

Date: 22 February, 2001

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

Such a diary can be restricted to only two or three days, as that is about as much variety as the carer sees.

In our case, there are days when there is no outside influence (we don't see anyone)—these are the majority; there are days when there is some outside influence (Day Centre, or friends calling)—now we are banned from the Day Centre, these are very infrequent. Add to this any day may be good, or it may be bad—for the patient, and therefore the carer. In Jan's case, her symptoms are cyclical: there is a short patch in the middle of each month that is better than the rest--generally. Towards the end of the month is the worst time.

Good days are dangerous because they lull the carer into thinking that life has settled into some sort of normality. What is normal is relative to the current condition of the patient, and what is normal to me today, was not so a few months ago. The problem is that one wants to believe that things are getting better, or at least stabilising, and no matter how many times one is brought down with a jolt—the next day one is hoping again.

Time		Notes and thoughts	
00	00	Jan slept; I couldn't sleep at first.. too much to think about.	Since her last stay for assessment, Jan has insisted on our having the light on throughout the night. This keeps me awake. I have installed a dimmer, but it is still disturbing, though not as disturbing as her reaction if the light is off. Each night I close my eyes, hoping not to need to open them again.
01	00		
02	00		
03	00		
04	00		
05	00		
06	00		

		<p>Woken up by Jan moving in bed. She was not coherent enough to say what she wanted but I assumed she needed the bathroom. Went to the bathroom. Needed to show her how to use the toilet and see her through the process, as I have to each time we go there. Managed to get her back into bed quite quickly. Took some while to settle because the bed was 'too hot' and Jan needed to be shown how to lie down.</p>	<p>Each morning I wake up and think, "Oh No". The opposite of waking from a nightmare... each day to wake <i>into</i> a nightmare. This was a better day: often we are up at 3am or 4am, then need to make up to 5 trips to the bathroom within 10 minutes because she forgets she has been there already. Can't chance not taking her in case it is not a false alarm. Also, on returning to bed, she is often in and out several times, arranging and rearranging the clothes. Sleep starvation is a major problem for the carer, and once awoken, the remainder of the night is largely wasted. Jan is losing her ability to speak coherently recently—something common in younger people with Alzheimer's, I understand. This makes conversations difficult and very confusing for both of us. We have long and rambling conversations and neither of us has the foggiest what we are talking about; good politician material, perhaps. She lost the ability to write over a year ago. Her attention span is too short to be able to watch television, listen to the radio or music, or to read.</p>
07	00	Some sleep	
08	00	<p>Got up. Jan had been awake for a while, but I had managed to talk her into staying in bed—otherwise we would be going to bed even earlier at night. Laced her early morning orange drink with Lactulose as she tends to constipation, and she won't take Movicol, which the GP has recommended.</p>	
		<p>Tiny breakfast as Jan finds food texture a major problem now. This rules out cereals, even when soaked. Recently she has liked toast, but the past few days that has been 'too chewy'. Made several pieces of toast, and she ate maybe a half round. While she drank the orange juice, she wouldn't touch the tea, which she once loved. Managed to feed one of the cats while Jan was drinking orange juice.</p>	<p>A difficult thing to understand is that Jan no longer realises that hot tea will cool, given time. Once hot, always hot, and though she generally tries her tea again—it is only once it is far too cool to drink. The millisecond when it is the correct temperature always eludes us. Heating the tea up or pouring another cup causes us to go through the same motions again. Another problem is that Jan touches the outside of the cup and says 'very hot', when the tea inside is just right. She can't understand that the cup stays hotter than the tea. We can only use one type of cup anyway because all our other cups are 'too heavy'.</p>
09	00	<p>After breakfast, showed Jan the way upstairs—she no longer recognises the house as her own, and needs guidance everywhere. Selected the most likely clothes for her to wear and put them on radiators.</p>	<p>Clothes are a problem as Jan tends to wear the same things every day and responds badly to change. She has worn the same bra for 3 months now—she won't change to let me wash it. Buying new underclothes is a problem as places like Marks & Spencer will not allow men into the women's changing rooms. Jan is so fussy that the option of buying clothes, taking them home, and returning them is not a practical proposition.</p>

10	00	<p>Jan dresses in the bathroom as she finds everywhere 'cold', even though we keep the central heating on all the time. Every day I explain why she needs to change from her night clothes, and then have to help her into all the clothes. We always have an extended discussion about sweaters before I can get one on her. Before putting socks and shoes on, I show her where to stand and how to clean her teeth—I need to do this every time.</p> <p>We put Jan's socks and shoes on in the bedroom and each day they are 'tight' or 'uncomfortable'.</p>	
		<p>By 10.30 we were downstairs—I have to watch Jan on the stairs as she is losing spatial co-ordination and might fall. I show her where her comb is kept and she combs her hair, once I have shown her where the mirror is. I show her where to replace the comb, then give her a Galantamine tablet to take. Since the last assessment exercise when the hospital gave us a pill box to use, I rarely have trouble with Jan taking medication that is in the box. Any other medication she will refuse.</p> <p>Once she has taken the tablet, I leave her for 5 minutes and go upstairs to do my own teeth and shave.</p> <p>By the time I am back, Jan is saying '<i>who is this?</i>' and then thinks I've been away for ages.</p> <p>I try do do a little office work in the lounge, while keeping an eye on Jan, who normally wanders the ground floor, talking to herself. I keep the front door locked to prevent her wandering further afield.</p> <p>I empty the dish washer and re-fill it with breakfast things.</p>	<p>While I am looking after Jan full time at home, I am also, in theory at least, holding down a full time job, in computing. My company has been truly amazing in its support. The Managing Director's father had Alzheimer's, which must help in understanding.</p> <p>I have an office in the attic that I was once able to use, but now I can't be that far from Jan, except when she is sleeping, or for very short periods during the day. I make the excuse for frequent toilet breaks, to enable me to go upstairs and check my e-mails, or answer calls.</p> <p>I have bought an additional computer to keep in the lounge so I can still work down there.</p> <p>My first trip to the attic is part of the first trip upstairs of the day, (to shave) after breakfast.</p> <p>This morning Jan was very concerned that she should not 'be a pest', and kept repeating this. Finally I reassured her yet again that she wasn't but added that I would tell her if she were to be a pest. This seemed to satisfy her.</p>
11	00	<p>At around 11 I always make coffee, sure in the knowledge that Jan will probably not drink it. It serves as punctuation in the morning, and gives me something I can complete in a satisfactory manner. When I need an outlet, I cook Welshcakes, or make sherry trifle or cold apricot soufflé—things which Jan likes and originally taught me how to make, but now has no recollection of that.</p>	<p>Today, Jan first refused the coffee and cake I offered her, then decided she wanted it, then decided she didn't. Finally she had most of it.</p>

		Reminded Jan she had a hair appointment and started the process of getting her ready. During this time she forgot where she was going and for the first time showed some confusion over the hairdresser's name. Helped her on with her outside shoes, then went outside to warm up the car—she is very susceptible to cold. Left car engine running while we got her coat and gloves on, then gave cats some food before leading Jan to the car.	Jan needs help in getting into the car—she tends to put the wrong foot in first. I have to look after her seat belt.
12	00	Parked outside the hairdresser—easier that way—and walked her inside. Helped them to get her jacket off, and put her into a gown. Told the hairdresser she needed a cut.	Jan's hairdresser and his staff are wonderful. I told them early on what the problem was, and they are really caring in looking after her. She gets agitated when I leave her to park the car as she thinks I am abandoning her.
		Parked the car and looked briefly at magazines in W H Smith. Returned to collect Jan. Helped her out of the gown and into her coat (the staff tend to try and put her left arm in the jacket first, while Jan always wants to put the right one in). Put a scarf on her and her gloves. As it was dry, I walked her back to the car. She was 'cold'. Drove her straight home.	Having a car with heated seats is a great boon when Jan has problems with temperature.
13	00	Let her settle for a few minutes then took a loo break to check my e-mails. Can't leave her for long at all after a trip out as it disorients her.	
		Asked what she wanted for lunch, knowing it would be baked beans on toast. Cooked it for her, but she ate only half—she gets frustrated with manipulating the knife and fork, and I'm starting to need to feed her. Suggested she have some lemon drizzle cake—her favourite—and she did manage most of a slice, with a little tea.	When I am heating even baked beans Jan is full of wonderment at how anyone can do such a thing. About everything else, she continually asks me 'is that alright?'
14	00	After lunch, Jan paces the room continually, talking to herself. I spend time filling in this diary, with a couple of 'loo' trips to check and reply to e-mails. I talk to Jan as she paces and as I try and do things.	Jan can't relax and rarely sits down. She is constantly 'scared' of almost everything and lacks confidence to do anything.
15	00	From time to time, I sit with Jan or walk with her to look out of the window.	
16	00	There are several business 'phone calls to take and make; this unsettles Jan and she says she is 'hopeless' or 'useless'.	
17		As another natural break I make tea and warm scones. Jan likes this and we sit together to eat. Television is on, but it disturbs Jan as she can't differentiate between what is on the screen and what is real.	Jan eats less and less. From a normal weight of 8.5 stone, she has dropped to 6 stone 10 oz, and I'm having difficulty holding at that. She won't take food supplements. I have to try and get food into her at every opportunity, regardless of mealtimes.
	00	Jan is still standing or pacing. Another loo stop to do a final check of business e-mail.	Permanent standing and pacing together with constipation leads to backache.

18	00	Another punctuation: a St. Clement's for Jan, laced with Lactolose; a double vodka with orange for me. Jan also takes an Olanzapine tablet with the drink. Some problem in swallowing it, as she is slowly forgetting how to take tablets. Sat with her after, but she couldn't sit for more than a couple of minutes. Incoherent conversation.	Jan drinks far too little. I have two occasions each day, breakfast and before dinner, when she will take an orange drink. I have to use those occasions for administering things like Lactolose and Promazine. If I use one, I can't use the other, and I have to use my judgement to decide whether Jan is more at risk from constipation (which exacerbates the dementia) or from sundowning and violence (which we need Promazine for).
		Started to prepare dinner, peeling potatoes and tidying the kitchen. Jan stays on her feet in the lounge. Television is on, but she can't relate to it.	Night time or rainy days are welcome as Jan is less likely to try and walk out then.
19	00		
		Eating dinner. Jan having problems with cutlery and deciding what to eat. She seems to have problems seeing the things on the plate. Generally anything with a dollop of butter on top is more likely to be eaten. She left half the food - almost all the minced meat, which causes texture problems. The peas were, as usual, left untouched.	I'm trying to put off the time when I need to feed Jan. I've been through the same process with writing, remembering, cooking, cleaning, dressing, undressing.
20	00	Sat on the settee together after dinner. Jan fell asleep against me.	
21	00	Made dessert, apple pie and custard. Jan asked for more apple pie as she was hungry. Ate it all. During the dessert I went into the kitchen to cook some fish for the cats. Jan joined me there, confused because I had left her. I took her back to the table to finish.	The cats, which were Jan's idea originally when we had our first one 30 years ago, get a very raw deal now. Jan can't remember their names and never fusses them. If I fuss them she takes it that I am ignoring her. I'm considering re-homing them.
		Tried to get Jan to sit down afterwards, but she wouldn't. Tidied kitchen, went up to make the bed and tidy the cats' room (yes). Came down, filled hot water bottle. Took Jan and cats up to respective bedrooms. Shut cats in.	
22	00	Undressed Jan—explaining why, as I do every night. Took her to the bathroom to brush her teeth. Showed her how. She went to the loo, then we returned to the bedroom where she took another Galantamine.	Jan's greatest fear is incontinence. Why, I can't think, as she has a bladder that might have been built at Harland and Wolf's - she only goes to the loo twice each day, with often a 15 hour gap, and no sign of problems.
		Put Jan into bed - this takes some manipulation as she can't get in herself. Gave her some water to drink. Went to the attic to check last minute e-mails from the US.	
23	00	Shut off computers and went to bedroom to find Jan wandering around. Put her back into bed, gave her more water. Went downstairs to complete this diary on the computer down there. I can hear her wandering around again as I type. On returning upstairs, I put Jan in bed again, gave her another drink of water, and eventually she dozed off.	Working with computers may help in caring for this kind of case, as one tends to loop around doing the identical things in much the same way as computer programs loop!

		Got to bed myself, read for 15 minutes then slept.	This is the only time I get to myself during the day and a brief read before sleep at least gives me some different characters to be with. The television programmes I really would like to see I record, and when there are 4 or 5 tapes still unwatched (because there is just no time anyway)—I simply record over them.
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Jan and Bruce at Christmas 2000
Piano is Jan's but she can no longer play it.