

Chapter 1

Beginnings

It's a Saturday morning in 1993. We're all in the living room, and the rain is beating against the window. Clive is sitting on the floor poring over the jobs section of the local paper; I am on the sofa with Alan on my knee; Rachel is playing quietly in a corner. It has become one of the many rituals that I dread. We are looking through the paper for jobs for Clive to apply for. I am irritated because I want to be doing the host of chores that is waiting for me. Clive is out of work, so I can't see why he can't do these himself and instead leaves them for me to do in my precious free time. I am also irritated because I can't see why we have to look at the paper together. Why can't he do this himself? However, it has become a routine, and it is very important for all of us that Clive get a job, so I try to hide my irritation, and concentrate on the paper. Teachers? No – not Clive. No qualifications (Oxford biochemistry degree apparently doesn't count). Drivers? No HGV or PSV licence. Clive turns the page, and looks interested and enthusiastic. I lean over his shoulder and look. Christ Church College is looking for porters and security men. That sounds good to Clive. I look at the salary offered,

and then point out that the wages they offer are what we would have to pay a childminder, and so we would in fact be worse off if he took that job. I ask acidly why a recently retired Army Major, with said Oxford degree, and experience in bomb disposal and ammunition movement and storage, should want a job directing tourists round Christ Church – surely his ambitions run higher than that. Clive gives me a long, despairing look and turns the page.

It's one of the great regrets of my life that I let that opportunity slip by. I can understand now, knowing what I know now, why Clive couldn't and didn't explain to me why he was keen to apply for a job as college porter. He had never been one to explain himself to others, being a believer in the 'least said, soonest mended' school of thought. He was already having increasing difficulty with language – a symptom of the illness no-one yet knew he had. But I was the eloquent, articulate one, good with words, good at understanding things; the one who believed in sorting things out, the one who was not ill. The truth is that by then I was sick of trying to 'sort things out' with Clive. We could have conversations and apparently come to decisions which he later ignored. It never occurred to me that he had an illness which was slowly destroying his abilities to read, to talk, to comprehend the world about him. It was a realisation that came slowly over the next months and years. But I still regret losing that moment.

So where did it start, this illness that stole Clive away from us before we realised that anything was wrong? It's a very difficult question, and one with no clear answer. My best guess is in the late 1980s. We had returned from Dubai, where we had been living for a few years. For complicated reasons I stayed longer than Clive, but we were together again from May 1986. It felt great to be back together – we bought a house, and I started haunting DIY shops.

I was very much enjoying doing up the house. The people we bought from had been very heavy smokers, and it all needed

redecorating – new bathroom, new kitchen, new carpets and curtains – all great fun for me, but not really Clive’s cup of tea, and I was wondering what we could do together. I came up with what seemed to me to be a brilliant idea – I would learn to fly.

Clive had learnt to fly very soon after we were married, paying for the lessons with an inheritance from his grandad. After that, everywhere we went Clive found the local flying club and kept in a few hours a month. He had really wanted to join the RAF like his father, but his eyesight wasn’t good enough to be a pilot. It seemed quite a good thing for me to learn – Clive could help me with the theory, and then we could maybe buy a share in a plane and go gadding off at weekends. Clive was very unenthusiastic when I suggested it to him, and a little later announced that he had decided to give up flying. What he said was that he couldn’t afford to do enough hours to be safe. He wasn’t prepared to discuss it any further, and so I just accepted his decision. Was this an early symptom of his illness, or just an unrelated incident? I wish we had been able to talk about it more, but at the time there were other things on our minds.

Clive had become more and more insistent that he wanted a family. This was another of the many things we never discussed when we married – Clive probably assumed family would come along, and I always thought that I was not the maternal type. I never had much strong maternal instinct; when my sister-in-law proudly gave me her new daughter to hold, I was very scared that I would hurt such a small, fragile bundle. I had a job (well, as Clive moved a lot, a succession of jobs) which I enjoyed, hobbies and friends, and plans for the future which I didn’t want to give up. It was all very well for Clive to talk about starting a family – there was no expectation that he would give up his job to stay home and look after the children. And, of course, it was me that would have to be pregnant, and even the most well-intentioned book or friend admitted that giving birth was hard work. So Clive had to talk very long and hard to get me to agree. He could be very persuasive, and I felt fairly secure that he wouldn’t leave me in the

lurch, so I agreed. I did make a proviso that I would stay put with the family. I had enjoyed moving around the world with Clive, but I didn't think it would be the same with small children to care for. Most places we went I spent the first few weeks driving round quite lost, trying to find my way to the shops, the bank, the sports centre, and even my way home. I couldn't see that being quite so much of an adventure with children in the back of the car.

While I was pregnant, we discussed the last holiday we would have on our own, and agreed to go cycling in France. I bought a bike (Clive already had one, and used it to cycle the 12 miles to work and back), and we had a couple of gentle Sunday afternoon bike rides. After one of these, Clive came back with tickets for a holiday in Tenerife. It was a very good holiday, and I assumed he had decided my cycling was too gentle for him and didn't want to hurt my feelings.

Rachel was born in March 1988. Clive adored her. He hated to be away more than was necessary, and was driving back one evening from an exercise in the Thames Estuary when he crashed the car into the lane divider on the motorway. Fortunately no other car was involved, and his was still driveable. He made no fuss – Clive never did – but got back into the rather battered car, finished the drive home, told no-one but me and quietly got the car repaired. He assumed he had fallen asleep at the wheel. Maybe he did. Maybe the accident had nothing to do with what was to come. But it was the first accident he had had in 20 years.

A few weeks later he noticed an irregularity in his heartbeat. It was not causing him any drama, but he always got things checked out. The GP he was with then referred him to the Oxford hospital, who fitted him with a 24-hour monitoring tape. I delivered the tape to the hospital, and Clive went off for another Army job. It was Friday. Just after I returned home from dropping the tape, the telephone rang. It was the hospital. Could Clive come in immediately for a check-up? I explained he was away, and we agreed that he could come in on Monday, when he would be back. 'Oh', they said 'and don't worry, there really isn't a

problem, but it would be better if he didn't drive too much before then'. I visualised Clive driving back to Oxford from the Isle of Man, and said that was OK. My imagination went into overdrive. Rachel was four months old. I was feeling particularly seedy and sorry for myself with undiagnosed early-morning sickness, and Clive was away. He had not informed the Army about what was going on – not something I was happy about, but he was adamant. He was back on Sunday, took a few days leave, and turned up at the hospital on Monday morning. I went with him. I can't remember who looked after Rachel – it is possible I took her with us as she was still very small and portable, but it was also a time when we did normal things like finding babysitters to leave children with.

A few hours later we were told Clive had sino-atrial disease, which is a problem with the heart's natural pacemaker. It's common in the elderly, but almost unheard of in an otherwise extremely fit middle-aged man. However, the consultant was very clear. This was what was wrong with Clive – the palpitations he had been having were only the start of what could be a very serious problem. The solution was fairly simple – fit a pacemaker – and his only concern was what was the best sort of pacemaker. They could fit a modern pacemaker that would allow Clive to continue his active lifestyle – running marathons, scuba diving, jumping out of aeroplanes... He would have to be careful going through airport security checks, but otherwise he could continue life as normal. So this was what he proposed to do.

Was the heart problem connected with his subsequent illness? I don't know. There is no known link between dementia and sino-atrial disease, but it seems to me very strange that something should stop the control centre of Clive's heart working properly a few years before he developed a disease of the brain – the body's control centre.

Clive and I needed to talk. I was not happy myself. I could not imagine the Army would be happy to let Clive continue in his current job with a heart problem, however benign. Clive liked his

job, and wanted to keep it. He decided to have the pacemaker fitted, and tell no-one. He would not be talked out of it. The heart specialists knew what his job entailed, and were happy that it would be safe to continue with a pacemaker, and not safe to continue without. The pacemaker was fitted. All my worries seemed to be groundless. Life continued, fairly happily, for a while. Alan was born in March 1989. After a few months, I found myself a part-time job.

There were a few disagreements, but I could easily convince myself they were normal. After several months, Clive couldn't remember the names of the people I worked with. He had a curious blind spot about remembering when I had arranged to go out and he was expected to babysit. He always used to be an avid reader, and I noticed that he had stopped reading books. But then, I hardly read too many books myself those days. Clive loved the children, and was a very modern, hands-on dad. We were a very happy family practically all the time.

I got really annoyed with Clive when he decided to adopt a friend's cat – the friend was posted to Germany and couldn't take the cat without considerable expense. I was quite happy to have the cat, but Clive asked me when Alan was only about a month old, and I was still struggling to cope with two babies. I said I was happy to have the cat, but please not until the day before Clive's friend left for Germany. Clive agreed that seemed reasonable, and then came home that evening with the cat in a basket. No cat food. No litter tray. Just the cat, which he decanted from the basket. Then he went out for the evening. I was not happy.

A few weeks later we were due to go on holiday. I wanted to go diving in the Isle of Wight; Clive wanted to visit some friends in the Isle of Man. Instead of deciding which was possible in the ten days we had off, Clive decided we could do both. We would drive 250 miles to his mother's house, leave the children there, drive another 100 miles to the Isle of Man, spend three days there with his friends, return to pick the children up, drive to the Isle of Wight, set up camp there and I could go diving. I knew who

would be organising the camping, the ferry tickets, the packing, the children... Clive would not be persuaded that the plan was impractical; I was too pig-headed to give up my diving. Eventually I invented a crisis at work that meant I couldn't get any time off at all, and we stayed home.

We had more holiday trouble at Christmas. I wanted to visit some good friends in Dubai, and Clive somewhat unwillingly agreed to come as well. I booked tickets, and eventually set about getting ready to go. We were flying from Gatwick, and parking at the airport. The journey normally took two hours, so I thought leaving three hours before we needed to be there would be plenty. Clive disagreed, but didn't tell me until half an hour before he wanted to leave, when he started agitating about being late. Getting ready was not trivial, as we were travelling with two toddlers, and I wanted to leave the house in some sort of order. Things got more and more heated, until Clive went off in a huff and sat in the car, blowing the horn and revving the engine from time to time. This is a story many parents will recognise, and only worth noting because it showed a side of Clive I had never seen before in the almost 20 years I had known him. Clive had been selected by the Army for training in bomb disposal. They don't select men who are excitable or have a bad temper. Clive had always been imperturbable – bomb-proof, indeed. I got my act together as quickly as possible, and we set off to the airport. Most unusually, I was driving. As we drove down the M25, Clive demanded that I stop the car immediately, as he wanted to get out – he had decided against coming. He didn't want driving to the nearest town, or even the next exit; he wanted to be left on the hard shoulder. I managed to jolly him along, and we got to the airport, and eventually out to Dubai, where Clive declared he had flu, and took to his bed for a few days. He certainly wasn't well – this was a man who never had colds or flu.

When we came home, things settled down again for a few months, and were pretty much OK until Clive came home from

work with, as he put it, 'a proposition he would like to put to me'. How would it be if we all moved down to Salisbury?

He was due a posting (the Army moves its people around quite regularly), and had been steadfastly refusing all attempts to post him to a desk job in London. Clive was never one for desk jobs if they could be avoided. He was also getting somewhat depressed about not getting promoted, and I could never persuade him that maybe the two might go together. The possibility of a job had come up near Salisbury. It was a job for which he was very well qualified, and might give him the promotion if he did well, but...it was in Salisbury, and that was too far to travel daily. He wanted his family with him; there was a house there; would I move?

This was breaking the agreement we had made when we started the family: that we would buy a house and settle down. I never fancied the idea of moving around every two years with children in tow. It was fine when there were just the two of us, but this was different. Still, Clive really wanted the job, and the children had not yet started playschool, so there wouldn't be too much disruption for them. It would mean losing my job, but I had always managed to find something. So on the whole I could find no cogent reason for refusing. I'm ashamed to say it put me in a bad mood for a very long time. I should have refused, or agreed and gone along wholeheartedly. But I couldn't.

So we moved. The house we moved into had suffered a leak from the central heating oil tank, which had soaked into the chalk floor underneath the kitchen. The Army dug progressively deeper holes to try to get rid of the appalling smell, which gave me permanent sinusitis. The disruption to the house meant entertaining was impossible, and we moved at the end of July, when all the toddler activities I was used to going to shut down for the summer. I found it difficult to make new friends, Clive was working very hard, and to top it all I couldn't find a job. I was very miserable and very grouchy. It was July 1990: a few weeks later Saddam Hussein invaded Kuwait.

Clive's workload increased, and he was really needed. He should have been totally fulfilled and happy. He wasn't. His work was classified, and he would not talk about it, but it was obvious that he felt frustrated and at odds with his boss. In February 1991 things came to a head.

Clive had to go for a routine Army medical – the first since he had had the pacemaker fitted. Once again I tried and failed to persuade him to report the pacemaker in advance of the medical. He thought it would be a great joke to turn up for the medical and let the doctor discover the pacemaker. The doctor did not agree. Clive's boss didn't get the joke either. Clive was sent on immediate gardening leave.

The story that came to me via Clive was that the boss had been unhappy with Clive's work for some time, and had decided that the pacemaker and heart problem were the root cause of all Clive's difficulties. Clive had apparently been producing very poor, inappropriate and poorly spelled written work for some time, and had already received several verbal warnings and one written warning. No-one asked why a heart problem should cause problems with writing. Clive was also reported as being stubborn and difficult to manage. Despite this, at a further medical Clive was downgraded one grade medically because of the pacemaker, but no-one looked any further for a medical reason for his difficulties at work. And, of course, he now had a large black mark on his record. Anyone wondering at his stubborn, uncooperative, uncommunicative attitude in the next 18 months looked no further.

We had gone, as a family, to a curry lunch in the mess. The place was quite full, and seating was at a premium. We filled our plates, and looked for somewhere to sit. There was a very large space free, but the Colonel had not yet got food, and that space was very obviously being left clear for him and his wife. My heart sank as Clive headed for it. I tried to point this out, but Clive was having none of it. 'I've as much right to sit there as he has' he declared loudly, and sat down. He was carrying the children's

food, so I had little choice but to join him. A few minutes later the Colonel came up, noticed us, and was not best pleased. 'You're sitting in my place', he hissed venomously. Clive refused to budge. Other, more sensible people hastily made space. It did not help our relationship with the people around us.

Clive was sent for another medical, and managed to persuade the doctors that he was very fit, and was graded A2, or whatever such number the Army uses. I don't know if anyone investigated the alleged link between his poor performance at work and the drugs he had been taking for his heart. Anyway, there was no suggestion brought home to me that it was anything other than a personality clash between the Colonel and Clive.

Once his medical status was sorted out, the Army quickly found Clive another job a few miles down the road. He miserably described it as a 'blanket-stacking job'. He was only there for a couple of months, and we were on the move again, back to Oxfordshire and another Army house. This was a more responsible job, with people Clive had worked with before, and he seemed much happier. I was quite surprised when he came home wanting to discuss taking redundancy. The Army was downsizing, and there were some very attractive packages on offer. I didn't like to seem too much like a wet blanket, but I found it very worrying. Clive may not have been particularly happy at work, but it was a steady job with a reasonable income, and we now had two toddlers. I tentatively asked about other jobs. Clive had it all sorted. He would get a job as a teacher – he had a biochemistry degree, and should be able to teach chemistry. We started taking the *Times Literary Supplement*, and checking the pages for likely looking jobs. We talked about moving back to Yorkshire, where we both originally came from, and where we both still had family. Clive put his papers in, and was accepted. He was finally due to leave the Army in September 1992. Whenever I raised the subject of money, he laughed at me. Of course he would get a job; it was just a case of waiting for the right offer to come along. I didn't like to point out that there hadn't been any offers so far.

I don't remember him actually applying for any teaching jobs. The subscription to *Times Literary Supplement*, was cancelled by him. When I queried this, he said he couldn't teach without a teaching certificate, and he was too old to go back to college. Once again, I was surprised. It was not like Clive to decline such a challenge, and he was only 45 – still plenty of time for another career. But he wouldn't be persuaded, and talked of becoming a TEFL (teaching English as a foreign language) teacher, then a security consultant. He even arranged a TEFL course, but managed to arrange it at a time when I had already booked and paid for a diving holiday. It shows how deep the rift between us had grown that I didn't even consider trying to rearrange my diving holiday. I don't think he ever rearranged his course – he certainly never went on it. In the meantime, I had found a job, working part-time for a computer consultancy in Oxford.

Clive was short-listed for a high-profile job with a security firm, for which he had to prepare a talk. The talk was a joint effort – Clive decided what he wanted to say, and I generated overheads on the computer for him to use. He didn't get the job. He was very puzzled because one of the interviewers had asked if he was dyslexic. That was the first real suggestion from someone outside that Clive was having problems with words – why didn't we follow it up?

After that refusal, Clive came home with another suggestion – I should work full-time, and he should be a house-husband. It wasn't exactly what I had had in mind when we started a family, but I could see his point, and it was surely better to have at least one salary coming in. I increased my hours of work, but Clive seemed unable to cope with the house-husband bit.

For step one, Clive decided he had to improve his cooking, and asked me to teach him a few meals that we all enjoyed. I thought the simplest was pasta, bacon and cheese, and carefully explained the recipe to him. He had difficulty understanding some of the instructions, and his idea of bacon pieces 'one inch long' was wide of the mark, but still... He seemed to be getting

on OK, so I left him to it, only to be brought back to the kitchen a little later by the smell of burning plastic. Clive had picked up a spatula meant for scraping out cake mix, rather than a fish slice, and was chasing pieces of bacon round the pan with an implement which was steadily melting away in his hands, and coating the pan and the bacon with burnt plastic. Clive hadn't noticed, and seemed very hurt when I insisted on throwing the whole lot out and starting again. His other attempts weren't very much better, and so we compromised on ready meals when it was Clive's turn to cook – more expensive, but at least we ate.

Step two was taking over more child care, but one day I came home from work to find a policeman on the doorstep, holding our three-year-old son Alan by the hand. Clive had taken both children to the swings, and Alan had wandered off – he could move like greased lightning when he wanted to. I never got the complete story, but Alan had been found wandering around his playschool, the other side of a reasonably busy road. I was very concerned, but Clive laughed it off. Whatever might have happened was irrelevant; nothing had happened, and he would be more careful in future. I continued to worry, but really didn't want to give up my job – I was enjoying the work after two years of unemployment, and it was beginning to look as if my salary would soon be the only money coming into the house.

Step three was Clive taking over the washing, but he never got the idea of washing different clothes at different settings – everything went into a hot wash. I soon learned not to put my work clothes into the laundry basket – I had to wash them quietly by hand when Clive was out – and everything else turned a gentle shade of pink. We had just bought a tumble-dryer, as I got sick of wet washing around the house all the time, but it couldn't be installed properly, as we were in a rented house, so every time it was used the vent had to be put through the window. Clive could never remember to do this, so whenever he used the tumble-dryer the whole house filled with steam.

When he cleaned, he was not happy with hoovering round the furniture and dusting the visible surfaces. The Army and his natural habits made him very conscientious and fastidious. Every clean was a spring clean. All the furniture got moved, and all the knick-knacks washed if at all possible. To begin with, most things ended up back in the right places, but as his memory got worse that became less likely. Eventually we would end up with all the furniture at one side of the room, as Clive shifted it all to one side, hoovered that end of the room, moved the furniture to the other side, hoovered the second side, and then put the Hoover away and stopped. It was frustrating to come home and have to move things before we could have tea, but at least the house was clean.

I gradually took back most of the jobs, but I kept my office hours up. After all, we would soon be down to the salary from one part-time job.

September came and went with no sign of a job for Clive, and we moved out of the Army house and back into our own – fortunately within reach of Oxford. I increased my hours of work. Clive talked again about becoming a house-husband – the major trouble with that was that he could never remember anything I asked him to do. He was a great cyclist, and went everywhere by bike, but persisted in buying eggs and bringing them home in a rucksack – they rarely survived, but I washed the rucksack, and Clive didn't seem to notice. For Rachel's fifth birthday, she chose a birthday cake from the local shop. I had long since discovered that icing cakes was not one of my strong points – however simple it looked in the book, it proved too complicated for me. The chosen cake was a sponge built up to look like an elegant lady in a crinoline, and Clive offered to collect it on the big day. I was busy trying to organise the party we had arranged, and agreed without really thinking about it. It also came home in a rucksack on a bicycle, with predictable results. I tried to patch it together, but it didn't look quite as good as it had looked in the shop. Fortunately the rest of the party went well, and so we avoided too many tears.

Clive kept on applying for jobs, but I had to help him fill in the application forms. Occasionally he got an interview, but never an offer of a job.

Clive gave a talk to the Rotary Club my brother belonged to. My brother told me the talk had gone very well, but it was a pity there were so many spelling mistakes in the overheads. I couldn't understand that. Clive had given me a travel scrabble set for a wedding present, and we had played many games over the years. He consistently and annoyingly beat me almost all the time – how could he be making elementary spelling mistakes? We watched a French film with subtitles on the TV, and Clive really annoyed me by continually asking for a translation. Again, I couldn't understand it. His French was much better than mine, and there were subtitles in any case. He said he couldn't read the subtitles as he didn't have his contact lenses in, and I believed him. Whenever I read a bed-time story to the children, Clive left the room, and always managed to find an excuse not to read to them himself. I found this inexplicable and very upsetting – it did not occur to me for a long time that he was probably unable to read easily by then.

It wasn't just words and spelling that were difficult. Once we had recognised that Clive's spelling was very erratic, he started bringing all his letters to me for checking. Clive had always done the household admin – he didn't trust my last-minute approach. One day he brought me a cheque he had written to pay a bill. The bill was for one hundred and two pounds; Clive had written a cheque for one thousand and two. He was perplexed at my insistence that he start again. It was a perfectly good cheque, and if it was for more than we owed on this occasion, well, we would just be in credit for a few months. He didn't seem to take on board that the cheque would probably bounce, and, if it did clear, we would have no more money in the account. The idea that the money might run out seemed inconceivable – this from a Yorkshireman who had always known the value of money. I thought once again

he was getting at my worry-wort habit, and resolved to worry less in future, but keep a much closer eye on our finances.

When we moved back to our house, we had to buy a few small things, and I decided I wanted some cane waste-paper baskets. I had seen some in a shop in Abingdon, and so when Clive was going shopping I asked him to pick two of these up. I described them quite carefully, told him which shop they were in, and even where in the shop they could be found. Clive nodded agreement, and then came home with a couple of plastic buckets from Woolworths. I probably did weep with frustration and irritation, but Clive was unrepentant. I wanted waste-paper baskets; he had provided receptacles for waste paper, which had the advantage of also being waterproof. I thought he was trying to stop me being so picky and house-proud, and we used the buckets for many years. They didn't quite have the look I had had in mind (when I cared about such things), but they were indeed effective. In later years I got heartily sick of these waste-paper bins, as every doctor Clive saw seemed to think they were very interesting, and showed the difficulties Clive was having with language. That is certainly possible, as his language skills were deteriorating, but I also think it might be that he had disliked being asked to run errands.

The papers before Christmas were full of tokens to collect to get a cheap cross-channel ferry crossing, so you could have a day trip to France and stock up on cheap wine and beer. Clive was very taken with this idea, but he didn't collect any tokens or discuss the idea with me. He just went to the local travel agent and bought a full-price ticket. He then drove to France and bought lots of cheap wine and beer which I had to find storage space for. It all seemed very strange to me, especially since Clive brewed his own beer, and he preferred English bitter to continental lagers. At least the car got him to Calais and home – round about this time every car we owned gave trouble. They were no newer or older than cars we had owned at other times, yet every car stopped working inconveniently and expensively. I can only assume that Clive's very smooth driving style had become rougher and more

wearing on engine and gearbox. It was also about this time that I took over the family driving. It was never discussed, and I can't really remember how it happened.

Clive still doggedly continued to look for work, and signed on at the local job centre. I have no idea how he got on with them. He should have been entitled to a little unemployment benefit, but he persisted in taking a job an old colleague offered him, which offered a few hours' work in London two or three times a month. The pay never paid the expenses he incurred travelling to and from London, and of course each time he worked he signed off benefit. So whatever he may have been entitled to we never got. The redundancy payment diminished with alarming speed, but Clive shouted at me whenever I mentioned it. He would get a job, he was certain. He rang me at work one day to tell me that he had been offered a job – when I got home I looked at the letter and he had actually been sent an application form. But Clive always put up a good front – he always had a reasonable explanation, and I was too busy to take much notice by now. Conversations with Clive seemed quite pointless. Whatever we decided, he'd ignore it and do whatever he wanted, so I just let him get on with things, and tried to keep the rest of the family going. Every Friday he bought a local paper, and we would spread it on the floor and go through the jobs section looking for possibilities. I'd help him fill out the application form, and he got a few interviews, but never anything more.

Finally, he was offered a job, as a security consultant with a firm in Yorkshire. The job was very close to his mother's house, so he arranged to go up and stay with her, and see how things got on. If it worked out, we would look for a house up there. He lasted three days, and was sent home in a hurry. The firm never told him why they didn't find his work satisfactory; they found it 'too embarrassing'. They also never paid him. Unfortunately, while he was there, his bicycle was stolen.

After his redundancy from the Army, Clive joined the Territorial Army (TA) and went on weekend training exercises with

them, probably about once a month. I never heard how he got on until there was a two-week exercise down at the coast. Clive was sent home early, and a letter to me (this was the first time the Army had contacted me) explained that this was because he was becoming a 'laughing stock'. I didn't consider the letter closely, and can't reproduce it now – it ended up in shreds in the rubbish. I tore it into pieces the size of a postage stamp, and, when I couldn't tear the pieces any smaller, I took scissors to them. A few days later I got a telephone call asking me (not Clive) what was going on, and a few days after that a letter from the TA dispensing with Clive's services after 23 years in the Army. No advice about any possible change in his pension entitlement was offered.

Just after this he admitted to me that he was having problems with reading and writing, and asked me to start accompanying him on the hospital visits. His story was very confusing – like everything at this time. He had apparently already been to see one specialist, who couldn't find anything wrong and referred him on to a neurologist. It was all very complicated, and I can't go back to get the full story from Clive's hospital notes, as they were lost without trace.

Clive and I went to a consultation with the neurologist. The story of Clive and the waste-paper baskets was discussed at length, as were the egg-shopping trips. Clive was referred for a series of neuropsychological tests – as far as I could see, mostly pen and paper tests taking about an hour each. I would meet Clive, deliver him to the hospital (he was not by now reliable about getting to a definite place at a definite time, and the hospital was very close to where I was working), sometimes wait for him and sometimes go for a walk, then collect him and see him safely on his way home. On one occasion there was a fire alarm, and so the three of us sat outside in the summer sunshine, and naturally talked about what the tests showed. At least, the subject seemed a natural one to me. The person doing the testing – a very nice young psychologist – got very upset, and said that she should not have to give us the results of the tests – that was up to the

neurologist. But it was clear that Clive was doing very badly in some of the tests, and that his problems were not confined to any particular area. Because of his pacemaker, Clive couldn't have an MRI scan, but he did have a CT scan (a type of X-ray), which didn't show anything amiss. He also had a lumbar puncture, where a needle is used to extract some of the fluid surrounding the brain and spinal column. Lumbar punctures are notorious for generating headaches, and the standard instruction is to take life very easy for a few days after the test to give the body time to replace the fluid. Clive interpreted this in his own inimitable way: he had cycled to the hospital for the test (I don't know where I was on this particular day), so after it he cycled home – six miles, up and down a very steep hill – and then he hoovered the house. I came home to find him sitting down complaining of a slight headache. The next day he got up as usual at 5:30 a.m., cycled to the pool and went for a swim. Then he cycled home. I told him what an idiot I thought he was, and tried to persuade him to go to bed and lie flat. He refused, but eventually allowed me to ring the GP. She was sufficiently concerned to come out and see him, and ordered him to his bed to *lie flat*. He was prepared to follow her instructions, and downstairs she signed a sick note for him – the first of many. It was the first time he admitted he was unfit for work. I remember the date – it was 15 October 1993 – Clive's 46th birthday.

With hindsight

How could I have been so blind? Clive's behaviour was so different from earlier, and things he had always managed competently were now beyond him. The truth is that things changed so slowly and gradually that each step seemed perfectly reasonable. People do have conflicts with their boss. Husbands can forget they have promised to babysit on a particular night; they have been known to forget their wife's birthday. Dementia is very rare

in those under 65; most GPs won't see one case in their career. And Clive, after the very early stages, never admitted he was having difficulties; indeed, he became very good at hiding any problems. But our life could have been so much better if his illness had been recognised earlier. All the fights and arguments could have been avoided. We could have had three more good years together, and made the most of Clive's time with his children. If Clive's illness had been diagnosed in 1989, before the problems with the Army, we could have made the most of the time we had left together, instead of spending a lot of it in irritation, misunderstanding and misery. And our finances would have been much healthier.

I attended a conference not very long ago when one of the speakers, an American geriatrician, said he was against giving people a very early diagnosis. He explained that to give a diagnosis of 'possible early dementia' would stigmatise the people concerned, affecting their relationship with everyone around them, might stop them driving and would generally make their lives much more difficult, without in any way helping them. I wanted to ask him about an early diagnosis for younger people, people with a job, a mortgage and possibly a young dependent family. An early diagnosis for them might mean retirement on grounds of ill health and a pension, rather than the sack and a life of poverty. But I never got the chance – the conference was very busy, and I could never catch his eye. Sure, dementia is very difficult to diagnose even when it is quite far advanced, but there are conditions with similar symptoms which are treatable, and even, if the eventual diagnosis is dementia, it makes subsequent life much more comfortable if the person with dementia is able to take medical retirement, and keep the pension they are entitled to. It also gives them time to make other arrangements and, if they wish, make such things as a living will.

Even with hindsight, I find it difficult to see what I could have done differently. Things changed so slowly, and the initial symptoms were so nebulous. It never occurred to me to try and

see my husband's GP. I didn't realise that there was a medical problem. In fact, I still have difficulty understanding an illness that can cause someone to forget how to spell. At the time, Clive was registered with an Army doctor, so my seeing him would have had implications for Clive's work, and in any case I would not have expected him to see me. Perhaps I could have gone to my own GP, but I already seemed to spend far too much time there with the minor accidents and illnesses of two toddlers. I didn't have any close friends I felt able to confide in, and I felt very much like a nagging wife. In fact, for a long time I wondered if the problem was mine and not Clive's. I didn't even talk to Clive's or my family. It was impossible to raise such a topic over the phone. When I finally allowed myself to confide in a close friend, I felt as if I had betrayed Clive in even admitting to such doubts.

I was frustrated and very worried for most of this time. Clive used to say that if I didn't have something to worry about I would worry about the things I didn't know that I ought to worry about. Again, hindsight is wonderfully clear, but what was most disturbing about this time was that Clive wasn't at all worried about the things that were wrong. That insouciance, that calm acceptance of things, that inability to see the consequences of one's actions, is very much a symptom of his illness.

What is clear to me now is that if I had recognised that the difficulties I was having communicating with Clive were not just mine, and that the people he worked with were having similar difficulties, the last ten years of Clive's life could have been much easier and happier.