynamics may change. The person with the illness may have to give up work if they are still in employment. If you are already retired, you will look at things from a different perspective. Many people look well into the future and zoom from the start to the end of the illness, as if a middle period does not exist.

This study explored the effect a diagnosis of dementia had on couples' relationships, from both of their perspectives. An application was submitted to the Averil Osborn Fund of the British Society of Gerontology to fund a small research project and received their favourable consideration.

Methodology

Couples were invited from all over Scotland through an advertisement in Alzheimer Scotland's newsletter, to take part in the study and a total of ten decided to participate. The ages of the couples ranged from late fifties to late eighties. Of the ten partners, seven people had been diagnosed with Alzheimer's disease, one with frontal lobe dementia, one with a mixed dementia and one with Lewy Body. There were eight men and two women. It was imperative that only one person in a couple had a diagnosis of dementia, as it would spoil the outcome of the research if both partners had the illness. This was because both collaborators' perspectives were needed to determine the impact dementia had on the relationship. In this study, both the person with dementia and their partner's answers were of equal importance.

People were initially contacted by telephone to be given a brief overview of the study and appointments were then arranged in writing. There were two visits to each participating couple; the appropriate consent was sought and forms signed on the first visit and the interview carried out on the second visit. Each person was also provided with an information sheet about the study and questions were answered or explanations given

when asked. It was emphasised that anyone could withdraw from the study at any time, without giving an explanation. Both members of a couple had to be willing and able to take part. Each interview was recorded to be transcribed and analysed later.

The interviews were semi structured and conducted in the comfort of the couples' own homes. A questionnaire was designed, divided into four sections: 'Pre-diagnosis, at diagnosis, post-diagnosis and ongoing situation'. A pilot study was carried out to test the validity of each question; a small number of questions had to be altered before the study commenced and some wording simplified. Each interview lasted between 50 and 80 minutes. The questions were pertinent to bringing out the theme of the impact dementia has on relationships. As a person with a diagnosis of dementia, I am well aware of the sensitivities of the partner with the diagnosis and the need to allow time to absorb a question and to formulate a response.

Analysis

Each interview was transcribed in full and studied on an individual basis. Notes were made on different coloured paper and stapled to the transcription to capture significant data on the impact dementia has on relationships from pre-diagnosis to the ongoing situation. The transcript was read twice, firstly for an initial assessment and notes and secondly to verify the validity of the data.

The data was then divided into the responses of the person with a diagnosis and their partner separately. The coloured notes were then looked at for each, to decide if any response matched both the person with the diagnosis and their partner, or if the colours indicated a conflict of opinion, on the impact dementia has on a relationship. This was repeated for all ten transcripts.

All transcripts were looked at for a third time and the coloured notes for all the participants were studied to ascertain if there were any emerging threads between the couples and their experiences. The publication, "How to Analyse your Data – A Practical Guide to Research Methods" assisted in this process.

Anticipated Outcomes

It was of particular interest to ascertain if the ten couples had common threads running through their experience with dementia, or if diversity would be found.

Before diagnosis, it was an expectation to find that dementia was 'the elephant in the room'. The person knew there was something wrong with them, other people also knew, but nobody could quite put their finger on what it was.

Sometimes it takes a long time for someone to get a diagnosis and others are told they have another illness, for example depression. This puts a huge strain on a couple and the uncertainty must have an impact on their relationship. The partner with the diagnosis may

be perplexed and their partner possibly frustrated and annoyed. It is imperative to find out if it took a long time to get a diagnosis, as you cannot draw a line and move forward until it is made. This should be an interesting outcome.

If anyone is taking one of the drugs that appear to help cognition, but not cure the disease, it is expected that although some people remain the same, some may find an improvement.

If the person with dementia attends a day club or goes out with a support worker, it should help a couple, as the time apart should be of benefit to both parties. It is of concern that in some instances, the person with the illness goes as they feel they must, not because they want to. It could be an expected outcome to find the partner with dementia is reluctant to go and their partner is glad of the break.

The outcome to the stigma question is very difficult to predict. Some people simply cannot cope with the ill person and so they simply avoid them, which can lead to isolation in some instances. The expectation is to have a mixed bag of answers to that.

Some questions, although simply constructed, may open up avenues of further interest. It is very exciting, as although you can visualise expected outcomes, it may well be the unexpected that is of significant value.

The expected outcomes may not reflect the actual outcomes, which makes any research study exciting. If one knew the definitive answers there would be no need to ask any questions.

Format of results

After the transcription and analysis of the data was completed, different ways of presenting the material were considered. The presentation is in essay form, each couple represented by their own short chronicle complete with quotes.

All couples' names have been changed to respect anonymity.

Andrew and Davina

Changes were subtle before diagnosis. Davina noticed that Andrew's driving was different. He got lost on several occasions, which caused agitation. For example, ending up on the Lanark road when he was meant to be driving to Bo'ness, which was strange, as Andrew had a photographic memory. On another occasion, he was driving back to Edinburgh from the north with his wife and ended up by mistake in Stirling Castle car park. Andrew was very upset by the Stirling occasion and kept repeating, "What will I do, what will I do now?" which was distressing and perplexing for Davina. He was extremely stressed and agitated. Another change before diagnosis was Andrew's relationship with money. In one notable incident, he withdrew a large sum of money from the bank but was unaware that he had withdrawn it and the money was found in various places, including amongst underwear and pullovers. These factors prompted the couple to seek advice from their doctor, as these factors put a strain on the relationship.

Davina approached the GP by herself initially, to explain the problems Andrew had been having. The GP was wonderful. They then went together with a list made on a large piece of card, which the GP kept to help with the referral and a copy was sent to the psychiatrist. An appointment was made and the specialist made a diagnosis within weeks.

The psychiatrist - a woman - called at their home and as a painter was decorating at the time, they sat around the kitchen table. Davina said, "The diagnosis was appalling. The psychiatrist - the second witch in the Scottish play - had a copy of the list of concerns I had given to the doctor. She asked the usual rubbish and said that Andrew had Alzheimer's disease, he should make a will and for me to get a deed of attorney. She then said good morning and left." It was distressing to hear the news given so coldly, even though they both thought it could be dementia.

Davina was both shocked and relieved at the diagnosis. Andrew said, "It was something I had to accept, so I accepted it," and they both treated it as they would any other illness.

They made an appointment to see someone at Alzheimer Scotland the following week, when they received a book and some leaflets. Some of the advice in the book was to get rid of rugs and footstools, which they duly did. They had always eaten a sensible diet, so no changes were needed there. They then decided to tell everyone they knew for Andrew's safety and then started the search for a research programme, where his brain might be useful on decease. It took many months during which time Davina was recovering from the shock and trying to sort out all the papers and financial aspects - all of which were in a mess. Indeed, it took three years to trace everything.

Davina made use of Alzheimer Scotland's Dementia Helpline on a few occasions. Davina said, "I phoned several times during the night and cried to them and they listened. Now I seem to be able to cope on my own but I know they are there. It was so helpful. You are

lying awake at two in the morning and the tears are coming and you can pick up the phone.” The hardest thing initially is to admit to a need. This illness cannot be dealt with without professional input from GP’s, Health Visitors, Social Workers etc.

Within a month, Andrew was prescribed Aricept, one of the cholinesterase inhibitor drugs and this proved to be very helpful. He ceased to be quite so agitated. It also seemed as if a clear diagnosis was better for him, than the months of wondering what was wrong. Support workers were great for Andrew as this enabled him to go on outings, which he enjoyed very much. He particularly enjoyed visiting the City Arts Centre, playing skittles and going for walks. Andrew said, “During the Edinburgh Festival I listened to a Russian band playing in Princes Street Gardens, which gave me enormous pleasure.” Davina said, “The outings are great for Andrew because he can enjoy male company and do things that I would not be able to do.” It also allows Davina to have a rest, as she gets so exhausted.

Immediately you know who your friends are. Davina said, “Our children were fabulous and still are,” which was in contrast to some friends who were simply disinterested and not wanting to know. However, Andrew and Davina carried on as normal and had a laugh about it, although it did trouble them to some extent. From three siblings the news of the diagnosis evoked different responses: First sibling, “That’s what you expected; keep your pecker up,” second sibling, “You frighten people off by telling them” and third sibling, “That’s what you expected,” followed by a change of subject.

As time passed the couple adjusted. Dementia affects all aspects of a relationship and the balance changes. Davina has her own health problems and can become speechless with exhaustion. She said, “One evening I was so whacked I could not even do Andrew’s eye drops.” The small things mean a lot in the relationship and this was upsetting. Davina was advised to pace herself but she said, “How can I pace myself when I have all these demands?” She also said to the children, “It would be so much easier if I did not love him so much,” although they have been together for 53 years.

Andrew goes for respite, which makes a big difference to him, and the break gives Davina a rest. He is very positive about it and treats it as a holiday. He is unaware of the passing of time or the seasons and at home, Davina sorts all his clothes out for him, to prevent him putting on the wrong clothes for the time of year. Davina said, “I have far less time for myself and far less time to look after myself. I have given up the things I did to look after Andrew and have no personal life. I do not even go to the book club. I do not resent this, it is simply a fact.” There are so many changes to the relationship and some are quite fundamental. Davina said, “I explained to my son when we were all out for a meal, that although his dad looked at the menu, he had lost the ability to choose. I discuss the menu with Andrew and help him with his decision. I wanted my son to understand the change in dynamics and that I was not simply taking over.” They both keep the same pocket diaries and check regularly. Each evening Davina writes a “Post-it” note with the following day, date, year and what is happening. This goes in the front of Andrew’s diary. When things go

wrong, the couple blame “Al”, not the person. Constant confirmation is needed. Discussions about how much freedom can be allowed with safety are frequent, as this needs constant adjustment.

Davina took over all the financial aspects of their lives after diagnosis and has to take responsibility for every decision in their lives. She is so glad that she is still capable. Andrew gave up driving which he enjoyed and kindly allowed himself to be driven everywhere. Davina can drive, which now proves to be very useful. Although Andrew missed driving, he said, “Once you know you cannot do it, then that is it. I am fortunate I can still do the small things, like going for the paper or taking a list to the supermarket for a few items of shopping.”

The couple both realise that the illness manifests itself differently with each individual and there is no logic in its effect. It may be possible to achieve something one moment and not the next, which is incredibly frustrating. In fact, everything is very unpredictable.

Although inevitably life has changed, their love for each other is as strong as ever, even greater. The love is deeper and Davina remarked that they have had a very fortunate marriage. Davina said, “I still love him, very much.” Andrew said, “I still love her too and care for her to the best of my ability, which unfortunately is not much on some occasions.” One of the biggest impacts on the relationship has been Andrew’s memory loss and behavioural changes. Davina said, “It is far from easy to see your best beloved so often bewildered and insecure. It is quite astonishing how much sympathy there is for a heart problem or cancer but mention Alzheimer’s or dementia and so called friends disappear.” The couple remarked that as time goes by they have less time for these people anyway, as they thrive on the regular routine provided by social services and careful organisation.

Very sadly, six years on, the couple are now moving into the next phase and Davina often has a little weep about it. Andrew is shortly moving into permanent care and because of recent experiences; she knows it is the right decision for them both. Davina said, “Although it is very sad, I know we will have some joyful days together in the years to come.” Andrew said, “Well to me it is sad too but I know it is for the best.”

John and Edwin

John was very tearful as he described how his relationship with Edwin slowly changed from pre-diagnosis onwards. They met at a conference 13 years ago and set up home together in 2000, when John was 57 and Edwin 50.

The years passed and they were very happy together and both enjoyed their work and hobbies. They both loved their golf, snooker and chess and played all three regularly. John retired in 2006 at 63. Edwin was 56 at the time and still in employment.

Towards the autumn of 2007, John noticed changes in Edwin. He was concerned but not overly alarmed. Edwin could be offhand and vague and at times downright snappy. John made allowances, as being retired; work pressures were now behind him. He appreciated the fact that Edwin was still in an office with all the politics and a heavy workload. John thought that Edwin needed his batteries recharged and after the Christmas break, he would be okay.

Christmas day arrived and it was a disaster. Edwin did not want to go to friends as arranged but told John to go if he wanted to. John decided to stay at home with Edwin to try to make the day as pleasant as possible. As they had been going out for lunch, there was nothing prepared so they had cheese on toast. John said, "I was in a bit of a daze wondering what on earth was going on but felt Christmas Day was not the time to explore the issues. Edwin was relaxed and I did not want to put him on the defensive or trigger a bout of anger." Edwin said, "I was sick of the expectations that Christmas threw up. Spending too much, visiting people, eating too much and having the usual conversations." They watched television and chilled out. John suggested a game of chess and was very aghast when Edwin flared up. Edwin said, "Yes, I did flare up and told you to stick the chess pieces in the bin. I was relaxed watching television and yet again you were putting pressure on me to do something else." John decided to go along with the rest of the day as it unfolded and did not make any suggestions as to what they should do. Edwin appeared happy sitting with his feet up, staring at the screen and not making much conversation.

John decided to have it out with Edwin on Boxing Day as he felt they could not continue as they were. Edwin said everything was okay and he was just tired, but John persuaded him to see a doctor after the festive period. The doctor thought Edwin was depressed and prescribed antidepressants. Nothing much changed in the early months of 2008 and Edwin was still moody and lethargic. He kept losing things and kept accusing John of hiding the car keys. By April, he had given up driving of his own accord. Edwin said, "Each time I went in the car I felt I was starting from scratch. I used to sit for a bit before I would start the engine and repeat to myself, mirror, signal, manoeuvre and then I would drive off if I were satisfied. More often than not, I would switch the engine off and start again, as I kept losing my train of thought. It was so exhausting and I was getting into such a menacing mood, that I decided to give up driving and get the bus."

Unknown to John, things had been going badly at work for Edwin. He felt his workload was too much and fell further and further behind. He had an informal chat with his boss and Edwin told him he was simply going through a bad patch and would catch up. Unfortunately, apart from the work taking him a long time, he kept getting work back to redo. Edwin said, "I did not think things would improve, so I tendered my resignation, worked my notice and left. I told my boss I needed a change of direction but the reality was I could not cope with work anymore." John was not annoyed when Edwin told him he had resigned from his employment, although he was surprised that Edwin had gone to such extremes. John said, "We did not particularly need the money from Edwin's job. Although not rich by any manner of means, we were comfortable. I did not envisage Edwin getting another job, partly because of his attitude and his apathy. I felt he would now relax more and we could spend time on golf and hopefully he would get back to his cheery self in time."

Although Edwin had given up work there was no improvement in his attitude. He still complained of being tired but blood tests revealed nothing. He came off the antidepressants as he said he was not depressed, just unbearably exhausted. He was referred to a psychiatrist and received various tests and a scan. He was very quickly diagnosed with Frontal Lobe dementia. Edwin said, "What a relief to finally know what was wrong with me. At least I knew I wasn't being bloody minded and heartless on purpose." John was saddened by the news and angry that their future had been stolen. He said, "I was devastated by the diagnosis."

The couple decided on a short holiday to come to terms with the diagnosis, although it was not a success. Whereas John envisaged games of golf and snooker, Edwin slept late then pottered in the hotel room for most of the day. He now ate sparingly as he had lost interest in food. Never a drinker or a smoker and a great fruit and vegetable eater in the past, he grew bitter and questioned why he should have got this illness. He said, "I think the advice to eat 5 portions a day of fruit and vegetables is a load of cobblers. I did just that and still got this horrible illness." John said, "We do not have a relationship anymore. We just live in the same house. I feel I am constantly walking on eggshells as anything I say can trigger an explosion of temper and swearing. The most trivial remark can cause this."

John decided after the holiday to try to get Edwin interested in something. He had resigned himself to the fact that Edwin did not want to pursue their joint hobbies anymore, dine out with friends or go to the theatre but decided to help him find something to do. Edwin joined a day club for people with dementia where he could take part in various activities, such as dominoes, cards or pottering in a small garden plot. He also got his lunch there and John felt he could play golf and see his friends whilst Edwin was at the club. Although John was free to do what he wanted, he felt he did not want to leave Edwin on his own doing nothing. However, the day club did not last long. Edwin said, "I could see people got a lot of enjoyment out of the club and the staff were superb. It was not for me though. I had no

interest in any of the activities and resented being with strangers, when I did not even want to be with friends.”

Edwin decided he only wanted to be at home, as he no longer felt comfortable in other peoples’ company. Edwin said, “The smallest thing can irritate me and I am far more relaxed on my own. I know this is not an ideal life but I enjoy the calm surroundings and there is less chance of an upset, except with John.” John has to deal with everything in their lives. He is now responsible for all the finances as Edwin is not interested. If John did not cook Edwin would not eat. Edwin said, “Of course I would eat. Possibly only bread and jam and the like but I would eat.” Edwin cannot be bothered to take a shower but will do so if John prompts him. He takes ages getting dressed but that is preferable to him lounging in pyjamas all day. If John wants to meet friends at night, Edwin is fine with it. He is perfectly happy at home but John still sometimes feels bad about leaving him. Edwin said, “I am glad when you go out as I feel you are watching me all the time and judging me. I think you feel I could do more. You are always going on about golf and I do not feel like it. I am so tired after a game that I resent feeling worse than I usually feel and resent you for talking me into it.”

Friends of the couple have tried to intervene and encourage Edwin to do things. However, if people visit, Edwin does not join in the conversation but will answer if asked a direct question. John said, “It is quite odd to witness, as Edwin used to be so gregarious. He has even asked people to leave, as he felt they had stayed too long.” Edwin said, “I do not mean to be rude and ask people to go in a nice way. Sometimes I feel like screaming at them to get out but try desperately to hold back.” Someone suggested buying a dog to get Edwin out of the house on a daily basis but he feels he could not look after an animal properly. In fact, he thinks it was a stupid suggestion as he can barely deal with his own issues.

John sometimes thinks it would be better to separate as a couple and Edwin agrees. Although John still loves Edwin, he feels downtrodden by the life they now lead and fears for the future. They have no sex life now, as Edwin is not interested. John is not even sure if they are still friends. Edwin said, “I think we are still friends but I do not know if I love John or even care about him anymore. I feel I have lost the ability to care and only concentrate on getting through each day in the best way I can. Sometimes I think it would be better to part and I could live a quiet life at a sedate pace and John could live a normal life. He still has amazing energy and deserves to be happy.” John is not surprised at what Edwin said, as he suspected that is how he feels. He used to be so caring and loving and that has gone. Sometimes it feels like being with a stranger and one that does not particularly want to be with me. Edwin said, “Sling your hook then, if that is what you want.” John is not perturbed at all by the remark as that is typical of the new Edwin. The illness has pushed them apart and perhaps there is no future together. Time will tell. John said, “This cruel illness has destroyed everything we had together.”

Keith and Amy

Keith was diagnosed with Alzheimer's disease seven years ago but could not remember much about the diagnosis and was not aware of any changes to his relationship with Amy prior to this. Amy was aware that pre-diagnosis Keith had become more reliant on her, as he could not remember things and he was not aware of things she expected him to be aware of, which she found difficult. He was also less sensitive than he used to be.

The GP was very helpful when Amy first approached with her concerns. However, as Keith had recently had pneumonia, it was thought he was still in the recovery stage and it was another couple of years before they voiced their concerns again. Keith does not remember much about this either and Amy said, "It is great this memory loss, nasty things like pneumonia are put into his forgetery and are forgotten about."

Various tests were performed and because Keith's late father had Alzheimer's disease, this was a consideration. It was obvious Keith had a severe memory problem and when tests were completed Keith was prescribed Rivastigmine, although nobody actually mentioned Alzheimer's disease. Amy eventually asked the specialist and the diagnosis was confirmed. Amy said, "I already knew the diagnosis before they actually said it, so my wobbly time had come before that. Therefore, my feelings were inevitability, sadness, challenge and because I had nursed people with the very severe form of the disease, for me there was a whole luggage coming along. I knew what it meant or could mean." Keith said, "Feel is just a word and I am quite happy with that."

The couple decided to be completely open about the diagnosis and put it in their Christmas family newsletter.

After diagnosis, Amy took on responsibilities that had been Keith's. She particularly found it difficult to deal with finance and the car, both driving it and caring for it. Keith loved driving but had to give up. Amy said, "Keith had a driving test at Astley Ainslie and was told he was a really good driver for his age but because he could not remember where he was when he was out, he was no longer safe, so they would have to take away his license. They were really nice about it but he really enjoyed driving, which I don't particularly." The couple had already made wills, but after diagnosis they both made joint power of attorney and it is now activated.

One of the things Amy found most difficult early on was trying to convince Keith to give up the counselling, spiritual care and pastoring that he did, because he could not see that he was not coping. Although quite a few clients left of their own accord, his supervisor and Amy persuaded him to retire, saying as he was approaching 70, it was time.

There was no resentment about the situation only sadness. Amy said, "There is no point in resenting things, as this is where we are and we will just have to get on with it."

Amy found that the Rivastigmine helped enormously. Within a month of Keith starting the tablets, there was a dramatic improvement in all sorts of areas, for instance his memory and location; not back to where he had been before, but a very definite improvement.

The couple did not experience any noticeable social stigma after diagnosis, although they were aware that some people you may have expected to keep in contact have not, although it is only a few. Amy said, “I do sometimes wonder if we would get invited out for more meals if Keith did not have a diagnosis but it is pure conjecture.”

Amy joined Alzheimer Scotland and although she has not had a great deal of contact, what she has had has been good. She has had occasion to telephone the Dementia Helpline for emotional support and she received helpful literature.

Keith keeps up some interests he did prior to diagnosis. He continues to go out with a walking group as he has done for years, also his art class. He also goes to a Tuesday group to join other people with a diagnosis and the time apart helps the relationship. Amy appreciates the time to herself to do other things, like yoga, or simply getting her hair done. She thinks it is important to have time to spend on their own activities.

If Amy goes away, she has a complicated system of friends and relatives who cover for her. Everything has to be planned to accommodate this. She is beginning to look at respite but it has not happened yet.

Keith does not particularly feel their relationship has evolved into carer and cared for. He said, “I do not feel in that sense cared for.” Amy said, “In a way that is good, because I must be managing it in a way that he does not feel over bossed by me. Inevitably, some parts of the relationship remain but I am very conscious of the responsibility of caring. When I am planning a day, I am not just planning what I will do, as I have to make sure that Keith is covered.” There has been a big shift in dynamics in the relationship. All the decision-making in the relationship is now left to Amy but Keith is very amenable to the decisions that are made. There is no longer much input from Keith. If there were a discussion about what to do on holiday, Keith always used to have an idea of what he would like to do, for example mountaineering. Now, he does not offer any suggestions, so this is a change since having dementia.

The memory loss and behavioural changes are significant factors that have affected the relationship; also Keith is no longer as dominant. Amy has to cover for Keith a lot and there are the little things, like constantly losing glasses and seeing that Keith is properly dressed. For example, one morning he had two pairs of socks on. Amy said, “There are problems, but there are also good things to come out of the illness. Because my husband is less inhibited, he is freer to express fun and joy. He was a bit buttoned up before, especially with the grandchildren.” This is great and the youngsters enjoy spending time with their grandfather. Keith would have spent a bit of time with them before but now he is totally with them all

the time, playing with them. In the past, he would have been writing sermons and going out visiting. On the other hand, Amy said, “I find my husband’s obsession with tapping things very difficult and when he swings around lamp-posts, I find it slightly off-putting.” This illustrates how dementia can change people and in different ways. Keith also opts out of things. Amy had a lunch party for Keith and invited 20 people. After the meal, Keith disappeared to his room for a sleep, without saying goodbye to anyone. He gets exhausted far more easily and reacts as he sees fit.

Keith has retained a sense of humour. When Amy asked him what he would say to someone who had just been diagnosed with Alzheimer’s, Keith replied, “Hard luck, because they might not be able to spell it.”

Amy had not realised the incredible variations within the disease and that there is a kind of stereotype which Keith does not fit. She had mentally conditioned herself to a certain outcome, partly because of her nursing experience and because of his late father having the illness. Keith’s father stayed with them for the last few years of his life and he was what Amy considered to be typical of someone with a diagnosis of Alzheimer’s disease. He exhibited behaviour that she expected. He wandered, he was depressed, he was incontinent, did not know who Amy was and thought Keith was his father. Most of the caring fell to Amy but when she got to her wits end; mopping accidents off the floor, Keith would come in the door, calm the situation and take over. He was brilliant. They were both glad that they had nursed Keith’s father, but it was tough. Therefore, although, there are a lot of changes and difficulties, it is still not what Amy expected. It is also very different jointly caring for a parent, than it is caring for a spouse.

Life in many ways carries on. Amy does not feel trapped, because as long as she has cover for Keith for meals etc., she can attend her prayer meeting and Keith can still walk the dog.

What Amy felt has been lacking is one person from the dementia unit, allocated to support her as a carer, throughout the illness. The named person could be contacted if she was stuck. Someone who knew the language and landscape. For example if Amy was going away, this person could point her in the direction of social work, or anything that was available. A personal co-ordinator for a person with dementia and their carer would be great. This person could pull all the threads together.

The couple hope they can continue to enjoy what they have and Amy will respond to changing needs, as they arise. Amy concluded with, “Our sex life is no longer the same, which is a sadness.”

Martin and Isobel

There were no specific changes to the relationship prior to diagnosis but Isobel knew Martin was not the same.

When Martin and Isobel approached their GP together, he was helpful and understanding. A specialist diagnosed Alzheimer's disease, over three years ago.

Isobel said, "I wasn't surprised because of the changes in behaviour." Martin said, "I was relieved and stopped driving." Isobel was pleased with this decision.

There were no particular changes made after diagnosis. Isobel said, "I did not know anything about the illness so went along with it and read leaflets and dealt with things as they unfolded. Although I had an idea of what dementia is, you do not have a clue until you have to look after someone who is staying with you."

It took a while for the diagnosis to sink in and for the couple to adjust. Both partners did not resent the situation and tried to be accepting. Martin was prescribed the drug Exelon and they both feel it has helped.

The couple have not been aware of any social stigma and still see friends. As they have a family who visit, they are not isolated.

Isobel was given a leaflet about caring but was not initially told about Alzheimer Scotland. You have to find out things for yourself. She read in a magazine there was a dementia café in Edinburgh that they could visit and they now both go once a month. If Isobel had not read about that, she would not have known about it. They were told about holidays organised for people with dementia in Strathyre and they decided to try it. They both enjoyed the holiday and Isobel said it was an excellent experience. She feels it is important to find things to do together, as well as apart.

Martin goes for a walk with a support worker each Tuesday and the time apart helps the relationship. Isobel said, "I need it, as it is the only time I have to myself." Martin said, "I enjoy going for a wander."

The relationship has developed into carer and cared for and Isobel has to cater for all Martin's needs. He likes to potter about in the garden, cutting the grass, which gives him an interest and Isobel can do things in the house, knowing he is safe. Nothing appears to affect Martin and he carries on doing what he can. Isobel said, "I am curtailed now, because my husband needs constant supervision. His hobby was repairing things but he cannot do that now. Sometimes he cannot find the tools, or when he takes something apart, he cannot put it together again. His brain just won't let him do it."

Dementia affects all aspects of the relationship but memory problems are a significant factor. For Martin his sleep can be affected. Martin said, "When I am asleep it can be interrupted and I also fall asleep more."

The couple both take the view that the best way forward is just to get on with things. Isobel said, "I now find other things for Martin to do. He is willing to do the dishes and helps with food preparation. Sometimes, dishes get put away in the wrong places but it keeps him occupied."

Martin and Isobel have always enjoyed the outdoors and used to have a boat, as they enjoyed sailing. They still walk together, although Isobel's pace is not as good as it used to be but Martin could not go on his own, as he may not be sure where to go, if he got into a street he did not know. Isobel commented that no two days are the same with dementia and said, "I feel it is all very unpredictable and anything can happen. That is why supervision is needed at all times, especially in the kitchen. This morning we have to find the plate for the microwave that Martin has misplaced. Something happens on a daily basis. Sometimes it is only small things but a constant awareness is essential as it could be dangerous."

All responsibilities now fall to Isobel and Martin can no longer be left alone in the house for his safety. Isobel said, "I now have to do one hundred percent of any organisation that needs to be done. I am responsible for everything, from cooking to Martin's wellbeing, sorting his medication, looking after finances and keeping him safe. It is all part of caring."

Someone from the Royal Victoria hospital visits the house once a year to ask Martin a set of questions to ascertain how things are. Up until recently, there has not been much change in Martin, according to his answers but Isobel notices a difference in him, probably because she is there all the time.

Both Isobel and Martin are very positive and are living life as well as possible and take each day as it comes. Isobel said, "Martin won't remember what he did yesterday but we just have to get on with it."

Paul and Sarah

The first indication that anything was wrong with Paul was deterioration in his driving. Paul said, "That was pointed out to me and I would also park the car and leave the door open." He enjoyed driving but Sarah was worried about the changes in him. Sarah said, "If another driver sounded their horn, he would automatically assume he had done something wrong. It was a confidence thing." He would also ask Sarah directions but not in time for him to take any action and then he would panic. The reassurance Sarah had to give was constant. Although his road position was fine, his speed was okay and he indicated in time, his confidence levels were dropping.

When Paul was in the house on his own at night he sometimes felt strange. Paul said, "I was looking at mirrors and things and had the notion that someone else was in the house." Sarah said even when she was in the house this happened. The house had built in wardrobes with mirrored doors and when they were both in the bedroom he thought there were more people there because of the reflections. In the same way as Paul left the car door open, he would leave doors open in the house. There was a distinct lack of consideration. Sarah said, "Paul would leave all doors open, including cupboard doors. If a door was opened, he would not close it and I found this odd. In all fairness I would get angry with him. He would take the dog out for five or ten minutes and leave both the porch and main door open then complain of the house being cold when he returned. There was no consideration for me." Paul said, "I would say it was cold in the house and ask for the heating to put on, unaware that it was my fault." Paul also experienced memory problems. Sometimes he would take the dog out for a walk, the dog would walk on ahead and Paul would forget all about him. He would return to the garden and wander about in the cold wondering why he was out and would return to a cold house. Sarah said, "I began to realise there was a problem, when Paul started forgetting about the dog. However, the red herring was that he always had a justifiable reason."

Sarah tried to minimise this particular problem and bought an automatic door closer for the porch door. The lack of co-operation from Paul was frustrating and caused some strain and friction. Sarah said, "I was asking Paul to do something and it wasn't happening. He was getting angry with me and slamming doors so I made this compromise."

Paul had a great need to go out but wanted Sarah to be with him. He had no concept that they could not just get up and go, as some household chores needed to be done. All the normal things like washing dishes, hoovering, tidying up etc did not concern him. He wanted to get up, wash, dress, breakfast and go. Sarah said, "To be fair Paul was always a bit like that but in the past you could reason with him. I could say I wanted to put washing out and tidy up and he would be okay. Even if I asked him to Hoover he would comply but that all changed." Sarah interpreted Paul's behaviour as being defensive and uncooperative and Paul admitted he may have become more stubborn.

Another change was, Sarah's brother was helping Paul to become familiar with the computer and Paul was finding it difficult to follow instructions and to hold onto information. Sarah said, "Paul would say he understood and would carry out a procedure, whether it would be opening up the computer, going onto the internet and negotiating his way or printing photographs but he required a lot of instruction and repetition to be able to hold onto the information." This was an indicator that Paul's ability to hold onto information was reduced and to overcome that it was suggested he jotted things down, as a memory aid. Sarah said, "Paul bought a notebook and I said, even noting down bullet points would be useful. I felt I was being supportive but Paul would get irritated with me." Paul said, "With hindsight, I realised writing things down was not going to get me anywhere, as I was unable to take things in, although at the time I did not know what was wrong."

The penny started to drop that there was something very wrong was when Paul asked Sarah about things that happened some time back and he was surprised at her recall. Sarah told him about a particular event and Paul said, "How can you remember all that?" He could not understand or accept Sarah's ability to recall so much. Sarah started to keep a diary of things that happened, so she could answer Paul's questions. He wasn't happy until he knew what happened, when it happened, who said what, and where they went. Unfortunately, this did not help as much as Sarah had anticipated. Sarah said, "It didn't help because Paul was unable to accept that what I had recorded was the way things were, because he did not have any landmark in his memory. If anything I think it caused a bit of conflict and became another irritant." Paul said, "It was just something else falling by the wayside."

The friction between them went on for quite some time until Sarah persuaded Paul to visit the doctor. The doctor saw Paul and told him to come in again the following week and to make a double appointment to address the memory issues. After the second appointment Paul was told that his memory was not as it should be for someone of his age and guided him to accept the memory issues and a scan was arranged. The results of the scan were forwarded to the GP and Paul was told a lack of blood flow to the brain and some shrinkage could be causing the memory issues. The GP did not mention Alzheimer's but referred Paul to the specialist. At the visit to the consultant he was given some tests. He was called back to the specialist for the results and was diagnosed with Alzheimer's. From first seeing the GP to the diagnosis was under three months, which was not as stressful as a long drawn out process.

Paul said, "I went in to see the consultant on my own and was shocked at the diagnosis. There was not much compassion about it. The specialist said he thought I had Alzheimer's but I could have nine years to live." Sarah felt very sad at the diagnosis, although it wasn't unexpected. She said, "When I was called in, the consultant said he had the results of the tests and scan and Paul unfortunately had Alzheimer's and that would give him a lifespan of five to ten years. I was angry because we did not need a prognosis at that point, with so much living still to do. It was so unnecessary, as it was a double slap for Paul, firstly to get

his diagnosis and then to be told so matter of fact his lifespan was shortened. No sense of hope, no sense of something could be done to reduce this or to slow it down; that came later. To be fair, his face and his body language suggested that he was trying to break it gently but the words were still the words and that is what you hold onto. There is a lack of humanity and it makes you realise that you are items on a conveyer belt.” Sarah was so upset that she was given a two-minute breather. The couple were then told about medication and were given a sheet on Aricept and invited to ask any questions. The lack of concern was felt by the couple. Sarah said, “I think it is all in a day’s work to the professionals and they get desensitised to the impact of a diagnosis and what people have to adjust to. I am well aware of the constraints on the system, having worked in the NHS but there is always room for compassion. You can only give people time once and that is when they need it.”

The couple knew they had to move on from diagnosis and continue with their lives and at least Paul’s behaviour could now be explained.

For the first couple of months the couple kept the diagnosis to themselves, then gradually told people, starting with friends and people who they thought would be understanding. They decided not to tell Paul’s golfing acquaintances, to avoid any kind of gossip at the golf club. This also applied, generally speaking to ex colleagues. They also did not want to burden other people. Sarah’s mother was also in hospital at this time.

After diagnosis Sarah apologised to Paul for thinking he had only been being awkward. She was upset that she had been impatient with him and had misjudged the situation. Sarah said, “I now knew that Paul was not simply being thoughtless, careless and inconsiderate but had a valid reason for his behaviour.” The diagnosis made a level playing field for the couple. It made Sarah able to make allowances for Paul. She realised that his abilities were altered because of the illness and his normal thought processes were interfered with because of this.

Before diagnosis the couple had been making various changes to their home and had been contemplating installing a gas cooker. They decided against this, as Sarah felt it was better keeping things as familiar as possible for Paul and they are deliberately avoiding any more change. Financial matters have been sorted out, to avoid any complications in the future and to make life flow easier.

Neither Paul nor Sarah experienced any feelings of resentment at the diagnosis. Paul was prescribed Aricept and said he felt the drug has helped him. Paul said, “I am thinking better now.” Sarah said, “I cannot say, because I have no insight into how confused Paul’s brain was and how difficult he found it to sequence tasks.”

The couple did not experience any kind of social stigma after diagnosis, although are aware that some slights can be perceived. Paul said, "I think people can with the edge of a word, cause you to question if the character is getting at you, but I have not had a blatant insult."

Support from Alzheimer Scotland was welcome. Paul said, "The fact is, to discover someone who is interested in you after diagnosis is welcome and by having contact with them you can meet people in a similar position and receive empathy." Sarah said, "I feel that contact with Alzheimer Scotland post diagnosis, is what turned it around for Paul."

Paul had a visit from an occupational therapist who talked to him to assess his abilities. Sarah and Paul have a different perspective on his abilities. Sarah said, "What Paul thinks he is capable of doing and what I think is at a slight variance. His Alzheimer's affects his balance, his ability to judge distances and step off and on pavements, he has great difficulty going up and down stairs and he gets very unsteady if he has to use buses. It is difficult to keep him motivated and positive. He is not going to his golf because he is not capable of going through all the tasks of setting himself up to go, getting there, choosing clubs, knowing where his ball is and not leaving his trolley."

Sarah now has to do certain things that Paul no longer can manage, including small things like using the video and surfing the internet. There is a big shift in dynamics in the relationship. Alzheimer's has disabled Paul from driving and making a decision to go and make the tea for example. Sarah said, "It is no longer just husband and wife. Paul is no longer able to be spontaneous, courtesy of the illness. He is disconnected from lots of things that in the past I would have asked him to do. Lack of motivation is also an issue."

The illness manifests itself in many ways but the key aspects that have affected Paul the most are his lack of motivation, tiredness and the fluctuations in emotions. Paul said, "I can be emotionally flat at times and at other times I can be very excitable or tearful. After showering and dressing my mind can switch off before completion and I think that is enough tiredness for today, thank you very much."

The features of the illness that perturbed Sarah the most was trying to identify where Paul was coming from so that she could respond appropriately and the way that it has changed him emotionally is perhaps the most significant. Sarah said, "Paul can get quite easily excited, especially if something different is happening. He looks forward to it but the excitement affects his ability to do what he needs to do to achieve it." Paul depends on Sarah a lot more, almost all of the time, from small things to more important. One of the big things is when he is looking for things and cannot find things and this happens very frequently. Sarah said, "When Paul is looking for something his brain does not seem to perceive what his eyes are looking at. For example, he was looking for the telephone directory yesterday whilst I was upstairs and he called up to me that he could not find it. I told him it was on the bottom shelf of the bookcase, right hand side. I realised that was two instructions and although I repeated it several times, he did not find it. I said it all slowly;

keeping my tone of voice right, so there was no irritation or annoyance. I came downstairs and Paul watched me taking the directory from the bookcase and he had never seen it. He was starting to defend himself not wanting to be a nuisance.” Paul said, “I could have sworn it wasn’t there.”

As Paul’s wife, Sarah does not get annoyed. What she has done is shifted from a wife to a carer role and copes this way. This is her response to Paul’s limitations because of his illness. In certain situations she uses nursing techniques, which she would not use as a wife. Paul feels he is more inhibited.

Paul can see a future beyond the illness and does not feel doomed. The illness has caused a shift in the relationship but Sarah has not analysed it as such. The couple have to deal with the situation and Paul feels they have related better in the past few months. Sarah said, “Mr Alzheimer came to visit us, he wasn’t invited but he is here to stay. Therefore we have to put things in place to ensure he disrupts our life as little as possible. That requires Paul and me to enter into a partnership. It is a wee bit one sided but it is still a partnership. It is only one sided in some areas, as in other areas I am getting something out of it as well.” Paul has kept his sense of humour. It was a bit dampened for a while but it is coming through now.

Despite the illness the couple’s lives have continued in a positive way and they have a lot of living to do yet and there is still a lot of fun to be had. They just have to find out the best way to do it, with wee tweaking here and there.

Paul said, “Mr Alzheimer is not going to run the show.”

Dominic and Linda

Dominic and Linda were busy running their own business seven days a week and working long hours, so pre-diagnosis the changes were gradual and subtle. Dominic noticed that Linda was forgetting things and becoming weepy and tired and everything was becoming a burden. She worked very hard in their shop and he thought that she was having a breakdown. Their relationship continued as normal with no particular problems, despite wondering what was going on with Linda.

Linda was reluctant to see a doctor, because she knew there was something wrong, although the couple did not know if it could be depression, a breakdown or what it was. Linda's daughter-in-law and family came for a couple of week's holiday and Dominic mentioned to her that he did not think Linda was hearing things properly or perhaps she just wasn't taking things in. The ears were an excuse to get Linda to go to the doctor. Her daughter-in-law accompanied Linda to the doctor to get her ears checked and when they were found to be all right, she told him the other things that had been happening. Dominic wasn't there, so he did not know how the doctor reacted but this was the first approach to establish if there was anything wrong. The doctor diagnosed depression and Linda was prescribed a course of tablets. This was in 2005.

The shop had been sold before the depression diagnosis, despite Linda no longer working in it from around 2003, which was a big life change, and as there was no improvement in Linda's condition she was referred for a scan. It was discovered that she had had a stroke and it was seen that it was affecting her memory. Linda was referred for another scan because it was detected that there might be something else. It was then that she was diagnosed with mixed dementia in 2006. By then Dominic realised that would be the outcome and although he felt numb, he was not shocked. Linda said, "I just had to get on with it." So much had happened in their lives from selling their business, then the initial diagnosis of depression and the diagnosis of dementia was just another milestone. Dominic said, "We came out after receiving the diagnosis and decided to carry on as normal as possible and do things together, without fuss and without making a big issue of it." As the business had been sold before the diagnosis of dementia the couple decided to enjoy some holidays and walking. The business had been a joint husband and wife team and as Dominic also had some health problems there were no regrets. Dominic said, "Prior to selling the shop, by the end of 2002 into 2003 Linda wanted out of it. It was a no goer; end of story."

Family and close friends were told of the diagnosis when it was confirmed. With hindsight Dominic said that a few years prior to being diagnosed with dementia, Linda went on a short holiday to visit family and friends in 2001. She packed okay for the holiday and managed the flight but on the holiday she became confused and slightly distraught. Obviously, something happened that could have been a stroke. Some people can have a small stroke without realising it. When she came home she was a bit distraught and was a different woman from then on. However, she still managed in their shop for a few years despite tearful moments.

There were no real feelings of resentment from the couple. There were initial thoughts of why me but in general everything was taken in their stride. Dominic said, "Overall, I just take it all in my stride. What happens later on as we go down the line, it might be a different matter for me but that is what I don't know. Obviously, I have an odd moment to myself sometimes." Linda was prescribed a drug called Reminyl but it was difficult to tell if the tablets had made a difference.

The couple have many friends and have not experienced any social stigma. They are very sociable and mix a lot.

As the couple do a lot together, there is no need for a support worker. Linda still goes with a friend to visit her sister. Dominic said, "Linda still sometimes goes away. The last time she was away was to visit her sister. However, her sister said she was a bit weary after a week and wanted back down to see us. I don't know what will happen this year."

The dynamics in the relationship have changed and Dominic takes on more of a caring role. When the couple worked in the shop it was an equal partnership but now he is responsible for all the finances and paying the bills and he employs a housekeeper to assist, twice a week. Dominic said, "You name it, it is all through me now."

Various aspects of the illness have affected the couple. Dominic thinks Linda tires easily, although she disagrees. Her communication is not as good as it was and she can have difficulty with her words. Dominic said, "One of the changes is Linda's words can come out jumbled and the communication side of things has diminished." Dominic is very patient with Linda and although she may want to do some things and cannot, he completes the task. Dominic said, "If Linda is asked to do something and she finds it difficult, it is far easier to do it yourself to avoid irritability and going through all that procedure."

There is no easy way to continue except to take each day as it comes. Dominic said, "It is a very sad illness, slightly devastating in fact. You always think on how things were and Linda was so full of fun. She was such a chatty and happy person but that has all been stripped."

A cure for the illness would be fantastic and Dominic and Linda are no different from other people in hoping for this. Dominic said, "Obviously, a cure would be fantastic but to be quite honest, even if there was something when the illness was diagnosed to stop it where it is would be great. The tablets are not really stabilising it, because I can see a difference. However, whether the condition would deteriorate more quickly without the tablets, I do not know." It is sad to see the loss of independence in Linda and as time goes on Dominic witnesses progressive losses. Dominic said, "There are a lot of things that Linda cannot do. Apart from the communication, she can no longer jump on a train on her own to go places and can hardly go down the street now. She used to take the dog to the woods but that phased out, as she was getting more scared. Linda also used to go to the shop and pick up

the paper but that is dropping off.” Linda had nothing specific to add but the couple are determined to continue their lives filled with joy and good times for as long as possible.

As long as Linda is happy, Dominic is satisfied.

George and Louise

For George and Louise there were no particular changes to the relationship pre-diagnosis and things continued more or less as normal.

The GP was very helpful when first approached. George said, “He was very helpful, he listened to me and asked questions. I explained I wasn’t quite as usual.” Louise said, “The doctor was helpful and he referred George immediately to Stirling Royal to see a consultant.”

Initially George visited the GP on his own about something else and just mentioned his other concerns about himself in the passing.

From first visiting the doctor to diagnosis took about six months and the diagnosis of Alzheimer’s disease was made by a specialist and George and Louise were together to receive the diagnosis.

Feelings can vary when a person receives a diagnosis of dementia. George said, “I thought, surely not, surely there has been a mistake. It was a bit of a shock but I decided to carry on in the usual way.” Louise said, “I was annoyed at the consultant’s attitude, therefore I felt protective towards George. He was very patronising, lacked what you might call a bedside manner and he was dismissive. I have since dealt with another consultant who was so much gentler, kinder and sympathetic.”

The couple were open with everybody about the diagnosis. Louise wanted to go along with whatever George wanted and he wanted to let people know.

George and Louise did not make many changes to their lives but tried to carry on as normal. However, George gave up playing the organ in a church he attended because of the driving involved. He could still drive but he would have needed somebody in the car to go with him to the church and Louise couldn’t go each week. That was the one main thing he gave up after his diagnosis and it was something that he enjoyed doing.

Neither George nor Louise experienced any feelings of resentment. George was prescribed Aricept and he feels this has helped him.

There was no social stigma of any kind after diagnosis. Louise said, “Everyone has been very nice and nobody has given us the brush off.”

Louise attended a series of meetings run by Alzheimer Scotland for carers. She found these very helpful and learnt more about the illness, advocacy and safety measures amongst other things.

George is involved in various activities. He goes to a lunch club on a Thursday, where there is a whole host of pastimes available, including singing, games, discussions, mosaics and walks. A support worker accompanies George on a Friday. They have visited a museum and

cathedral and went for walks and coffee. George said, “I enjoy the activities, very much so and I like to play the keyboard at the lunch club to accompany the singing.” The time apart helps the couple, as it is nice to have a break. Louise said, “It is nice for George to meet fresh faces and not be stuck with me all the time.”

Louise always dealt with the finances in the relationship and continues to do so. She now has to do more in the garden and now does all the driving, whereas before this would be shared. Decisions, although discussed now tend to be unilateral. George said, “I miss driving and can get confused about where I have put things. I can still play the piano though, although I miss playing the organ in church on a Sunday.” The aspects of the illness that have affected Louise the most are varied. Louise said, “Behavioural changes are significant. George has a need to get out all the time, which means we are out morning and afternoon, when there are times I could be doing things in the house. The lack of discussion is another factor.”

George takes part in drug trials at the Glasgow Memory Clinic and the couple are willing to take part in any research that can help people with a diagnosis of Alzheimer’s disease. Whatever they can do to help, they are both willing to do it and this is something they can share.

Louise finds it sad that George’s musical abilities have deteriorated. Louise said, “George taught music and still plays at home but it is sad to see a decline, with mistakes creeping in and wrong notes being hit frequently.”

George and Louise hope to face their future together with positivity and deal with events as they come.

Mark and Tessa

Mark did not notice any changes to their relationship before diagnosis but Tessa did. Tessa said she felt that Mark had become selfish and self-centred in general and could only think of himself. Tessa said, "Before diagnosis I used to accuse Mark of being selfish and only thinking about himself. For example I would ask him to leave the door open for Mary if she was coming for her lunch but he would leave it locked. We did not know at the time but he could not probably think of anything else. Of course we did not know that it was Alzheimer's." Mark admitted that he thought he done some stupid things for example running over the road without thinking after leaving a taxi.

The GP was helpful when first approached with the concerns. Mark thought he might be depressed and the couple went to the surgery together for the appointment. Because they mentioned at this appointment that Mark had been driving round roundabouts the wrong way, he was referred to the hospital straight away, although the doctor thought it could be depression.

Mark had some x-rays and when they returned to see the specialist for the results they were told it was not dementia but that was not to say he could not get it sometime in the future, because anybody could get it. Tessa said to the doctor, "You are telling me that Mark has not got a dementia, Alzheimer's or any other forms of dementia. I am very glad and no disrespect but I hope I never see you in your professional capacity again and goodbye." The next morning - at 8.30am - the couple received a telephone call from the specialist, as he had decided to investigate things further. Tessa said, "It makes me wonder if I hadn't said that to the doctor and just said great, fantastic, goodbye..." After this telephone call, Mark saw another consultant and had various questions and tests. This specialist wanted to see Mark three weeks running but he could only do two, as the couple were going on holiday. Between the holiday and seeing Mark again, this specialist thought he had got a lot worse and he had indeed been bad on holiday. Mark was given a scan, and the diagnosis of Alzheimer's was presented to them by the original consultant. The diagnosis was made within months of visiting their GP for the first time.

The diagnosis was a bit of a shock for Mark and he asked the consultant how long he might have to live and the reply was maybe ten years. The consultant then asked Mark how long he had thought he had had the illness and Mark responded with maybe a few years. The consultant then said he could take that time off the ten years. Mark said, "I was devastated about this and have kept thinking about this ever since." Tessa said, "I was absolutely devastated at the diagnosis, because although I did not have a real insight into the illness I knew it wasn't good. We came out of the hospital and I was feeling a bit dazed by the news. Although Mark had driven to the appointment, I drove home and he has not driven since. The doctor told him that he had better not drive."

Mark quite openly tells people that he has Alzheimer's disease and the couple did not hold back the information from anyone. Mark said, "I do not try to put it away because it won't go away and I just have to work with it."

A number of changes happened after diagnosis. Mark had to stop his work eventually, because he could not manage the work, although he was a pensioner by that time and of course he stopped driving. Tessa did not alter much in her life immediately because it didn't really hit home. A Community Psychiatric Nurse visited and gave the couple various tips, such as putting up stickers on cupboards to say where the cups were in the kitchen. Tessa said, "I felt Mark wasn't as bad as to need all that. The tips weren't much use at the time but that was not to say that they may not be in the future and some are now. She then went and that was us left."

Mark did not feel any resentment about the diagnosis and after leaving work decided to be positive about things. He was initially happy, because he was not working anymore; he could please himself for the first time in his life. That was only initially, because living with the illness changes your life. Mark said, "I felt I had to do something and just not sit here, because nobody is going to come along." Tessa said, "I felt cheated because it was not going to be the retirement we had planned." Mark was prescribed Aricept immediately and felt it initially helped to keep him on an even keel but not so much now.

There was no social stigma after diagnosis or at least none noticed. Tessa said, "I did not notice it, but I am sure there was in some instances but I was not aware. You hear of some people saying that their friends just stop. Mark said, "People have been kind and have nearly all wanted to help me."

Post diagnosis, the couple did not have any support. However, after a year they decided to seek help. Tessa contacted a voluntary service who referred the couple to Alzheimer Scotland. Prior to getting involved Tessa telephoned the Dementia Helpline and the person was very helpful and sent out an information pack. Tessa said, "It changed Mark's outlook right away. The support you got and involvement, really made a difference to both of us. I think Mark would have been sitting vegetating at home without his meetings and drop in. Goodness knows where we would have been today without Alzheimer Scotland."

Mark is involved in various activities with a support worker, including the golf driving range and bowling. He also attends a drop in centre run by Alzheimer Scotland. Mark said, "I mostly enjoy it but some days with the bowling, I get the ball and something happens and it just turns and the folk are jumping about." Having time apart helps the relationship and Tessa also works. Tessa said, "I work three days a week and that gets me into another environment. It also gives Mark a rest from me." Mark said, "I am the boss on these days."

Tessa has to look after Mark more now and do things for him that he would have been able to do himself before, so the relationship has evolved into carer and cared for. Mark said,

“Tessa does a hellava lot of work for me, every day. She has lost a lot of her own self to me, she is working, making sure I have clean clothes and the place is clean. If I lose things, Tessa looks for them.” Tessa did everything with regard to finances all their married life, so there is no change there. Tessa said, “The illness has taken away Mark’s independence and it has taken away a lot of my own time. I have hardly any time to myself. Even if I wasn’t working three days, I am sure these days would be filled with something else and it is as well having an income.”

The aspects of the illness that affected this couple the most are varied. Mark said, “I feel the complete loss of independence and the inability to do things. I also have to think, think and think to be able to do things. I get lost easily. The big thing I hate is the buses, because they seem to forget where I am.” Tessa said, “The memory loss means Mark cannot be independent of me. It has also changed our long-term plans and it changes your current plans, because you have to think before you book a holiday, planning it to suit and length of time. You have lost your spontaneity. Even going out for a meal has to be planned. In one restaurant the toilets were downstairs and I like to go with Mark as he gets lost and it is easier to stand outside the door. It wasn’t easy to get to and there we were burrowing along and when we got back our plates had been cleared away. Things happen, but you try not to let them happen again.”

Tessa and Mark are continuing their lives in the best way that they can. Tessa said, “It changes your life but if you come across a problem, you just have to try and circumvent it, without it stopping your life.”

Aubrey and Betty

Betty did not notice any changes to her relationship with Aubrey before diagnosis. Aubrey noticed a distinct change in the way that Betty did things. Aubrey said, “There were slight changes in the way Betty would do things. For example, she would start making a cup of tea and forget all about it and go and start another task. Lots of small things like that; just general bits and pieces.”

The GP was very helpful when they first consulted him, together. Betty said, “He was very helpful and a very good doctor.” Aubrey said, “He took on board what we said and he referred Betty to the clinic.”

Betty saw the GP in November 2007 and had a CT scan in January 2008. There were only a few months between the diagnosis of Alzheimer’s disease and first visiting her GP.

The diagnosis was made by a specialist and the couple were together when the diagnosis was presented to them. Betty said, “When I was told I had Alzheimer’s, I said to the specialist if I’ve got Alzheimer’s, I’ve got Alzheimer’s and if that is going to be, then that it is going to be. I am not going to worry about it.” Aubrey said, “I more or less expected it but I was still disappointed that it was. Like Betty, I feel we just have to get on with it and make the best of it.”

The couple did not hold back the diagnosis from anyone and have been as open as possible. They have made no physical changes to their lives post diagnosis and try to live as normal a life as possible. Betty had stopped driving a long time ago and sleeps a bit more now.

Betty has experienced no feelings of resentment about the situation and has just taken everything on board, as she knows she can do nothing about the illness. Aubrey is not in the least resentful either. Aubrey said, “I do all the cooking now and I’m happy to be able to do it.” Betty was prescribed Aricept and she feels this has helped her. Aubrey said, “She was three points less on her last memory test, so I feel it wasn’t keeping her up there.”

The people have received no social stigma at all and people have been sympathetic to the situation.

The couple both receive support from Alzheimer Scotland. They attend various things, including a drop in centre. Betty said, “If Aubrey wants to do something I can be there, once a week. I get coffee and a soup and sandwich lunch and there are various activities. I like meeting other people.” Aubrey attends a carers’ group once a month. They also go to coffee mornings. Betty is a member of the Eastern Star and they still go to social events.

Aubrey feels he has to take a more caring role in the relationship. Aubrey said, “I have to do things for Betty that she cannot do for herself.”

The aspect of the illness that has affected Betty the most is memory loss but she does not miss cooking. Aubrey said, "With the memory loss, Betty tends to get a bit frustrated at times. If I can get frustrated at something, it must be doubly so for Betty and upsetting." Betty said, "If I've lost something in the house, I'll say, I had it there, where is it? It is annoying, even if it is a simple thing."

Betty's motto is what will be, will be and she'll go with the flow. Aubrey said, "I would like to think that there could be a cure. If not I would like it to stay at this point and not deteriorate."

Betty said, "I will try and do the best I can with my life now. I am happy enough. If I go dolly and don't know where I am or what I am doing, I want Aubrey to put me somewhere." She still likes going shopping with Aubrey and likes buying handbags. The theatre and ballet is an interest and she goes a couple of times a year with a neighbour, as these are not Aubrey's interests.

To be able to continue with their lives and interests for as long as possible, is what this couple hope for.

Matthew and Barbara

Prior to diagnosis Matthew noticed a difference in his blood circulating through his body which caused tiredness. Barbara thought he was a bit lethargic and wondered if it was slight depression, but because he has a retiring personality anyway, she wondered if it was being stuck at home after giving up his consultancy and having retired from his MD job.

The GP was helpful when first approached with the concerns. The couple went to the doctor together, as this was what they usually did. Barbara said, "I don't want to appear derogatory, but as helpful as a GP can be. We voiced our concerns and were told they would be checked out."

A diagnosis of Lewy Body dementia was made within months by a specialist after tests and the couple were together when the diagnosis was presented to them.

There was a mixture of feelings after diagnosis. Barbara said, "It did not totally surprise me because I was gearing myself, once Matthew was having tests that it could be Parkinson's or Alzheimer's or something similar. When it was confirmed, you kind of go blank and numb and there is a heaviness and sadness in you. You can't explain it and you don't want to be a worrywart and look away down the road and yet you know it's not going to be easy. It is afterwards that things start to come to your mind and you start to worry and think."

Matthew said, "I did not think it was noticeable." Barbara said, "I think Matthew had a form of denial, in a way, because he didn't notice anything wrong with his driving either."

The diagnosis was not kept from anyone. Barbara said, "Close friends we've never kept anything from. We did not back off from telling family and friends; it was just quietly mentioned. Obviously, we did not shout it from the rooftops and we wouldn't have phoned up acquaintances or people we only saw once a year to tell them."

The couple carried on much as possible to maintain their lifestyle and did not make many changes. Barbara officially retired in October 2004. Friends had asked the couple to visit them in Australia before but Barbara was always busy teaching. The friends said there was no excuse not to come now and the couple decided to accept now, while they could.

Barbara said, "Knowing there was something wrong with Matthew, we decided to go to Australia, after discussion, as we knew we may not be able to go in the future, although I knew some people thought I was foolish." They went early in 2005, for six and a half weeks and it wasn't as good a holiday as it should have been, because Matthew wasn't well, with other health problems, not the dementia. Barbara thought it was perhaps a combination of things. Barbara said, "I think it was the jetlag, altitude, his blood and tiredness. Matthew was slower; he ate slower and did not say much. We decided to do something one day and rest the next and our friends were very good." Matthew said, "The holiday was very pleasant." Later that year the couple went on holiday to Bulgaria and the holiday was

enjoyed. Barbara said, "Matthew was fine. Obviously there was a slowing down, a slowness to chat to people and converse, although he would respond if you spoke to him."

From the Bulgaria holiday in 2005, the couple never got away again. They planned to go coach tours, but holidays were cancelled for various health reasons.

Matthew did not have any feelings of resentment about the illness but felt he had to depend more on Barbara. Barbara said, "Initially you are so gutted that you are numb and your emotions are all over the place. At different stages other emotions surface. I don't understand it and I don't think I'll ever accept it." She goes on to say, "My husband is such a good guy, pillar of society, man of integrity, kept himself fit, healthy, good diet, good lifestyle, everything and you cannot understand why it has to come to them. The fact of the matter is, I did feel a resentment at some stage, I don't know at what point but lots of these feelings come at different stages and you think your life is gone." As their family were away from home now and happily married, they felt they could have travelled more or moved but the illness has changed all that. Barbara said, "There were so many things we could have done but you are told, don't move as you are all on the level, stay where you are with that sort of illness and suchlike."

Matthew was prescribed Exelon and this has helped maintain his abilities, although this is difficult to define.

The couple did not experience social stigma and they have good friends and family. Maybe with one or two acquaintances there has been a backing off, but it could be some people do not know what to say and don't want to make things uncomfortable for Matthew.

A support worker comes on a Tuesday morning and she goes through Matthew's football albums with him and plays catch ball among other activities. Matthew enjoys these visits. Barbara can pop out for shopping. This gives Barbara much needed time on her own and she can come back refreshed but she does not have the time to do a lot.

The relationship has evolved into carer and cared for because it had to. Barbara said, "Largely, predominately, because you would not be in that sort of relationship if you did not have the disease, so that automatically changes your role, but you never lose your basics." There has been a big change in dynamics in the relationship. Barbara is responsible for everything now inside and outside the home. Matthew said, "I handled all the finances before the illness and paid the bills and renewed insurance but I am quite comfortable with that now." Barbara said, "Matthew also did the gardening, although I did the hanging baskets and the flowers. I cut the grass now and rake up leaves and attend to the guttering, all things that Matthew attended to, on top of running the house."

The aspect of the illness that has affected Matthew the most is his inability to jump in the car and drive to visit family. For Barbara it is a variety of things. Barbara said, "It is never ending really. I am doing more now at 67, than I did when I was younger. I have a heavier

load and more of it, when I should be doing less. I do not have any free time and you can't keep calling in the same people to cover. It is a shame to put demands on people and I don't want anyone to feel a commitment and feel stressed by it and spoil a relationship. I save it for when I really need them. Matthew's lack of mobility has been the biggest thing. I love Matthew to bits though and we have always been together. I would be lying through my teeth if I said I enjoyed my life as it is, but I want to look after Matthew and keep him comfortable for as long as possible."

Nothing has been smooth but the couple continue as best they can. Carers come into attend to Matthew's needs, several times a day. As Matthew is incontinent and not mobile, the couple cannot just nip out and please themselves anymore. Although the carers are necessary, Matthew said, "It is an invasion on your privacy."

Barbara feels that although it is not an illness that you want, you have just got to get on with it and do the best you can. You need communication and someone to point you in the right direction from the start of the illness. You also need consistency.

The final word goes to Barbara, "Lots of things fly around in your head and although the loss of an envisaged future is paramount, it is important to focus on the here and now."

Outcomes

Diagnosis

Most of the diagnoses were not long drawn out affairs. Where there was a delay, there was a reason. In the case of Keith and Amy, Keith had had pneumonia and his symptoms were attributed to the recovery stage of that and it was another two years before a definitive diagnosis was sought. Because of this there was less stress on the couples' relationships.

Caring

In all the relationships the partners experienced a huge shift in dynamics. There is still the couple relationship but it sometimes comes secondary to the carer/person with a diagnosis of dementia relationship. Although people are happy to be able to assist their partner, it is still a huge responsibility. It is almost as if there are two relationships in each partnership and this is one of the biggest impacts that dementia has on relationships.

Love

Most of the couples have a loving relationship that transcends the illness, despite the difficulties of the illness, except John and Edwin. Although John still loves Edwin, Edwin is not so sure, as the illness appears to have blunted his feelings. Andrew and Davina have been together for 53 years and despite Andrew's diagnosis he still loves his wife but acknowledges it is only to the best of his ability, which is not much a times.

Loss

The partners without the diagnosis are all aware of the loss of the partner they knew before the illness. In two instances the sex life had either diminished, or disappeared. The partner in the caring role experienced lack of freedom and the person with the illness had lost their independence. Dominic realises that the illness has stripped Linda of some of her personality, as she used to be so happy and chatty. The loss of a future people had planned was a significant factor. Not being able to drive any more was a significant factor in curtailing the freedom of the partner with the diagnosis.

Dependency

All the people with a diagnosis of dementia were reliant on their partners to varying degrees. Some needed their clothes sorted out, others their medication and for some it was everything.

Role Reversal

All the partners of the person with the diagnosis have had to take on tasks that were formerly the domain of their partner. Responsibilities for finance, cooking, decision-making, organization, driving, gardening and household tasks are the most common.

Stigma

Andrew and Davina experienced some disinterest in their situation from friends. Keith and Amy did not experience any discernable stigma, although Amy wondered if they may have got invited out for dinner more, if Keith did not have a diagnosis, but admitted that this was only conjecture. Paul and Sarah were not aware of any stigma but Paul admitted that sometimes slights can be perceived. Matthew and Barbara did not encounter social stigma from family and friends, but felt that some acquaintances had backed off. Barbara had an explanation for this though.

Support

Some of the people with a diagnosis did not have a support worker but others did. The time apart from their partner doing other activities helped the relationship and enabled their partner to have time to do other things. Andrew and Davina used this service and Davina liked the fact that it afforded Andrew male company. Edwin joined a day club for people with dementia but he left because he did not enjoy it, although he acknowledged other people did. Keith had time apart from Amy as he attended an art class and was a member of a walking group. He also attends a Tuesday group for people with dementia and the time apart helps the relationship. Amy appreciates the time to do other things like yoga or get her hair done. Martin goes walking with a support worker once a week and this allows Isobel time to herself. George is involved in various activities, which pleases Louise and it means he is not stuck with her all the time. Mark is also involved in different activities with a support worker and attends a drop in centre. Tessa still works part time, so this is a good solution and the time apart helps them maintain a good relationship. Betty attends a drop in centre and this allows Aubrey to attend to anything he needs to do. Barbara can go shopping when a support worker comes to the house on a Tuesday to sit with Matthew and involve him in activities.

Drugs

Of the people who were prescribed the cholinesterase inhibitors, some felt the drugs have helped maintain ability in the partner and others are unsure. Davina felt that Andrew was not as anxious after being prescribed Aricept. Amy felt that there was a dramatic improvement in Keith after he had been prescribed Rivastigmine, for example in memory and location. Isobel feels that Exelon has helped Martin but did not elaborate. Paul feels Aricept has helped him but Sarah is unsure because she has no insight into how confused Paul's brain was before. Linda was prescribed Reminyl but Dominic finds it difficult to tell if the drug has helped. George feels that Aricept has helped him. Mark felt that Aricept helped to keep him on an even keel initially but not so much now. Betty feels Aricept has helped her but Aubrey feels her memory test scores are diminishing, so it is not keeping her up there. Matthew was prescribed Exelon and this has helped maintain his abilities.

Conclusion

At the core of this study is the fundamental difference in outlook of the person with a diagnosis of dementia and their partner. Lack of insight on the part of the person with a diagnosis is a huge factor. It is telling that the person with dementia will tell you what they can still do and the partners' take is that they actually cannot. For example in the case of Keith and Amy, Keith does not think their relationship has evolved into carer and cared for. Amy is pleased that she must be caring in a way that Keith is not noticing. What Paul can do is at variance with what Sarah knows he can do. All this can put a strain on a relationship. All the relationships have developed into carer and cared for to varying degrees, despite the outlook of the person with the illness and this will continue to evolve as the illness progresses. The carer in the relationship loses themselves to some extent because of the dual role of partner and carer. In some instances it is difficult to find time for themselves without arranging cover, if they want to do something. The whole landscape of these peoples' lives has changed. Isobel states that Martin needs constant supervision and she is curtailed and something happens on a daily basis. The impact that dementia has on relationships is manifold, as the small couple snapshots of life with a diagnosis of dementia depict.

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