

Date: 23 February, 2001

(Less detailed) N.B. This is an example of a good day

Time			Notes and thoughts
00	00		I feel very disloyal to Jan writing about her day-to-day condition, and even talking about it with doctors.
01	00		
02	00		
03	00		
04	00		
05	00		
06	00	Jan awoke and was very restless, pulling back the sheets and trying to tidy the bed from within. Asked her if she wanted to go to the bathroom and she said no. She continued to rearrange things. Took her to the bathroom. Put her back in bed and she eventually settled, though didn't sleep.	
07	00	Eventually we both slept some more.	
08	00		
09	00	Jan was confused and slow; helped her into her housecoat and slippers then guided her downstairs..	
10	00	Laced Jan's orange juice with Lactolose. Jan ate a tiny piece of toast but it was too 'chewy'. Drank a little tea.	
		Led Jan upstairs to dress, as usual, in the bathroom.	

11	00	Led Jan downstairs to comb her hair. Showed her the location of the comb and the mirror. Gave her a Galantamine tablet.	
		<p>Went upstairs to call the Day Centre. I was asked not to bring Jan there until further notice.</p>	<p>We have been trying to get Jan to attend the Day Centre for 3 months—we have been edging her towards accepting it. We have not been successful so far, as they have insisted on my taking her there and then running off when her back is turned—something I hate to do. When pressed to do something she is not comfortable with—and particularly by people she does not know—Jan can turn to violence to show she does not like it.</p> <p>Recently I have stayed there with her for some time and she forgets that I'm there and talks to other patients. This I believe to be the way to go.</p> <p>Jan went to the Day Centre last Wednesday. She was quite calm going there, and I was encouraged. My intention was to stay there with her for an hour or so, and then take her home, easing her into acceptance.</p> <p>The Day Centre supervisor is on sick leave at present and her boss was there. I spoke with her for some time about Jan's case. I was then encouraged to leave Jan there for a couple of hours. This I did.</p> <p>When I collected her I was told she was going to be banned from there as she was disrupting the other patients. The normal staff could do nothing about this decision, though they said Jan would remain on their list.</p> <p>Support services</p> <p>The Day Centre is/was the principal hope.</p> <p>Social Services has funded 8 hours per week of a health care assistant, but has never provided this because of lack of resource—the person. It needs to be one or two people, consistently the same ones, to minimise confusion to Jan.</p> <p>The Community Care team is very good, but can provide only 1 hour per week.</p> <p>We have had a full half dozen consultants in the past 15 months, as there has not been someone permanently in post.</p> <p>It took me 6 months to complete the forms for Disability Living Allowance—very painful to have to put in writing all the detail. We now, after a review, get the full rate for care and mobility.</p> <p>E-mail is a boon in contacting our GP (who is excellent) and we get fast prescriptions and home visits that way. I was the first person to diagnose it some 3 years before the consultants finally did.</p>

			<p>Other Support</p> <p>Jan's blood relations have abandoned her and do not even phone, with the exception of her eldest sister who telephones once a week, to tell us how ill she feels. She will not stay in the same house as Jan as 'it is too much of a strain'.</p> <p>My family have been as supportive as it is possible for people not living with this to be. Close friends and colleagues at work have been a revelation and have been very supportive; I made a decision to let everyone know the problem as early as possible. The only person that does not formally know is Jan, though she knows that things are 'serious'.</p>
		Made coffee, though as usual, Jan did not drink it. Telephone call from her consultant during this, who asked if she could call in.	
12	00	Consultant called and recommended reducing the Galantamine to 4mg per dose. She would have taken Jan off the medication entirely if I hadn't said we would phase it out. She would also have stopped the Olanzapine. I sometimes wonder what training these people receive.	
		Prepared Jan to drive to Farnham to collect the village magazine. Warmed up the car.	I produce the Churt Magazine—the local parish magazine--mostly to retain some contact in the locality, outside the house..
13	00	Collected the Magazine and called in at Safeway to collect some food. Jan was very muted after the doctor's visit.	
14	00	Made the usual baked beans on toast. Jan ate most of it and finished off with lemon drizzle cake. Left most of her tea.	Each trip to be assessed (there have been 2 assessments so far) returns her to me more damaged. Result of last 4 week assessment was that I needed to accompany her to the bathroom every time, and also it turned her off her lifelong love of tea, and her liking for coffee.
		Did some work in the afternoon, mostly phone calls, but with frequent breaks to reassure Jan.	A quandary: Jan wanders around under all circumstances, but when I'm making phone calls, she gets very confused and tries to be a part of them. She sees herself as 'hopeless'. If I don't make calls, I don't work at all.

			<p>Working with computers has been a major boon. It has enabled me to keep my job: my company installed an ISDN connection and had supplied computing equipment prior to my needing to be at home full time (although I already had my own computer); e-mail and my mobile phone have enabled me to keep in touch with my customers and colleagues and otherwise very widely; my lifelong interest in computers has given me something to hold on to—imagine if I were a plumber... there's a limit to what you can do with a pipe.</p> <p>Latterly, my second interest—photography, coupled with computing--has led me to buy a digital camera. This technology enables me to give Jan a picture report of where we have been, or whom we have met, on the very same day. Sadly, even this has diminished as we now get out less and see fewer people. Hopefully the better weather of summer will change that, should we both last that long. The digital camera, plus e-mail, enables me to keep our friends in touch, pictorially.</p>
15	00		
16	00		
17	00	Made tea. Crumpets proved to be too chewy, so Jan had some more lemon drizzle cake. She left her tea.	
18	00	Gave Jan a St Clement's, laced with Lactolose, with her Olanzapine.. Very unsettled. Double vodka for me.	Actually I don't measure the vodka, I just slop as much in as I feel like; this is certainly a double measure or more. I recently tried to pick up smoking as a habit, in the hope of getting a quick and fatal lung cancer, but life isn't that easy—cigarettes are such foul things.
		Jan walked about while I cooked dinner.	
19	00		
		Jan left most of her dinner—smoked haddock, poached in butter and milk. It was tender but Jan still found it too chewy. Cats didn't like it either. Pity, haddock is more expensive than fresh salmon now!	No joy in cooking now. No variety; no entertaining; no sharing. Also, No holidays, no television, no music, tiny amount of reading, no companionship, no future, no wine, no gardening, no hope. Doesn't leave too much.
20	00	Jan dozed in front of the fire while the BBC gardening programs—a must in the past—were on.	
		Made crème brulee for dessert—a dangerous option as the burnt sugar coating could be 'chewy', but Jan ate it all. Cooked cats' fish and made the bed, collected the hot water bottle etc.	
21	00		

		Went up to bed—took the cats and closed them up for the night. Went through all the usual motions of getting Jan undressed, after explaining to her why. Showed her how to clean her teeth, gave her a reduced Galantamine tablet, then put her into bed.	At one time I could get a couple of hours work in at this point, but Jan will wander about if I don't get to bed soon after her.
22	00	While I was getting ready for bed, Jan wandered out a few times.	
		Both in bed. I read for 15 minutes, while Jan slept.	
23	00	My light out; Jan's still burning, as usual.	