

Maisie & Sarah

A journey through Alzheimer's



by Sue Bull

My grateful thanks to:

- The local branch of the Alzheimer's Society for their incredible support, especially when times were hard
- Chris Forsey for the excellent cartoons
- All who have helped in so many ways
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I hope that you will find words to encourage you, cartoons to make you smile and hope for the journey ahead.

Happy reading

All views expressed in this publication are personal to the author and do not represent the views of the Alzheimer's Society

The aim of this booklet is to help people with dementia and their carers to have the best quality of life possible. The journey can be very frustrating and difficult, but there are some things that can be said and done which may make it that bit easier for everyone concerned.

The diagnosis of Alzheimer's disease or other form of dementia often comes as no great surprise. People with dementia may once have had an excellent memory, but gradually forget even the most significant conversations. They may have been incredibly house-proud, but slowly the fridge is filled with out-of-date food and everything seems just too much trouble. They may have had marvellous navigational gifts - but finding the way back to the house becomes one bridge too far.

Maisie and Sarah

Maisie was 67 years old and had lived alone since her husband died four years previously. Her married daughter, Sarah, lived in the next town and visited her once a week.

Diagnosis

Sarah had become increasingly concerned about Maisie's loss of memory and changed behaviour and had called the doctor. Both Sarah and Maisie were feeling frightened by what the doctor might say. The doctor recognised this and took plenty of time to explain the tests that he would like Maisie to undergo. These happened within a few weeks. Maisie and Sarah went together to see the consultant. The bottom of their world seemed to fall out when they heard that Maisie had Alzheimer's disease. They were told that plaques and tangles were forming in Maisie's brain, causing the death of a large number of brain cells. The consultant said that no one was quite sure why these changes took place. He took time to listen to their questions. Maisie and Sarah both felt shocked and angry, but also relieved that there was an answer to the past months of confusion. They went back to Maisie's home and had a good cry.

Coping

Maisie and Sarah were given leaflets about the disease and the contact number of the Alzheimer's Society. During the following few weeks, they found out as much as they could and began to make plans for the future. Maisie wanted to stay in her home for as long as possible and so they telephoned the Social Services Department to see what home care arrangements there were in their county.

They reviewed Maisie's financial position and took advice on setting up a Property and Financial Affairs Lasting Power of Attorney. This would let Sarah run Maisie's financial affairs if or when necessary. They recognised that Maisie would soon need more help, and applied for Attendance Allowance to help reduce the financial burden.

Maisie was very determined to retain some control over her life for as long as she could, but she recognised that at some point she would need Sarah to make decisions on her behalf regarding, for example, her daily routine, medical care, moving into a care home, and the type of life supporting treatment she should receive. So Maisie and Sarah took advice on setting up a Health and Welfare Lasting Power of Attorney to cover such things.

Hope

Mother and daughter worked hard to find signs of hope in the face of this terminal illness. They asked to be kept informed of any developments in drug therapy, which might slow down the progress of the disease, and listened to people who had survived living with Alzheimer's for a number of years. They discovered that Maisie might be able to learn new tasks, although it might take her longer than previously and they deeply valued those who supported and prayed for them at this dark time.

Family and Friends

Having lived in the town for a long time, Maisie had many friends in her neighbours and in the church. She was shocked that many of them ceased to visit her after she had told them the diagnosis and Sarah was very cross at their behaviour. But then they learnt that their friends' reaction was not uncommon. Some of them were unable to bear the pain of Maisie's pain. Others were challenged about their own frailty. Sarah and Maisie gave their friends the opportunity to express some of their fears and forgave those who just kept away. They also learnt who were the friends that would stand by them whatever the situation.

Feelings

Visitors

Maisie soon began to differentiate between people who treated her as a client, who talked over her or assumed she could not understand anything, and those who rightly knew that she was a unique human being who would retain the ability to be loved or rejected long after she had lost the power of speech. Her favourite visitors, professionals, or friends, were those who did not begin to speak to her until she could see their smiling faces, for they knew that a disembodied voice would be confusing.

They were the ones who seemed to care about her and gave her step-by-



step instructions if they needed her to do anything. If there were two of them, they made sure that only one of them spoke to explain things, to limit the potential for confusion.

Bluff

As Maisie began to lose her short-term memory, she began to bluff her way out of situations so the extent of her loss would not be recognised. At first Sarah was cross with her apparent deceit, but then realised she was trying to protect herself from a terrifying reality.

Laughter, tears and screaming

Both Sarah and Maisie found that tensions were reduced when they could laugh with, not at, each other and about the latest situation. Even when Maisie had forgotten who she was, shared laughter brought some healing and light relief into the pain of their loss.

Sarah often tried not to share her own feelings with her mother: she did not want to cause her anymore pain. But sometimes she did, when she felt it appropriate, and found that Maisie could still understand and occasionally say something helpful.

As the disease took its course, Sarah found herself getting very angry and impatient at times. She knew that Maisie could not help keep asking her what time it was, where she was, who she was: it was the disease that was speaking. But Sarah also knew that she was no saint, and sometimes had to take herself out of the room to scream or pound a cushion before returning to speak again to her mother. These breaks did seem to help her feel that she had at least a little control over the situation, and they prevented Maisie bearing Sarah's anger and wrath.

Both Maisie and Sarah were going through a living bereavement. It felt that each day there was another little or large loss to bear, another change to adapt to. This was hell, and sometimes there seemed to be no end to the pain. Sarah recognised that she needed to look after herself, and give herself some breaks, so that she would be able to continue to care for Maisie.

Old hurts

Sarah and her mother had always got on quite well, but they learnt things about one another during the journey of caring that they had not previously known. Past hurts, not previously expressed, also came to the surface. In some ways this was another challenge, but it also enriched their relationship and gave them a stronger bond.



Practicalities

Safety

Maisie began to sense that everyone was watching her, waiting for her to make a mistake. If she burnt the dinner, would they stop her cooking? If she lost her purse, would they take her money away? Sarah has to walk on the knife edge of concern for her mother's safety – what if she didn't just burn the dinner but the whole house – and a desire for her to remain as independent as possible for as long as possible.

Sarah contacted the Disabled Living Foundation for practical advice on living with dementia. She found particularly helpful its fact sheets on safety aids which would help Maisie live at home in safety. She also began to learn that, just when she thought they had life organised as well as could be, something in the course of the disease would change and there would be new situations to adapt to. Sarah slowly began to realise that she was changing, in a different way, as much as her mother. She was not the kind and patient person she thought she was, but someone being challenged to the depths of her ability by the effect of the disease on her mother. And, of course, she made many mistakes.

Incontinence

Having taken great care of herself, Maisie was horrified and ashamed when she had her first little 'accident'. Sarah reassured her and, when it happened again, asked for a specialist nurse to come and give advice. Maisie hated this part, and was rude and aggressive to her visitor. Realising that incontinence was another loss of control for her mother to bear, Sarah tried to reassure her and lighten the atmosphere.

It was a struggle to get her mother to wear the incontinence pads, but eventually she did. The nurse took the opportunity to tell Sarah that a urinary tract infection or virus could make Maisie more confused and

incontinent than normal. If her condition suddenly deteriorated, she advised that the doctor be called in case there was some other reason for her increased confusion.

Washing and dressing

Maisie had always been a very private person and there was no way that she was going to have someone helping her wash and dress, thank you very much. At first, when Sarah realised that her mother was probably forgetting to wash she began to run some water for her mother to wash in, on her now daily visits. She also labelled the bathroom and bedroom doors so that her mother would possibly remember where to go.



She began to lay out Maisie's clothes in the order they should be put on, to make it as easy for her as possible. But it seemed to become much more difficult.

The noise of running water seemed uncontrollable and threatening to Maisie. She was convinced that she had just had a wash, when that was not so. And she felt that she was about to be attacked when someone tried to remove her clothes.

In the frustration of the situation, Sarah eventually realised that it would not be the end of the world if Maisie wore odd clothes and occasionally didn't have a wash. She also learnt that this stage would pass and that Maisie would one day forget that she ever knew how to wash and dress herself.

Eating

Maisie had always laid a lot of emphasis on doing things properly, and so it was hard for Sarah to see her forgetting how to use a knife and fork. Sometimes Sarah chopped up the meal before giving it to her mother, making it easier to manage. Sometimes she cooked food which could be eaten with a spoon. And sometimes she just accepted that her mother was happiest eating with her fingers, and who was she to stand in the way of other mother's enjoyment? Maisie became confused by the pattern on the plates, thinking that it was something to eat, and so Sarah bought some new, plain plates.

Sarah noticed that Maisie would often forget that she had eaten, or insist that she had just done so and did not want anything else. Pre-meal times became potential scream times until Sarah realised that 'little and often' of highly nutritious food was a solution to their problem. Her mother happily nibbled away at the food put in front of her, and Sarah felt less stressed. She encouraged her mother to have vitamin drinks and ensured that she could not choke on anything if she tried to fill her mouth with food and forgot to swallow.

Going out

Driving

Shortly after the diagnosis of Alzheimer's, Sarah began to be concerned about her mother driving her dearly loved car. Apart from her own safety, she was scared that she would cause an accident or not be able to remember the details of what had happened. Sarah spoke to the doctor, who gave Maisie a check up. Maisie understood that the DVLA would have to be notified of her diagnosis and finally agreed to stop driving. She realised that it had become a great stress for her.

Support Groups

The local branch of the Alzheimer's Society invited Maisie and Sarah to a support group. At first they were loathe to attend, but later on were glad to speak with people who were experiencing the same difficulties and challenges. They recognised that the fear of losing the mind and of being left abandoned is present in everybody and were helped by having contact with people who could enter into their pain.

Maisie had said that she never wanted to go to a day centre. She knew that some people really enjoyed attending, but felt that it was not for her. Some well-meaning people tried to persuade her, but she remained determined and eventually her wishes were heard.

Invitations

Sometimes Maisie would receive an invitation to go out for a meal or for a trip into the countryside. Her friend thought that she was being kind, but for Maisie the idea contained all kinds of terrors. Her world had been gradually shrinking, and she usually felt fairly safe at home. But how would she cope away from the familiar? How would she know what to do, where she was, how to get home? Occasionally she was persuaded, against her better judgement, to go out. She became agitated and wanted to go home all the time. The suggestions of outings soon came to an end.

Meeting half way

Communicating

Maisie's speech began to deteriorate. Sarah realised, however, that her mother would often use a word or phrase which, with some good intuition and lateral thinking, could give a clue as to what she wanted or was trying to say. In her better moments, Sarah made these struggles into a joyful game.

Maisie had not been a saint before the disease and was certainly not one now! In time-honoured fashion, she began to take out her anger and pain at the situation on those closest to her. Sarah became very upset at the apparent injustice of this, but in speaking to her support group realised that it was a very common practice. She began to spend more time talking with Maisie rather than dashing round trying to catch up with the jobs.

Helping out

Independence was very important to Maisie and she wanted to retain it for as long as possible. When she could no longer undertake a major task such as cooking the dinner by herself, Sarah helped her mother by breaking down the work into manageable steps. Instead of saying 'can you do the vegetables, please?', she would go to the fridge with her mother to find the carrots, go to the kitchen drawer to find a knife, and remind her how to peel the carrots. Maisie received a sense of value and worth whilst she retained these skills and could put them in practice.



Reality

Sometimes Maisie would say that she had just seen her mother (dead for 20 years) or had been busy weeding the garden (when Sarah knew that she hadn't moved from her chair). At first Sarah, in her desire for truth, wanted to contradict her mother, but she soon recognised that this was not the most useful approach as Maisie became even more confused or felt that she was being called a liar, when her reality was saying that she HAD seen her mother. Sarah learnt to say 'how did you feel when you saw your mother?' and 'are you tired after all that gardening?' Such affirmation helped Maisie explore the feeling behind and reasons for her words, such as a longing for comfort or a desire for usefulness.

Whose problem?

Maisie used to be so house-proud but then the dirty crockery became piled high and the house was a mess. Sarah looked and saw a health hazard: Maisie looked and saw safe familiarity. When there was no immediate danger, Sarah decided that it was more helpful to let Maisie live happily in the mess than cause her deep distress and confusion by tidying.

Around the house

Wandering in the home

As the disease advanced, Maisie found herself no longer knowing where she was. She began to incessantly wander about the house, looking for someone or something that would represent safety and love. She was trying to escape the pain of her loss. Sarah got to her wits' end: she found it almost unbearable to see her mother like this. Nothing seemed to work: neither distraction techniques nor a soothing voice. Sarah spoke to the doctor, who prescribed a sedative, which worked in Maisie's case.

Wandering outside the home

However careful Sarah was, Maisie sometimes managed to get out of the house and wander around the neighbourhood. Sarah was terrified that some harm would come to her mother, and so she warned her neighbours and the police. She also put an identity bracelet on Maisie's wrist, so that she could be easily identified.



Falls

Maisie began to be unsteady on her feet and occasionally felt that she was going to step into a deep hole when the colour of the carpet changed. Once Sarah found her on the floor and couldn't lift her up by herself. She rang the ambulance service who quickly came and helped Maisie back into her chair, having checked that nothing was broken.

Going to bed

Gradually night and day ceased to be distinguishable for Maisie, and so she protested when Sarah said it was time for bed as she was just planning to get up. Sarah learnt to say what time of the day or night it was "it's two o'clock in the morning" and tried to start a cosy routine which Maisie would associate with going to bed. Maisie developed a fear of the dark and so a nightlight always burnt in her room. Sarah also left a note in her room, saying that it was not yet time to get up. This helped Maisie stay in bed, whilst she could still read. Sometimes, when the battle over going to bed seemed very hard, Sarah left Maisie safely tucked up in her chair for the night.

Keeping going

Conversation

Although Maisie increasingly forgot the meaning of words, she still enjoyed people talking to her, especially when they spoke slowly and used short sentences. Sarah also learnt that Maisie became more forgetful and less coherent in the evenings, and that love and understanding covered a multitude of frustrations at such times.

Memories

There seemed to be a sometimes happy balance between finding things for Maisie to do which would provide her with some stimulations and enjoyment, and not letting her become overwrought. Sarah found that producing a life book, showing the story of Maisie's life, was a good way to provide interest for her and help her remember stories from the past. Looking through old photograph albums also provided her with some pleasure.



Faith

Having had a strong faith all her life, Maisie was deeply hurt when the church could not seem to cope with her disease. She was grateful to those who continued to come and pray with her and read her the Scriptures. As time went by, she ceased to understand the meaning of the words, but always seemed to receive some comfort and strength from the times of prayer. She also continued to enjoy singing, when prompted, and Sarah and her visitors were amazed at how she could remember and still sing the words of hymns learnt in childhood.

Radio and television

Maisie used to enjoy listening to the radio but began to be confused by the disembodied voices: where were the people, and who were they? She began to watch more television, and for a time this provided her with good company. Then she began to wonder who these people were that were with her in the room. She accepted Sarah's reassurances for the most part.

Losing inhibitions

Loyalty had always been one of Maisie's attributes so Sarah was horrified when Maisie began to make passes and exhibit inappropriate sexual behaviour to anyone who came to see her. She learnt that this again was another part of the disease, and explained the situation to visitors before they arrived. She also found that giving Maisie extra reassurance sometimes helped.

Carers have needs too

Asking for help

The process of obtaining sufficient help for Maisie from Social Services, which were grossly under-funded, was akin to crossing a minefield at night wearing a blindfold. As Maisie's condition progressed, her care needs kept growing. Sarah became worried that Maisie's demands on her were becoming more than she could cope with. Sarah realised that she had to be politely assertive, and have the courage to ask for what was needed. She tried to keep to her personal rules of being straightforward and not aggressive, but the lack of funding and the pressure under which the Social Services were working sometimes made her forget her resolve. She decided to write to her MP, to bring the chronic shortage of funding to his attention.



Attachment

Maisie became terrified of Sarah leaving the room, and would be calling out for her until she returned. She was like a little child, abandoned by her mother with no concept that she would ever return. This behaviour was very demanding for them both. Sarah learnt that sometimes Maisie would forget she existed as soon as she had made the painful departure.

At other times Maisie would still be upset when Sarah returned. Sarah learnt that, for her own sanity, she would have to have breaks away from Maisie, and that Maisie would get over the loss on her return. Sarah also found a friend who was willing to visit Maisie on a regular basis and over time Maisie began to feel safe with her as well.

Lucidity

Just when Sarah had resigned herself to the thought that parts of her mother had permanently gone, Maisie would suddenly become incredibly lucid, almost back to her old self. Sarah learnt to treasure these moments, which became less frequent, when they arrived and not to expect them to continue.

Dangerous feelings

Strong feelings were stirred in Sarah as she tried to care for Maisie. On the one hand she felt very protective of her in her vulnerability. On the other she recognised that she, as we all do, had it in her to abuse that vulnerability. She learnt to try to take care of herself, and give herself space, so that she would be able to look after her mother without being overwhelmed. When things seemed to be very fraught, she decided to talk to her support group. There she realised that she was not the only one with these feelings, and the very owning of them helped her to carry on coping.

Going into a home

Maisie had always said that she did not want to go into a home, but eventually Sarah realised it was impossible for one person, even with care assistants, to look after Maisie any longer. She examined a number of homes, and tried one out by letting Maisie stay there occasionally for respite care. At first Maisie hated it. She refused to eat, and would call out and try and bite the careassistant in her confusion. Gradually she became used to it, and the strangeness of her new environment was replaced by a feeling of safeness. Sarah visited her most days. Maisie began not to recognise her, but Sarah carried on visiting, as she knew that she was a calming presence on her mother.

One day her mother caught an infection and 24 hours later was dead, with Sarah at her side. The journey through Alzheimer's was over, and Sarah began to grieve the final loss of her mother.

Useful contacts

National

Alzheimer's Society, National Office
Telephone 020 7306 0606
Website www.alzheimers.org.uk

Age UK Advice Line

Telephone 0800 6781602
Website: www.ageuk.org.uk

Disabled Living Foundation

Telephone 020 7289 6111
Website: www.dlf.org.uk

DVLA

Website: www.gov.uk

Your local area

Citizens' Advice Bureau

Council Offices

GP

Social Services

Solicitor

Age Concern (local charities still continue in lieu of Age UK
in some places)



A MILLENNIUM AWARD SCHEME
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