

Carers and Support – Pre-Residential Care

Following my mother's dementia diagnosis the ACCESS support service arranged for her to have home care visits every day and a hot meal delivered at lunch times. This care plan commenced on the 1st.June 1996 under contract to Suffolk County Council. The carer visits were provided by Home-Care of Ipswich. Originally these plans contained a provision for my mother to attend the Minsmere Day Centre at Heath Road Hospital, Ipswich where, amongst other things, they could monitor her dementia. Pick-up transport was provided but she refused to go most times so she lost her place in October 1996 and the care plan changed. Subsequently, defined appointments were made and I took her myself for these regular assessments. These are covered separately.

My mother had been prescribed medication for her condition, see later, and it was left to the carers to prompt her each day to take the medication. Unfortunately, boxes seem to go missing or my mother took pills on her own and it got to the point where she couldn't be trusted so a lockable case was used for the medication (dosset box) such that the carers could access this for her and prompt the correct dosage. Now because I lived 150 miles away, I was quite detached for my mother's care although just organising and arranging from afar was a busy task in itself. To understand more about my mother's condition I asked the carers to note anything relevant in a diary I had put in the case. This they agreed to do and although my mother had several different carers, I am **particularly grateful** to Margaret and Doreen for providing the care for my mother and letting me know of any concerns. The comments below are the words written by the carers themselves. In retrospect, it is clear how the Alzheimer's is progressing over time from these entries. Essentially she moves from Stage 4 in 1997 to early Stage 6 in 1998.

Excerpts from the Day Diary and Access notes

- 29-9-96 11 phone calls to me; thought she heard voices upstairs
- 30-9-96 carer couldn't get in, lights on and milk left on step.
- 1-10-96 very confused, table laid for a funeral; tearful and upset; persuaded to be taken to Minsmere; saw doctor; recent problems just 'dementia taking it's toll'; enjoyed visit, very happy
- 3-10-96 refused daycare
- 17-10-96 refused to go to daycare again
- 29-10-96 had been treating a sore lip with roll-on deodorant which she thought was Vaseline
- 4-11-96 said she enjoyed washing up after a meal
- 2-12-96 mother had drawn 2 weeks pension ~ £200....could only find £60 in the house when I looked.
- 4-1-97getting ready to go away with her son.....phoned son....she is not due to go away with him
- 14-1-97 ...has eaten all the cakes that were bought the other day....they were wrapped up and put away but she found them
- 16-1-97 ... was still on about going away....unpacked case in the hope that she will forget about it
- 17-1-97put out clean clothes for her to change as she has had them on for 3 weeks...
- 30-1-97confused about time of day and time of year..
- 4-2-97can anyone throw any light on what happened to all the ham in the fridge?...
- 5-4-97 ...eaten a whole sponge cake today that I only brought in last night..
- 2-5-97 ...had locked herself out and was next door, good job I had a spare key..light went out when I turned the kettle on but next door sorted it out..
- 7-5-97.. says she has had tooth ache all week..
- 12-5-97 ...apparently has been phoning her daughter-in-law all afternoon, she is very confused today..
- 13-5-97 ...was in her night gown at 5.05pm ready for bed and said she was having an early night.....told her it was far too early for bed
- 15-5-97:...in her nightie and dressing gown again at 5.05 pm....
- 26-5-97 ...in her nightie again when I arrived at 5.05pm.....said she was just going to bed...told her it was too early so she said she would stay up a bit longer..
- 27-5-97..brought her a chocolate sponge and a pack of yogurts in last night...tonight it was all gone..don't know where she puts it all..
- 2-6-97 ..at 5.05 today she was in bed...came down and let me in after a lot of knocking at the door..
- 3-6-97 ..keeps going on about going to the day centre...I have told her countless times that she doesn't go there anymore, she has not been since last September as she would not go when they called for her..
- 5-6-97 ..at 4.55 pm already in bed, came and let me in after knocking on door and shouting through the letterbox..

- 9-6-97.... eaten a whole sponge bought yesterday, don't know where she puts it....doesn't put on any weight..
- 10-6-97....already in bed at 4.00pm...told her it was too early for bed and if she goes to bed now she won't sleep later
- 12-6-97...very confused, thinks son and wife and daughter are staying with her and coming back tonight..
- 27-6-97....in bed when I called at 5.00pm..
- 1-7-97...in bed at 5.00pm...had to knock several times before she got up to let me in..
- 3-7-97...was going to bed when I arrived at 5.05pm...
- 4-7-97...somehow she had gotten hold of an empty box of pills and a chemist's bag...was insistent that she had already taken a pill and that someone else had been in...
- 5-7-97...all ready for bed at 4.15pm..
- 7-7-97... already in bed at 4.15pm...
- 9-7-97...at 4.15pm was waiting on the doorstep with her coat on, says she is going to the local school for tea with her sister...turns out she should have gone to a children's concert at the school 2 days previously..
- 10-7-97...arrived in morning to find table had been set out with bread put on plates all over the table thinking she had someone visiting this morning....cleared it all away and washed up..
- 12-7-97..all ready for bed again at 5.00pm...she had cuts on her face, looking as if she had been cutting her hair..
- 14-7-97..was down the garden watering plants when I arrived..
- 15-7-97....all ready in her nightie for bed at 5.05pm...
- 17-7-97...in her nightie ready for bed at 4.05pm....says she has had a bath (don't think so!)..
- 21-7-97... in bed when arrived at 4.15pm, table was laid for a tea party, says her son is coming tonight, also Jackie, to sleep there...
- 22-7-97...she looked very smart today...
- 23-7-97.. she had the gas ring on the cooker on but it was not lit and the house smelled of gas...when I arrived she was at the front door with the door wide open..
- 24-7-97....all ready in her night clothes when I arrived at tea time...
- 25-7-97...thinks son and his wife are coming to visit tonight....told her that they came to see her the previous Saturday..
- 28-7-97...still on about going to visit her son and also going to the day centre, asked how my baby was, I told her it would be a miracle if I had a baby...
- 31-7-97..says she has been out to see her sister this morning...still keeps going on about the day centre and that her son is coming tonight...she thinks today (Thursday) is Sunday..
- 2-8-97.. found her ready for bed at 4.00pm..told her it was far too early for bed...still asking about my baby (which I don't have)..
- 4-8-97....all ready for bed again at 5.05pm.....she says she gets up early so is tired now...still going on about the day centre..
- 12-8-97..in a bit of a tizzy at tea time trying to put on tights as she thinks she is going to the day centre..
- 13-8-97...kept me waiting on doorstep for 10 minutes as she had gone to bed...had to bang on door and shout through letterbox...she has no idea of time, she thinks it is 10.20pm..
- 14-8-97...at 4.45pm she had the table laid for a tea party..says her son is coming and she is going to the day centre today..
- 15-8-97... still asking about the day centre but seems glad when told she doesn't go anymore..
- 24-8-97.. had table set out for her son and wife, said they were all out downtown with their daughter..
- 26-8-97....seems to be improving a little...
- 27-8-97...at 5.30pm she was in her nightie..
- 30-8-97...still repeats herself and gets confused about her son coming here and Jackie sleeping here...
- 1-9-97...arrived at 4.45pm, she had 2 dressing downs on and a nightie..said she was just off to bed..
- 2-9-97...doesn't seem to be making much progress on the Aricept, still as confused and forgetful as before...still keeps on about the day centre and my baby....thinks son is coming and Jackie sleeping here..
- 9-9-97...Minsmere appointment
- 16-9-97....it is a Tuesday and she thinks her son is coming tonight, cannot convince her he is not...she thinks it is Sunday
- 17-9-97....found her in her night clothes standing at the front gate..

- 19-9-97...morning visit found table all set out, thinks son is coming..we had a chat and I put all the things away...
- 21-9-97.....4.20pm visit, found the gas on but not lit...
- 23-9-97....keeps on about her son coming tonight..
- 25-9-97...morning visit, says her 2 sisters are upstairs asleep...tea time visit she is ready to go out to the day centre..says her eldest sister is staying with her (she had passed away years previously)
- 26-9-97...ready for bed at 5.10pm..
- 2-10-97...gas fire was on when I arrived but not lit...
- 6-10-97...lost her front door key...strong smell of gas when I arrived but nothing left on..
- 7-10-97...very strong smell of gas at tea time but everything was turned off when checked...
- 9-10-97....Minsmere appointment
- 12-10-97....strong smell of gas when I arrived..
- 15-10-97...strong smell of gas this morning, said she had just turned the fire on.....ready for bed at 4.00pm..
- 18-10-97..strong smell of gas at tea time..she had the grill on but not lit..
- 21-10-97...next door said there was a smell of gas, someone was going to come round and check it..
- 22-10-97..said she was going to see her sister but couldn't find the key to the back door..
- 23-10-97....she was ready for bed at tea time...she had the kettle on the gas to make a cup of tea but the kettle boiled dry...
- 28-10-97..at tea time found her standing by the front door waiting for her son to arrive....explained he will not be here tonight..
- 2-11-97...she wouldn't eat anything for tea, said she had already eaten?
- 3-11-97.. all ready for bed at 4.05pm..
- 5-11-97.. found standing by the front gate in her night clothes..
- 6-11-97.. found standing by the front gate in her night clothes again..
- 8-11-97.....managed to burn the new kettle..
- 10-11-97...found standing by the front gate at 4.50pm...
- 12-11-97....she doesn't smell very pleasant..gave her a bath..
- 13-11-97..Minsmere appointment
- 17-11-97...Ready for bed at tea time..
- 19-11-97...turned on immersion heater in morning ready to give her a bath in the evening but she had turned the heater off....managed a shallow bath..
- 20-11-97....found a whole slice of burnt toast floating in the toilet at tea time....
- 24-11-97...very confused tonight..
- 26-11-97..strong smell of gas when I arrived at tea time...very confused tonight..
- 2-12-97..said she had been out to the day centre today...said her eldest sister is visiting her mother at the moment..
- 4-12-97....has a large bruise on her buttock, said she had fallen down the stairs..
- 5-12-97...very strong smell of gas at tea time, grill was on but not lit
- 6-12-97.... very strong smell of gas at tea time, grill was on but not lit...burnt toast left..
- 8-12-97...not dressed as usual when I arrived in the morning, said she had not been to bed and was just going...could not get her to eat or drink anything, she just wanted to go to bed..at tea time, finally managed to get in, she was still in bed, didn't want much tea, just wanted to get back to bed...
- 13-12-97...hardly recognised her today, she was properly dressed and bed was made....we had a chat and a cup of tea
- 15-12-97....gas on under grill at tea time but not lit..
- 24-12-97 to 29-12-97.....spent Xmas with son and his wife
- 30-12-97...waiting at the front door when I arrived...very confused, thinks her son is here...got very upset when he didn't come in, she keeps wanting to go to the front door to see where he is...
- 31-12-97.. a little more settled today, said her son had gone home....at tea time in the freezing cold, she was standing on the front doorstep waiting for her granddaughter to come home...she is crying because she thinks her granddaughter is lost..have tried to explain that there is not a little girl staying here but she can't take it in..
- 1-1-98.. said she felt like her old self today..
- 7-1-98...a bit confused today, waiting for her son and his wife...
- 9-1-98...ready for bed on arrival at tea time..

- 12-1-98...confused tonight, thinks her son is coming tonight to take her to his for Xmas...she said she was going to make some mince pies to take....managed to settle her down..
- 13-1-98....full of smiles today, said her son and his wife came to tea last night...
- 15-1-98...Minsmere appointment
- 16-1-98...gas on again this morning..
- 23-1-98...very confused this morning, she thinks her son is coming to take her to the hospital (Minsmere)...found her in a right state when arrived at tea time...very strong smell of gas and kitchen window wide open...had her coat on and said she had been round to see her sister today..
- 31-1-98...tried to arrange for a bath but she keeps turning the immersion heater off...
- 6-2-98...thinks her son is coming tonight....gas turned on but not lit..
- 10-2-98...confused this morning, table all set out for dinner...thinks her son is coming...
- 26-2-98....a bit confused, table was set out...
- 3-3-98....very confused this morning...she thinks her sisters are all coming home because her mother has just died...very tearful.....we had a chat and cheered her up..
- 4-3-98...a lot better today... two gas rings were on but not lit...said she couldn't light them..
- 8-3-98...tearful this morning, said she was thinking about her mum.....tried to cheer her up..very confused at tea time, said she was going to the day centre..
- 12-3-98...in a joyful mood this morning, said she had just come out of hospital after having her hip done..
- 19-3-98....she had turned off the immersion heater switch again so couldn't give her a bath.....put some tape over the switch hoping she wouldn't..
- 22-3-98.....wouldn't answer the door this morning...
- 24-3-98....had the grill turned on again but not lit...
- 25-3-98....she was standing at the front door when I arrived at tea time....had to make irish stew for her as she had left her dinner in the oven and it was burnt to a crisp..
- 26-3-98...on the doorstep again tonight at tea time.....both the grill and front burner of the gas oven were on but not lit.....strong smell of gas in house...
- 27-3-98...wouldn't answer the door this morning...
- 28-3-98.....she had taken the tape off the immersion heater switch and turned it off so very little hot water again..
- 29-3-98....took a very long time to answer the door...
- 1-4-98...on about going to the day centre again tonight....tried to get through to her that she doesn't go there anymore..
- 2-4-98...very confused tonight..
- 3-4-98...was crying when I arrived this morning and could not walk straight..said she had fallen over and hurt her back...had a look but couldn't see anything...
- 11-4-98.. standing at the front door in her night clothes at tea time..she was freezing cold..
- 12-4-98...very confused this morning...wants to know where her mother is..
- 13-4-98..very confused this morning....she is looking for a cat...arrived again at 5.00pm and found the front door wide open...she was down the garden looking for her eldest sister (deceased).....says she is going to go to the day centre tonight...keeps crying and putting her coat on to go out..have tried to calm her down but to no avail...
- 14-4-98....didn't want to get up this morning...she is still worried about a cat...I think she has been looking for it most of the night but said she couldn't find it...gave her breakfast in bed...at tea time she is getting ready for bed..
- 15-4-98....standing at the front door again when I arrived at tea time..
- 16-4-98...had locked herself out again but neighbour let her back in..she was freezing cold..very confused again..
- 17-4-98.. table all set out this morning and lots of bread....very confused.....standing at the front door again at tea time and very cold...she had been making cheese-on-toast...kitchen is in a right mess..
- 21-4-98...Minsmere appointment
- 25-4-98...unable to get in this morning..
- 30-4-98....could not do her any toast this morning as the grill rack has disappeared!..
- 4-5-98...waiting for her sister to bring in sandwiches at tea time..
- 7-5-98....getting ready to go to the day centre when I arrived at tea time..

- 13-5-98..said she was going out to tea with Jackie when I arrived at tea time...she had put all the heaters on in the bedrooms..
- 19-5-98...very confused this morning and crying for her mother...
- 23-5-98...up and dressed when I arrived this morning, said she was going to a wedding...at tea time she said she already had her tea and that she was going out with her son.
.....That evening she smartened herself up, put on a suit, and went for a long 3 mile walk, got totally lost and was found sitting on a grass verge. An ambulance was called and she was admitted to hospital.