

EVIDENCE TO ASSEMBLY COMMITTEE
DISCUSSING TREATMENT AND FUNDING OF STROKES
IN S.E. WALES

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INTRODUCTION

In addition to this introduction, there will be three sections, viz:-

Section 'A': My wish list i.e. what treatment, I think, I should have had when I had my stroke six years plus ago. At that time I knew absolutely nothing about strokes. I have learned much since.

Section 'B' My personal experiences: Of course these are not statistically significant and may be totally eccentric. However, I do not think so because there were many elderly people on the ward I was in and, so far, as I know, all except one (who, alas had Parkinsons) also had strokes. There was also a young man whose stroke symptoms were roughly the same as my own. He got moved very quickly. However more about this in Section 'B'.

Section 'C' My present life. Believe it or not, I am in great form but I am keeping the good news to cheer you up at the end.

SECTION 'A' MY WISH LIST

2.

I hope I will not leave anything out. As I have said, when I had the stroke six years and five months ago, I knew absolutely nothing about the diagnosis or treatment of strokes. I was seventy years old a few days after I was admitted to hospital and had no reason, at least that is what I thought, to even think of a stroke.

List follows:

- 1) More training of individuals, families, GPs and Geriatricians about how to suspect or diagnose the possible approach of a stroke.
- 2) More stroke Consultants.
- 3) Proper stroke units in every area of Wales.
Specialist stroke staff viz nurses, neurophysiotherapists, psychologists, information givers.
- 4) Brain scan within three hours and "clot busting" treatment available 24/7.
- 5) More support after discharge.

SECTION 'B' MY PERSONAL EXPERIENCES

These, of course, are not statistically significant, and indeed may be eccentric. However, as I have said, virtually all of the people on my ward were in the same position as myself. Indeed, I think, most were worse off than I. Each experience I will describe illustrates reasons for my List (Section 'A').

Some three months before the stroke, I started to feel very tired, and it felt as if I was carrying my legs, rather than vice-versa. So I went to my GP a number of times; He suggested I had anaemia and that I should take some iron tablets. I said that I could not. They made me feel so ill, I just ended up in bed anyway. So I asked for injections as one of my sisters had to have. However, he said that treatment was no longer used. He omitted to say there was such a thing as infusion which I ended up having later much to another GPs surprise. I cannot remember why I was sent to that consultant. At the same time all this was going on, my sister was asking me to come to Dublin (I think because she was giving a 'do' for the enlarged family). I had been telling her that I did not feel well enough to come. However, when she heard that my GP had said I had anaemia, she said 'only a bit of anaemia', and without telling me she booked and paid for my plane tickets. So I felt I had to go. I am not sure how I got through those days. Apart from my legs being peculiar, I could not get warm.

My sister thought a walk round Dublin Bay would do me good with the fresh air. I certainly did not walk fifty yards, and then we headed for the plane home. I did not feel good. A strange thing happened when I arrived back in Cardiff, which goes to show that someone, (I still do not know who he was), recognised I really was not well. I was sitting on the plane waiting to off-load, when a man came up to me; he asked if he could help me with my cabin luggage. I was astonished, because, though I felt really ill, I did not think I looked that bad. So I thanked him and said I would be fine. To my complete astonishment, when I arrived at the carousel to pick up my other luggage, there was a man in uniform there. He had taken my luggage off the carousel and put it onto a trolley and escorted me to the car that was meeting me. I was so glad to get home. I put the central heating on high. I still do not know who this man was but I now suppose he must have been a doctor. Two days later I was in accident and emergency with a stroke.

Even the run up to that was a bit peculiar and shows my ignorance. That night I fell over twice but persuaded myself that I had tripped because I got up each time. Also I did not want to be calling an ambulance out needlessly in the middle of the night. However, something must have told me things were wrong. So the next time I got up to go to the 'loo' I took my mobile with me. This time when I pulled my pyjamas up, I fell over and could not get up. I tried to hop but, because my balance was all over the place, I couldn't, so I had to ring the ambulance then. I remember being very glad it was somewhere between 6/7 am (I think) and that my neighbour would be awake to let the ambulance people in. (I live alone). I cannot remember if I rang her to warn her they were coming or not. In the end it was her daughter who let them in. (I now have an alarm button).

I should add that during this time I had taken myself off to a psychiatrist thinking I was going mad or at least depressed and she noticed my legs. I should also add I should not have 'psychoanalysed' like that. I had done something like it once before after my sister died of a terminal brain tumour (astraglioma grade 3 / 4). That time I thought I was grieving too long and had got depression. However my then GP, Dr. Payne, (a very good man, alas now deceased), decided there really was something else wrong with me. It turned out to be pernicious anaemia and I have had successful injections of B12 ever since. However, he told me off, good and proper, for psycho-analyzing, and that I was never to do it again. I think he had got a bit of a fright because he told me afterwards (thank heavens) that he thought I had leukaemia.

This brings me to another point (and please remember I am still not sure about the timing of all this, but I am sure that when this next happened, I had not had a stroke'; though my back and knees were injured. The spine injuries (including the neck) were caused by a riding accident. I was 'brought down', I did not fall off, so I got some compensation. The knees were injured when I fell over some hidden rubbish on the pavement.

In any case my nephew and godson; three years a consultant, and with his wife planning to have a baby, suddenly had an unexpected illness (I will not go into all the details) and was paralysed from the neck down. He died a month later at the age of 38.

It seemed to me that my heart was playing up, so I decided, though I felt a fool, that I would follow Dr. Payne's advice and get my heart checked (privately – so I must have felt quite peculiar). I went to a Dr. Masani, and suddenly in the middle of the scan, to my own and Dr. Masini's astonishment, wet tears started on my cheeks. So I told him that Paul, my nephew, had died that morning at 6 am, so I was a bit upset. Then it was his turn to be astonished because he knew Paul and his wife. Dr. Masini offered to stop the test but I said we might as well get on with it. Not having it would not help Paul. I have to say I was surprised to find that I had atrial fibrillation. I now know that this should have warned people that a stroke could follow. However, since I did not at the time connect heart problems with the possibility of strokes. I still never thought of that possibility. However, it is, perhaps, surprising that my GP did not either – he must have had the notes. Mind you, later (6 plus years) when I did find out the connection, it provided me with a consolation. My father had a fatal heart attack. We all knew he had heart problems but he would not elaborate. Since at the same time I got a Ford Foundation Fellowship to Stanford in California, I tried to get information from his GP but to no avail. So with some persuasion I went. However, I came back for my father's and my birthdays and we had a great time planning a trip for him to DC to meet with friends he knew there. A few days later he collapsed with a heart attack and was DOA. I was really upset with the Coroner's Officer when he told me they were going to do a post-mortem on the brain as well as the heart. I did not know the connection. I do now but at the time I thought they were doing it to teach students. Not that I would, in any way, argue that this consolation or indeed any other good that emerged from my having a stroke, provides any justification for having a stroke and its poor diagnosis and/or treatment.

To return to the main theme, the ambulance took me to Accident and Emergency at UHW. A stroke was diagnosed. I was surprised to find that not only could I not walk which was obvious, I could not touch my nose with my fore finger. Everyone was very nice and while waiting to go to a ward (a couple of hours I think) I was allowed to sit in a wheel chair. This was a blessing because those trolleys are dreadful if you have a bad back. Now, there is a blow-up kind of mattress they use. I would much prefer a memory foam topper.

As I write this I keep dozing off. I cannot understand it. I feel good, I had a good night's sleep (it is 8.50am). I am interested in what I am writing about, also I have opened the windows and doors for fresh air. My hand writing

has gone to 'pot'. The poor person who is typing this report is having a terrible time. This is one of the reasons the report is so late. This dozing does not happen if I am doing something physical or out with people. Maybe it has something to do with the stroke; I must ask Dr. Shetty or one of his juniors.

Again to return to the main theme. (Really I have no discipline to be wandering about like this). From Accident and Emergency I was sent to some kind of temporary 'waiting ward' while they decided what to do with me. That was interesting, I thought one of the medics was a bit 'touched in the head'. Actually I think he thought I was a 'funny one'. He saw in some notes I had taken in with me, that I had a private health insurance. He suggested that I went to a private hospital where I would really have fun. I decided to ignore him because a) at the time I thought I was not ever going to have much fun again b) it was a very poor insurance and would not have covered that. So I decided to concentrate upon a nurse with the object of persuading him to let me have a zimmer frame. I reckoned that if I got one of these I could kind of 'crab along' the edge of the bed, and if I could do that, I could ask for a bedside commode. That way, at least, I would not have to ring the nurses 'n' times at night. In the end I got the frame and also a commode, but it took ages (or seemed so), and I also found out later I was given the wrong sort of frame, it should have had wheels on the front legs. When on the next ward I got one of these and it was much easier to use. I suspect as Easter was coming up (at least I think so) everyone was in a rush to get things cleared up.

After that ward (some days, I think) I went to another ward which, initially, I assumed must be a stroke unit because, as I said before, everyone around me (all except one poor thing had strokes). After a bit, I decided it could not be a stroke ward. I could not understand it because UHW is a teaching hospital. It first dawned on me because the physios were not neurophysios. (I knew this because I saw the physio treatment my sister got at St. Thomas's in London, when she had her tumour). We were only getting assessment physio, though I did get a proper zimmer with wheels on the front legs. So I decided to exercise myself. (I knew about exercises because the injury to my spine had been going on for about 20 years at that time, and I got some sports experts to advise me on exercises and I had been doing them for years when I could. (I had good patches fairly frequently after I decided to go to a Chiropractor. At this time, I had also discovered I could no longer write. You must find it peculiar, but I felt perfectly certain I was going to learn to write again. So I practised my alphabet again and again. As soon as I thought I had my signature pretty well perfect I wrote to my bank. The belief that I would relearn to write was, I am certain, based on my experiences when I was

evacuated at the beginning of WWII and I lost the ability to even recognize my letters. (I was six years old so no-one believed I could ever read or write. They thought I was boasting and it nearly drove me mad, since I had been reading 'Catriona' before all this. It was my Father's favourite book as a boy). I was also told my Father had died; he had not, but to cut a long story short, my writing etc. came back one day when the other children were spelling messages to each other (they thought I would not understand). Suddenly in the middle of this I heard "agh" and I thought that is my name and my reading and writing came back immediately. The supposed death of my Father caused more trouble (because of an unbelievable series of incidents). When I met my father again just before VE Day, I thought they had the wrong man. I always could remember these things. However the stroke 'business' brought it all back, but with feeling. Only now I was 70 years old and a whole lot of this became understandable. Amazingly, I think at the age of 70, I became psychologically integrated. In any case I am a much less conflicted person and I am happy. Now I would not advocate having a stroke for this 'cure' to happen. This, I think, indicates the need for psychological care after a stroke. Also, of course, there are other more normal reasons for such care, and if I remember them I will write about them.

All this time (only about three days) I was wondering why UHW had no stroke unit. I was also wondering why I never saw my consultant (name over my bed). I was not wondering why I waited three or so days before I had a brain scan, because, at that time I did not know I should have had such a scan within three hours. Also I did no wonder why I had not had a clot buster because I had never heard of this. In any case I would not have been given one because I was diagnosed with a bleed in the brain. It was not until 6 + years later when I saw Dr. Sketty, I actually found out that I had had a clot.

The next thing I found out was that though the name of a consultant was over my bed, in fact he was no longer at UHW; he had moved to Bristol or somewhere. The whole ward was in the charge of a, not surprisingly, stressed young medic. Furthermore, unfortunately, I stressed him more by reacting badly to the first drug he prescribed for me. It upset the balance of my potassium and sodium salts. I think that would have been OK but, rather stupidly, when I was given another drug I asked some nurses if there would be any side effects. I took the drug, of course. However, the nurses told this, already stressed, young medic that I was asking about the possible side effects of the drug. When he saw me he hit high 'doh' and demanded to know if I was resisting drugs and was I taking what he had prescribed. He was really cross with me and I got annoyed and decided that I did not think any more kindly of him than he thought of me, as I saw it. I was, of course, taking the drug; I was only asking.

The next thing that happened, I asked the physio for a tennis ball to squeeze as I thought I could improve my fingers' strength by squeezing it. Unfortunately this was a mistake; it was not my grasping that I had trouble with, it was releasing, which I found out later first when I tried to operate my laptop and when I pressed the keys, instead of having one 'A' for instance, I ended up with a line and a half of 'As', because I could not lift my fingers fast enough. It was years before I found out you could slow down the keys. That would have been really useful information to have been given. However it would have been better if the physios had told me how to exercise my fingers in an appropriate way. Unfortunately, later, as a result of the side effects of a drug I did not need (and am not now taking as I have been properly diagnosed and medicated) and also because of stress, I developed a peculiar thing with my finger tips. (I have forgotten to tell Dr. Shetty about that). It became very uncomfortable indeed to touch the computer keys. So now I am about to get a microphone dictator system attached to my laptop.

Then the next thing that developed was that the only young person on the ward (a young man in his twenties I would say) was transferred somewhere else; whereupon I thought, 'there is a stroke unit somewhere but it is only for young people, and 'we old sticks' were left in a Geriatric Ward' (which actually was the type of ward we were in).

I went on with my practising and think I had only been in hospital 2 weeks by this time; however, it seemed much longer. One day I decided to walk without the zimmer but I was afraid to do it without someone being around to catch me if I fell. So the next time one of the physios was on the ward assessing another patient, I asked if when she had finished, she would stand about four yards in front of me and I would try to get across the gap and she could catch me if I fell. Very kindly she agreed; really it was a very happy moment. I made it and we started to laugh as did the other patients (those who could). It was a laugh of pure happiness. It was just like a child's delight when he/she makes his/her first steps to the front of a couch. I was beside myself with pleasure and delight. Later it bothered me, I was worried about making my fellow patients feel worse when they saw me doing so well while they were not. Then I began with the walker moving about the whole ward (as distinct from the room I was in). Then one day I was allowed out of the ward on my own and without a wheel chair and eventually without a walker or a stick. I was still doing my exercises.

Then the next thing that happened was one of the nurses came to me and said it would be much better for me if I left the ward and went home. I was not feeling that secure and went paranoid. I thought they (especially the young medic) wanted to get rid of me and get my 'bed night' free. Oh boy! Was he annoyed when I said something to that effect. I WAS being paranoid and this is another reason for a psychologist to be on tap. They were not just going to send me home, I was going to get help, viz grab bars, a commode, people visiting me twice a day for six weeks. I was even taken into the centre of Cardiff and walked (without a stick) albeit with a helper on either side of me ready to grab if needed. This was not needed. So after four weeks, instead of the six originally suggested, I decided that, provided I could keep the commode, stools and grab bars, I could

manage. I had for years been employing a lady to help me in the house because of my back injuries. I still cannot lift because of them, and the stroke did not help. If I do not take care, my trigeminals can go out, also my brachials and my sacroliacs as well as my lower spine. (I have popped my discs, and also the nerves that go down the legs, I forget what they are called). So over the years I had learned to be careful and I employed help. I managed to keep working with the help of the Chiropractor and frozen peas. Now I am told I have arthritis of the spine. At the moment I am in no pain at all. In a way the stroke protects me because I am not so active – another good thing from the stroke, but again I must stress there must be better ways of reaching this condition without getting a stroke and heart problems. I had only spent three weeks in hospital; I am pretty sure of that.

After I had been out of hospital for a while, to my horror my walking and everything else seemed to get worse not better. It took me ages to realise why this was. Really I should have been informed about this possibility and the things I could have done to prevent it.

As I have said, I was jolly delighted and relieved to be able to walk so quickly and without a stick. However, what I did not grasp was that I was not walking as I used to and my muscles were going. I have lost two stone – all muscle, (I am certainly eating well) because I was really kind of staggering instead of striding. (Before the accident happened to my back my main holiday consisted of 25 mile a day walks, followed by a really hot shower and a super dinner and friends to talk with). Even after the back, in the good times, I would start exercising again and if I got a long enough break, I would walk for as far as five to seven miles.

Anyway I found my muscles getting weaker despite all my attempts to exercise etc. So I got myself a pretty walking stick. But then I realised that after a while I could no longer walk from the hips. I was walking from the knees. Now I have found a walker with wheel movement that helps me walk from the hips and walk further. I have had this piece of equipment three weeks and I swear I am walking from my hips and I can feel muscles being developed. This is great and I am happy as “a pig in clover”. Also I swear my B12 injections are easier because I have some muscle. It would have been so much help if I had been told from the beginning such information and about this piece of equipment.

To go back, at some point I seemed to be getting to feel pretty ill. I had an appointment with one of Mr. Masani's juniors and he suggested Warfarin but when he looked at the notes and realized I had been diagnosed with a bleed he said 'Forget I said that. It is a pity though'. I said 'you mean it is the lesser of two evils not to have it'. He said 'yes'. I thought he was referring to it being a pity about my heart. Obviously since I had had a brain bleed (supposedly) it was better for my brain if I did not have it. (I knew Warfarin was a kind of rat poison, as I have not lived in the country for nothing).

Then I got really ill and landed up in UHW three times. I do not remember most of this. Some two months later a friend said 'I felt sorry for you over November, Christmas and the New Year. I asked her what she was talking about. She told me I had been in hospital three times. I got a bit confused about who was making what mistake. Then about a month or so later, I thought if I really had been in hospital three times, I was due some Insurance money. So to be certain I wrote to the Legal Section of UHW. They confirmed that my friend had been quite right. So then I began to think really hard and I found I could remember something, i.e. ringing friends at Christmas time to apologise for not being able to come to lunch. The next thing I remember was being in hospital with a mask over my face. I also remember being taken into a room and laid on my stomach and then I felt a thump on my upper back. I do not remember going back to my bed. I do remember beginning to feel improved. I ceased to wear the mask; a nurse washed me; and a physio walked me up and down the corridor. I also got the impression I had had fluid in the lung. I slept a lot; they called me 'the sleeper' on the ward. Then one day, (I think she must have kicked the bed or something because I was asleep as usual), a pleasant plump young woman told me I had arthritis of the spine. Then she said she was going on a marathon around Conamara; I promptly thought I was having a hallucination because she surely would have a heart attack if she went over the mountains (she did not have an athletic shape) and if she was going round them running, then it would be a shame. I know that area of country and it is beautiful. You need to walk and sit down to 'drink' it all in. The drug I was on could give you hallucinations. Two of the drugs were horrible – gout non-stop, pain in the muscles, joints, nightmares, eye problems, finger top problems. The side effects were supposed to include confusion but how does one know if one is confused if one is confused already!

To cut the story a bit shorter, after some years, I think it was at the second half of last year or the beginning of this one) I called out the GP – by this time I could just about reach the front door – and told her that I was not going to take one of the drugs at all, and the other I was going to cut in half (eventually I cut it to 25%). She agreed. I mean I was in a bad way and I thought it just was not worth it. I began to feel a bit better and decided to do up my house internally and get a downstairs wash room with space for a shower so that I could avoid going into a nursing home. (Honestly, on top of everything else, the builders injured my good leg).

The GP decided to send me to a stroke specialist. This was the first time I was to see one. It was the 6 years and 2 months (approx) after I had first had the stroke. She referred to to Dr. Shetty. However, when I got to UHW, he had a very heavy work load and I saw a junior. Dear heavens! I never met anyone with poorer doctor-patient relationship skills, and I hope I never will again. (I have had information to the effect that he no longer works in Cardiff. I sincerely hope this is true, but I feel sorry for the people to whom he had gone). He greeted me with the information the I had had a clot (he was right but I did not know this at the time). Before I had time to open my mouth to say 'but I understood I had a bleed', he went on 'you probably have had lots of them and are going to get

premature dementia. I must give you a test'. Whereupon, he dashed out of the room and came back with the test sheet. The first thing he asked was "what day is it?" – without thinking, I looked at my watch which has this information. I did this quite automatically. He was enraged. Honestly I thought 'this young man will have a stroke himself if he gets like this'. He sprung up and shouted at me 'you are cheating, I will take marks off you'. Then he said "What date is it" I said 'the 10th'. He said 'I suppose you have read that off your watch as well'. I was still feeling a bit narked, so I said 'No, I did not. I know that today is the 10th because yesterday was the 9th'. (Of course, I knew what day and date it was I had this appointment and I had come on my own). Anyway he got more annoyed. Then he said 'now I have some maths tests for you'. Honestly, he was practically rubbing his hands with glee. I decided that he was a nasty bit of work because it is not correct procedure to use the work 'maths' when giving IQ tests and such like because of 'maths anxiety'. You are supposed to say something like 'I have a few numbers for you' or some such. In any case it was not maths. It was simple arithmetic. You had to subtract one number from another and then another number from the result and so on and so on. Really he was testing my concentration and short term memory (I have to add I failed the names, another question. I knew I would. I have had nominal aphasia since I was thirteen!) However, he said at the end 'you are good at maths (good job he did not ask me to do long addition – I need a calculator). I suppose I will have to give you 27 out of 30'. Then he said 'I will leave the Warfarin to Dr. Masani'. One of Dr. Masani's juniors, after looking up the notes, had decided I could not have it because I had a bleed on the brain. Again, before I could open my mouth, this charming medic said to me 'I don't want to see you again'. Whereupon he opened the door and shouted to the secretary 'I do not want to see her again'. So then 'I was out on my ear' and decided that I would have to go to my GP and get her to send me privately (for which I would have to pay). By this time I no longer had my private insurance and in any case the insurance I had had would not have covered this. My GP agreed, and tried to send me to Dr. Shetty, but I found that Dr. Shetty did not do private work and I was pretty frightened. I thought I would have to go to Bristol or London or somewhere in order to consult someone who was capable of telling me whether I had a clot or a bleed. I felt I would never get that far. Then I had a great bit of luck. My legs swelled up enormously and began oozing a sort of yellow fluid. I waited a bit to see if it would go away, then I thought I had best go to my GP. He took one look at it and said 'you have to go to A & E immediately.' I said I could not go immediately because I had three builders in my house and I had to go home and tell them who my lawyer was and that he had 'enduring power of attorney' and would settle all bills etc. if I died or went gaga. (I had also signed an advanced directive ages ago). It was a nice day. By this time I thought I was going to be landed in hospital again and would probably get some infection, so I dawdled about, packed a few clothes and sat in the garden and drank tea. It was after 6 pm when I decided to go to the A & E. They were doing various tests and things when a man stuck his head between the curtains and it was Dr. Shetty. What a consultant was doing in A & E at that time I have not the faintest idea. Before he could open his mouth, I said 'have I had a bleed or a clot'. He said 'a clot'. He took 7 minutes only to decide

what my medication should be. I know this because the X-Ray man was grumbling that he only had 5 minutes and Dr. Shetty could not have exceeded this time by more than a couple of moments which included making me an appointment with him as an out-patient. He looked quite pleased when I said I did not want to stay the night. I learned later, from one of the nurses, that he was indeed pleased. This was in June last as far as I can remember. Now I am a different woman. I am on 3 entirely different medications and have just been referred to my new GP for the Warfarin because I am doing so well. I am extremely impressed by Dr. Shetty. I have found out he has 6 children and yet does not do private work but devotes all his time to the NHS.

I am also highly impressed by Janet Williams. She runs the Stroke Society (and continues to support us despite the fact that her mother had stroke not long ago). I have found this society to be really helpful, socially, psychologically and every other way. It has done a great deal for my morale. Yet I only found out about it accidentally by reading an article in a national magazine. When I was first in hospital with the stroke, I asked if there was such a society. I was told the only one for stroke patients in Cardiff was for people who could no longer speak. It would have done me a lot of good if I did not have to wait nearly 6 years to find it existed; hence the item on my 'Wish List' for information givers.

By now it should be obvious why I wish for proper Stroke Units, stroke specialists, and so on and so forth.

Finally on the information side; because one of my builders had injured my good leg, a friend got inspired. Her brother-in-law had been given by a friend a walker with 4 legs with wheels, brakes, a seat and a place on which one could carry things and he gave it to me. It is a great bit of equipment. You can move from the hips and I love it. I walked using it, from Rhymney Street, Cathays, to and from UHW this week having a nice rest in the old Victorian graveyard on route. I really like that place and used to walk around it often; and also did a little shopping and went to the photographic shop and posted a letter. The hospital has now agreed to transfer me to my GP for Warfarin checking. I wish I had been told about this piece of equipment before. Really it must save money in the long run because it costs so much and will result in few calls upon the NHS. Furthermore, I bet all of this exercise will improve my osteoporosis which had gone up from borderline to medium. I wrote to the consultant saying I did not want any more medication than that which I was on. I bet him that I would be improved in a year or so and this was before I got the piece of equipment. I now feel this view to be even more likely to be true. I know it will not do much for my inability to lift but that is due to my spine injuries. In any case it does help even with carrying. I have just had this piece of equipment for 4 weeks last Thursday.

I have changed my GPs, am now registered with a surgery in City Road and pharmacist at the Co-op also in City Road. I can get to them very easily with my walker. I decided to change when it came to me that the administrator in my previous surgery must have no notion about what patients may need. He or she

Seems to have taken over. When UHW stopped the provision of my Warfarin and transferred its provision to my GP, I rang the practice up to ensure they had got the letter and the prescription was available. I was told it was and that my, then, pharmacist was collecting it. When nothing happened and I was running out, I rang the pharmacist who said they did not know anything about it. Now so far this could have just been a misunderstanding and all could have been well. However when I rang my practice I was told they no longer used faxes so I would have to go and collect the prescription which was not even at the address of my part of the practice. It was at Pengam Green. Now because of my neck I cannot ride on a bus. (I have subluxed 2-3, 3-4, and the way the drivers stop and start the buses causes my neck to go out and my trigeminals and brachials also I was feeling tired a bit tired. The lady who helps me was with me, so I paid for a taxi to take her to Pengam Green and wait while she collected the prescription and then drive her to the pharmacy. Truly I think administrators need training in the needs of patients to give them precedence. The values of administrators (or some of them) seem to conflict with the public service values needed in the NHS. *

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E. C. C. C.
8.10.10*

Another thing infuriated and upset me greatly. When I was in the Geriatric Ward 7B. You form bonds with your fellow patients especially those beside you. Also you get to know them. A lady on one side of me had a really bad stroke. Now I had read the book by the French Journalist "The Butterfly in the Bell Jar", so I began to talk to her using questions that required only 'yes' or 'no' answers. I watched her eyes and head. It worked, she understood me and responded. When the curtains were closed around her one day, I heard a man (presumably a psychiatrist) asking her questions requiring more complex responses. I thought 'Oh God, they are going to warehouse her in Whitchurch or somewhere'. It was too much really and I found myself shouting to this man 'you are asking the wrong questions - you have to ask questions requiring only a 'yes' or 'no' answer'. I think he heard me and responded quite nicely. I hope he did but I have never been sure I wish I knew what happened to her. This was another reason why I got paranoid when I was sent out of the hospital so quickly. I was worried about what would happen to her if I was not around to kick up an almighty stink if she got sent to Whitchurch. She had not been sent when I left. I should have gone back and checked what happened.

MY PRESENT LIFE

Truly, it is impossible to convey to you how much better in every way I have become recently. I really think it is a scandal that it has taken six years of misery for me to reach this state. Also it is special individuals' sense of public service and their kindness and preparedness to make personal sacrifices that I am now a 'happy bunny'. The NHS as an organisation seems to be making it more difficult for them, rather than helping.

I enclose a photo showing I have completed a 'Fun Run' last Sunday. True it was only 2 kilometres and I finished last, but I collected some money for the charity

and I was given a medal. Also, today is only Thursday and I am improving all the time.

However, I wish that someone could find out what happened to "The Butterfly in the Bell Jar" lady. Six years ago at the beginning of last April, she was on Ward 7B (I think that is the name) beside me on my left side. I would be grateful if I could be told what happened to her. You need not tell me her real name, which should avoid confidentiality problems.

Oonagh Hartnett

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* Additional ~~size~~ ^{note} - ^{stated at} ~~see end of~~ ^{Para 1 P.12}

I am overgeneralizing in all directions:

No doubt, there are, at least, some administrators who are conscientious and responsive to their social responsibilities just ~~that~~ ^{as} there are medical who can be evil, stuck up and furious. One fond of money, as well as politicians who can be extremely self-advancing, self-interested & fraudulent. As for us "sweet" old ladies, we could make the hairs stand on the back of your heads if we took the fancy.

So, let us, this time, try to transcend our worse parts and do something for the poor people who are, after all, kept from what I ~~do~~ believe is the most non-frequent, humble class. Put