How it all Started

My mother was a bit confused on her 80th birthday but not really showing any signs of dementia apart from normal forgetfulness in old age. She was able to exist on her own and look after herself but because her short term memory appeared to be failing rapidly, I wrote to her doctor for advice in December 1996. She could no longer recall events of the previous day, kept repeating the same question or remark in a conversation and couldn't retain simple facts such as our address or days when we would visit. We noticed these changes occurring gradually over the past couple of years but hoped it wouldn't get any worse and she would remain able to look after herself in her own home. Unfortunately I think she realised what was happening and got quite upset and even more confused, even frightened. The problem for us was knowing what to do about the situation, we tried to suggest that she should see a Doctor but she couldn't manage a visit on her own without help, we would have had to somehow try and take her along. We had an added disadvantage in living 150 miles away.

Her GP., Dr.Watson from the Derby Road practice in Ipswich put us in touch with ACCESS. This was a jointly financed team between Health, Social Services and Age Concern that had been operating successfully in Ipswich for a number of years. To comply with the NHS and Community Care Act, the staff worked with Social Services approval as named assessors. On the 29th.January 1996, 3 people from ACCESS visited my mother and assessed her. They confirmed her dementia with a series of questions. A social worker was assigned to my mother's case and did make regular visits over the following months to check on her.

Although my mother was managing on her own up to a point, it soon became clear that money from her pension was disappearing, her washing wasn't getting done and the house wasn't getting cleaned very well so we had to step in with visits as regular as we could to sort her finances, do her washing and ensure she was stocked up with food. However, in March of 1996, I found I had to apply to the Court of Protection for Power of Attorney. My mother was aware of this and agreed.

In May, it was clear she had probably reached Stage 4 and ACCESS did a more detailed assessment. The following are extracts of their report:-

Agnes is a pleasant independent-minded lady who prefers to manage without assistance and in the past services have been refused. From time to time she experiences acute confusional episodes as at present, when coping is much more difficult. Currently is weepy and distressed, deluded and halucinated. Believes a cousin and a child staying with her and sees people in the garden. Not dressing, neglecting diet and self care.

Elderly neighbour (90) very anxious - phoned son yesterday as Agnes not dressed all day and wandering up and down the garden. Son and daughter in law visit as often as they can from a distance. Until now, homecare refused. Sister lives quite close, visits once a week.

Agnes cannot understand why she is so upset. Has become preoccupied with the death and funeral of a sister who died 5 years ago - believes it is happening now. Usually refuses services, including home and daycare - prefers to be in her own home functioning independently. Currently not objecting to a little help. Son and daughter in law very anxious on her behalf and have tried hard to persuade her to accept help. Requested today's visit having been alerted as to problems by next door neighbour.

Arthritis (arms) but not severe. Confusional episodes. Early dementia ? Mobility good. Self medication likely to be a problem. Generally communicates well - somewhat repetitive. Generally a pleasant cheerful lady. Currently weepy and depressed, somewhat agitated.

Deluded and hallucinated. Loses things. Burns pots and pans. Forgets the days. No longer safe with appliances. Self neglect and neglect of diet. Agnes generally feels she is still coping well. Normally a fastidious, well groomed lady - things appear to be slipping a bit. At present accepting suggestion of a little help

As a result of the above, several things kicked in, Meals on Wheels were provided, home help was agreed and with agreement from her doctor, she was seen by a Dr.Nejo from the Psychiatry of Old Age Directorate, Minsmere House attached to Heath Road Hospital. Extracts from his report as as follows:-

Thank you for asking me to see this 81 years old lady who lives alone in a three bedroom house and whom I assessed at home on 30th May 1996 in the company of her Social Worker from Age Concern/ACCESS. I gathered that over the last two days she has become increasingly confused, wandering out at night to look for an imaginary missing little girl and a man, constantly distressed and worried and ringing neighbours and police for assistance with regard to her search as well as self neglecting herself.

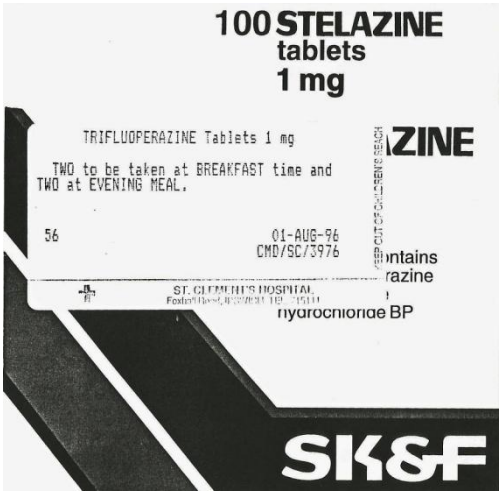
She admits to at least two years of gradual forgetfulness but in the last two to three weeks there has been fluctuating confusion with forgetfulness resulting in her losing items within the house, forgetting peoples birthdays, and most recently alarmingly burning an electric kettle which she placed on a gas fire as opposed to plugging it in to the mains in order to boil water. She is disorientated in time, thinking that she retired from work a year ago and was a voluntary visitor with Age Concern for various people including this missing man and little girl whom she believes are from the Bramford area of Ipswich and are a part of a group of people that she frequently saw and visited. Furthermore, she is convinced that a sister who died six years ago in fact died three weeks ago. She admits to feeling upset at her recent inability to remember things or to attend to her self care and has been experiencing intermittent low mood, tearful bouts and falls, especially towards the evenings.

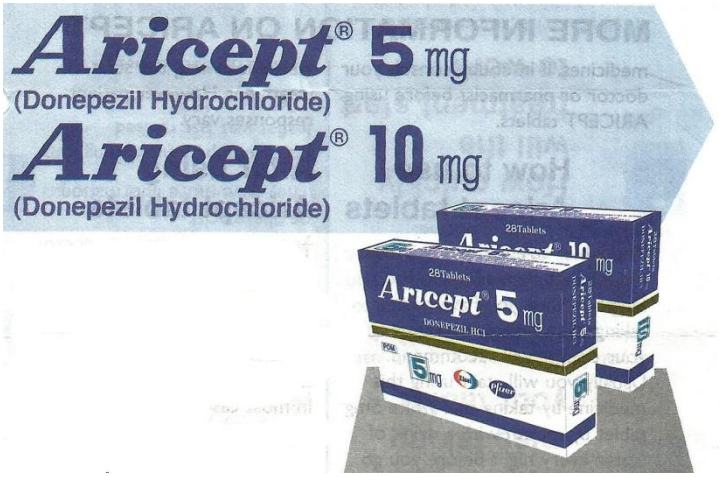
There is no known past psychiatric history and she describes herself as having always been a worrier. There is a history of recurrent nose bleeds and hypertension but she is currently on no prescribed medication.

Mental state examination revealed a small, bespectacled, tidily dressed lady, who did not appear malnourished but there is evidence of eroythema abiene around her left knee area, presumably from sitting too near the fire. She exhibited a good eye contact and rapport and was ambulant unaided. There was no speech problems and although somewhat anxious with evidently catastrophic reactions to her memory deficit she did not appear clinically depressed and nor did she exhibit any suicidal ideation or intent. Her fleeting visual hallucinations and delusions are as described above. She scored 30/37 on the Blessed information/memory/concentration test with marked disorientation in time, poor short term memory (0/5), patchy non personal memory with good concentration.

My impression is that this lady is suffering from a probable multi infarct dementia and/or dementia in Alzheimer's disease with superadded delirium. She has agreed for us to admit her to the Day Hospital for a period of assessment and as discussed with you today to be commenced on Stelazine 2 mgs bd. Her Social Worker has arranged for carers to go in at least twice a day in order to provide her meals and to prompt her medication. She is due to commence attending our Day Hospital on Tuesday 4th June 1996.

Now Stelazine is an anti-psychotic drug for the management of schizophrenia (anxiety and hallucinations), not dementia. The problem with this drug was the massive side-effects. It is no longer prescribed. Within a week my mother felt very hot. By the end of June, my mother had developed a shuffling walk, stiffness and uncontrolled movement in the arms and legs, significant weight loss, extreme fatigue and difficulty with eating. ACCESS made Dr Nejo aware of the problems. I complained both to him and Dr Watson. Thank you NHS! Before my mother started taking Stelazine she was confused certainly but physically fit. After taking Stelazine she was quite disabled and housebound.





Between June and August, my mother was offered 2 days a week at the Minsmere Day Centre but regularly refused to go (see Carer's notes), partly caused by the Parkensonian side effects of Stelazine making it difficult for her to walk. So she was transferred to an outpatients clinic at Minsmere and I accompanied her to make sure. She was reviewed by Dr.Nejo on the 24th.July as a result of my complaints regarding the overpresription of Stelazine which was then *supposed* to be reduced to 1mg bd which should have reduced the unwanted side effects of the drug. It was also planned to give her a CT scan at Minsmere but it was impossible for her to co-operate with that. During the

3rd week in August she was seen at the Minsmere clinic by Dr. M J Stevens, the Consultant Psychiatrist. She scored 22/30 on the mini mental state examination (MMSE) which qualified for a trial on Aricept, 5mg a day. On the 12th.September 1997 she was reviewed again and although there was no change in her MMSE score, she was no longer making repeated anxious telephone calls to me. There were no obvious side effects. One month on, again there was no change in her MMSE score but we had noticed she had started remembering things and on one occasion she had prepared and cooked some vegetables which she had not done for a very long time. This was encouraging and the daily Aricept dose was increase to 10mg. ACCESS had reported that my mother was more settled and cheerful as well. In an assessment on the 18th.March 1998, Dr Stevens wrote:-

She was cheerful and told me that she thought that her brain was working better. Her son reported no deterioration but was pleased with how well and quickly she had adjusted to being back in her own home after a break at his home, a marked contrast to the degree of confusion she had displayed on a similar occasion last year.

On examination her MMSE score remained at 23/30 and her Blessed score 22/37. Both scores have shown no deterioration since just before she started the Aricept last August. Her extra pyramidal tremor was slightly worse.

I concluded that the lack of cognitive decline was likely to be due to the Aricept and therefore left it that she would continue on 10 mg daily until next reviewed. I had intended to suggest that the Stelazine be changed to Risperidone 1 mg daily in the hope that this would keep her delusions under control without producing such marked extra Parkensonian side effects.

On the face of it, the Aricept seemed to be working and stabilising her dementia. One of the things that surprised us when assessed at Minsmere was her numeracy skill, she was still very capable at adding and subtracting. Because she had been a cashier way before computers and calculators, she had to do plenty of mental calculations and this was still there is her long term memory function. Unfortunately the Stelazine didn't get changed by her GP, Dr Watson, as requested, and her tremor did not improve. The 23rd.April was the last time she was seen at Minsmere and on that occasion Dr.Stevens observed that:-

This lady's mental test scores were essentially unchanged when she came to my clinic this week. She was cheerful and her son had noticed no deterioration in her memory. However, she was reported to have been wandering outside in her nightie and to have left the gas on unlit at home. Fortunately, she herself had suggested that she might go into residential care. I understand that her Social Worker will be showing her one or two places with a view to putting her on the waiting list

Indeed, she had really reached the 'tipping point' and to her credit she did realise that so it was arranged for her to have a trial week at a Residential Care Home in Ipswich (June 22nd to 3rd.July). The situation was getting a bit out of control for her to remain on her own and we were becoming very anxious about it all. However, on the 24th.May 1998, my mother, very uncharacteristically, went walkabout, was found lost and disorientated, an ambulance was called and she was admitted to hospital.