

**This extract is Chapter 1 (Crisis Weekend) of**

**BUT THEN SOMETHING HAPPENED:  
A Story of Everyday Dementia**

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First published in 2012 by Golden Books  
[www.goldenbooks.co.uk](http://www.goldenbooks.co.uk)

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ISBN 978-0-9573079-0-2

BUT THEN  
SOMETHING  
HAPPENED

**A Story of Everyday  
Dementia**

**Part 1**

Fred, Mary and Me

## Chapter One

# Crisis Weekend

### **An everyday story**

Fred and Mary are my parents and this is our story, an everyday story of dementia in the family, how dementia changes everything in ordinary and extraordinary ways. Our story is both commonplace – old people with minds befuddled by dementia are everywhere once you start looking – and unique. Every family affected by Alzheimer's or other types of dementia plays out a different drama and has a different story to tell.

Ours has had a particular poignancy because my Mum, Mary, and my Dad, Fred, were both affected in different ways with different types of dementia at the same time. For me, their daughter, living nearby, as the drama of their joint dementia played out, they gradually shifted from parents into people, individuals who'd each had hopes and dreams which were finally coming to an end.

When I started writing this memoir I believed Fred and Mary were the central characters with me, their amateur carer, as a mere supporting artist. Only belatedly did I see that this is very much my story, that I was – am – very much a participant, that the role of witness, propper-up, the one who keeps their mind as others lose

theirs, has its own special kind of suffering. For a long time I didn't want to acknowledge this; for a long time my image of myself was as 'OK, fine, I can handle it'.

This may have been because I never consciously chose the role of carer. Rather I fell into it, almost by accident, starting by helping out as my parents got older, the way in families you do, and then helping some more, and more as their minds became muddled. And suddenly, or so it seemed, I was the 'responsible adult' in the family.

Even this I only fully realised with hindsight. I was so busy coping, keeping a cool, confident, swan-like exterior, that I failed to notice the furious paddling beneath the water line. There was another factor too. To me carers were selfless people who devoted their entire lives, twenty four hours a day to caring for their loved ones. And that wasn't me. I was not selfless, and I had my own life, my own home to maintain. And therefore I underplayed my role, saw myself as just helping out. And where's the stress in that, compared to what 'real' carers go through? Except that I didn't always know what to do. Like thousands of other amateur, part-time yet crucial carers, I felt responsible for my charges yet lacked the experience to know what is best for a couple who are both in different ways losing their minds. This is therefore the story not just of my parents' progressive joint dementia, but of my trial and error efforts to carry them until their accumulated weight grew too heavy. That part of the story is dedicated to 'amateur carers' everywhere.

At the same time, like all good stories, Fred and Mary's is also a love story, though I didn't appreciate at first the strength of their love. For children, even extremely grown up children like myself, Mums and Dads are parents first, lovers only a distant second. What I did know was that Fred had always been a bit of a romantic: the kind of man who'd slip a small volume of poetry into his pocket as he prepared to go out on flying missions as a young RAF Navigator in World War II. I knew too that he'd loved Mary

since the moment he set eyes on her, in a fairground, in 1934 when he was just seventeen. And here they both were, more than seventy years later facing mental meltdown: was their fairy tale about to reach a brutal end?

## **An inconspicuous start**

Our everyday story of dementia in the family starts in the telling with a sudden drama yet the foundations were being quietly laid years before. Dementia, particularly Alzheimer's, is insidious, creeping up slowly, wrapping its tendrils round you, gently at first then squeezing harder. The saga of my parents' joint dementia, therefore, has no definitive starting point. Or none that any of us were aware of at the time.

What is clear is that by 2005 we – Mum, Dad and me – were definitely beginning to struggle as Dad's spirits sank lower and his GP prescribed increasing doses of anti-depressants. At this stage depression was the diagnosis not dementia. In early 2006, worn out by trying to keep their household going as well as my own, I'd requested a Social Services visit to see if I could get them some help. Though the social worker declined to recommend a 'care plan' she noted Dad's depression and referred him to our local Older People's Mental Health Team. The Community Psychiatric Nurse appointed to assess his mental state felt that what looked like depression didn't quite fit the pattern and might be something more. To check her suspicions she referred him to a specialist in old age psychiatry. In the summer of 2006, just before his 89<sup>th</sup> birthday, Dr Denning visited him at home and diagnosed, not Alzheimer's but a vascular dementia, possibly caused by mini-strokes that had gone unnoticed.

At the same time though largely unremarked, Mary was developing the symptoms of either Alzheimer's disease or a similar form of dementia. Like two out of three dementia sufferers, she has never been formally diagnosed. The closest she came to a

diagnosis was that day Dr Denning visited Fred and informally observed from her speech and behaviour that she was 'probably in the early stages of Alzheimer's'. She was not his patient, however, so no action followed.

## **Muddling along**

During this earlier phase Mary and Fred were still living in their own home, muddling along with a couple of hours a week outside help fixed eventually, not through Social Services but from an excellent local charity called Crossroads, backed up by me. It came as a shock as I began to see, only dimly at first, that both their minds were failing in different ways. Though their welfare had been weighing on my mind and sitting on my shoulders for a good couple of years I hadn't known what was wrong. This was several years before dementia hit the headlines and became the talking point it is today.

In my amateur carer role I'd been visiting more and more, and worrying when I wasn't, steering the family ship on an increasingly shaky course. But Mum didn't really seem to notice the propping up, believing, I now realise due to her dementia, that she and Dad were coping independently, complaining that Dad wasn't doing the vacuuming often enough. Having no experience of dementia I didn't recognise the signs.

After Dad's vascular dementia had been diagnosed that day he became the focus of my attention while Mum's odd behaviour tucked itself away at the back of my mind. At that stage Dad's dementia did not result in major confusion – instead the effects were more specific, attacking those parts of his brain responsible for higher functions such as word finding, planning and motivation. He was aware he and Mum weren't coping very well but his impaired ability to plan and make decisions meant he no longer had the capacity to do much about it. Not that he ever mentioned his vascular dementia, and taking my lead from him I

didn't mention it either. His response to what must have felt like a hopeless situation was to escape from it all by spending much of his life asleep.

Though Dad's vascular dementia and Mum's 'early stages of Alzheimer's' were not discussed, their effects were definitely showing – a household of two people with different kinds of dementia does not run smoothly. When they gave up on their weekly shopping trips to Tesco, I ordered their food and groceries from Tesco Online; when they could no longer organise eating, I ordered their mid-day meals from Wiltshire Farm Foods. These were delivered fortnightly and stored in their freezer. Dad learnt how to 'cook' them in the microwave (vascular dementia leaves more faculties intact than Alzheimer's, in the early stages at least) while Mum continued to believe that she prepared their lunch. When they stopped going out – Mum because she came to believe she would topple over backwards if she went out, in staying indoors she believed, falsely, that she was acting on her doctor's orders – I collected their prescriptions and loaded 'dosset boxes' for Dad to take his pills (many) and to give Mum hers (only thyroid); if light bulbs failed or appliances faltered, I went round there to fix things. When Dad had physical health problems I accompanied him on numerous hospital visits (emergency admission for anaemia, endoscopy, macular degeneration) as well as hearing aid and eye tests and GP visits. With difficulty, I washed their hair; with little skill I acted as their hair stylist...

If anyone had asked me why I was doing all this, I wouldn't have known the answer because I hadn't asked myself the question. They were my parents. They needed help. Who else was going to do it? What would other 'amateur carers' say?

## **But then something happened**

During this build up period – which only became a build up with hindsight – the important thing for me was that we were getting

by, or so I chose to believe. Doctors, social workers, psychiatric nurses, none of them seemed to be taking our family's double dementia particularly seriously. So why should we?

But then something happened.

Or rather a series of things happened, starting one summer weekend, that brought the fragile edifice we'd constructed tumbling down. I shouldn't have been surprised to see our house of cards collapse, but I was. Had I been in denial? Some might say so but actually it's more complex than that. Though I was aware that dementia was attacking the brains of both parents at different rates and in different ways, they seemed nevertheless able to function, after a fashion. What I failed to factor in was that they were functioning because I was propping them up. And also because they were two: two even with damaged minds could still support each other. Up to a point.

And so unconsciously I gave them the benefit of the doubt. Took them at face value. Maybe they weren't too bad after all. Until it was obvious they were worse than I thought. Or Mum at least, her Alzheimer's-type dementia more advanced than we'd realised.

By the time their dementia story stopped rumbling quietly along and erupted into a full scale crisis it was mid-2007, the year both Mum and Dad celebrated their 90<sup>th</sup> birthdays, Mum on 2nd February, Dad on 23<sup>rd</sup> August. Their love story was well advanced by then – they'd been married for 68 years.

But between those two birthday celebrations, one July weekend, life as they, and I, had known it finally came to an end.

## **Crisis Weekend**

The Weekend that changed everything began on Friday 13<sup>th</sup>, an inauspicious date on which Mum, Dad and I shifted from 'muddling along' to the next stage of 'something needs to be done'. We were typical, it turns out, in that people with dementia can



often muddle along for years until... Until what? Until something happens, a fall, an accident, a flood in the kitchen, the gas left on, a small or not so small drama that moves the action inexorably forward. Like a play or film, there's a crisis, an 'inciting incident' that triggers the action that follows.

Not that I saw this at the time. You don't when you're one of the players. That Weekend my mother was the central character with my Dad and I as supporting leads. The day before, Mum had been still reasonably active around the house, today she suddenly declares she can't walk: her knee is swollen and painful, as I can see when I pop in to check they are OK.

Dad hovers on the sidelines, depressed and withdrawn, worried how they are going to manage. Mum's thyroid pills are still in the 'dosset box'. 'Have you not been giving them to her, Dad?' I ask as though somehow it's his fault. Still focused on somehow getting by, fitting in Mum and Dad's care with my own life, I desperately want everything to be OK but it so clearly isn't. 'She's up half the night', he says. 'I don't know where she sleeps'.

Time, I think – naively as it turns out – to call in the Professionals. I'll get the doctor out to see Mum. It's not as though she's been a massive drain on the NHS – she hadn't seen her GP for about four years. I'd been to the surgery in her place to report her increasing confusion but no GP had actually seen the degree of her mental breakdown. The doctor can look at her knee and sort out her mobility, I reason, and at the same time actually observe her dementia and finally make some professional assessment of her mental confusion. I ring the surgery mentioning these two problems, the knee and an opportunity for the doctor to observe her mental state: they promise a home visit any time after 12.30 pm.

## **Scene 1: Friday 13<sup>th</sup> July 2007: The doctor cometh**

12.30, a ring on the bell: the doctor, youngish, slim, dark haired, brisk. Mum and Dad have daytime TV on, as lots of housebound people do. Doctor demands it be switched off. Tone bossy and peremptory. None of the kindness and compassion we crave. On this inauspicious day, this visit is getting off to an inauspicious start.

Mum is sitting in a low chair. Ignoring Dad and me, doctor crouches down beside her, addressing all her remarks to ‘the patient’, which would have been admirable had the patient been in possession of all her faculties. She talks at top speed, too fast even for me. I already have bad feelings about this visit. Hasn’t she read Mum’s notes? Didn’t my message about Mum’s dementia get through?

Doctor rattles on about ‘arthritis’ and ‘compression stockings’ she apparently thinks Mum should be wearing. Mum, for her part, looks very plausible, as though she’s understanding – people with dementia, I’ve discovered, seem to retain an uncanny ability to put on a good show for strangers. ‘Your pain in the knee is caused by arthritis’, doctor slows down and speaks louder. Perhaps she thinks Mum is deaf. ‘Arthritis’, Mum repeats slowly, looking up at me for enlightenment.

‘Can you bend your knee for me’, doctor asks. Mum smiles vacantly. Doctor asks again. And again. Has she never come across dementia before, the way it makes you forget the meanings of simple instructions? When Mum does not obey does it not occur to her to wonder why? Apparently not. I’m reluctant to spell out the problem but she leaves me no choice: ‘She doesn’t understand you. She doesn’t understand what you’ve been talking about. She’s got dementia’. I speak quietly, trying to be discreet as we still haven’t talked about her dementia directly to Mum. The closest we’ve come is to laugh with her about problems with her memory.

Doctor stands up, abandoning her ‘concerned crouching’ position: patients with dementia can apparently be talked about in their presence as if they weren’t there. Instinctively I step forward, putting myself protectively between this doctor and my Mum, trying to minimise the damage. Mum has always been super-sensitive, easily upset by unthinking remarks. Dementia hasn’t changed that. And she is certainly not completely gaga.

Doctor snaps into ‘social care’ mode seeming affronted now that her time should be wasted on a condition that’s surely the domain of social workers. ‘What are you worried about?’ she demands. ‘Do you want her to go into a home?’ At this point Mum going into a home hasn’t crossed my mind. We’ve been muddling along, haven’t we? ‘Do you like living here?’ she asks Mum. ‘Yes’, says Mum. ‘Or do you want to go somewhere where they could look after you better?’ Mum looks puzzled.

## **‘All you’ll get is a diagnosis’**

Doctor plunges into the realms of Social Services and care assessments. Hang on, I’m thinking, isn’t dementia a medical condition, a malfunction of the brain? ‘Can she have a mental health assessment?’ I ask. Doctor is doubtful: ‘All you’ll get is a diagnosis’, she says.

All we’ll get is a diagnosis. All. All. Isn’t that what we want: to understand better what’s wrong with Mum? Isn’t it important to know? Apparently not: it’s only later I learn the statistic that two out of three dementia sufferers in the UK are never properly diagnosed. Though with recent government initiatives this statistic may have changed, Mum to this day remains one of the many dementia sufferers without a formal diagnosis.

As a gesture towards assessing Mum’s mental health doctor quickly goes through what I’ve come to call to myself the ‘Alzheimer’s questions’ that are supposed to show how near or far removed a patient is from reality. The official name for this test I

discover many months later is the ‘mini mental state examination’ or MMSE. Essentially the MMSE is a series of questions about simple facts such as time and place and who people are that any ‘normal’ citizen should know. Doctor asks Mum her address. No response. Mum smiles her way through this and the rest of the interrogation. Your date of birth. Mum smiles. Your age? I’ll whisper it, she says, but doesn’t. What year is it? Don’t know. Mum fails the entire test till the last item: ‘Can you count backwards from 20 for me’. That Mum can do: she worked as a comptometer operator in the days before calculators and computers and she’s very handy with numbers. Though that skill hasn’t left her, however, it’s not enough to save her from doctor’s judgement of definitely demented.

But dementia, probably of the Alzheimer’s type if we are to believe Dr Dening’s observations are correct, is not, apparently, a medical diagnosis. Doctor does not seem too concerned about how Mum – and the rest of us – will cope with her seriously malfunctioning brain. At one point she looks over to my 90 year old Dad, his diagnosis a year ago of vascular dementia presumably in his notes, and says: ‘You’re alright, aren’t you?’ I hear her words as completely uncaring as though she is saying: ‘Surely you, old man with vascular dementia, are alright to look after your severely demented wife’. I guess this was the price Dad paid for looking both years younger than his age and much fitter than he actually felt.

Doctor says she’ll make a referral to Social Services and invites me to make one too. Or to follow up hers. She’s back to her mile-a-minute mode of talking. I’m not really very clear what she’s saying – something about referrals getting through quicker if they come from a doctor. We come full circle, back to Mum’s knee (those compression stockings again – she gives me a prescription for stockings) and – oh yes, better check Mum doesn’t have a urine infection (urinary tract infections (UTIs) are known to be common in old folks and liable to result in mental confusion). Can Mum provide a urine sample? Doctor proffers a container for the sample

but doesn't offer any clues as to how to get the required sample out of an old lady with a hole in her brain where the idea of urine sampling used to be.

## **Marks out of ten?**

And she is gone. I wonder how many marks out of ten she'd give herself for this consultation. Upset and angry at her brisk treatment of my vulnerable parents, I go off to Boots for compression stockings. I scarcely notice my route as I go over and over in my mind the sheer awfulness of this doctor's performance. I was the one who called her out too. Guilt at exposing them colours my anger as mentally I compose an official complaint.

There is something else too. By her obtuseness this doctor has forced Mum's dementia much further out into the open than I've allowed so far. Up till now I'd kept it closed up in a corner of my mind – I both knew about it, and yet acted much of the time as though it wasn't so. Part Two (in the chapter 'Why didn't we see it coming?') explores this self-protective ability many of us have both to know painful things yet at the same time act as if they are not true.

My mood is not improved when Boots prescription counter rejects the prescription for stockings. Apparently the doctor should have referred Mum to the District Nurses who are then supposed to come and measure. My already lengthy 'official complaint' expands to include failure to be up-to-date with stocking supply procedures.

This was the first, but sadly will not be the last, time I come up against the apparent indifference of the medical profession to mental confusion. For them dementia seems to equal social care. Carers coming in. People to do the personal things patients with failing minds can no longer do for themselves. But what about 'mental care'? What about advice for living with dementia? Advice for those living with dementia sufferers?

Even the word ‘demented’ is an unfortunate one, suggesting, as it does, madness. People with dementia are not mad. They have frail and failing minds in the way that others have frail and failing bodies. And yet...Failing minds do raise questions of identity that failing bodies don’t. If Mum tells a nurse, as she did later while in hospital, that she and my Dad don’t have any children yet, where does that leave me? When she whispers to me, looking over at Dad, ‘Are you married to him?’ what does that say about their nearly 70 years of marriage?

It’s questions like these that make dementia both frightening and fascinating. Frightening because of the apparent ease with which whole swathes of our past can be wiped out, yet fascinating, the way an individual can live in different time zones at the same time (Mum could tell the nurse they have no children yet accept the nurse telling her in the next breath: ‘I was talking to your daughter on the phone...’). Fascinating too in the way a new person can emerge, recognisable yet unmistakably different.

## **Scene 1A: Later that day: The urine sample**

Whatever we think of them, doctors do have a certain authority. If doctor wants a urine sample from Mum, even if I think it’s pointless, then I feel some obligation to provide one. But how? This is my mother: proud, private and puzzled by the world. She’s a native English speaker no longer able to understand the simple English sentence: ‘The doctor wants a urine sample’. I can’t just give her the container, send her to the bathroom and expect her to produce some pee. And anyway, it’s a messy business at the best of times, getting a sample of urine into one of those specimen bottles.

Dad is still closely enough in touch with the world to understand what’s needed. Saying ‘urine sample’ clearly isn’t going to get us very far, so we try varying the terminology. Doctor wants some of your wee-wee...your pee...your pittle. ‘Pittle’ hits the spot. Doctor wants some of your pittle. ‘Can you do a pittle, Mum?’

'I've just been', she says. Curses. We all start laughing. 'Can you do a bit more? Into this' – the specimen bottle looks ridiculously small. More laughter. 'Do it in a cup', Dad says. A burst of laughter from me, but actually it's not a bad idea. If she could wee into a bigger container I could then transfer some into the bottle. 'Better make sure we wash it up before we make a cup of tea!' It's becoming a big joke.

Cup in hand I help Mum upstairs, persuading her back into walking mode though her knee is clearly painful. She manages to get up to the bathroom. We pull down her pants and I try to encourage her to hold the cup between her legs – I've no idea if she understands what we are trying to achieve. She can't grasp she needs to hold it so I try to keep it in position and we start giggling. 'Can you do a bit, Mum. Doesn't have to be much. Just a drop'. But nothing comes. Not a single splatter. The cup is completely dry and we're practically in hysterics.

Never mind, I say. We'll try again later. Sorry, doctor. I did my best.

## **Back to front burner**

At this stage in the drama, in my mind I've dismissed 'the Professionals' as useless. On reflection well after the event, I wonder if I still saw myself as able to rescue the situation, assuming as I had so far that we could cope largely on our own, the perceived inadequacy of the Professionals serving to reinforce my natural bent? As a family we'd always been independently-minded, not easily putting ourselves in other people's hands. I guess I wanted things 'back to normal' however haywire normal was becoming. Mmm. You can learn a lot about yourself once you stand back and take a dispassionate look at the way you care for those you love.

Staying in 'rescuer' mode that Friday 13<sup>th</sup>, I go home and think about how to maintain Mum's mobility now she's got such a painful leg. Should I be getting hold of a wheelchair? Maybe then I could

take her out. I imagine walks along the river, Mum enjoying the fresh air, commenting on the boats...she hasn't been out of the house for a year, she who had so loved to go on little outings to 'look round the shops.' She hadn't been persuadable to go out, due to that belief she'd adopted that she'd overbalance and topple over backwards. But if she had a wheelchair. Why hadn't I thought of this before? I consult the internet and phone the Red Cross and various other wheelchair-providing organisations.

A shadow, however, falls across these idyllic river walk fantasies: I need to grapple with another, less agreeable, more urgent problem. Earlier in the day, on top of everything else, I'd noticed Mum's skirt was wet at the back, and so, reluctantly, I bring forward from the back burner, where it had simmered very gently for some time in response to finding dirty pants hidden in odd corners, to the front burner, the fact that Mum is becoming incontinent. At least some of the time.

## **Scene 2: Saturday 14<sup>th</sup> July 2007: Incontinence Saturday**

For the first time that Saturday morning, I think about incontinence, not in a general way but very specifically as it relates to Mum. What it means. What to do. What shall I do? This drama is becoming a crisis. I phone a friend.

Briskly she initiates me into the world of incontinence pads, those bought from Boots, according to her, being superior to those provided free by the District Nurses. Not that so far we have consulted any District Nurses.

Reluctantly abandoning my usual leisurely Saturday morning Guardian read, I go upstairs to my office to consult my other friend, the internet, to find – I should have guessed – that there is a whole world of incontinence products out there, pads and disposable pants of all shapes, sizes and absorbencies. They'd been there all the time, of course, but I'd had no reason to see them.



A barely formed thought floats through my mind: ‘Mum may have to go into a home sooner than we think’. I note it in the diary, the ‘Dementia Diary’, I’d started to keep so I’d recall the events of this time. It was that awful doctor who planted the first seed. And here it was starting to sprout. Mum or Dad going into a home had not even been on our radar till she mentioned it. And even now it was just a small grey cloud.

From my internet wanderings I also print out an article written by a woman caring for her husband who has Alzheimer’s. ‘Pooh is not toxic waste’, it was called, setting me pondering about what we call what comes out of us and, in the normal course of events, goes down the toilet: this woman chose ‘pooh’. Not that Mum is ‘doubly incontinent’ – nice euphemism – but maybe one day she will be. I’m certainly starting to realise that this is a ‘big crisis’, a real recognition that she is not functioning on a very basic level. Dealing with bodily waste: you can’t get much more basic than that.

But I can cope, can’t I? Of course. And so it is that on one of the busiest Saturdays of the year, Cambridge heaving with tourists in cheerful gaggles, my partner, Terry, and I are in Boots hunting down incontinence pads. Bemused by the choice, I select a packet from the ‘medium’ range, which seems a safe bet. And we buy a new packet of pants for Mum from M&S.

Later I go round to Mum and Dad’s and try to explain to Mum that she needs to start wearing a pad. I demonstrate by putting a pad into one of the new pairs of pants – I’ve got a larger size to accommodate a pad. I manage to get the pants plus pad on her – which is not hard as she isn’t wearing any pants. One of the things I learnt early is that people with dementia can forget to put on articles of clothing, or put on several of the same thing.

I do all this in a matter-of-fact way, as though it is the most natural thing in the world. Mum doesn’t question, doesn’t resist, doesn’t protest. We are suddenly in a different world together, a world in which I’m helping her pull up her pants as she once

helped me pull up mine. Though my mind might be lagging behind, my actions show that I do recognise the extent of Mum's mental damage.

I put pads into two more of the new pairs and leave them for her to change into when necessary. What could I have been thinking? Did I really believe she was understanding me and would dutifully put on these fresh pads? Much more likely, I was still in the grip of wishful thinking, desperately wanting things to be OK, clinging on to my own life, terrified of being submerged by my parents' needs. Or rather what I saw as their needs: though I'd brought incontinence to the front burner, peeing in your pants may have been way down their list of concerns.

Mum wanted to lie down after these exertions. Maybe she thought it was bedtime rather than afternoon. Dementia sufferers can get very confused about the time of day. I went up to her later and saw she was lying with her head hard up against the headboard. She looked uncomfortable and I helped her put her head properly on the pillow. I think she had forgotten how to move down the bed. I was learning that dementia can affect you in very basic ways. Simple movements that were automatic suddenly no longer are. People can eventually forget how to eat and drink. I didn't want to think about that stage.

### **Scene 3: Sunday 15<sup>th</sup> July 2007: Lunch on the floor**

So far on that Crisis Weekend, I'd been going back and forth to my parents' house, dealing with doctors and incontinence and Mum's painful knee, while at the same time clinging limpet-like to my own life, to my yoga and other pleasurable routines, to my whole identity as an independent person. I was still just an amateur carer after all. Wasn't I? Just helping Mum and Dad out.

Well, no, actually, at this point I was their lynch pin – I just didn't want to recognise it for fear of becoming a 'real' carer.

As the 'responsible adult' of the family I was catching a glimpse of what it might be like to slip unwarily into a 'proper' caring role. Unwarily because being self-employed with a portfolio career as a consultant/coach/occasional mediator I had plenty of flexibility to organise my work as I chose and to take time off to deal with doctors and hair washing and rush round in emergencies. Already I was taking more and more time off.

So far I had viewed this flexibility as a positive. I could be there for my parents, popping round, sorting out problems. But I was becoming increasingly terrified of being swallowed up by the task of caring for them. Not because they demanded it: they never actually demanded anything. But because I had taken it on and now it was taking over: their predicament was becoming part of me. Any time I had a conversation with a friend or colleague I hadn't seen for a while, I'd immediately start talking about them. Mum and Dad were constantly on my mind. I was carrying them on my shoulders. And it was scary. I was the one keeping them afloat, but in spite of all my efforts, I was failing – we were all beginning to sink.

## **Have you told Chris?**

The Sunday morning of that Weekend, I went to yoga, as usual. A great class. I walked into town with my friend, Carole, as usual, and, as so often, we talked about my Mum. Terry and I met up in the Caffè Nero, as usual, and we talked about his poems and life in general. One of my most pleasurable routines. Slowly I began to slip out of my role as amateur caring daughter and relax into me as me.

Back home I was reading the Sunday papers and thinking about making our lunch. It was 1.30 pm and I was hungry having not eaten all day. And then the phone rang. It was my brother, Alan, a couple of years younger than me and living about 50 miles away in Stamford. He'd just called my parents to say he and his

wife, Sue, would be visiting them later that afternoon. Dad had told him that Mum was sitting on the floor and he couldn't lift her up. 'Have you told Chris?' 'No', Dad says. Instead he's served her lunch on the floor – and her breakfast before that, it transpires. He said he'd found her 'in the morning'.

This was Dad's vascular dementia kicking in, I realised later: he genuinely can't plan or make decisions. If something happens, he doesn't know what to do. We shouldn't therefore have been surprised he hadn't tried to get help, but we were. He could seem so normal we didn't realise for some time the full extent of his brain's deterioration.

I drive straight round – luckily it's only a five minute drive – and find her propped up, her back against the sofa seat, remarkably perky considering she's been sitting there for hours. I have the feeling the situation doesn't seem that odd to either of them. 'She's all wet', Dad says. So much for my illusion that she'd put on the pants I'd carefully furnished with pads.

Using my pelvic floor muscles to protect my back and the upper body strength I've developed through years of yoga, I manage to lift her up on to the couch. She's very heavy, like a dead weight. And her leg is still horribly painful. She also smells. I'm going to have to wash her and change her clothes.

To a 'real' carer, washing your Mum after she's peed herself may seem commonplace. To an amateur carer like me it's a first. She's in pain, back to saying she can't walk, so we can't get upstairs to the bathroom. Yet she needs to be washed and her clothes changed. I know my parents don't have a washing up bowl, but they do have a plastic bucket.

I run some warm water into the bucket, get hold of a flannel, soap, some clean clothes, including one of the pairs of pants lined with a pad, take Mum's blouse off and do a rather cursory underarm wash. I don't change her bra. At this stage my attention is more directed towards her bottom half, which meant I didn't notice the angry red rash in the deep fold under one of her breasts

that showed up later: a fungal infection that was the source of an odd smell I been noticing but couldn't place. But that was then, and this was now. I dried her top half and threaded her arms through a clean blouse.

Now it was time for the bottom half. I decide for modesty's sake to get Dad out of the way, though I guess in nearly 70 years of marriage there's not much of each other they haven't seen. It must have been my own possible embarrassment I was guarding against. It's a struggle to get her skirt off; I get her to stand up and hold on to me so I can remove her pants, then from a rather awkward angle, wash then dry her bottom and legs, talking all the while in that cheerful, encouraging way that seems to come naturally to carers but may be highly irritating to those they care for: 'We'll just pull these up now' ... 'There you go' ... 'How's that?' ... 'Well done' ... 'All finished'.

Washing ordeal over, clean and dry, I get her into a chair. She's insisting she can't walk, and I'm panicking inside as to how we are going to manage if she can't get to bed, can't get to the bathroom. Something else is weighing on me too: I'm planning to be away next week for a couple of days on a retreat that I feel a profound need for – it's my way of trying to look after myself to give me the strength to better look after Mum and Dad. How on earth are they going to manage?

Yesterday Mum said she couldn't walk, yet she did walk upstairs, working out as she did so how to distribute the weight so her leg didn't hurt so much. Clearly some of her mental faculties were still working. I persuade her to try this again to give her some confidence back. We go upstairs together – she makes it but I'm fearful she could fall if she tried it alone. Things really are falling apart. I wonder if I can organise a commode and some nursing care for her for the few days I'm away.

### **Scene 3A: Later that afternoon: 'I thought I was dying'**

I'm starving by now, so I get her settled, reassure Dad that Alan will be here soon, and go back home for some lunch. Not long after Alan rings to say they arrived to find Mum on the floor again. She's fallen, apparently, on her way to answer the door. 'I thought I was dying', she tells me when I get there. 'As white as a sheet'.

Alan wants to call out the out-of-hours Duty Doctor. I'm unconvinced given what happened when I called the GP on Friday, but Alan works in Social Services and has more faith in 'the system' than I do. Two falls in one day, he says – we need to find out why. You ring them then, I say. And he does. Though I've done most of the caring for Mum and Dad, there have been crucial points at which he's insisted on bringing in 'the Professionals', where I would have struggled on for longer, trying to cope. This was one of those pivotal points.

We waited over two hours for the Duty Doctor's visit but when he finally came it was a lovely young Irishman who took Mum seriously. I regret that I didn't take in his name when he introduced himself as I'd like to put him forward for sainthood – his competent compassion was so much what we needed after the awfulness of Friday's doctorial experience.

He gently examined her, diagnosed a fever indicating an infection somewhere, said she needed to be admitted to hospital for a few days for the experts to find out what was causing the infection. They'd get her back into shape, he assured us. When he said 'hospital' I was taken aback. For me 'going into hospital' was about being really ill. Surely she wasn't that bad. Even in the midst of crisis I was trying not to make a drama out of it. As the doctor did the necessary paperwork it started to feel as though 'the system' was swallowing her up. But at the same time I was hugely grateful that this most compassionate representative was taking charge. I didn't have to be totally responsible, to shoulder all the burden.

Could we take her up to the hospital? the doctor asks. Quicker than trying to organise an ambulance, we're told. It's agreed we'll go up in Alan and Sue's car. We gather a few things together – pyjamas, flannel, soap, towel, slippers, comb... what does a person need in hospital? We get Mum ready to go – of course we explain what's happening and assume, because it's simpler that way, that she understands. Dad kisses her goodbye – she's been the centre, and the love, of his life for 70 years, and here we are taking her off into the night with little awareness of what this feels like for him. Maybe he already knows, or fears, that she won't come back. As for Mum, her leg was painful so the struggle to get into the car took all her attention. She left in the clothes she happened to be wearing. There was no waving goodbye, no last glance.

### **Scene 3B: 8.30 pm: Fun and games in Medical Assessment**

The doctor's instructions are to go to A&E and hand in his letter. We arrive, grab a wheelchair and push Mum inside to take her part in the human drama that is A&E at night. Couples, youths, anxious family groups, and Mum, in her wheelchair, with no very clear idea where she is. Not that this fazes her: people are a source of endless entertainment for her and there are plenty of people here.

As Mum is to be admitted into hospital, our first destination is the Medical Assessment Unit which shares a Reception Desk with A&E. It's moved from when I came up to Addenbrooke's Hospital with Dad last spring when he had an emergency admission for extreme anaemia. Just over a year ago I had blithely assumed that Mum would be OK on her own while Dad spent a couple of nights in hospital. That's how tough I believed her to be when the reality was that her mind was already breaking.

Not that she'd been so confident she'd be OK. I remember her saying after spending the night on her own: 'I was alright', as though she was relieved and rather pleased with herself. It hadn't

occurred to me she wouldn't be OK even though her dementia must have been already present. Another example of taking her at face value.

What could I have been thinking of? I guess the answer is that I could only cope with one of them not being OK at a time. Back last March, Dad was in the limelight, Mum relegated to a minor role. Today, Mum's the star of the show. Dad's at home, offstage, where he is playing out his own drama. I fail to anticipate that one too.

We're asked to wait in A&E till they're ready for her in the Medical Assessment Unit. A somewhat overweight girl is sitting nearby. Fatness is one of Mum's prejudices, commenting on fatness one of her favourite topics. 'Look at that fatty', she says, not loudly but not quietly either: dementia can remove or reduce inhibitions. We try to shush her. 'Look at her!' Mum insists. Alan's wife, Sue, turns the wheelchair away so Mum's looking towards a wall rather than the waiting patients, but Mum isn't having any. 'I'd rather be back there', she says turning her head. Sue relents and turns the wheelchair back. A young black girl with dreadlocks comes in. 'Do you see that hair!' Mum exclaims – we're saved by being called into the Assessment Unit.

We're shown into a cubicle and with difficulty get Mum out of the wheelchair and on to the bed. It's around 9 pm by this time. My abiding memory of the next three hours (we're there till after midnight) is of laughter. No real idea what is going on (because, I guess, she's unable to remember from one moment to the next what she's told), Mum turns everything into a joke. This is her strategy, the one she adopts to cope with the outside world – we haven't seen much of it so far as she hadn't needed it at home. But it's a good one – her laughter is infectious: the doctors and nurses end up laughing too. Asked by an administrator her date of birth, she doesn't know. Asked her age though, she plays to the gallery; acts all coy and giggly, 'I'll whisper it', she says. And she does. '90', she mouths in a moment of clarity.



## Examined head to toe

The assessment process seems to be a series of head to toe tests: and the first nurse who comes to start the process is Lynette, short, black, pleasant but not particularly cheery. Though Mum isn't racist, she does belong to that generation and small town background for whom black, or 'coloured' people are still unusual, and therefore may be commented upon. I'm hoping, therefore, that she won't make any remarks on Lynette's blackness. She does show a sliver of surprise and looks over to us for some reaction, but finding none, she accepts Lynette's ministrations. Nevertheless, I find myself chatting brightly, non-stop so as not to leave any gaps for an unfortunate remark to intrude. As Lynette leans over her Mum seems fascinated by her short black wiry hair, but whatever she's thinking, she keeps it to herself.

A junior house doctor called Ruth introduces herself. She's lovely – warm, considerate with a wonderful bedside manner, happy to joke with Mum. In layman's language she explains the assessment procedure, the blood tests and X-rays and efforts to find the source of Mum's infection. They're nothing if not thorough, I'm thinking, listening to Ruth, and wondering how long it will be before the system blunts her youthful kindness and enthusiasm. But just at this moment she's perfect.

Ruth leaves and Sue notices Mum's feet are twitching. 'What's wrong?' 'I need to do a pittle', Mum says, trying to get up off the bed. I get hold of Lynette who goes off to fetch a commode. Mum's very agitated; Lynette seems to be taking a long time. Mum's bolt upright by this time, mustering all her strength to push herself to the end of the bed so she can get to a toilet. 'She won't be long', I say but Mum's eyes are staring straight ahead. 'Fred! Fred!' she calls. But Fred isn't there.

Lynette shows up at last wheeling the commode. Lifting Mum on to it is a challenge as she can't easily follow instructions; her leg is painful and there's not much room in the cubicle. But we

manage. She pees, relaxes and we all laugh. She's also, rather conveniently, produced a urine sample.

The tests definitely show an infection but they're still not sure of the source: is it urinary? Chest? Or could it have something to do with that nasty rash that was revealed when Lynette undressed her and put on a hospital gown. It was a shock to see it, so raw and red. Mum has large breasts that have drooped with age, and this was right in the fold. There was some toilet paper covering it where Mum had tried to treat it herself. She'd never mentioned it or showed it to anyone, of course. That was her way, even in dementia. Deal with personal matters personally, that was always her strategy. Telling others only means interference and interference means trouble.

When it seemed there could be no more examining they could possibly do, Lynette comes back to take a mouth and nose swab. The throat swab Mum can accept and dutifully opens her mouth. But a stick up your nose! She laughs at the very idea! And laughs. And laughs. Lynette begins to laugh with her. We all do.

Though it's late at night and we are fading fast, Mum doesn't seem tired. On the contrary, she's perking up and seems to be quite enjoying herself. One of the male nurses has a Mohican haircut which she tut-tuts at but can't keep her eyes off. Ruth reappears to say she's going off duty and that her supervisor, the Registrar, who she tells us is tending a very sick patient at the other end of the hospital, will come and check her findings. Then they'll get Mum on to a ward.

When the Registrar eventually turns up he treats Mum with kindness. 'Kindness' is a word Mum doesn't lose even as her dementia gets worse. She remains aware of being treated with kindness; she remains able to say so. He's black too and as he bends over her, Mum is fascinated by his hair as she was with Lynette's. He organises a final X-ray of her painful leg, after which, at nearly 1 am, she's taken to a ward. Not to F4, the 'care of the elderly ward' where she's 'supposed' to go. They don't have any

beds. So she's taken to the Emergency Surgery Short Stay Ward, her bed wheeled through the deserted corridors by two cheery young men.

The nurses get her to bed. She laughs happily as we leave her there. It's a strange place she's come to in the middle of the night but she doesn't seem too worried. I guess when you're mentally confused everywhere is strange.

It's Monday morning already. The Weekend is over, the action now well underway. As the curtain falls for the interval, we three supporting players go out into the night.