

Transcription of a Journal

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The Day the World Stood Still

14TH MARCH – Mothering Sunday

This is a strange reason for starting a diary. The main purpose is to give me a foil, someone to talk to, to reflect with, to learn from now that Maggie has (temporarily and partially I hope) gone.

The house is full of reminders. Her water glasses by the bedside, a notepad with Choral Society business on the living room table, cheques on the pin board, a half-finished bottle of Chianti – everything seems to suggest that if I close my eyes and wish she will walk through the door. It's now Tuesday night – the 16th. Three days ago we were in bed together. We talked about life and houses and memes (from this week's *New Scientist*) before going to sleep. That neck ache was bothering her again. I had massaged it the night before – tight right neck pain and tenderness – especially tender at the base of the right occiput. The massage had worked though and the closeness led to lovemaking – wonderful, tender lovemaking. The headache on Saturday was 'different', 'not just muscle' – but it went away.

On Sunday it was croissants for breakfast then to the computer for me to finish my first Open University assessment – to be posted on the day! Maggie & Mum went to church. Elinor slept after a 3am return from clubbing with James. No lunch in the oven to worry about as we were all off to Kathryn's for Mothering Sunday lunch.

Aileen McVey rang at 11.10 or so to say that Maggie was dizzy and unwell – she sounded worried.

When I got to the church Maggie was lying on chairs outside the service. She looked fine really, smart and jewelled and in control even if she was the patient. She had had some dizziness and felt

odd and, when it was suggested she lie down, had felt unable to stand without falling. She made it to the chairs with help.

She thought she was 'having a stroke'. I thought so too – obvious left facial weakness, tinnitus, paraesthesiae in left arm and leg – but all mild really – I thought about taking her home and calling Philippa. I guess what worried me was the nystagmus – all over the place! She had bothered to get someone to check her eyes to observe it! Even with the wacky nystagmus I was thinking cerebral stroke . . . well, not really *thinking* properly at all I guess – just worried – the nystagmus was all wrong. We walked together to the car and the heavy lean to the left was worrying too.

A trolley in A&E at Stoke Mandeville came next – in through the back door and quick attention – good too, a nurse called Viona, then the A&E SHO, the med reg – Dr Doudu . . . It was the neuro exam he did which made me think properly – cerebellar stroke: the lean, the past-pointing with the left hand, the nystagmus . . . but I still hadn't cottoned on to the facial nerve weakness on the left.

We talked a lot – long gaps in A&E! What, why, why me . . .? Maggie didn't want her head opened, neither did I, we thought about bleeds and clots and tumours – I don't think we mentioned that – just as well after Jane Wholey. The CT scan 'to exclude treatable causes' (bleed) was welcome – we had such hopes of it. No right gaze in either eye was worrying though.

A thorough explanation from a pleasant radiologist – Dr Sconge – The scan – the results, which were shown to me and explained thoroughly to Margaret – normal 'no tumour, no bleed'. We were almost euphoric – no operation needed – just a stroke, just a clot, just a moderate problem which would surely improve with time.

I'd already 'phoned my folks and 'phoned again with the results. When I got back into the cubicle with Maggie after 10 minutes, she was worse – still not really frightened I don't think. We actually talked for a couple of minutes about the problems – left hemiparesis and some slurring of speech. 'Normal in form and content though', I thought – can't be *too* bad. I told the new nurse – a shift change had occurred while we were in the CT scan. The med SHO who arrived after half an hour or so was new too – nobody had seen her before who saw her then – would it have made any difference? Probably not – don't fall ill on a Sunday!

Our talk changed. 'Will I die?' came up but only briefly. We got more worried. We wanted to go to the ward where we would be attended to and looked after and get more information but we had to wait for an hour plus for a chest X-ray. We agreed a one squeeze for 'yes', 2 squeeze for 'no', 3 squeeze for 'ask a better question' system – just in case. Maggie's speech was becoming difficult – form & content normal but articulation not good – tongue weakness, palate weakness . . . I remembered the absent gag reflex at Dr Doudu's first examination.

Then a chest X-ray and off to the ward and settled in to bed. It seemed clear at the time but 2 days on the timing is getting blurred. Other things had happened. Aspirin had been prescribed after I called for the SHO – and had been given promptly – soluble; Maggie had been able to swallow but *I* had said she hated the taste so she couldn't speak by then. I had asked for and obtained paper & pencil so she could write to me instead – quite well, if a little shakily, with her right hand. I had made a decision – no buts – to get Elisabeth home and when she was settled into bed in the ward, Elinor in attendance, I called Neil – about 6.30pm by now, and he set off for school.

Elinor made an 'ABC' board because Maggie's writing was now illegible due to tremor and incoordination. We were alone again for a while and continued by 'point and question' our serious conversation of earlier in the day. This was bad. We were both frightened and tearful and close and terrified. We made some decisions and discussed principles – Maggie led on everything.

- ◆ Elinor was to go to university.
- ◆ Elisabeth was to do her GCSEs.
- ◆ I would have the money to buy a house after all (the life insurance!) I didn't *want* to buy a house without her . . .
There were lots more and they started to crack me up . . .
- ◆ 'If I can't answer you decide.'
- ◆ 'I *don't* want to be cremated.'
- ◆ 'Where can you get buried now(adays)?' – No decision made about where. Halton would be appropriate in many ways I thought but I didn't say that. We've lived here so long. I would return to tend her grave. Friends abound in this area. Her church is here.

- ◆ ‘You need someone to look after you.’
- ◆ ‘I’m sorry’ – lots of tears after this. You don’t need to be sorry . . . I’m sorry . . . and so on. This was repeated a couple of times. We both had guilts and both cared so much. I guess we were both just deeply sad and sorry.
- ◆ ‘I wish I was generous enough to say find someone else.’ We’ve talked about our deaths many times before. This took a long time to spell out – increasing right arm weakness and past-pointing at the letterboard. I had always said – find somebody else if I go first. She had never said that but never not said it. It was a wonderful, loving thing to say and it was a *Maggie* thing to say – ‘I wish I was generous enough . . .’ from the most caring, loving, generous, jealous person I know. I love her so much.

Elinor came back about then and we ‘talked’ about other things. Right-sided coordination and weakness was getting to be a problem and death was a frighteningly real prospect it seemed. Dr Doudu came back and seemed surprised and distressed at the marked deterioration since he had last seen her. He tried to explain to us what was going on without mentioning nasty words like ‘death’ and ‘disability’ and things. I went with him to have a chat afterwards and asked if he would go back and tell Maggie herself all that was going on – warts and all – and he did, and very well indeed, carefully, considerably and accurately. He answered her ‘ABC’ questions too – the biggie was, ‘will I die?’ The answer was, ‘I don’t know’ and an explanation of the possibilities.

By the time Elisabeth arrived, and Neil, Maggie couldn’t really converse using ‘ABC’ very well. Elisabeth was shocked – the last message she had had had mentioned talking! Neil was shocked too – we walked and talked a bit. ‘Brain Stem’ was now being talked about properly – with all the ‘Brain Stem Death’ connotations I supposed.

We soon moved to ‘one for yes’, ‘two for no’ with eye movements and that was the situation when the others went home to bed. By 12.30am on the Monday Maggie was quadriplegic.

I missed a bit! For about 45 minutes before Elisabeth arrived Maggie improved – her speech returned and some *left* hand

movement. It was wonderful to hear her slurred, soft voice – it confirmed that she was still intellectually *normal*. She spoke to Elinor and to me. She had sent off her OU TMA on the Saturday – a discussion of cognitive and biologic models of health – she had come down in favour of the cognitive as providing the better description. She said, ‘I’m going to write to my tutor and revise my opinion of the importance of the cognitive perspective, without the biological perspective *nothing* works’, or words very close to that. It was still our Maggie in there. I was buoyant – she was improving already after just 12 hours, things were looking up. At 13+ hours things were grim – more despair.

11X at SMH was not impressive – a variety of nurses had bimbled in – no real idea at all if one was in charge or assigned to Maggie. No more aspirin arrived – it transpired that rectal aspirin had to be specially ordered – some while later a pharmacist was found to produce the necessary suppository. We were offered Paracetamol instead though! So when I asked if that would help reduce her clotting there was a mumbled answer about reducing temperature!! Maggie had been sweaty so I said, ‘Is she pyrexial then?’ I was assured (quick check at temperature chart here) that she had had a normal temperature last time it had been measured (some *hours* ago!). Oddly enough someone came to do ‘obs’ a few minutes later → 39°C+!! This was worrying, we had worked out ourselves that with a brain stem lesion the most likely causes of death were respiratory and temperature control problems. Fortunately Maggie got her temperature under control quite quickly.

The bed wouldn’t tilt – the mechanism was broken and every time we leant on it to pull Maggie up the bed it moved – a large label on the bed end said, ‘brakes broken’ we discovered on moving the spare sheets.

A nurse helped me lie Maggie down at about 0030–0100 when she had a coughing fit and went blue. We laid her half supine with her head sideways and she breathed well again. It was about this stage, while cleaning her mouth, that I noticed by accident really, that she had stopped gagging. So through the night she lay and breathed and I sat and watched and held her hand and sucked her out (oral suction only) when I thought she needed it. A ‘nurse’ looked in once or twice – I say ‘nurse’ because when I went to ask

for a suction machine, the two HCAs on duty said, 'could I wait for 10 minutes until staff came back from her break'! Eventually when they found the machine and reassembled it I had suction! So passed the night.

I *had* established that the staff were prepared to resuscitate Maggie – 'well no-one's said she's not for resus so I suppose we will'.

We tried some cyclizine too for the tinnitus – it didn't help at all. Delays here too though. Dr Doudu prescribed it – I went to check on it after 30 mins to be told it was IV which would have to wait for 'a nurse who'd done the IV course'. When one turned up she did the complete drug round first.

Lack of urgency, priorities, lackadaisical attitudes and general apathy had begun to get to me – and frighten me. Maggie was still comfortable when the girls came back at 0600, and was occasionally swallowing and coughing quite well so I came home to shower and change – in retrospect I think this was criminally risky – the ward staff, even the daytime staff, seemed to have very little idea of how ill Maggie was.

Susan gave me Philippa's number – she wasn't at the health centre when I called round – and she, having got over the initial shock, determined to get Maggie to a better place. I went back to SMH and started, gently, asking for information, help and so on. I managed to get a chest physio – who was super and was the first person to confirm our fears that Maggie couldn't protect her airway. The consultant pitched up too and recognised that there was a problem – he made the case for a transfer, and within 1–2 hours we had nursing staff who had woken up, an anaesthetist's assessment and a plan . . .

I *told* Maggie what would happen – no informed consent this time I'm afraid and so she was taken down to recovery for sedation, intubation, arterial line etc, and transfer to Oxford. The anaesthetist was excellent too and the ubiquitous Dr Doudu explained the options available at Oxford – thrombolysis, which Maggie and I had talked about (in ignorance of the possibility) in the car on the way to hospital.

The three of us had said 'goodbye' to Maggie on the ward – quietly and peacefully I thought – I wonder very much what she

thought about the process. Maggie made sounds in response to our 'love you', she tried so hard – fantastic effort, the first sounds for hours, and the last. We were trying so hard to be brave and optimistic and not show that we knew it might be goodbye for ever. When she was asleep and intubated we went in and were given time with her to touch her and pay 'last respects' in case it all went wrong. Then, a little over 24 hours since the stroke, we went to Oxford, Maggie in the ambulance, Elisabeth and I in one car and Elinor (via home and with Mum) in the other.

15TH MARCH PM – Day 1

Maggie arrived sedated, intubated and ventilated in mid-afternoon. She looked so peaceful, not a line, not a wrinkle, just calm and sleeping. ITU was a different world from a general ward in a DGH. Organised, competent, thorough, aware, peaceful. Sitting by Maggie I began to relax a bit as it sank in that she wouldn't die by accident anymore, the illness or the treatment might kill her but she wouldn't aspirate or choke unnoticed. Later in the day it also sank in that I didn't have to stay awake and try and be around all the time – that was a huge relief.

Maggie went for her angiography 4-ish (I think it was about then – I'd lost track of time really). Dr Burn, with Dr Hand the neurologist gave me the results – Elinor, Elisabeth and me. 'Blocked basilar artery, blocked right vertebral, diseased and narrowed left vertebral, everything else OK.' I asked about the areas supplied by the basilar where it was blocked – pons & medulla. I think up until then I'd been thinking cranial nerves and tracts. Elisabeth and I had had a long conversation about cranial nerves in the car. I guess I started to think about motor nuclei and complicated bits – my neuroanatomy was never good and I just remember pons & medulla as being a nightmarish 3D mix of all sorts of regulatory functions. I got more gloomy about prognosis when I heard that. My reckoning, confirmed by the doctors since, is that there is no predictable relationship between function and anatomy in detail in particular cases. That is: infarct will determine the maximum possible recovery state (minimum deficit) and ischaemia may recover but the areas of infarct (determined at MRI later this week hopefully) once known will still not tell us exactly

what might be achieved and the area of ischaemia, which is not currently knowable, won't help either because degree of ischaemia matters so much.

Two things came out of this discussion – a greater awareness for me that the anatomical details are of secondary importance to the function actually obtained – what you get is what you get – so time and patience are the key. And a determination to go for the thrombolysis.

Earlier, before the sedation, at SMH I had asked Maggie two questions:

- ◆ from what you have heard about the thrombolysis so far (trial, possible benefits, possible risks . . .) what do you want to do?
 - Don't know/not enough information (three movements)
- ◆ if the worst comes to the worst and you can't make the decision will you trust me to do it – to make the best decision I can?
 - Yes (one definite yes)

Elinor and Elisabeth were there too, and understood and asked questions, but I led and said 'do it' and they concurred.

The post-thrombolysis angiogram showed two patent but damaged vertebrals but no clearance of the basilar artery blockage. They were unwilling to give a bigger dose because of the risk of bleeding and/or dislodging clot/plaque/whatever from the vertebrals. So we didn't know what result we had. The ward promised that we would be kept informed of changes and they would keep Maggie sedated until we were there – so we went home to eat and talk and rest. The radiologist was very good – explained to us three about the operation and the risks and then came up to explain to all of us (Mum and Kathryn too) about the result. The ward lent us a model brain and a huge circle of Willis to make it easier.

Two days of *very* turbulent emotion: love and despair and hope and more despair sometimes following one another so fast that there was no time to think – no idea of what the feelings meant or why they were happening or what the events meant or how to react, clinically, emotionally, practically – and all the time against

a continuous intrusive background of ‘why us?’, ‘why Maggie?’, ‘we had such plans’, ‘I must cancel the holiday’, ‘has the VISA been paid?’, ‘will she die?’, ‘will I ever hear her voice again?’, ‘how will I look after the girls?’, ‘a bungalow by the sea perhaps’, ‘maybe I could work from home’, ‘can we afford to keep Elisabeth at school, Elinor at university *and* buy a house fit for Maggie *and* look after her at home if she is quadriplegic . . .

At home there was no time to reflect either – the telephone rang continuously. I got better at giving the standard briefing without crying. So many distraught, disbelieving people who love her so much – I wished I could offer them any hope.

16TH MARCH – Day 2

Despair again! I got in (me and Elisabeth) to find that they had stopped the sedation. So Maggie was awake, intubated with some ventilatory assistance and no-one knew what her eye movements meant. I got a bit mad and got a lot of profuse apologies – the message from yesterday hadn’t got across to today. Anyhow we were soon back in Yes/No conversation – we’ve speeded it up – just ‘UP’ for ‘yes’ and ‘DOWN’ for ‘no’ now – quicker and simpler; and ‘UP/DOWN/UP/DOWN’ for ‘Disagree! No!!!’ which happens occasionally.

We’ve established some baseline information. It’s easier to move eyes up than down, she has no pain, she would prefer a tracheostomy to the ET tube, sensation across face and whole body is normal, things like that. One of the nurses suggested we write them down for the information of all, so we did.

Dr Hand gave us all (M included) a good briefing on the situation – the cause was vertebral artery dissection – in retrospect the severe right occipital headache which Maggie had had on Saturday night while we were in bed. It happens to some people for some, usually unknown reason – basilar artery embolism is the result. Would earlier transfer from SMH have helped? No – they wouldn’t have attempted lysis if the vertebral bleed had been that recent.

So: the plan is sit and wait – what you get is what you get. The tracheostomy can’t be done until the heparin is stopped – another balance to be struck – maybe tomorrow.

TRANSCRIPTION OF A JOURNAL

We have started informal 'shifts'. Two cars and the help of friends makes that possible. So Elinor can go shopping and come in a bit late. Moira brought mum across after lunch and, after persuasion, came up to see Maggie – I had already asked Maggie and gained her agreement.

She *does* show emotion when friends visit or when we touch on emotive matters. Her eyes do become moist though she doesn't seem able to physically cry – which nerve is that? I asked if she could cry 'in her head' and she said, 'no'. That is terrifying – to be filled with love and despair and not be able to cry.

I went up to work to speak to Sandra before going in to the hospital – she is fielding lots of calls and needs to be in the picture. She was a few minutes late so I got to sit in the car, quietly with the window open and the sun streaming in and the birds singing and the breeze blowing and for the first time I couldn't stop the pain from welling up. I cried until it hurt and wailed and wailed and finally was able to blub the truth – 'I want Maggie back – I want you back – I want you back'. It helped. It terrifies me that, with nothing *but* solitude Maggie must feel like that all the time and she can't cry. I wish I could be with her. I wish I could be inside her head and feeling her fear and frustration and sharing it and taking it away and easing her anguish. My poor brave love.

I 'discussed' (yes/no style) with Maggie the problem of us going away to sleep and of advocacy. I'm still concerned, even with the wonderful nursing care, that someone will do a procedure or say something and hurt her or ignore her etc without realising that she is conscious and can feel everything. We spoke to the sister (Ann?) who was very understanding about it and liked our 'notice' saying 'I am conscious', 'I can hear and want to understand' and so on and said she would not only display it but have it formalised and printed and so on, so that everyone would get the message.

This was the sister who was the first in this whole business to ask Maggie what she would like to be called.

'Do you prefer to be called Margaret?'

'No!'

'So do you prefer to be called Maggie?'

'No!'

Pause – I suggested she try 'Mrs Cromarty'

‘Do you prefer to be called Mrs Cromarty?’

‘Yes!’

I think this was the first time they had realised Maggie was really cerebrally intact *and* had a personality *and* had a sense of humour *and* could enforce her views. The organisation on the ward is such that everyone since has called her ‘Mrs Cromarty’!

We split the last few hours. Elinor & Elisabeth left an hour early to go home and cook and I left at eight. That meant that we all sat down together to eat a proper (stir-fry) meal and talk over the day and plan for tomorrow. (Morse code day – I reckon we can aim reasonably at getting at least one word out of Maggie which is her own and not a guessed yes/no question which may be of no importance to her.)

I managed to speak to Steve in the evening and had a pleasant chat, much needed.

How does Maggie feel not being able to chat at all – talking was always so important to her and she never had my love of solitude. It’s just not fair.

17TH MARCH – Day 3

Not a bad day but some problems.

Elinor & Elisabeth were going in first so that Elinor could talk to Maggie about her university fees application and other things. She was then taking mum for a change of clothes at Tenbury. I was going in after them at 1030–1100ish.

Once alone I couldn’t bear it, I felt I was failing Maggie. As a result I arrived shortly after the others, before E&E had gone in, I took over, went in with Elinor, hogged the conversation and all the good topics – cards, flowers . . .

I cut Elinor out and left Maggie so tired that Elinor never really got a conversation all day. I *must* moderate my behaviour and consider others more (including Maggie). We *each* need some quality ‘awake’ time alone with mum/Maggie. We discussed this later – it will happen from tomorrow!

We tried to begin some routines. We started the day with mail and cards. We opened Maggie’s first card in front of her and read it out. Delightfully, she could read the ‘Get Well’ on the front – another bonus. I told her about an RAC loan offer

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and a new bank card which I had binned and filed for later use respectively. Later we discussed this over dinner – we won't do that again – *all* Maggie's mail will be taken in and opened in front of, and discussed with, Maggie – *she* can decide to bin junk mail. Autonomy rules OK!

The big success of the day was the revised communication system. I was practising Morse code with my eyes in the car on the way in and found it bloody difficult! So instead we went for an 'ABCD' system with us calling the alphabet and Maggie opening her eyes on the correct letter. It worked brilliantly and it was so nice to hear Maggie's 'voice' and to be able to talk to her *knowing* that we were addressing *her* needs. The first three questions showed the complete intactness of her intellect as well as common sense, compassion and humour – *certainly* Maggie.

'Am I going to die?'

'What can I do to help?'

'Can I snooze?'

Mum C didn't come in this evening (as expected – not emotionally up to it I think) but Neil, Jane and Dad all visited for a few minutes. I am so glad they came and that Maggie would see them despite her gross tiredness. In the middle of that Jackie Petrie arrived ('popped up' from Bournemouth – a likely story!). It was wonderful to see and hear her and Maggie (*indecipherable*) becoming quite emotive. Jackie said a nice prayer for her.

Initially Maggie didn't want people to see her like this, 'initially' being the first day – at Stoke Mandeville. She said 'no' to the padre but has since said 'yes' to family, Moira, Jackie and (though they haven't visited yet) Deb and Jane Pick. This is good I think; I have pushed the idea with Maggie and others that people *must* see her like this if they are to accept, in months to come, that her resulting disability is an improvement and not a deficiency. I want people to view her positively as 'much better, what an achievement', 'how wonderful', not negatively as 'disabled' and 'how dreadful'.

We returned to the tracheostomy question later. The duty anaesthetist gave us a brief about how, when and why it would be done and then I asked Maggie if she had any questions.

'Yes'.

We asked a couple of, 'Is it . . .?' questions and got, 'No' for an answer so the anaesthetist went through the whole thing again – any questions, 'Yes'. I said we'd ask Maggie about it in slow time, so we did.

The answer, when Maggie spelt it out was, 'I have already got one' – so that's a bit of a disconnect there! Just shows how difficult communication is – we must be *very* careful to check and check and check – to think we had understood and take actions based upon that would be as bad as, or worse than, not knowing what Maggie wanted at all.

So today's low points?

- ◆ Excluding Elinor – for my own motives really. This will be a long job and I shouldn't be irritating other members of the family team so early on.

And high points?

- ◆ *Communication!!* Hearing Maggie's 'voice' again was simply wonderful.
- ◆ Jackie Petrie's visit – I loved the way she just instantly recognised Maggie as a person and treated her as such.

I cooked this evening. Tagliatelle carbonara – bacon was a bit overdone but it all got eaten so it can't have been bad!

Dr Byrne showed me the angios today. No basilar artery from its base to just below the superior cerebellars (so a few mm from death I guess if those had been occluded) – small mercies . . . Grossly distorted and narrowed vertebrals and normal everywhere else. Why? – no idea – he's never seen such grossly affected vertebrals with such normal circulation elsewhere so: unpredictable and just one of those things . . .

MRI at the weekend perhaps, which will show infarct. I'm not sure I want to know the result of that. It won't alter treatment and won't easily predict final function. It might give us a 'best possible' indication but so what. Take one day at a time, wait and see what we get and hope, hope, hope (but not unrealistically!) is the best bet I reckon.

18TH MARCH – Day 4

I wondered, driving in to hospital today, about my priorities. The girls had gone in for 10 while I went in to work to sort my claims (£300 we need!) and gone to the building society about the TESSA – 2 more weeks to spare – no rush. Because Maggie had it on her priority list perhaps? – but really because I've lost a bit of perspective I think. We are all rushing around *doing* things without really reflecting on the purpose or meaning of our actions. Calm down a bit boy, think and get your priorities right: 1 Maggie; 2 the 'team'.

Sandra has gone up to run her nephew's funeral, poor lass she has had such a time of things lately. It's not just us who have troubles. But it's Maggie's troubles that outdo everything else. I feel so desperately sorry for her. Such goodness, such hope for the future – all dashed. Then I think of what we have had – I'm so glad we went to Paris a few weeks ago, and so sad we won't ever do that again. That's been the day really, gladness and despair in equal measure with wild swings between the two. Euphoria almost, that we have hope for the future and despair that we haven't. Odd.

Maggie was pretty stable all day. Much more tired than hitherto but sleeping – seemingly genuine sleep – rather than just dozing for minutes here and there. She looks so peaceful when asleep. Philippa came at lunchtime – lovely to see her. She has worked wonders so far and will do so again I know when Maggie is home. Her support, and the local medical support makes me wonder if we should live around here – I doubt that we could afford to though. She gave us 'The Diving Bell and the Butterfly' which I had been meaning to read. I read Maggie the first three chapters but I think that it didn't help. Last week I would have been fascinated and impressed I think. This week it all sounded too journalistic. Maggie could write a better book about the practical and emotional issues and the realities without such extensive reference to previous stories (pre-stroke stories). Nevertheless I'll probably contact ELIS – they must have useful information.

The speech therapist came too. She seemed impressed by what we had already achieved and couldn't add much except to suggest a topic diary to speed things up. I tried to get one discussed and

drafted at dinner but caused a bit of a stir as the other three had different agenda – me railroading again. I backed off and the situation seemed to be defused alright. Nevertheless there are some tensions building between Elinor and mum – over driving too fast, washing clothes too often, general criticism, misunderstandings . . . We are all tense and have too little time and space to defuse things – must do what I can – mix us up a bit for travelling probably to start with. I will take mum in early tomorrow. Mick, Jane and Maureen are coming down I think.

The girls and I had a ‘mum’ type chat before bed though – in our room. That helped us three anyway. Mum won’t go to bed until we have gone and is always up first so there’s very little opportunity for the girls and I to talk. I mustn’t ignore their need to chat though.

Kathryn and June visited and came back for a coffee this evening. I dropped in and gave the Choral Society a 1-minute history – what happened, current situation, well looked-after, uncertain future. No crying – I’ve done it so many times now it’s almost automatic! They all seemed very moved and very grateful. Interesting how few associated consciousness and paralysis though – most were very surprised to hear that Maggie was fully ‘with it’ – ‘send three and fourpence . . .’

The benefits of one day at a time are that you don’t look too far forward – considering all the potential possibilities drives you mad. But you also don’t look too far back – what was was, what is is, what will be will be. It’s a recipe for survival but again means that I don’t reflect very much perhaps.

Jane and Mum were round first thing. Mum and I sat with Maggie for 30 minutes or so. Maggie was asleep for most of it and mum was OK, tearful occasionally but OK as long as we stuck to the practicalities and not feelings. Jane was very impressed with the talking by ABC, she helped to write the messages and suddenly realised this was *Maggie* talking – it transformed her view of the whole business. Very well worthwhile.

Finally, back at home this evening Bill Phillips called – as my GP. *Very* keen that I get myself a civilian doctor whom I trust to look after my interests. An interesting thought which I had not considered but he’s right of course. I will approach Philippa.

Maggie's bedtime words were, 'I WANT YOU'. I want her too, so much, so very, very much. Time and patience and loyalty and we'll see.

19TH MARCH – Day 5

I had planned to phone the 'second-rank' people in the phone book at the weekend – friends but not those whom we saw regularly, those overseas, that sort of thing – second-rank not second-rate! That would be one week in, things should be stable and I would have something hopefully optimistic to say. Then, while talking to Elinor yesterday I realised that I was looking wrongly at things. I had thought that the weekend would provide a bit of time in which to do things, catch up, do the telephoning, perhaps even sit and think or prick out some seedlings. But that's not right. We don't have weekends any more, nor does Maggie. Every day will be the same for her and for me. She can *never* have a break from her body – we can get respite by sharing and even by such things as walking to the car rather than parking close by but Maggie is stuck. I have decided to mark the weekends nevertheless by not wearing a tie – a symbol will be as important as any other way of signalling that one day is *not* just like the one before and the one after. We will all try to have a 'Sunday lunch' equivalent too – that might actually be a two course meal at 10pm on Sunday but it will still count. For the next few weeks we might arrange for one of the many willing volunteers to provide it. How will we break up the week for Maggie – different NG feeds won't help much. Perhaps the general reduction in ancillary staff (OT, ST, etc) will signify the weekend – if so will the weekend be relaxing, or boring, something to anticipate or something to dread? I think I will take a walk round the garden with her on Saturdays!

Today was trachy day. Mick, Jane and Maureen came first thing and spent a couple of hours so a busy and tiring morning for Maggie with lots of eye movements needed while dopey. I don't want her to feel that she is being used as a sideshow and Mum B is worried that she might feel that these are visits to pay last respects. We will talk about this – perhaps tomorrow. Maybe going down to family only for a week or two would be best – *Maggie* should

chose. Anyhow the trachy op went well. The ETT is out, and already Maggie's tongue seems less swollen and her salivation is much reduced – no dribbles all afternoon! Her face looks a little puffy, from lying down I suppose, but if I put my head on the pillow beside hers she looks just like she does after a night's sleep. Peaceful, a bit tousled, *lovely*. The OTs made an 'instant' splint for the arm without the arterial line too – to prevent contractures, and will make another for Maggie's right arm when the line is removed (soon I hope!). The speech therapists visited again to talk about topic books and showed us a Guillain-Barré Society example – we will think about it again over the weekend and try to develop a personal one for Maggie. The aim is always the maximum amount of information with the smallest number of eye movements. We changed the eye movement business too. Eye movements seemed (and Maggie says *are*) quite laborious – eyelid movements seem more fluent and expressive so we have shifted to those.

'The day the world stood still' seemed a good title for this journal. That's the way it felt last Sunday – like the world had hit an iceberg. I wonder if that's how it feels for Maggie? I wish the world *would* stop, everything just go on hold while we and those around us and Maggie worked and waited for recovery then, at some stage, we would press the 'Play' button and carry on with our lives together. Unfortunately while ITU *does* seem like a world apart: tranquil and ordered and steadily progressive, the world outside which we drive and walk through each morning and evening, is rushing on headlong. Newspapers arrive filled with trivia and disaster, TVs flicker in house windows, traffic streams, people chatter and plan – there's no stopping it. This afternoon particularly, even the quiet and controlled ITU staff were buzzing and nodding and chattering with pre-weekend euphoria. We sit as Maggie breathes slowly and steadily and quietly away the minutes of her ruined life. Will she ever catch up with the world again?

For three days now, since the last time I had a bout of uncontrollable sobbing and wailing (alone in the car in the early morning mist in a lay-by), I have had a persistent nagging pain immediately behind my left breast. It's not really noticeable if I'm talking with others or

doing. But when I'm quiet, sitting just holding Maggie's hand, or sitting as now in the visitor's rest room on ITU, or worst of all, in bed before I sleep, it nags insistently. Moving my arm or breathing deeply doesn't seem to alter it. I wonder if it's heartache.

[Later thought: indicator of increased general muscle tension showing first in the non-dominant arm/chest??]

I argued (briefly) with one of the anaesthetists today (Dr Downs). He had come to give me the third pre-tracheostomy briefing. I asked him to give it to Maggie and he willingly did, moving round to put his face in front of hers. Then he showed me the 'no need for consent for a procedure which needs doing' consent form – for unconscious patients who could not provide consent. I pointed out, rather pointedly, that Maggie was fully conscious and quite capable of consenting and had, indeed, done so in front of several witnesses (eyes 'up' the day – or was it 2 days – before).

'Ah, but she can't sign the form . . .'

I bashed on a bit about informed consent, dropping in (stupidly and rather rudely) that I was a member of an ethics committee that had been considering this subject only last week. He did the procedure anyway – and rightly so for Maggie *had* consented.

I approached him later and apologised for my rudeness and explained that I had had *exactly* the same response from the building society the day before over transferring money from Maggie's account to the new TESSA. How could my wife – who was conscious but completely paralysed – arrange for cash to be transferred. I did *not* want power of attorney which I felt would reduce her autonomy. They referred the question to head office.

Consent is consent. A signature is a signature. How did we get so muddled that the latter not only implies the former but is *necessary* to confirm it? This cannot be right. I hope that the doctors will consider their form more carefully henceforth – there seems to be a distressing degree of confusion, even among *very* highly competent ITU consultants, between paralysis and consciousness. If Maggie had been able to move her right hand would they have adopted the same procedure?

This is a topic ripe for a letter to the *BMJ* or perhaps better a thoughtful article for the *Journal of Medical Ethics*. I must ask

TRANSCRIPTION OF A JOURNAL

Maggie if I took the right attitude. I must also resist the tendency to gallop away on my high horse so readily!

The Meaning of Death

Maggie's questions about death:

'Am I going to die?'

'Everyone I see wants it – for me to die'

were not unreasonable in the circumstances. The first was entirely expected although it still cracked me up. The second worried me more. *We* desperately don't want her to die. I thought perhaps she was reading into people's expressions that they wanted her to die – or rather their voices. 'Voices' is a problem – people don't know what to say and when faced with no encouraging non-verbal clues they dry up even if they have thought of something. Tone of voice is a problem too – it's so easy to burst into tears unless talking about something completely bland and even then you can catch yourself out. I checked on expression – Maggie can see and recognise faces, I asked her, and so gross expressions she must be able to see too. Is it the look of people – startled, sad, grieving? I will check on this tomorrow if I can and try to reduce the problem by briefing new visitors beforehand. I've noticed they need a debrief afterwards sometimes too.

Anyhow, the question surfaced. What *sort* of death is the problem. After David Armstrong's forceful argument that death is a social construct I started to think differently about death. Maggie too had begun to think differently I know from her sociology and psychology study. Although, as I know from her comments shortly before she went 'under', she was revising her views of the importance of biology over cognition.

I broached the subject quite bluntly (perhaps too bluntly) at our evening chat. She is not biologically dead but she does seem

socially dead. Her body seems more like a coffin than anything else. It houses her remains and, were it not for her eye movements, we would have only memories to remember her by. Our talk out of her hearing, and perhaps (careless as we are of the feelings of the 'dead') in her hearing, has had morbid tones and content. 'She was . . .', reminiscing about times past, thinking not about what will be or may be but about what might have been. There is some explanation here for people's shocked expressions, their long pauses, their inability to communicate with a 'corpse'. Some people are not fooled as easily. Close family, who watched her body deteriorate while seeing her mind remain intact throughout, are convinced. Jackie Petrie was remarkable for her instant recognition of Maggie the person. Some other friends have taken minutes (or perhaps longer) to recognise that Maggie is alive, and not just alive but still *Maggie*. When the realisation comes it comes forcefully – almost as a revelation. Jane (Cromarty) felt it I am sure when she 'heard' Maggie (via alphabet and eye movements) ask to hear her news. Maureen Thorpe too. But to the rest of the world what is Maggie now? 'On hold' I hope; not dead, just suspended until she can be with them again. We must do all we can to keep her sane so that, when she can communicate with the world again – in normal 'social' life – she is recognisably Maggie. She will be different after her imprisonment I am sure. How should we help her? Just love, and advocacy, and care and hope (and prayer too, many would say). She will not die physically I feel – we *must* make sure that she doesn't die socially either. If the sociologists are right it will be just as important.

20TH MARCH – Day 6

Yesterday's trachy has been a great success. Maggie looks and feels better. She also has a fine bore NG tube instead of the Ryle's tube. She is still being given ventilatory support, PEEP only I think and 30% oxygen, but she is basically self-ventilating (this evening). All the 'successes' are wonderful both in lifting the veil of impending physical death and in improving her social appearance – I think people will relate to her and talk to her more easily now that her face looks normal, albeit without expression. There are other little hints of the future too – swallowing (involuntary only) started this

morning and has become steadily more fluent throughout the day, so her dribbles are much reduced – more comfortable and more socially acceptable of course.

Mum B is giving us a break today (her words) – we have all become a little irritable at home and have come across interesting new problems; in particular the pile of clothes. She has washed and ironed so much that there are no clothes in the system and we have run out of drawer space! Maggie's clothes especially are in piles on the bedroom chair! Elinor is a bit grumpy about it. Mum moans if she finds non-machine-washable clothes, and washes them anyway. She irons well and folds badly so that shirts are creased etc. Elinor plans to re-iron some things secretly tonight. However, all things considered we are getting on pretty well. I think mum has got the idea that Maggie will live now although our open family discussions about the possibility of death, organ donation, disability and the like are foreign to her. It must be deeply distressing for her to have lost a husband and have faced losing a daughter – although perhaps having a very disabled daughter will be like a loss for her. Will she want to resume a more parental role? Come to think of it how will Maggie and I get on if I am 'carer' as well as husband. I must make sure that I don't become too paternal. In my mind we are still *we* and still equal. I feel strongly that we must remain so for our new relationship to run smoothly – our old relationship had that at its core.

The highlight of the day though was the unexpected visit of Dr Derick Wade, Director of Rivermead – the Stroke Rehabilitation Centre. The first doctor or nurse to address Maggie first, then come and talk to us. His history-taking concentrated on her, what *she* was like, what she loved and did. We all said our bit – *all* including Jackie Hobday at that stage. Our assessment of the likely future – a spectrum between the current state and moderate disability, with severe disability likely, he felt was about right although unduly pessimistic at the lower end! He told us stories of previous patients who had been locked-in (nice to meet someone who has met the problem before at last) – all pretty optimistic (if mobile in a wheelchair under self-control but quadriplegic can be considered optimistic), but he realistically would expect speech within 2 years as a minimum – perhaps more and probably earlier.

Maggie feels more hopeful – she started swallowing today – awkwardly at first but more fluently by the evening. All reflex – nothing voluntary – but hopeful nonetheless.

The heartache seems to have gone.

Phil Hobday has lit a candle and intends to keep it lit. (Jackie has visions of it falling over and burning down her lovely new kitchen but I think it will stay lit whatever.)

I stood behind Maggie when Jackie first saw her and there was a flash of horror/surprise . . . Involuntary I feel sure although Jackie was (*fell asleep at this point . . .*).

21ST MARCH – Day 7

Well, if yesterday was swallowing day, today was spasm day. Maggie can cough now, quite well (and ‘chew’ when she has lots of saliva, and yawn impressively and sigh deeply – I know that that is involuntary but it sounds so heartfelt and meaningful nonetheless). However, each coughing bout provokes quite intense spasm (extensor at elbows and wrists, flexor of hands) and her left shoulder rises to her ear and stays there. She has flexor spasm of both legs too (dorsiflexion at ankles – withdrawal), and plantars go up. More awkwardly she turns her head – no she doesn’t – her head turns to the left whether she likes it or not which can cramp her breathing and swallowing.

We tend to think of all movement as voluntary; involuntary tics and twitches irritate and disturb us – spasticity and spasms which are obvious disturb us even more when seen in others – yawns are acceptable. Are sighs? Swallowing is normal and coughs – they occur voluntarily as well. So I say, ‘she moved her head’. But *she* didn’t – her body and a working bit of brain moved it – just an automatic maintenance mechanism – nothing voluntary, nothing conscious. Usual language does not adequately allow the nuances of expression which I need. I feel it important to be able to discriminate between what *Maggie* is doing and what her body is doing. Otherwise I will find myself taking involuntary movement to be evidence of consciousness and will, when it isn’t. The yawns

and sighs seem so normal and meaningful though that I might indulge myself with those.

To the Law's tonight for Sunday tea at about 10pm. A nice meal, pleasant, understanding conversation and to bed before midnight. What a week.

Problem is – we are getting in to the routine. We are discussing and making meaning of our situation. Maggie is included in our thoughts but is not personally influencing them much and she is not benefiting from any of the normalising effect of chatting, eating, socialising, which were such a central part of her life. I *must* remind myself continuously that *she* is the centre of this particular storm – otherwise there is a risk that I will simply pay attention to the storm and her. The time must be interminable for her, and the lack of banter and conversation like losing a leg – only she has lost legs, arms and everything as well as the ability to communicate verbally and non-verbally.

Communication is the key – we need to enable her to 'talk' as she wishes.

A worrying rash appeared today. Maggie had had her left arm splint on for about 6 hours or so. She had also had a bit of pyrexia, tachycardia and a rising glucose (sliding scale of insulin started). Probably just cellulitis from the arterial line puncture – I told the nurses about the *E. multiforme* though. We shall see tomorrow what's what.

22ND MARCH – Day 8

Oh dear. First communication this morning I initiated on the topic – 'How can we help you to communicate better'. Maggie said she wanted to speak (i.e. initiate 'speech') – she couldn't even ask for a bedpan. She had finally (and not surprisingly after a week of lactulose and senna) produced diarrhoea, had been aware of the need to go but, with coughing, had gone without being able to tell anyone. We discussed this with Melida who said she would ask about this regularly so that Maggie could 'yes/no' but I don't think that will be enough. Defaecation is presumably under 'body' control not 'mind' control so while Maggie might

be aware enough of what's happening to tell someone at the time I don't believe that she could hold on for an hour! The need for a call switch is even more urgent. Tomorrow could be the day for the technician I gather.

Everyone is good here but overall coordination of care seems lacking. Doctors (neurologists & anaesthetists), nurses, physios etc all talk and transfer their information but they don't really confer. So a coordinated plan of care doesn't seem to exist. Surely diarrhoea was predictable with no fibre for a week plus regular NG feeds/water/senna but the effect it has on nurse workload, Maggie's discomfort, distress and fatigue and, therefore, her ability to communicate, and therefore her ability to participate properly in her care . . . is amazing.

I got *very* grumpy this evening – again over lack of communication. The girls were kicked out for 10 minutes while the nurses checked for BO and tidied up. An hour later we rang the bell for ITU – no answer. Ten minutes later (as briefed) we rang again – no answer but Dr Schluman came out on his way home and stopped for a chat, ‘. . . good about the move to HDU isn't it?’

‘What move to HDU?’ says I.

‘Er . . . didn't you know?’ says he, ‘they are moving your wife now’.

I had had a look at HDU earlier and knew that a move within 24 hours was planned but I had wanted very much to tell Maggie about it all first. The nurses do talk but they do so quietly and quickly, and they use abbreviations and jargon and assume a degree of knowledge which Maggie, being unable to look around, may not have. I think I explain things more completely and I *know* that I check more thoroughly and patiently for understanding. Conversation is a two-way process.

Anyhow, after I rang the HDU bell and asked what was up, I got a ‘3 or 4 minutes just to connect the monitors’. Thirty-five minutes later a nurse (Ruth) came out to tell us about the delay (BO again) and I bit her head off. Oops. I apologised later and I think that all was squared away but I must be careful not to become aggressive if that may risk others' care of Maggie. Nevertheless I *must* be a

firm advocate for her needs and keep reminding everyone of the need to communicate.

Made a picture of Maggie – a couple plus some words – to put over her bed to remind everyone to treat her like a person.

23RD MARCH – Day 9

Setback day. Not so much setback as no progress I suppose but the girls and I certainly felt subdued and tearful this evening.

Maggie was very tired this morning – up all night with diarrhoea and frequent turns and bed changes – so much for peace and quiet of HDU! Communication was very sluggish and prone to errors, which made it slow and frustrating for us all. Maggie seemed to have great difficulty moving her eyes but, when she did, she still showed full cognitive abilities – no confusion or anything.

Deb & Jerry came – lovely, if tragic, to see them. Deb saw Maggie and was ebullient and chatty and just *normal*. I feel sure that Maggie will have loved her visit – there was the odd tear.

This afternoon was the return trip to the ward. I can't think that I have seen anyone more highly dependent than Maggie this week, but it was decided that she was ripe for transfer to the ward. There were odd glances and I was a bit upset but was appropriately reassured that the wards at RI were staffed much better and much more fully than those at SMH. It was so – but a night-time contingent of three nurses can't look after 23 patients, one or two of whom were highly demanding, and Maggie – more stable and less medically worrying but still totally paralysed with a catheter, a triple femoral vein line (line + heparin + insulin), plus NG feeds, plus hourly nebulisers and sucks, plus a tracheostomy, plus splints ×4, regular physio and a worrying arm cellulitis which may or may not have been the cause of a pyrexia/tachycardia!

We three were washing Maggie when, on a roll to the right, she had a coughing fit – just as in the morning. She went blue so we rolled her back and sat her up a bit. I sucked out some gunky, mucoid discharge and went to get a nebuliser from the nurse. That was set too high and ran out quickly. Maggie continued to cough and went blue again much to Elisabeth's distress. However, as in the morning, it settled with nebulisation and, by the time

the SHO arrived she was much better with her obvious *expiratory* stridor settling (it had been *inspiratory* earlier). The SHO looked in her eyes during this, the nurses took temperature and BP, and I got grumpy, asking for more oxygen, a 'T' tube and speculating openly about the availability of a bag!

Transfer back to the MDU and calm tranquillity left us all (Maggie included I think) feeling that we could relax again. I must watch out for getting medically involved but when a nurse is repeating 'she's dropped her SATS' rather than 'she's gone blue and has an expiratory stridor', I despair. And as to why Maggie had a temp, BP, pulse and pupillary reactions measured but no-one listened to her chest I don't know. Is it my age that makes me look at people rather than instruments or is it the fact that I'm a GP?

Gosh – huge rush of *déjà vu* over that episode all of a sudden – perhaps I have been there before.

Still, one day at a time – there will be some setbacks, let's hope that they are all as minor as this one.

24TH MARCH – Day 10

We arrived today to peace and calm, Cathy Scallon on duty, Maggie clean (and hair washed), with it and communicating, nebulisers running and coughing minimal, temperature reasonable, wrist infection improving. The girls (who were in for the first 2 hours) opened 2 days' worth of mail and chatted away and were quite manic. Our moods mirror the activities of the day – in particular the degree of communication with Maggie. If she's well, 'talking' lots and her statements or questions are optimistic or personal we are buoyant. If she is communicating well and her questions are troubling or her mood (as far as we can discern it) is sombre then we are low and subdued. If, as yesterday, communication has broken down through fatigue, illness or whatever then we are anxious, we bicker and question and we become dysfunctional.

I assume (massive assumption I know) that Maggie feels the same, in that loss of communication is overwhelmingly the most disturbing thing that can happen. Worse than the coughing, the apnoea, the spasm – *anything* physical. Communication is everything we have and everything we hope for.

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List of people to thank personally – not for the care they have given but for the manner in which they have given it.

- ◆ Ann Suttill and Melinda (?) – ITU
- ◆ Cathy Scallon – HDU
- ◆ Dr Peter Hand – Neuro
- ◆ Dr ? Shlugman – Anaes

Must ask Maggie and the girls to confirm/add to/delete from this list . . . What about the night staff? Ask Maggie I guess!

War in Kosovo looks imminent. The Serbs have been pushing forward for 24 hours plus, gaining as much good ground as they can I guess. We (NATO) will attack tonight it seems. It all seems rather unreal partly because I've missed the recent build-up. However, it was the only topic being discussed when the radio woke me this morning. It was only after I had listened for a few seconds that I realised Maggie had been talking to me. We had been having a discussion about recent events, how she felt while locked-in, how much she wanted to say . . . The news had driven the dream away and, although I lay still and tried, I couldn't get it back – just the memory of her voice remained. The first time I have heard it in a week. The heartache is back I notice.

Rising and falling
Peaceful, rest
Rattle of humidifier
Pink, relaxed, asleep

26TH MARCH – Day 12

Nothing yesterday – a 'stable' day with few plusses or minuses but little time to talk or think. Mum & Dad, and Jane and Moira and the four of us plus new staff, Andrew? Less aware and less willing or able to tend to the details of comfort and care. Then over to Neil's for supper. Lovely, if poignant, to see Billy and Freya so active and so full of life and hope. The bombing of Kosovo and Serbia began.

I came in early to see the neurologists really, and the ‘tilt table’ physio. Peter Hand, given the gentlest of nudges, spoke to Maggie and me about the future. I raised the topic of, ‘where is the much-hoped for initial improvement then – resolution of oedema and all that . . .’. He agreed that there had been none really and that, while there might still be a little, it looked increasingly as if any physical improvement would be long-term, small and slow. This was depressing news but predictable – I had been thinking on these lines for a couple of days as Maggie confirmed she had, and we were both concerned that the kids would soon start asking what was what. PH offered to (and later in the day did) speak personally to mum and the girls about this. Maggie felt it was best that such news should come from him rather than always through me.

He also raised the ‘death’ question again. He confirmed that the early risks had gone but that risks of serious illness were still present – aspiration pneumonia, PE, further stroke etc – in which case did Maggie want to be resuscitated. We discussed this for an hour and a half. Maggie’s comment ‘I think of Wilma and I think of me’ I didn’t understand. (Wilma is in the Ladies’ Fellowship – I have almost certainly heard all about her and in my typically selfish fashion have ignored or forgotten it all – I said I would check with Sue Edgar so that I understood her comment better!)

The basic decisions, confirmed twice using positive and negative responses, are:

- ◆ ‘Do you want to live?’ – ‘YES’.
- ◆ ‘Do you want to be resuscitated if you develop a life-threatening illness?’ – ‘NO’.

We also talked about her inability, given her total dependency on others, to take her own life or alter, in any way, the course of her own life. She would like to make a living will – *strong* yes! I will investigate.

We talked too about hope and practicalities. I see homecoming as very important and so does she. We agree entirely that the aim is for us to be *together at home*. That is the main social aim. I had never even considered nursing homes until PH mentioned them and I know that Maggie will be best cared for, *really* cared for, by us. Care is not just medical and nursing care. In fact, while both

(especially the latter) are important if Maggie is going to be stuck like this, her mental health is even more important. Not much point in going mad or suffering terminal boredom when the only bit left working properly is your mind.

Not surprisingly Maggie is depressed! I don't know how reliable the diagnostic criteria are in this situation where 'hopelessness' would seem to be quite a reasonable emotion but she has the lack of self-worth etc too. She *feels* depressed and would *certainly* like an antidepressant. I discussed this with the neurologists who will prescribe some paroxetine.

27TH MARCH – Day 13

7pm on a peaceful and sunny Saturday. Maggie lies asleep, sighing and yawning occasionally, the humidifier rattles and hisses, the heparin pump flashes quietly. A generally 'normal' day. Breathing much easier now, nebulisers work well, suction only needed once or twice while we are here, not hourly as before. We had a little experiment (using Elinor) with ECG leads attached to her temples – excellent response with lateral eye movements – tiny bumps barely above the ambient noise level with vertical eye movements. So no help really as a signalling device. I really want her to be able to call a nurse when she is on the ward. The nurses here will get the Mary Marlborough Centre on the phone again tomorrow. Maggie too would be happier on the ward if she could call. There *must* be a simple way of eyelid signalling – it only needs an on/off switch and her eyeball and eyelid movements are superb – especially the right.

She had the patch off this afternoon – she still has diplopia but it seems better she says and I certainly think that she looks straight at me with *both* eyes – the left had been looking over my right shoulder previously I felt. In the mid-afternoon, on testing, I thought that there was a tiny amount of left lateral movement of the left eye. Perhaps there is actually a tiny amount of right (nasal) movement in reality and she automatically uses it to conjugate her gaze. I should have asked if the diplopia worsens on left gaze!

As I was writing the first paragraph of this Maggie began 'chewing' again – usually this precedes a swallow or indicates that she has a lot of saliva. I sucked her mouth out at her request and

noticed some lateral movement of her head – there had been a little earlier in the day but left head-turning is always a feature of spasms with coughing/yawning etc. This time it seemed more deliberate though and Maggie thought so too.

After several tests we agreed. She can move, about half a centimetre, her head to the left, while lying at about 30° – it falls back to the right but there is no powered movement to the right. My heart leapt – really – bump . . . bump . . . bump . . . – we smiled (she was smiling inside too!). Just what everyone needed – a glimmer of hope.

28TH MARCH – Day 14

Arrived to find Maggie looking well and ‘helloing’ with her eyes. Her bottom lip looked swollen though and her tongue was sticking out about 1cm. She was tight around both shoulders and neck and had marked masseteric spasm. The nurse said it had been ‘happening a lot’, but continued doing BP, glucose etc. It took 30 seconds to gently push her tongue back into her mouth using the handle of a mouth swab (that was the nurse’s idea let’s be fair). There was a little ‘click’ as her teeth closed and her tongue popped back into her mouth. She had been in considerable pain and had not been able to sleep because of it. *This* is why I am so worried about the ward and why she must be able to call, and why she must come home so that we can care for her in a proper manner.

Sue & Terry came this morning (their wedding anniversary). *Both* confirm my feeling that Maggie looks much better – watching her almost minute-by-minute it is difficult to be sure that things are changing. They agree that her facial tone is much greater – especially on the right, and that both eyes seem more active and better coordinated. We are working on the principle that all movement is good movement, all tone is good tone. Distinct spasm contradicts the latter rule and she is certainly tighter around the shoulders than for some days – but a regular stretch helps enormously and seems to ease off the jaw tension as well.

The chap in the other bed (Talkalot Bear’s husband) is sitting up in a chair, eating his lunch, listening to ‘Just a Minute’, and most

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irritating of all, periodically adjusting the volume. It's not that it's too loud but it's the nonchalant way he just lifts his hand and flicks his gaze over to the radio and idly adjusts the knob. Doesn't he *realise* just how impossible each of these actions is for some people.

I've always loved watching you sleeping. In bed in the morning especially, all the day's concerns tucked away, your face smooth and unlined with the hint of fine smile creases under your eyes. Your breath ebbing and flowing – always so much faster than mine. Occasional movements of your jaw, sometimes a languorous swallow, and a sigh, and then the pattern of your breathing resumed. All perfectly normal. All just as I look at you now. But today you won't catch me looking at you, you won't turn your head, you won't smile gently, you won't say, 'hello'. You won't snuggle close and go to sleep again.

Last night wasn't good. Apart from the missing hour for the clocks I slept fitfully, for the first time really. Sleep has been short but solid up to now. The dreams were disturbing – mainly to do with being trapped, trying to escape but being unable to – there was a way out I know, I just couldn't find it. As usual they disappeared when the radio woke me and I was unable to cling to them. I do miss the weekend lie-in when dreams could wash to and fro on the shores of my consciousness for long, luxuriant minutes. I could savour and explore them – but gently – don't want to wake and ruin it all. No lie-ins any more. No-one to lie-in with anyway.

Maggie dreams too. Her night was disturbed a lot last night by tension, tongue-biting and, I guess, the usual noise and light which is present at all hours in these places. I don't know the detail but she doesn't like the dreams at all and she doesn't have the problem I have about not remembering. She has no option but to drift in and out of the dream state – remembering everything, however unpleasant. She can always tell the difference between awake and asleep (perhaps unfortunately, perhaps she can fly and run and sing when she is dreaming or perhaps she is just as firmly trapped asleep as she is awake). She has had some visual hallucinations,

probably just due to extreme fatigue. I remember my own (brief – only 12 hours or so) experience of sleep deprivation, white noise and enforced discomfort. The hallucinations seemed to help make it bearable. I hope they help Maggie too.

29TH MARCH – Day 15

The dam broke for Elisabeth. We had been at Sue and Terry's for 'Sunday supper' last night and returned well-fed and comforted. Elisabeth was quiet all evening and I had caught her looking tearful out of the corner of my eye on the drive home from the hospital. She denied everything – not a problem. Elinor and I had been sitting in the front discussing her European holiday, her return to work, going to university and, as part of all these things, money – which is clearly going to be in short supply over the next couple of years.

Once we got to bed she sobbed and sobbed and sobbed – to the extent of hyperventilation and being sick. Mum and Elinor and I all tried to help but there is no denying the circumstances. We ended up cuddling and talking. She had been thinking, as I do (and try not to), about the might-have-beens: the Summer Ball (her first and last probably – and now unlikely), 'Mum was going to make my dress', going to buy her Sixth Form suit, our holiday, 'Mum teaching me to drive', cooking, Sunday lunches, just sitting talking, hugs when she was sad . . . and the realisation had finally cut through – mum wasn't coming home, probably ever – at least not the mum she had known – someone different, silent, hidden, with two good eyes that flick up and down and nothing else. 'Where is my mom?', 'Will we get anything back?' So brave, such sensible questions – but no answers.

I have been flicking through 'The Philosophy of Consciousness' which the folks (prompted by Margaret – who else?) bought me for Christmas. The mind/body dualism arguments are covered of course. While Maggie's situation seems to demonstrate dualism – the mind/body split is *very* obvious – it does demonstrate their interdependence too.

Her body is doing little more at present than keeping her brain (?mind) going – all that to support a little bit of grey matter. But although her mind seems to be working as well as ever can she be

said to be conscious without an independent means (via her body of course) of communicating the fact. If you can't interact with your world are you conscious – is sentience enough?

The Glasgow Coma Scale of course doesn't seem to fit this situation very well. *Coma* implies *comatose* – *unconscious*. Not aware? Not reactive? Yet Maggie scores 6:

- ◆ 4 for eyes
- ◆ 1 for verbal
- ◆ 1 for movement.

I must check this – it doesn't seem sensible. Is her verbal score really the maximum? She can form and communicate perfect sentences – but slowly and without speech – surely a more demanding test of consciousness than doing it *with* speech. Likewise, substitute eye movements for limb movements and it's another maximum! Hmmmm.

The move to the ward threatens again. Three to four o'clock they said. Maggie is worried, frightened and generally unhappy about the idea. Particularly after last week's fiasco. With no call system and recent memories of bitten tongues and coughing fits I am worried too. Not for the risk of dying accidentally (as was the worry at SMH that first night) but for comfort and communication and care – and sleep: the woman is *knackered*. No wonder she eye-signs slowly by lunchtime. Her patience astounds me. Or maybe not. If she is impatient, frustrated, angry . . . so what? She can't show it – only feel it. I hope she savours these important emotions . . . but then swallows them. If she holds on to them too long they will leave a bitter taste and sour her outlook on everything and everyone for the future. All the new skills of enforced niceness, pleasantness, forgiveness, she will have to learn with no chance of a good shout or snap. I will miss our arguments. They were painful but cathartic, they hurt us both equally and benefited us both too. Now what will we do? I can find an ear – there have been enough offers. There are plenty of ears for Maggie too but what use is an ear without a voice?

So – it's now 8.30pm. We moved down here an hour ago. There

is a TV quietly playing the soaps in the bed next door (three to a cubicle). The lights are off, just a red night light off her face for obs (and for me to see to write this). The hiss/bubble of the humidifier seems quieter here and the air mattress hums and hisses even more peacefully. Maggie has been fast asleep for an hour. A whole hour – wonderful!

Lying on her back is nice – swallowing well and regularly with head central. Swallowing with much less chewing first. No coughing. So no spasms, no sucking out, no waking. Just apparently restful sleep. I hope she's dreaming of flying and singing and running through sunny meadows, and walking along cliff-top paths with a half-gale blowing and a wild sea far below crashing on the rocks, holding my hand.

'Cough, cough.' Still asleep though.

30TH MARCH – Day 16

A fullish day – and no time to write!

The girls and I visited Rivermead first thing – shabby on the outside, well-equipped and maintained on the inside and pleasant people. I had a bit of a tearful interlude when the 'Patients' Activities' woman started talking about their piano . . .

I think Maggie will do well there.

But she can't go until the gastrostomy is done and that won't be as soon as we had hoped. We have fallen foul of the Easter holiday – no operating so instead of 'today or tomorrow' it's going to be 'week Monday'. Still, maybe swallowing will be OK by then. I think it's pretty good now. Maggie dribbles a bit if her head is turned to the left – well you try swallowing with your neck flexed and turned hard left. The spasms associated with coughing turn her head leftward so this is a problem. However, generally swallowing is fluent and easy – and *entirely* reflex, not voluntary at all. The main swallowing problem is that Maggie can't open her mouth and has fairly tight masseters – not much good if you can swallow but can't open your mouth. The 'swallowing lady' came though. She will return tomorrow after 24 hrs with the trachy cuff deflated.

So – a résumé of the current situation:

TRANSCRIPTION OF A JOURNAL

Medically – better:

- ◆ Trachy behaving well with nebulisers 2 hourly, coughing productively into the trachy mask with occasional suction required – for the tube more than for deeper in her lungs.
- ◆ Wrist infections from the arterial lines have settled as has the swelling of left arm. The splints fit much better now though are a little loose (?wasting of muscles ?loss of fat).
- ◆ Heparin continues and Maggie has chosen Warfarin over Aspirin for later – better theoretical reduction of recurrence of vertebral artery problems with this.
- ◆ Flucloxacillin (at 2g 4-hourly IV!) continues.
- ◆ Senna and lactulose continue – little result (none actually) since the diarrhoea of HDU day 1.
- ◆ Prozac started yesterday after I reminded the doctors of last Friday's discussion.
- ◆ Leg splints when lying on back – not very comfortable but with these and regular leg physio (and the tilt table), no sign of contractures thus far.
- ◆ Skin is fine.
- ◆ Right eye won't close all the way. I got some hypermellolose drops a few days ago when Maggie said her eyes were sore. They help but we have to remember to ask her and put them in regularly.
- ◆ Urine output is fine.
- ◆ All feeding is through the NG tube – the drip stopped some days ago in HDU. The right femoral line persists for heparin via pump and for antibiotics qds.

Neurologically – slight improvements continue in voluntary movements:

- ◆ The left lateral gaze in the left eye which we first noticed 2 or 3 days ago is much the same – a few mm only but useful in that it allows Maggie better conjugation of gaze, less diplopia and greater ability to read. She favours the left eye for this (right covered).
- ◆ The left eyelid now fully mobile and under control. It also blinks (this started hesitantly a couple of days ago and is now normal).

- ◆ Head rotation to the left, gravity eliminated, is still present but is not powerful and not much use given that Maggie can't turn her head back to the right. Still, with the right support and springs . . .
- ◆ Today we learned while talking with the 'swallowing lady' that Maggie can move her tongue – weakly but nevertheless she can move it!

That's it for voluntary movement.

- ◆ Involuntarily Maggie now has apparently normal and well-coordinated coughing, swallowing, yawning and sighing. She cries, though tears are not profuse, with pain (tongue-biting) and with strong emotion.
- ◆ Apart from flexor spasms with coughing (and the masseter spasm), Maggie has a completely flaccid paralysis.
- ◆ Sensation seems to be normal (at least – touch and pain, I haven't formally tested anything so am not sure about proprioception, vibration, *et al.*).
- ◆ Hearing is normal – Maggie can hear doctors discussing at the end of the bed – we haven't let on quite how well she hears. Male voices seem easier to hear than female. The whole business is bedevilled by tinnitus (which is still no better or worse than ever) and then iatrogenic tinnitus caused by the humidifier.

In herself Maggie is depressed and feels useless. The 'everyone wants me to die' comments have stopped but the thoughts may persist. She enjoys the physio most – particularly the sitting up and the tilt table – things to *do* and things which make her feel that she is contributing to her improvement.

Neil and Jane's again to eat. I was so tired that I became quite incoherent after a couple of glasses of wine. I don't remember Elinor driving us home at all.

During the day I went home 'for a sleep'. But I couldn't (lied to the others about this and said I slept but I actually got a few hours while sitting with Maggie the night before). It was the first time

I had been alone in the house since the stroke. I walked around looking at our things and our home – *Maggie's* home – it has always been hers and I have always treasured it so much because of that. I cried a fair bit and slowly felt better. So I got changed and spent 2 hours gardening – wonderful to feel the soil and to do something practical. I started my birthday potato barrel and remembered Maggie's delight at my delight when I opened it.

Then I made a bacon frittata and ate that, with a cold glass of dry sherry – what will happen to Maggie's sherry now? When will we share pre-lunch sherries again? Then a check of the email, a shower and change, and time to leave for hospital (via the farm shop!).

31ST MAY – Day 17

A disturbed night I gather – coughing lots. The trachy cuff is now down. I suspect that she is lying flat or with her head rotated to the extreme left. They just need to keep her head straight – so it looks comfortable. If it looks comfortable it probably *is* comfortable seems to be a reasonable guide, but it amazes me how caring and pleasant nurses can put Maggie 'comfortable', check her over and then walk away leaving her neck flexed and twisted, hair in her eye and biting her tongue. Don't they look? Don't they have any imagination?

However, Maggie sat for the first time since the stroke today. On the edge of the bed supported by two physios. She enjoyed it but felt tired after 15 minutes or so. She looked good upright. Her feet went bluish and swelled quite quickly – a combination of poor arterial tone and knees squashed against the edge of the bed I think. Her face drooped downwards and she looked so sad and helpless. Her shoulders sagged and her arms lay useless on her lap. Only her eyes told how happy she was to be upright and bearing weight on a different area and looking me & the girls straight in the face. More tomorrow!

Dr Wade (& his SHO this time) dropped in – surprised and pleased to see Maggie on the ward. Interested in the tongue and eye improvements. More interested in the head movement but still looking for hand movement really – that would clearly

move her into a different category of rehabilitation. Nevertheless I got the impression that he is clearly looking forward to having Maggie at Rivermead and that he has high expectations. Not that *anyone* in this state can be said to be 'usual' or 'classic' I guess but Maggie is, I think, a bit unusual. Intelligent, with good insight, a supportive family, aware of the course of the whole stroke and the events following it – a good subject for research probably – and also one with a better chance of gaining lots from rehab than most I suspect.

1ST APRIL – Day 18

Orthodontist day for Elisabeth so we were in late – but still in time to see Jane Pick who visited and was delighted by the improvement in Maggie. What 2 weeks will do – we don't see the dramatic changes being there all the time but we are grateful, nonetheless, for the minor improvements as they occur. I missed mum and dad though who had come and gone (along with physio (stretching) and speech therapy) by lunchtime. We did physio (sitting) again – a good 10 minutes this time. Any more would not be possible I fear. Maggie will cope but the strapping young male physio student from Southampton University is getting cramps and backache holding Maggie up and the other two physios are having to take turns at holding her head. Heads are heavy.

The highlight of the day though was Billy & Freya's visit. Neil had wanted to drop in before they went to Sherborne for Easter and asked if Freya and Billy could come in. Maggie said, 'Yes' – a bit of confusion here – we checked the response a couple of times. So in they came – just for a quick hello before the off. We could have done it better I think. They were wide-eyed at hospital generally, drips and beeps and fancy beds and monitors . . . we should have given them time to see and to question and to understand. The girls gave them their eggs as they came in (bunnies actually but the principle's the same). Freya immediately addressed Maggie face-to-face (I had lowered the bed to put Maggie's face level with theirs – she was lying on her right side and easily able to look at visitors on that side of the bed). 'Thank you very much for the Easter Egg Auntie Margaret' . . . then she was shuffled away and

Billy was put in her place. I was sitting right behind Maggie's head so that they could look at me if they found Maggie's lack of expression difficult to deal with. Freya looked interested but formal and stiff – she needed longer to relax and I didn't have time to address her before Billy appeared. He looked amazed, wide-eyed, but not frightened or disturbed. He didn't speak so I spoke to him and told him about Maggie's eyes and which one to look at! – Stupid! But it was all I could think of to say. I was going to get him to hold Maggie's hand and just try to make the situation more normal but Maggie started to hiccough and I could see that her face was going red as a result. I thought that Billy might get frightened and tried to pass it off with 'Aunty Margaret gets hiccoughs some times', and was quite relieved when he was whisked off. It was only seconds later when I moved around and saw Maggie's face that I realised what was happening. She was crying. Tears had welled in her eyes as before in HDU but this time her face – no, her left jaw and neck – were pulled down in an exaggeration of the flaccid droop which I now consider normal, and she was sobbing. Clearly, regularly and loudly sobbing.

We discussed it later – and for the first time since the stroke I held her and we cried together about the mess we were in and – oh just *everything*. I hope she felt a release as much as I did.

I think that the crying will have been good for her – to be unable to express all the emotions which must be welling in her must be terrible – truly terrible. But, what was best for me was the fact that she could *sob*. She did it again as we cried. To my mind the trigger was *cerebral* – but the response involved facial and neck movement and control of breathing. Surely not reflex or automatic actions? They must have had a 'conscious' trigger and so a link between her conscious mind and her breathing control, tear production and neck and jaw movements must exist. I feel that we can hope quite confidently for further improvements. I must ask Dr Lo about this.

I suggested that I write to Freya and Billy – Maggie agreed that I should. To say thank you for visiting, I hope it wasn't too much of a shock, it meant a great deal to us, please come again later and spend some more time.

3RD APRIL – Day 20

Good Friday yesterday. My folks' last visit before their return home – and (at about 10 minutes) one of the longest meaningful chats I've had with dad! Just about the future, whatever it holds, family support, his feelings of isolation and both our feelings of helplessness.

Poor sleep last night – I sat up until 2, thinking, checking LIS on Medline (and in particular living wills – *nothing* on this which seems crazy – I will try again with a different search engine), reading . . . So today I have a vague, irritating headache and feel low. I had hoped for a little while alone but mum B insisted on returning home early with me last night (to make sure that she was there to meet Kathryn!) and didn't want to come in early with the girls so I brought her. Various irritations are beginning to surface but, at least on the surface, we are all getting on still.

Mum was planning to go home after the PEG (which was to have been last week but which will now probably be next week). Various things bug me: the way she won't fit in with our transport arrangements – she doesn't want to spend the length of time in the hospital that we do and so wants to come late and leave early. We only spend 1000–2000 with Maggie as it is – and feel guilty enough about that – she needs our care and advocacy even to get some sleep! I don't really see why Elinor (or Terry!) (or Moira!) should have to do extra trips when we already have two cars going in each day. Then there's the incessant stroking of Maggie's arm – something which I know she hates – but now that she is helpless anyone can do as they will with her body. I mentioned the stroking today. Maggie was trying to sleep but was clearly being kept awake by it. Why should I have to tell others what Maggie does and doesn't like done with her body? That's *personal* to her and me. But so many private matters are now public. We sit round the bed and discuss her spasms, her need for a bath, her hair, her saliva, the colour of the urine in the bag by her bedside, her bowels . . . Her bodily functions are common property now but she must still endure their machinations alone. We are all so patronising too – 'that's a good cough', pats on the hand, kisses

on the forehead . . . just like being a little girl again – a time that Maggie was richly pleased to have left behind her. If anybody says ‘choke up, chicken’, I shall scream.

Elisabeth needs her bedroom back as well – she has been sharing with Elinor for 3 weeks now. The bulk of her stuff is still piled up in bedroom and dining room – much of it unpacked with the Easter holidays nearly a week gone. She needs a bit of space, so does Elinor, and we three need to have a few days to ourselves before Elisabeth returns to school. I’m not sure how to approach all that? Mum is very reluctant to talk (*really* talk as opposed to inconsequentialities) so we don’t really know how she feels. The initial manic ironing and washing has settled now though – to a more practical and useful routine although Elinor still washes some things separately and does a bit of clandestine re-ironing! Elinor is back to work now – which seems to be OK – at least on an ‘early’ which means that she rises at 6, but, after a shift, can get to Oxford by 4pm-ish. We must make sure she doesn’t overdo it.

I need to cheer up a bit but I’ve been quite low for the last two days. Maggie’s mood has always powerfully influenced mine (and perhaps vice versa?) and it’s still true. Her expression of hopelessness yesterday is so sensible and realistic and so hard to counter. My dad feels useless too (and gave us a cheque ‘to help with the petrol’ – £1000!) – ‘because there’s nothing else we can do and we are so far away’. There’s nothing else we can do dad, and we are so far away as well: Halton to Oxford 36 miles or so, the thickness of a skull – a few millimetres, the distance between life as we know it and living death. Hopelessness is quite appropriate.

I bought two teddy bears for Maggie for Easter (well chocolate’s no good for her). I hope that she will be able to hold them – one in each hand to prevent contractures and to prevent her nails digging in during spasms and to stretch her fingers and to feel nice. I hope.

I feel a need to write, to try and make some sense of all this. I don’t want to *discuss* it because no-one else will understand. Maggie would of course. Trouble is my day is so taken up with doing

that I have no time to think and Maggie's day is no doing and all thinking. We are out of balance. This is what the future holds.

So near yet so far.

4TH APRIL – Day 21 – Easter Sunday

Not a bad day all told. A potential circus around the bed, with Easter egg swapping and Kathryn's birthday, was avoided – or at least made less compressed – by timely walks, lunch and toilet breaks and the fact that, it being Easter, the other two beds in the ward were unoccupied – so we could spread a bit!

Maggie orchestrated the day as much as she was able – egg time was announced and Kathryn's birthday time. There was also 2–3 hours sleep of good quality (by which I mean no coughing, no associated movements, no eye opening) – in 40-minute batches. It is staggering how alert Maggie seems after a nap: brisk, snappy eye movements, questioning, interested, tolerant of 'handling' – the latter is an assumption, I haven't checked. By contrast, when she is tired her left eyelid droops (the right is half open at its lowest voluntary point of movement) and it is clearly a huge effort to drag herself to wakefulness and respond. So when she has signalled 'I need to sleep', why won't people let her sleep? I make her comfy and sit quietly, perhaps touching an arm lightly but without sweaty holding and *certainly* without repetitive stroking. Others will spend 10–20 minutes checking and rechecking that she wants to sleep, thinking of last minute things to do, making noises, banging about – it's cruel. And then mum especially will hold her hand and lightly stroke her forearm up and down, up and down. I know so well that Maggie hates nothing more than that – it's not just the irritant effect but the patronising petting. To be helpless in the face of something that she would have vigorously resisted 3 weeks ago must drive her spare. I, politely as I could – honest – asked her to hold rather than stroke yesterday, effective at the time but not much use today I noticed. Elinor mentioned it this evening too – she is becoming very irritated by the petting and stroking – apparently she and Elisabeth get it too. It's a difficult balance. I want to be Maggie's advocate, I should be and am, but reprimanding her mother, even politely, even in her interest

may result in the 'huff', Mum's further isolation and a prompt and messy return to Tenbury . . . Maggie would hate that even more and would not be able to do her usual mediation over the telephone. I'll try to find time to ask Maggie about it tomorrow.

There is a need soon to address properly – all four of us – all *five* of us – what happens about Mum. I guess the best thing might be to move the office into our bedroom (which has probably become my bedroom for the remaining months we have in the quarter) and convert the small room into a visitor's room for Mum. She would feel less like an interloper and Elisabeth could have her room back. I'll discuss it with Maggie first.

The minister, 'Anthony', came again as he said he would. I asked Maggie if it was to be she and him, me too or 'all in' and she opted quickly for the latter. He started with hand touching, calling her 'Maggie' and meaningful stares – *not* designed to win favour at all. So I suggested that he read a prayer or something, he popped out for his prayer book and things went better, well faster anyway. Easter readings, prayers and then the Lord's prayer and out. Maggie signalled and gave us the message 'what a creep!' I can't remember what the comment was, or who said it, but someone said something witty and Maggie laughed. Quite spontaneously – panting, breathing, a distinct smile with the left side of her face and the full panoply of wrinkles at the corner of her left eye – several seconds' worth. What a marvellous sight – can that be *all* reflex? There has to be a connection somewhere in her head between whatever centre appreciates humour and whatever nucleus controls laughter. Are laughter and tears so basic that they are controlled at the same level as yawning, sighing and coughing? Is cognition required to cough? – probably not. But to laugh? – surely yes. If we assume that laughter is an evolutionarily old and basic act set off by a sensory trigger then what is that trigger? In this case was it conscious appreciation of the quip or was it the sight and sound of a burst of laughter from those around her?

Pending evidence to the contrary I am going to hope for a return of left facial movement – that would be odd given that left facial weakness was the initial presenting symptom – in that church 3 weeks ago.

The other highlight was an accidental awareness – Maggie looked round as someone appeared over my right shoulder – that she has regained some medial movement of the right eye – 2 or 3 mm of nasal deviation. So now she has practically conjugate *single* vision when looking ahead and slightly left and enough lateral movement to read columnar text. What a boon – to be able to read with both eyes will make communication so very much easier.

This evening she felt a little more hopeful. So did I – a little.

5TH APRIL – Day 22 – Easter Monday

I'm alone this morning – we are not sure what Mum would like in the way of transport but she certainly won't want to stay all day – so that means two cars. If the girls bring her later then Elinor can go back early with her – or I could I suppose. I don't really want Elinor doing 140 miles a day. Seventy is quite enough given our general levels of tiredness and distraction.

Maggie's right eye is looking sore in its lower half where it doesn't close voluntarily. It has obviously been getting dried out – *no* drops overnight apparently and, without us here, no-one to gently close the eye when she falls asleep. So 14 hours with a half-open eye and no moisture. A word in the nurses' ears needed again.

7TH APRIL – Day 24

Where have the last two days gone? You wouldn't believe how just being here and talking and tending and waiting eats up the hours. And I've not been sleeping too well over the last couple of nights, and I've been writing 'household business' letters, paying bills, cancelling our OU involvement etc – so no time at home really. Having said that Elisabeth and I did Tesco yesterday – she showed me how it all worked! This morning Elinor and Mum went in first (Elinor's shift changed to a 'late' at one day's notice so frantic changes of plan last night and she won't be able to join us at Neil and Jane's this evening). Elisabeth and I started the bedroom move.

Since this situation is going to be semi-permanent I thought it best that we generate a bedroom for Mum. That would allow her some space of her own and will enable Elisabeth to get her own room back, her things, her desk etc. It will also give Elinor some

personal space now that she is back at work. Maggie has sanctioned the idea and everyone agrees. So that means dismantling and shifting the new computer desk, the computer, telephone line, filing cabinets and so on into our bedroom. I have, nevertheless, left our bedroom still able to be reoccupied at a moment's notice by Maggie. Her bedside table, books, water glass, alarm clock are unmoved and her side of the bed is just waiting for her.

The general disorganisation goes on in the ward. There is no 'team' in the sense that there would be in primary care or that I feel sure there will be in rehab. The doctors go round and check on neurology (but have difficulty with questions about tracheostomy tube changes and bowel problems). The physios tilt, sit and stretch (all of which *greatly* enrich Maggie's life) but they turn up during speech therapy visits or washes, and yesterday they also managed to pull out Maggie's NG tube (feed all down the front of her nightie and the hassle for *all* concerned of having to have the tube reinserted). The speech therapists do various things – the 'local' ones appear to have stopped coming – we are already communicating well enough for practical hospital purposes. The 'swallowing' lady hasn't been since last Thursday when she fiddled about fairly ineffectually with a mouth-cleaning swab and some pink stuff ascertaining what we have known for a couple of weeks – Maggie can swallow reflexly but cannot open her mouth or swallow voluntarily. We have continued to 'clean' her mouth with water, pink stuff or grapefruit juice as she wishes and, for a treat at the weekend, gin and tonic – much appreciated! She swallows it all assiduously and to date has not coughed any of it up – though reflex coughing continues well. The 'aids' speech therapist had not returned following the 'box of goodies' episode but came this morning – I missed them. Blast – got the times wrong! However, Elinor said that the technician was just what was needed. Spoke to *Maggie*, understood that a call system was required *first* – then more sophisticated communication methods, and brought a spectacle-mounted infra-red switch which Maggie happily used to produce clicks and whistles. He will return after adjustments I gather but doesn't want to get in the way of the gastrostomy . . . The physios have just arrived (waking Maggie again – she has had 20 minutes sound sleep) – they are here to

do personal foot splints. While they were setting up, the nurse returned to do the after-lunch turn and then the SHO to take the INR bloods. He also gave us the brief on the tubes etc – gastrostomy at the JR on Friday as a day case (despite the nurse’s final assurance less than an hour ago that the gastrostomy was fixed at last – JR on Wednesday next, staying over on the Tuesday and the Wednesday!), and tracheostomy change today – here on the ward. After a quick but competent run through the plan (to Maggie too!) he took the blood and the physios began making the leg splints. Halfway through that the ENT surgeon arrived to change the trachy and went away again until the physios had finished. They did, leaving the bed soaked, so we tidied up temporarily covering the wet patches left from the bandages around the Scotchcast. The ENT surgeon returned and, after a bit of a palaver, persuaded us that changing the trachy tube would not be such a hassle as last time. It wasn’t – it slipped in quite easily but the associated spasm and coughing caused more distress than anything else – plenty of suction helped and eventually a nebuliser settled things down. By this time it was Elisabeth and I cleaning up the mess and making things comfortable again – it was all happening during ‘handover’ of course. Then a ‘top-half’ was needed to clean up the blood and the sputum and finally – it is now 1630 – a turn and sheet change to get her off her back (where she has been since before 1000) and to clean up the physios’ water. Just a normal day in the ward! Physios arrived 1350 – finally cleared up afterwards 1630!

Things *do* get done but often, it seems, by accident and *no-one* actually co-ordinates care. The nurses are the mainstay of care of course but they fit their bits in when they can and don’t appear to take any *active* part in care planning or coordination. When we arrived today we were told that Maggie was ‘coughing a lot this morning’. I asked her about a nebuliser. ‘Yes please!’ She had that, coughed up some sputum then settled down with no further coughing. We have known about that solution for a fortnight now but she had had no nebuliser at all during the morning although it is prescribed for 2-hourly.

The saddest part of the day was the ‘five weeks to get to Rivermead’ announcement. We will have to get rehab going in the ward as much as we can – communication especially!!

During the first week or so, driving along, I couldn't stop singing 'You are always on my mind, you are always on my mind . . .' though it was a bit repetitive as I only know about four lines of the song. That stopped and last week was a bit tuneless. This week it's been 'Why does the sun go on shining . . .' from Elinor's 'Ally McBeal' CD. That and the opening of *Cantique de Jean Racine* of course – which Elinor played for a short while at the weekend – the first time the piano has been touched since Maggie's stroke.

The day ended with a visit from Alison Hatfield, the SpR from Rivermead, just as Maggie was getting to sleep (again!). She had a long chat with us and with Maggie – was pleased to see the improvements of the fortnight since she last visited but (I think) disappointed to see so little. Taking someone requiring as much nursing care as Maggie does is clearly going to cause Rivermead some difficulty. She doesn't think they'll have any problems with the gastrostomy (I thought that was a requirement for getting there!) and 'feels sure' that they will be able to cope with someone who has a tracheostomy. There is a rehab doctor on call I gather but they can't take patients who might require a doctor overnight and they have no GP for ordinary primary care matters. We continued to say how much Maggie and we were looking forward to getting there. I have started asking what we can do, particularly for communication, in the meantime. Let's keep people thinking about it! We suggested too that physio and non-drug methods of reducing spasm were Maggie's preferred options – given the central effect of some of the drugs she was wary of reducing the effectiveness of the only thing she has which works properly – her brain!

8TH APRIL – Day 25

Poor sleep again. To bed at 1130 after supper at Neil and Jane's – the news that they were putting an offer on a house in Sherborne gave me a breeze of pleasure and great gusts of despair. They are both being very practically and emotionally supportive.

Woke early with worries about Maggie's breathing. We seem to have gone back a step with the new tube, given all the secretions and coughing – humidifier and mask again for 24 hours – then

she would cough up easy sputum. I had fears about her blocking the 'nose' and suffocating. She can breath through her own nose of course but not through her mouth because she can't open it.

I'm having life/death dichotomy problems again. In the hospital there is no problem – life is the clear priority. Maggie is medically better each day, neurologically improving very slowly and mentally as alert as her fatigue will allow. We are going forward and we think and talk of the future – the immediate future at the moment but it will be the middle and more distant future soon. Maggie wants to live.

At home, she is not there. Reminders of her presence are everywhere and we do things 'as mum would have liked it done'. The house has the air of absence – permanent absence – it is as if all the guests had left after the funeral and we are left to clear up, to remember 'the last time . . .', where we bought this, how much she loved playing the piano, her joy at cooking for others, her obsessive perfection in laying the table for special meals, Sunday lunch, sitting with the cat laid out behind her head on the back of the sofa, and lying beside me in bed. But there has been no funeral. All of Maggie's things, her shoes, her clothes, her jewellery are still hers but it seems just now highly unlikely that she will use many of her things again and impossible that she will return to Mansion Hill. Perhaps that's why it seems so much like a mausoleum – it was so much *her* house, as all our houses have been, and it will never be so again. We need a move, a fresh start. Meanwhile we will have to manage at Mansion Hill – the home without a heart.

Chair Day. The OTs brought a wheelchair and lots of Velcro-backed foam pads, the physios brought a sling and a hoist. After some palaver with pants and placement of the sling Maggie was hoisted airborne and with laughter (rather bubbly laughter which gave the assembled company a bit of a shock) was deposited in the chair. There followed some kerfuffle with said foam pads and the 'foam pad' OT measured up for Maggie's head support. Leg rests were adjusted and a bit of bottom shuffling was done to make sure that Maggie was all straight. She looked great – human again

– there is something about humanness which requires one to be upright. Head pointing forwards, not upwards! Fifteen minutes was enough (tired and a bit dizzy though she didn't develop facial pallor) – then back to bed (clean sheets with no wrinkles too!) She seemed to love it – but has been asleep ever since so it's a bit difficult to be certain. Roll on tomorrow – the gastrostomy will be another step forward.

9TH APRIL – Day 26

Gastrostomy day. I'm sitting by Maggie's bed in the RI again. She is fast asleep. It is 1345.

I arrived about 0815 in mid-wash. Maggie had had a so-so night again – good sleep from 0400 I gather from Gwen whom I bumped into coming off shift as I arrived. Once that was done I was brushing Maggie's teeth when the ambulance men arrived. A quick suck as the trachy was bubbling a bit and off we went – no time for a nebuliser or a stretch, both of which I had intended as a useful preparation for the bumps of the journey.

The journey over was faultless – I think Maggie enjoyed getting out, albeit in an ambulance. She could see a little I gather out of the back window and it must have been nice to feel fresh air briefly on her face. We were whisked straight in on arrival and I was welcomed to stay – refreshingly!

The first slight glitch was the realisation, once the radiologist had started the briefing, that this was to be an LA procedure, not the GA we had been expecting. This presumably explained the change yesterday from 'two nights' over to 'day case'. I explained that we had understood otherwise and that they may have a problem with a patient who was sentient and awake and who had marked, uncontrolled associated movements when subjected to pain or when distressed. The doctor decided that sedation would be a good idea.

They put the Venflon in first, then put a new NG tube down – the old one having 'fallen out' overnight apparently. Maggie started bubbling in the trachy tube at this stage, I could hear her and I was standing behind the glass screen – the other four, clad in lead, were around her. I could see her neck arching on the fluoroscopy screen beside me – they were passing the NG guide

wire under radiographic control – there was a loop in the tube which needed a bit of fiddling to straighten. The arching got worse as a coughing spasm started but they continued while making the usual ‘cooing’ noises – ‘well done . . . that’s fine . . . just a minute now . . .’ – irritating enough when you can *do* something about the coughing. It must have been irritating in the extreme for Maggie – powerless to control it and feeling more and more distressed by it, and the persistent application of the NG tube. She can’t open her mouth of course and the lip and jaw spasm worsens in these cases so she ends up breathing with difficulty through a half-obstructed nose and a half-obstructed tube. Eventually I called out and asked them to suck out (fairly politely I thought – I try so hard to keep the frustration and anger out of my voice – keep it calm and doctorly – don’t want to be labelled the emotive husband (though why *not* for God’s sake? I *am*)). They did suck the trachy out, the spasms quickly subsided and the NG tube went in a treat. The plan then was for midazolam and LA to do the procedure. I offered to leave at this point and they willingly accepted. I said goodbye when I left when Maggie, *after* the midazolam was still clearly awake. I pointed this out and the radiologist said something about not wanting her too deep. I talked about her not feeling pain and not being aware of the procedure. He promised to use lots of LA and that she wouldn’t feel a thing. I left feeling guilty that I had let Maggie down, that I hadn’t asked enough questions or reassured her appropriately. Now I also felt a bit grumpy about the informed consent angle and about organisation in general. The radiologist clearly had no idea what had been said at this end or what exactly to expect. The SHO at this end was not the right person to obtain informed consent. The radiologist (or someone from that division) should have done it. The ‘two hospitals’ problem perhaps has a part to play but the person hurt by it all, yet again, is Maggie.

Half an hour late we (the nurse and I) were called back in – all done – slight movement with abdo pressure as the tube was inserted but nothing else so, ‘she won’t have felt anything’. Maggie seemed less sure, she was awake and signalling. I haven’t had the opportunity to explore the detail but, although she doesn’t remember the whole thing (I think), she clearly felt a good deal of pain.

She slept quite well afterwards – it was 1045 by this time and she was on a trolley in the recovery room next door. After 2 hours the same ambulance men arrived to take us back – so, longer waiting afterwards than the whole of the rest of the business put together. Maggie ended up with sore heels from the pressure from the trolley but nothing else. Oh – and a new ‘nose’. The old one had fallen on the floor and been thrown away so they were going to leave her without! 2+ hours breathing dry hospital air – what would that have done for her tubes? Still – since the procedure she has had no nebuliser and no coughing or sucking. The trachy is settling down nicely.

I expect that the gastrostomy will do the same. Perhaps short-term pain and fear and hassle is a reasonable price to pay for long-term comfort, safety and convenience. Is it necessary though? Does it improve ultimate acceptance of the tube/stoma/condition? The balance is difficult to achieve but I still think that improved communication could do a lot for reducing Maggie’s anxiety and my frustration.

Settled again in bed and wishing to *sleep*. I have prompted for removal of the NG tube, some IV fluid before that 4-hour old Venflon blocks up, and some pain relief. The fluid went up quickly – so Maggie shouldn’t get dry now before the gastrostomy tube gets fired up tomorrow. Then Jenny came to take the NG tube up. As she pulled Maggie took long, slow breaths – there was no coughing or associated movement. I literally jumped up! ‘Did you do that? Take those deep breaths?’ ‘Yes’. Wow! Control of breathing. Maggie was tired but we did a couple of tests. She held her breath when asked, seemed to have more difficulty letting it go and starting breathing again but *she held her breath*. This way lies control of coughing and *speech*. She also managed to move (fractionally) the left angle of her mouth!

Dr Briley came round and had a chat – little more but little more is required really. Day-to-day decisions are made here at the bedside and in the ward and, after all, we are living day-to-day.

Dr Hand came round too and wrote up a shot of morphine. Maggie was so tired by this time that neither breath-holding nor facial movement would work! Typical! However, conjugate left

gaze is certainly improving with greater movement of the right eye – and as that has improved, just as in the left eye, so has the ability to close the right eye. Maggie can today close both eyes voluntarily! A great boon for sleep I am certain but also a relief for me that there won't be any need to sew the eyelid shut to protect her cornea – something which I have not mentioned to anyone but which I have been fearing.

So: although the day so far has (I fear) been one of pain and terror for Maggie (yet again) – and although I have singularly failed as a proper advocate of her needs (yet again) – she has made further small but significant neurological improvements (yet again!).

This is a miserable business on the whole. The girls and I are arguing, tired and intermittently tearful and depressed. We are full of guilt and fear and hope all mixed up in a painful cocktail. And we are aware the whole time that Maggie has much more fear and frustration and pain and anguish than we could ever imagine. I dearly wish that she gets as much hope from the little improvements as we do. She cries at such apparently odd times, while Dr Hand was here, over something he said – I can't recall what, it was fairly innocuous – why? What are the mental connections, the thought processes, the hidden fears that cause such outward expression of her anguish? I do hope that soon she can share her feelings with me.

12TH APRIL – Day 29

Nothing in the journal for 2 days over the weekend. Too busy and too tired and too many other issues – which seems ridiculous I know.

Maggie was tired on Saturday after the rigours of Friday. Very little communication was possible and I seemed to spend most of the day glaring at people who were waking her up – ‘Do you really want to sleep . . .?’ I had no useful talking time either – just ‘comfort’ matters really. Pain relief was a bit of a problem and we had a catheter disaster too. It blocked and I didn't cotton on to the fact that the new catheter bag was completely empty for a long time – some hours. That plus the IV fluids in quantity while we were

waiting for the gastrostomy to pick up to full speed meant that by the early evening stretch Maggie was very tight. Much greater tone than normal – I couldn't think that it was anything other than abdo pain from the gastrostomy site. By the time Maggie signalled and spelt 'catheter' she had a 16-week bladder and had begun to sweat and moan on exhalation (nice to hear her 'voice' but not ideal circumstances). I asked for help but there didn't seem to be huge urgency and Maggie signalled 10 minutes later 'wet' as she started peeing round the catheter. So the nurses now had a wet bed to change too and Maggie had even more unpleasantness and hassle. Flushing the catheter didn't help so it had to be changed. I held up one very tense leg while holding Maggie's hand but when another nurse arrived she 'offered' to take the leg. I told her to beware of spasm if Maggie sensed any pain. So when the next bout of bladder pain arrived the leg spasmed, the nurse dropped it and the bowl of water for washing was kicked clean over the end of the bed! So now there was a floor to clean too! Anyway it was all done eventually and within 30 minutes the catheter bag had 1600ml in it. Ouch!

It does strike one again and again that prompt attention when we 'call out' on behalf of Maggie would save her (and the staff) lots of hassle. Our voices though don't seem to be given the same credence as her own would be. I will keep an eye on bag-filling rate in future and Maggie will report *early* any sensation of bladder filling.

The highlight of the day was the Grand National. We all (Mum & Kathryn included) chose horses. Maggie, with a giggle, chose 'Strong Chairman' – just what I thought she would go for! We all watched the race together – a feeling of family participation which has been missing for 4 weeks now.

Scotland beating France in Paris by a thumping margin just topped the afternoon off nicely!

I spent the night. Just the two of us. Me seeing to comfort and sleeping when she was sleeping. At least 6 hours sleep (in 4 or 5 batches) between 9pm and 8am plus quite a bit of dozing. She does sleep better if I am there – it's just the immediate attention I

think – head put straight there and then after a cough, not half an hour later if the nurse notices – and the regular little stretches and shifts of position to stop stickiness and cramps and irritation and, I hope, the semblance of normality. I sleep at least as well in the chair as I do in bed at home! And I love the quiet and the dark and the chance to think and watch her. Too dark to write though!

Sunday was good for the kids but turbulent generally – relationships are being adjusted as we settle in for the long haul.

They arrived late, 1045, because Elinor had had to address Mum's needs – planning to go home for a few days (check house, sort life out, allow the three of us to be 'normal' for a while before Elisabeth goes back to school), unable to talk to Maggie about it – she 'can't' talk to her about matters which might be emotive, feeling guilty perhaps. I don't really know, she won't say how she feels really – couches everything in whispered little generalities. She asked Elinor to speak for her and so didn't come in with the girls. I went home.

The girls had several hours of good quality time with Maggie, she was awake and rested and communicating well. They were on their own, in control, without me or mum looking over their shoulders and without the interruptions of physios, *et al.* Good. We must make sure that the situation is repeated.

I was looking forward to a quiet few hours alone in our home. I have only been alone in the house for a few hours in the last month. It doesn't seem like mine/ours any more and I just wanted to sit in it and wander about and look and remember and relax and cry a bit. Mum was in the house of course so I headed for the garden and strimmed and cut the grass forcefully for an hour or so. It looked much better in the warm spring sunshine and I felt better too. I made an omelette for lunch with some new potatoes – mum had already had an egg – she couldn't wait – but she sat and had a mixture of banana, jam and ice cream while I cooked. I settled down to eat alone but she came through and started talking about the 'going home' business. Quietness and meal disrupted I discussed it with her and suggested that *she* should talk to Maggie about it – then she would know how Maggie felt rather

than getting things relayed through a third party. She agreed and seemed happier that she could stay – the ‘own room’ situation seemed to have helped too although she seems a little put out about it – I’m not sure why – something about ‘of course Elisabeth would have been happier sharing with Elinor if they hadn’t grown up with rooms of their own’ – true probably but hardly relevant in the circumstances.

Mum was doing her Scrabble game in the living room so I did some tidying and escaped to the bedroom – sorted out the ‘phone line for the computer, which is up and running again, and read an old John le Carré novel to try and just get away from everything for a bit.

Once back in at the hospital the girls left (after seeing Wales beat England with a stunning last-minute try from Scott Gibbs – we watched about 3 minutes of the match altogether but what a 3 minutes!) Scotland the final 5-nations champions, who could have believed it.

Mum did talk to Maggie – the gist being that Maggie felt that Mum would have a big part to play once she was home. I fell asleep in the chair and woke to them both sobbing so perhaps useful things were said for both of them.

After the evening stretch Maggie and I had half an hour to talk – for the first time in 3 days really. We covered more ‘emotive’ stuff than usual and for the first time talked about the future – the middle distance, not tomorrow. Perhaps we should have done that earlier so that our views were compatible and confident before we started talking to others. So far I’ve limited public speculation to, ‘she will come home’, and kept the huge and frightening practicalities of that to myself.

However, Maggie sees mum having a future role as washer/housekeeper with me as the wage earner. We *must* talk more about this. I saw *myself* as the carer (yes, I *know* we’ll need money and only I can provide it). I don’t like the idea of mum running the household – it will not be *our* household if she does. Who will provide the care? A nurse employed for the purpose? Mum? Me? Friends? . . .

Maggie’s view is, ‘You will have a job’. She is right of course,

we will have to have an income. But this break was to be the change in our lives – I would be able to work at a pace, and in jobs, that suited *us* for the first time. I would be able to spend time with her investing in a home and a lasting community. All that is changed of course but I had hoped for, indeed I had not considered otherwise, a situation where I was the principal carer and kept our house and worked from home – our income would be limited but we would cope and do it together. This was my earnest wish, my duty, my everything – *my* hope for the future. Maggie's may be more practical and, if it is what she wishes, then that's the way it will be. At the extreme it will mean a large house – accommodation for mum as housekeeper – if she will take on the role for a few years, perhaps accommodation for a nurse/helper, plus space for friends/visitors as well as the girls and me. That, and the wage bills etc, will mean a large income which probably means a full-time job in practice. That will leave me out as principal carer I guess. The last thing I had anticipated was being forced back into the sort of life which we were trying to escape by leaving the RAF. I work. Maggie stays at home. Just talking takes so long now that, if I am not there, we just won't talk. Who will talk to her and listen to her like I would? Will she be content? Will she be lonely?

There are even more worrying possibilities of course. If I am out of the house, away from her, immersed in work, out of touch with her thoughts, will I stray? If I can't talk to her who else will I talk to? The only person I've ever opened up to is Maggie. If I find another confidante what will that lead to? Weak as I am I may betray her love and trust. So I want to be involved to the maximum possible extent to guard against my own weakness as much as anything else. I have always done well at the things I involve myself with – and done them consistently and obsessively . . . I want to look after my wife and help her to still be *her* – as independent as possible. Because she is so physically dependent I fear that anyone else will, however good their intentions, make her gradually dependent in other ways too.

14TH APRIL – Day 31

'Too busy' again yesterday. In all day. Knackered by nightfall. No great highs or lows. Tilt table in the morning, chair in the

afternoon. A latish finish following tearfulness and frustration as Maggie, Elinor and I discussed university. Elinor is thinking of binning it this year, caring for Maggie for a year (and working), and perhaps reapplying next year.

After some heated discussion (including some pithy comment from Maggie) it was decided (I think) that she would accept one of the offers (which, she hasn't yet decided), and then ask to defer for a year if it seemed sensible nearer September. She must feel like I do – obliged to care – not for Maggie necessarily but for *ourselves*. I guess she will be driven and obsessive too. Ah well.

Today has seen some highs and lows though.

The low was when we had settled down (Maggie, Elisabeth and I) after the afternoon session in the chair. We were 'sorting' – pillow arrangement, splints, head position and so on. Maggie started crying and it got worse and worse – she was sobbing her heart out – and making an appropriate noise of course, sobbing and sighing and moaning high-pitchedly as she does when tense and breathing deeply. Add a bit of coughing with the increased secretions and it is easy to see why two of the nurses who are not used to her started to fuss around. One wanting to give suction (which Maggie did *not* want) and one, bizarrely, trying to take her temperature. All we wanted to do was hug and comfort her and find out why she was so upset. We eventually did so – she told us by blinktation – and it came as a blow. I had not been listening to her. 'Why don't you listen to me?' I could hear the accompanying wail and the anguish in her voice. This is me – the great communicator, advocate and friend. She wanted a bedpan too so Elisabeth and I went to get some lunch at the shop while the nurses did the business. I felt so distraught. The one thing that I am supposed to be good at, am proud of, teach others about – I had failed her. I think I must be a bit low myself because while munching my sandwiches and crying into my crisps I even began thinking about killing us both. Her first, then me – with her collusion of course. Such despair over a communication cock-up is quite surprising and very frightening. Some perspective returned after 15 minutes or so. It *was* just a communication cock-up and, let's face it, we should expect some given the difficulties we all face. Maggie forgave me I think.

I did talk to
Busy!

IT'S NOW 15TH APRIL – Day 32

I can't remember what I was about to say yesterday.

Note in the margin later – Yes I can – I talked to Debs about our role in Maggie's care and about the need for privacy to cry rather than lost of medical attention – she was extremely understanding.

However, the highs were further neurological improvement – at least I think it's improvement, I'm not sure about the significance of some of it.

Firstly, the associated movements have changed.

Left neck tension is generally high and right leg tension is high, arms are about equal – no change there. However, today the left extensor movements of the left leg became flexor! Why? No idea! But where the right leg shoots out like one of those hooters you blow through at parties the left leg bends to 90° or less. Does this presage anything?

Next, smiling is a regular and easy feature. Carolyn Dewhurst visited for the first time and, unlike those who visited in the first fortnight, chatted away simply and easily because Maggie was smiling and laughing and encouraging – with the left side of her face at least. I asked her about this. She still couldn't show me her teeth – no facial movement at all – but she could smile. She can only smile if it appropriate to do so, so she is making it more appropriate by conscious effort rather than smiling by conscious effort.

Lastly, the right head movement is present to a much greater extent than we realised. It has been masked by the generally high tension in the left side of her neck. However, on three separate occasions while lying relaxed, she quickly and easily turned her head to the right. Wow! The first time I saw it happen was when she turned to look at me. I was astounded – just a normal fluid neck movement. I almost shouted, 'did you do that?' She signalled, 'yes' and looked simultaneously as surprised and delighted as I did. That triggered a laugh which caused left neck spasm to pull her head central again but so what. It's a huge achievement. Head movement in *both* directions is useful whereas head movement in

one direction only is useless without someone, or some contraption, to pull the head straight again.

Elisabeth and I returned home early via Tesco leaving mum to be returned by Kathryn and Elinor to finish off and return to work.

Today the 'switch people' from Mary Marlborough Centre came again. The magic box wasn't charged and wouldn't work. After a brief charge it was good enough to fiddle with and we quickly got a very good 'click' – and this time, with the sensor facing the top lid – with excellent specificity – *no* false alarms. So bottom lid for sensitivity, top lid for specificity. We have the kit to play with over the weekend but the main problem will clearly be comfort. The glasses, big, clunky tortoiseshell things with no glass but heavy frames are remarkably uncomfortable and leave a line across Maggie's forehead even after half an hour. I will have to try something else – perhaps based on a head band . . .

Mum to the station at lunchtime. Fairly happily I think. We three have three days now to get our respective houses in order before Elisabeth returns to school.

18TH APRIL – Day 35

The days seem busier and busier. I have been topping and tailing 75+ letters and getting them ready for despatch in spare moments as well as washing up, preparing food, tidying, paying bills and – still most time-consuming of all – answering the telephone. It rings incessantly most evenings. The mail has dropped back to normal levels – really just friends and close family now – the usual pattern. Warwick Pike has moved on but rang to tell me that I was on compassionate leave for 30 working days – until 27th April – and to wish us all the best and to make again the offer (discussed already with Mike Ranger) of staying in for a bit longer if we need to while we get settled. I explained that we need the gratuity to buy a house!

We all went (all being the three of us – but you know what turns of phrase are like) to the Red Lion last night for a meal, instead of

fish and chips. After I had apologised for ringing Elinor's work to get her off an hour early (me treating her as child instead of adult again) it went very well. We all relaxed, we all talked properly for the first time in days and nobody 'phoned! Well worth doing.

Maggie continues to improve slowly. She seems to be sleeping more easily, more deeply and for longer periods (2 hours plus sometimes). Her face alters daily. On the left she now has normal tone, including some small forehead wrinkles and a little frown, her chin and cheek look normal. On the right things seem to be 2-3 weeks behind the left – so her chin is tightening up and the mouth to nose crease is deepening but there are no eye wrinkles or forehead wrinkles yet. Crying, laughing and smiling all occur readily now on the left, and there is a hint of voluntary movement at the angles of her mouth left and right – but only a hint. Smiling etc are emotionally driven moments which she can cause to occur voluntarily by feeling the right emotion! Left neck movement is becoming stronger and right neck movement is occurring more often but needs a relaxed neck – she can't overcome the increased tone in the left neck but, once relaxed, she can move her head to the right – an up and back rotation – against gravity! I think we could try head switches again soon. The eye switch is currently a non-starter because the glasses on which it is mounted are uncomfortable by design! I am working on a headband with a switch mounting made from Velcro and a bit of a drinks can! As Maggie says though, 'Whose benefit is this switch for?'

Things are looking up a little I feel. Maggie thinks so too but is still, not surprisingly, burdened with a huge weight of despondency. A couple of millimetres of right eye movement gained, while definitely a 'good thing', does not compensate for a life in ruins.

I discussed the return to work issue with Maggie yesterday. She is right. It has to come. I will go back at the end of the month in the mornings. 8-12 probably. I can be in Oxford for 1 and will only really miss the wash and the first physio session. Then I can stay until 8 and get home in time to eat, pay bills etc and go to bed . . . It will be difficult but doable I think. With Elinor back

at work already and Elisabeth back to school today life will then be as 'normal' as we can get it in the circumstances – all ready for rehab!

Meanwhile I will do my consultation 'lecture' at Cumberland Lodge next week. Richard, Philippa and Maggie all think it will be a good idea.

19TH APRIL – Day 36

An eventful 24 hours.

Yesterday lunchtime Maggie complained that she had stopped improving. A few hours later, while the trachy was capped (1 hr 5 min on the second occasion), she was using the opportunity provided to try to speak. She can't phonate unless the airflow is sufficient and that only occurs during and after coughing, laughing and crying. The moan is an 'aaaah' – as if she is in pain and she can't make it 'eeee' or 'iiii' but she can use her tongue to alter the sound a little and she is certainly developing better lip movement. Elinor came in from work – Elisabeth left in a huff – I haven't got to the bottom of why – but I said to Maggie, 'Say hello to Elinor' and she did – a recognisable if slurred word, 'Hewwo' – and in *her* voice. Wonderful!

The eye switch may become redundant after all because right and backward head movement is stronger too so a head switch may be an interim possibility. I think the eye switch for computer/writing use is probably going to be the best bet even though it isn't much use as a call system. My brilliant idea of focusing on the top lid rather than the bottom results in much improved specificity of 'clicks' but they are in the wrong sense so none of the kit works! Now it is eyelid=off, eyeball=on whereas all the kit is based on eyelid=on, eyeball=off. Oops!

However, a head switch may be a better idea soon. Head movement to the right and back is stronger still, though not yet enough to compete with left neck spasm or gravity. Or maybe a jaw switch! As Maggie finished speaking she was able to tell us that she could open her jaw. And so she can, slowly, if she relaxes, and about ½ cm. Wonderful again!

I took Elisabeth back to school in the late afternoon – just as

the Edgars arrived for communion. Elisabeth seemed fine, back amongst her friends and with lots to think about and do. I had a pleasant and useful chat with Mrs Steel about Elisabeth too – the story so far, Elisabeth and short-term arrangements and exams, and Elisabeth and the medium-term – the 6th form. She will let the examiners' know about Maggie's problems, not that she feels Elisabeth's results will be too badly affected but best be safe. She also pooh-poohed my financial worries about the last four terms. The Guild will sort it, a bursary will be available etc – the bottom line was that if Elisabeth wishes to stay she will stay. What a huge relief. Elisabeth will *want* to come home of course, when we have a home, but the school will support that too – no need for a term's notice . . . I even got a cuddle.

Today Maggie is exhausted – it's 1500 now – after a wash, a stretch a $\frac{3}{4}$ hour sit, a tilt table (and a faint) and 2 hours with trachy blocked, and a visit from Jane, and the OT to measure up for new hand splints, and the pharmacists (bowel Rx) and the dietician . . . and a move back to bed 1 – the original bed in which we had such trouble 3 weeks or so ago.

22ND APRIL – Day 39

Busy, busy, busy. Each day is packed with work at hospital and work at home. Sitting thinking at either place is out it seems. Still, it's worth it. Kathryn is here just now and, at 1600, the day is quietening down. My current gripe is the water. Today's has still not begun – they haven't got any vacutainers (again! – that's three days in a row). They did notice this morning and someone (good old someone) was despatched to borrow one as Maggie went for her bath. Six hours later no water and no-one can remember who 'someone' was. Still, the swallowing test with the blue dye was done today – no dye seen immediately or after an hour – so we will be officially on liquids by mouth soon I hope. It is so hot in here – we have a window open today which helps, and the fan runs continuously but Maggie (and we) still sweat freely – she because she is surrounded by sheets, pillows, air mattresses, *et al.*, and we because we are lifting, moving around and so on. She has been saying that she is thirsty for some days, her urine output

is low (or at least we think it is – the nurses aren't sure what has been passed/recorded and today the charts seem to have been lost!) and yesterday *again* she had a blocked catheter – just sludge and concentrated urine. No-one seems to know exactly what urine output they would like to achieve so no-one adjusts flow in to match flow out and no-one adjusts for increased insensible loss due to sweating. No wonder Maggie's bowels are clogged up. Anyhow I have been waging a slow campaign about fluid intake for a couple of days – asking questions, making gentle inquiries, saying 'physios are finished, we're ready for the water now . . .', and waiting for responses. Today I managed to collar the dietician who seemed a bit irritated with the ward – she had written them a programme about it all and seemed surprised that it isn't being followed particularly exactly. The solution to, 'is she dehydrated?' – get the SHO to do U&Es! Whatever happened to urine SG and urine volume?

Anyhow – we will make sure she gets enough fluid. Water, OJ and (via Kathryn) G&T have joined the grapefruit juice today. 2ml at a time via syringe is greatly appreciated and readily swallowed and causes no hassle at all

Deb came today and Jilly is due tomorrow – Easter hols are over and everyone is back in circulation. Moira rang this morning and she and David will come perhaps at the weekend. Marge will be delayed – her father-in-law has had a stroke!

Movement is returning apace – sort of, it's never fast enough or dramatic enough, we always want more and faster – Maggie does too. Every twitch regained is both wonderful and frustrating.

Eyes:

- ◆ snappier but no greater range of movement. Some reduced VA (R worse than L) investigated by the ophthalmologists – no worries but not really sure why . . .

Head:

- ◆ good powerful L rotation and extension now, extension is fairly central too and enough to start getting her head out of

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trouble in bed, but not yet powerful enough to pull her head back if it falls forward when sitting out. R head rotation is free and easy if she is relaxed but difficult otherwise.

Face:

- ◆ Improving tone on the right but *normal* on the left, lip movement (voluntary) is returning on both sides and she has a quiet smile, a maniacal laugh and a very expressive set of left eye and eyebrow movements.

Jaw:

- ◆ Opening! A couple of millimetres of teeth separation at the weekend, slow relaxation which took 20–30 seconds. The feeling was obviously wonderful because, success having been achieved, she laughed and the spasm immediately returned and closed her jaw! However, this afternoon she opened her mouth 1cm or so on several occasions – *certainly* enough for a spoon – and, while it is open she can move it side-to-side – chewing next!

Ankle:

- ◆ On Tuesday – day 37 – Maggie moved her right ankle. It sits in inversion unless splinted but she was clearly able to invert/evert it by 1–2cm at the toes – and . . .

Hand:

- ◆ On the same morning she moved her right thumb – abduction and adduction of a few mm.

While the neck, jaw and mouth movements are wonderful and presage eating, looking and speaking, the ankle and hand movements are of a completely different order. Peripheral nerves. Below the neck. Wow! What do they presage?

Yesterday things developed further – the thumb movement was little better but Maggie was able to flex and extend all her fingers for a few mm either side of the rest position. Today I held her hand so that she could show the physio and her ring finger flexed/extended a couple of cm! Really useful movement.

This evening I held her hand so that she could show Kathryn and she was able to flex the first and fifth metacarpals – the palm-cupping movement.

All of these things are great to see and even better is to participate in Maggie's joy. Her face when I held her right hand up in front of it so that she could see her hand movement! Excited like a child seeing its first balloon.

I need to loosen up – or do I? Elinor and Kathryn are joshing Maggie all the time. She laughs and spasms almost continuously. She *seems* to enjoy herself but ends up tired out and stiff. They communicate with her so slowly. At least – they allow *her* to have *her* say so slowly with all sorts of stories and irrelevancies and guesses during Maggie's sentences so that, by the time Maggie's words are complete they are paragraphs out of date. I guess that's the way the world is, and is going to be, for Maggie. She has no chance of repartee or of shouting anyone down – unless her speech comes back in spades.

I try to be calm, allow her to relax, encourage her to work at movements and speech, talk *her* thoughts at *her* pace with no (or very little) interpretation from me. So the others irritate me for the way they play with her as if she were a doll – no not a doll. Still Maggie. But *their* Maggie, not Maggie's Maggie, not my Maggie. I am sure that I am as possessive and directive as they are. And I know I irritate Elinor – glorious happy blunderbuss Elinor.

The answer I know is she needs all of us, with our different attitudes and actions and irritations. I *must* back off a bit and let her have a life apart from me, as she has always had. Once I am confident that she will come to no harm though. That's why I'm sitting in the pub now, having a relax and a quiet beer and writing to myself. Elinor and Kathryn are doing the evening stretches. I will have an hour or so then, quiet with Maggie, for us to be us alone before the drive home. Elinor's turn to cook – I wonder what. And I wonder when Maggie will taste 'normal' food again – soon I think.

23RD APRIL – 40 days in the wilderness

What's due to happen on day 41 I wonder?

I'm in 'Jude the Obscure' again at 10 to 8pm. Sent out by Maggie to get some supper before we settle down for night. They stop serving food at 7.30 so it's a pint of Varsity and two packets of crisps – which will be quite sufficient.

A good day I gather. Four hours of capped trachy, with laughing and coughing included. Jane visited in the morning and brought a 'toilet seat' head pillow in the form of a duck – it may work I guess. She had to get it from Mothercare (!) so Maggie is not overenamoured with it – makes her look silly! Then Jilly followed – she was normal Jilly I gather; what a blast of fresh air that must have been. Elinor didn't remember her. I wish I had seen her, I need a blast of Jilly too; concentrated and acerbic common sense and caring.

Di and Ivor came too – what a couple. Chat and gossip and irrelevancies and love with solidity, compassion and dependence – they were still there when I arrived from my day's 'rest'. Looks like the original problems that people had talking to Maggie are gone. They were just chatting normally – Maggie never could get a word in with Di anyway!

This evening I opened two day's worth of mail – mostly uninspiring and routine but, remarkably, a letter from Lindsay (16 point – A5 width!) enclosing the WCS committee minutes for Maggie's perusal. They pass muster but Maggie wishes to respond formally so we will begin that this evening. She seems appropriately chuffed that everyone is including her in things. The letter she wrote is bearing fruit – there have been a couple of emotive replies so far and there will be more. I am staging their sending so that we don't get a rush and then nothing.

Soon it will be time to start Round Robin 2!

My 'rest' was useful.

Pick up the car from servicing, haircut, building society, post office, home. Bins back from the front, washing out, breakfast and paper, in to work, chat with Sandra, pick up papers, hunt for 'Consultation' presentation – no joy, must be at home, back home, hunt for 'Consultation' presentation – no joy – Arghh! I don't have time to gather everything again, there were 40+ references! . . . empty washing-up machine, do washing up from last night, bring washing in (raining), water greenhouse, put washing out

(dry now!), empty bins through house, bring washing in (raining again) and put it on rack to dry, make scrambled egg lunch, wash up, clean kitchen thoroughly (except the floor), iron shirts and nighties, take 'phone call from building society about M's accounts, check HBOS (£999 overdrawn!!! – Arghh – transferred insufficient to cover school fees – transfer £1000), time to go, leap in car, head for hospital . . . Quite relaxing actually!

25TH APRIL – Day 42 – 6 weeks – Sunday

A day both peaceful and traumatic yesterday. I stayed over on Friday night. Maggie was tired but we watched 'Gardener's World' and 'Have I Got News for You?' together before sleep. We both slept quite well, eight hours in total I should think between 10 and 8. The trick is assiduous attention to position. If position is right then sleep follows, if not then wakefulness, discomfort, increased tone, spasm, coughing, more spasm, worsening tiredness, anxiety, increased tone . . . The nurses on hadn't got a clue really – they would do a turn then walk out leaving Maggie's arms all over the place, no splints or bears, head to one side – worst of all was the cheery, 'Is that alright Margaret?'

'No', very firmly with the eyes.

'OK then, let us know if you need anything', and off.

It is probably ignorance and lack of insight rather than lack of compassion although that may be an issue too. The most worrying thing is the huge variation in the standards of care. Some nurses are excellent, most are middling, a few are worse than nothing if not actually dangerous. I haven't seen anything that would damage Maggie permanently occur yet. I have seen major discomfort ignored or caused – who knows what psychological effect that will have.

Yesterday I 'helped' Peggy give Maggie a bath – although having helped with two now it quickly became evident that I was the experienced one. However, all was peaceable and went well. The bathroom queue was rather long so we didn't get in until lunchtime. We were still tidying when Pat arrived, so Pat dried Maggie's hair while I popped for fish and chips and a pint in the pub across the road. Shortly after I returned Elinor and Kathryn arrived too and, in amongst all the talking and fiddling Maggie

became quite distressed. Thoughts of the future and the past mainly – the things which get us all going. There was a disconnect, Elinor went off, Pat and Kathryn had already gone for a walk and Maggie and I were left crying together – at all our problems and dashed hopes but also because we weren't able to manage the family properly – simple lack of communication. Two of the nurses came in after a while because of the noise – Maggie can't cry quietly – and we had a brief and fairly terse discussion before they left. If she can cry for five or ten minutes with no-one in earshot that doesn't matter but when they hear they come en masse, draw the curtains and want to 'do' things. At least no-one tried to take her temperature and BP this time and we were left alone to cry and talk. I went along to patch things up afterwards, not entirely successfully I fear but at least I made the approach. Elinor and I were fine again by the time we sat down to our Saturday chips. I don't know how Maggie was, I can speculate by multiplying my own distress and frustration by ten, but I don't know.

This morning I arrived at 10 to find Maggie washed and brushed in bed. A bad night again due to poor position according to her. Rose said it was a bad night due to diarrhoea – an inevitable consequence of the co-danthramer which produced the red urine yesterday. Maggie had had a bath because of the diarrhoea – a bath during which, according to Rose, 'everything went wrong'. I haven't asked for the details. Maggie looked shattered. I gather that she also required a lot of suction and that her sputum was nasty green-looking.

When I walked in she was coughing, but then her head had fallen down, forward and to the left so that her chin was squashing the Swedish Nose forcing her trachy tube to rub on the inside of her trachea. Righting her head stopped her coughing. She wanted a nebuliser which I gave her, and after a suck of loose, thin, pale-yellow, moist-looking sputum (and alteration to sitting position and arm position) she has fallen peacefully asleep.

The feed has been stopped since before the bath (? 9am and it is now 1120), 'to give her a rest'. How the dribble of food into her gastrostomy would disturb her I don't know. Feeding often falls behind with other activities and we don't want dehydration (and

blocked catheters) again thank you – a risk with the diarrhoea too I guess. So I've suggested that they restart the food. No point in her getting hunger to add to her other problems.

How do I feel? Frustrated, useless, tired, tearful, very much in love. I'm not sure how much longer we can go on like this but, like Maggie, we have no choice. There is no respite. There is no alternative. We have to keep at it, pushing ourselves and encouraging others to give her the best possible chance for the future. Then we have to build the future. Deep breath, keep going . . . And back to work next week?

30TH APRIL – Day 47

What a week. 'Back to work' involved considerably more hassle than I expected – but I think it's workable and oddly enough I feel more *use*; and I don't think Maggie's care has been materially affected.

I'm doing half days, leaving work at about 12 and getting here at one-ish – still plenty of time to meet the afternoon visitors and communicate on Maggie's behalf. I will still be in on the morning care during the weekends and the late mornings are in the hands of the physios mainly – who are fine now with all aspects of care and communication. The nurses are much happier too and our relationship seems to have settled down nicely. They had their 6-weekly shift change at the start of the week and so we have lost Debi and her team and gained Lucinda and hers. We took the opportunity to chat formally with Lucinda about our various roles and relationships – an excellent idea getting things out in the open from the start. We now feel happy to do our bit without sneaking about, the nurses feel empowered to do their bit without upsetting us and, hopefully, we will avoid Maggie's care falling in between two stools.

We have all had a few tears this week – just general hopelessness really. Thinking about the day *after* tomorrow is not good for anyone's health. Still, lots has happened and Maggie seems more buoyant this Friday evening. I await my fish'n'chips in 'Jude the Obscure'. She is sitting in bed, trachy capped off without any of us present! Only possible because yesterday we finally cracked

the call system. Maggie's head movements are now powerful and well-coordinated enough to operate a pillow switch with ease and Lucinda is still waiting for Avon to call! She slept well last night and was able to call for turns and splints with only two false alarms – but those were related to coughing and switch placement, so not problematical. It's a huge relief to me – and to her. Martin Wozencroft from MMC has taken the eye switch away and over the weekend we will work on communication using a finger switch – the right ring finger now has powerful flexion at the PIPJ and sufficient extension to switch 'off' too.

The major advance this week though has been above the shoulders. Power, range and coordination of neck movement have improved dramatically. Maggie started nodding and shaking her head on the pillow today as an adjunct to eye movements for 'yes' and 'no'. She can get herself out of most awkward positions if her head falls, can *almost* control her head when sitting in a chair and can wiggle it side-to-side to readjust it on her pillow when coughing causes her to flex forward and lift head and shoulders from the bed.

She now has a wide range of left facial movement and right facial movement is beginning at the corner of her mouth and round her eye. Right eye closure is now normal.

Best of all her lip, tongue and jaw articulation are noticeably better day-to-day – so speech *will* come, and soon I think. The only difficulty is phonation, which is still mainly on the back of the increased airflow which results from coughing or laughing or crying. But it's coming. With thought she can noticeably deepen her respiration and slow the rate – this may be a 'Yoga' reflex though rather than true control. She can't hold her breath although she can block expiration a little – ? a straining at stool reflex?

All of these things give me so much hope. If we can communicate by normal speech we can do anything.

A few weeks ago I confessed to Maggie (I think!) my hope that she would be able to attend The Creation. She said, 'No', resoundingly to my recollection but I confess that that may have been in a dream, or it may be something I meant to do but never got round to mentioning. She was right of course – impossibly

impractical, she couldn't sit then, or breathe properly and she hated the idea of people seeing her. She went, 'Ahhh' this evening, quite tunefully instead of the usual low moan, while we were doing voice practice. I said, 'not bad, you might even make The Creation'. She flashed and said, 'I could attend'. Wow again! What optimism, buoyancy, aggression, hope . . . We talked it over a bit (I talk, she flashes 'yes' or 'no', usual system . . .). The evening performance, church packed, long night, lots of visitors, coughing uncontrollably . . . could be a problem. But the rehearsal, friends only, no audience, can leave if gets tired, can cough, easier to organise in the middle of the day . . . 'Yes', she said.

Then reality set in. It's only three weeks away, she is bed-bound and her maximum time in the chair is two hours. *But* the Aylesbury wheelchair lady came this week and a better chair arrives next Thursday and, most importantly, there are three weeks to go! Three weeks ago, I looked it up in this book, was gastrostomy day and the first hint of left lip movement. A lot has happened since then and will happen in the next three weeks. So – to planning.

We will need Elinor and Pat (and ?Elisabeth – important event after all) and a bit of support from the hospital/Rivermead and an ambulance (Halton?) or a tail-lift van to hire . . .

It can be done – and it *will* be done!

3RD MAY – Day 50

Elinor's in tonight so I will be alone at home for the first time since the stroke. It should be OK. This life is normality now. It's difficult to remember the tearful, despairing early days when the 'phone never stopped ringing and I kept rehearsing Maggie's obituary just in case. We have several 'interim' months now while we wait, and wait, and work, and wait to see what we will have to plan for in our new life together.

I'm looking forward to the planning and the doing. The waiting is truly awful. I wake at about five each morning and think about it for an hour or so. What will we do, where will we live, who will care for Maggie, how much care will she need, how will we pay for it . . . and then, what will our relationship be? Husband and wife (and in what senses?), carer and cared for, partners, nurse and patient . . . I quickly start swinging between wild optimism and

hopeless despair, euphoria and hope, tears and sobbing. I'm still not sure what is real and what isn't, what is a reasonable hope or plan, what is fantastic or stupid?

I just want Maggie back, *my* Maggie. She wants to be back too – we both know that that is unreasonable and unlikely – at least for years to come. So there will be a new Maggie, a new us, but with lots of the old us incorporated. When will we know we are there? When will the new us be established, will we keep hoping for more until we are old, every day looking for physical improvement? When will we say (as we have been coming to do with the arrival of secure middle age), *this is us*, like we are, like we like to be. All our friends have achieved that same stability – more or less. We are starting out on a new life just as much as if we had decided to jack everything in and sail round the world. Who will be with us on this journey? How long will they last the pace? (How long will we?)

Maggie wants to talk and walk and cook and be herself (she hasn't mentioned playing the piano though). I want all we can get. We already have more than I had originally hoped for. So where are we and where will we be?

- | | |
|---------------------------------|---|
| She will come home. | <i>Definite now.</i> She can breathe, feed and be hoisted to bath and chair . . . |
| She will talk. | She will probably be able to talk in a few months. 'Hewo', 'No', 'Mama'; recognisably (to me) today. She needs better breath control though, to phonate and laryngeal control (for vowels) and tongue control (for gutturals – the tongue-tip vowels are coming already). |
| She will drink (and maybe eat). | Better tongue control will sort voluntary swallowing out too. She can't shift food to the swallowing position properly. Having said that she ate half a chocolate mousse today with minimal aspiration. There is a prospect of losing the gastrostomy in time. |

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- She will get rid of the trachy. The tracheostomy will be gone I feel certain. Four hours capped today and still going strong when I left! Jaws and lip opening are becoming independent and she can therefore breathe through her mouth if her nose is blocked. Protecting her airway doesn't seem to be a problem (by coughing) and better gag and swallow would settle things. After that things get more woolly – or perhaps run into the late '99 bracket by which time we must have made some decisions.
- She will operate a computer. Her right hand already has useful 'click' functions proven with a switch today. But new today is wrist flexion and extension on the right. Weak, small angle but present and everything she has now started weak and small.
- She will watch and listen. Neck movement is strong and getting stronger so, combined with good left eye movement she has excellent senses. Eyes and ears are useful and have few limitations.
- She will operate a wheelchair alone. Hand/neck movements are good enough (or will be) for this. Now then, is that enough for us to be us and her to be her? *Probably* (but we will both be different people).
- Will she need 24hr nursing? As to other things: Moving in bed (turning) – possible but will need big proximal muscles to return on one side at least.
- Will she cook? Moving hand into useful positions (and therefore cooking! . . .) – probable/possible/don't know = but a reasonable hope for the right at least.

Will she walk? Walking is unlikely I think. It requires such power and coordination. But we could hope for enough bilateral arm power, or unilateral leg power or both to make transfers possible without a hoist! That would be a huge bonus . . . I've left sex out of the list so far. It seems obvious to me from the way we act and feel about each other even now that that will be inevitable. Best I go ahead and get the 'snip' as planned!

5TH MAY – Day 52

Dr Wade came again today, with another new SHO. Maggie was in the chair having been capped off for 6 hours plus, moving head and fingers and jaw and smiling. Anyhow he just dropped in the, 'so we'll see you on the 17th.' First we, or anyone on the ward had heard about it but so what. The 17th it is! More hope, more steps forward.

The chat with Jan Keating yesterday was useful. The first formal consideration of where we are headed. Pretty much along the lines we have 'discussed' between us – which are outlined on the previous pages. I will go for the Tim Huins job (or the West Midlands job) or similar. We will buy a house that is wheelchair friendly in an area which *we* want, in a community which *we* want. Just as we were going to do anyway. And we'll build a home and join a community just as planned. So that's that.

Still getting the despair and heartache though, and the 5am wakening. When I'm with Maggie I'm content and can't bear to leave her alone at the evening's end. If she's with the girls, or a few other selected people, it's fine now. I can take a break, as I am at the moment – in 'Jude the Obscure' again. But at night, leaving her to the *staff* I don't like at all. I spend much of the time when I have time (cooking, eating, sleeping . . .) thinking about the discomfort she could be in, her frustration, her loneliness, her pain, her feelings of uselessness, her lack of control. When I'm heading for the hospital I just want to *be* there.

I got very grumpy with Lucinda yesterday (? a day or two ago, at 1000) – which was unfair because she is one of the best. When I

arrived Maggie just looked a mess. Instead of setting to and sorting her out I kissed her and said, 'hello', and then went for a nurse. Lucinda came quickly and asked if anything was the matter so I let loose: 'her knees are bent up and falling out of bed, the catheter is therefore pulling and she has cramp in her legs, the hair is in her eye, which is therefore watering, red and painful, she is bent over so that her trachy is uncomfortable and she is coughing, her arm splint is digging in to her thumb but worst of all someone has removed her pillow and switch so that she can't call a nurse . . . Oops. Maggie can get into that state in one cough, a few seconds. I apologised. But I was right about the switch. The ultimate in loss of control is to know that you *can* call and that the switch system works and then not be permitted to use it – worse than not having it in the first place.

But, on the whole, a good and hopeful day.

8TH MAY – Day 55 (Elisabeth's first exeat)

This is desperate. I don't know how I'm going to manage. When Maggie is improving, or achieving, or just content things are bearable. But I feel exiled at the moment. She is sitting in her chair with Elisabeth and Kathryn so she's OK, and cared for, and they seem better able to please her than I at the moment. She won't even look at me, just turns her head away. I feel cut off from the world. She *is* my world and if she won't look at me, cries when I try to help her – what can I do. I'm just worthless.

I feel sure that it's frustration and lack of communication, on both our parts, but how can we sort it out? Peace and quiet and hugging and talking would do it but there's only half hugging possible and there's no privacy. We can't talk with an audience. I'm the one who takes responsibility so I'm the one who gets the blame. Some day for Elisabeth too. Her first day with her mum in three weeks and it's been coughing and anger and crying most of the day. Elinor will turn up from work via Tesco in an hour or two, all bounciness and will, again, step in to a tense and tearful situation and take over. Elisabeth will be irritated, I will be sidelined and Maggie will probably perk up, start laughing and be her 'normal' self again.

It's just not been a good day at all. Maggie's hopes were high of 24 hours with the trachy capped. I'm staying tonight for that reason – no that's not so. I'm staying tonight for *us*. The trachy-capping is timed to fit with me staying.

We arrived to find the wash in progress and two unfamiliar nurses getting in a mess. Maggie was hot and bothered, had slept poorly through coughing all night, and the washing, dressing in pyjamas, making comfortable was slow and cack-handed. It was done eventually but she still looked uncomfortable. No hair wash again and no bath since last weekend. I mentioned that but, 'the bath's broken . . .'. I asked about the bath on Kilner ward which we used last weekend but the nurses didn't know about that! Then the trachy cap was lost. Anew one was sent for and the cleaner eventually found the original, still in its pot, hidden under the bed.

I showed the staff nurse how the cap worked and we set off. Maggie coughed a lot, just dry coughing and rather sticky, white, foamy mucus – just from repeated irritant coughing I think. The collar was tight and I could see the trachy give a tiny 'kick' at the end of each breath, as the tube caught on her trachea presumably. The thickish white mucus was difficult to blow or cough past the trachy and, after 90 minutes, Maggie gave in and we removed the cap. Loosening the collar seemed to help too but only a little. Maggie puts the coughing down to swallowing. I suspect that she is getting some inhibition of swallowing because of the 'catching' and the coughing. Vicious cycles.

Anyhow, by mid-afternoon Maggie is sat out in her chair. She wanted 'hand practice' so I started the right hand physio as I've seen the physios do, after offering handwriting practice again! Somehow I couldn't do anything right. I'd only just begun, with simple flexion under power and a mixture of active and passive extension of the fingers, but Maggie wasn't happy. She spelt out, irritably, slowly and between coughs, 'S-T-R-A-I-G-H-T-E-N' but the coughing and crying and spasms became so bad that we couldn't understand what she wanted. Several bubbly 'No's were pleasing to hear though. Eventually, after agreeing to her wishes not to be sucked, not to have the trachy and nose cleaned, not to have her feet put back on the rest, I told her I was going to do it anyway. I sucked out, straightened her up and at last we could

communicate again and the coughing stopped – but she won't look at me.

Am I being hard? Am I a nurse now and not a husband? Why does she reject me? I can see and hear her problems, problems which she can feel I know, but if I can see that she is breathing sputum and mucus in and out *why* won't she say 'Yes' when I want to suck it out? It solves the problem!! As it is I spend more time preventing people *doing* things to her than permitting or encouraging things to be done. I ask her what she wants, and obey her wishes, to a much greater extent than family, friends or nurses. I will let her bubble and cough to a degree that is painful – the heartache is back again over the last couple of days – if she wishes it. In eight weeks I've only done something *against* her instructions a couple of times (although I am as guilty as anyone of moving her arm, wiping her mouth, adjusting her neck to make her look comfortable – rather than enabling her always to be comfortable).

I don't deserve this. She deserves it less. How will we cope?

I can get a break. Others can 'care', look after her, talk to her.

She has no breaks, not ever. I love her so. I *can* give her a break by being there in case, but allowing her her freedom to sleep, cry, cough . . . This may be my most useful function.

Guiding Principles

MAGGIE'S AUTONOMY IS PARAMOUNT

If I won't let her cough, cough, cough . . . endlessly when she wishes to how much more difficult would it be to let her die/ be killed if she wished it. I have an inkling of the problems of implementing living wills.

There's me too. I can't be buoyant, flippant and cheery when I'm not. Others can do that. I will do what I do best. Love her, be constant and dependable, caring and *there*. Others can *make* her laugh. I must just *enable* her to laugh, to cry, to think, to be.

14TH MAY – Day 61

In the groove. Back working in the mornings 8-ish to 12-ish, over here for 1-2-ish, leave 8-ish, home 9-ish, eaten and washed up by 1030-ish, odd jobs and phone calls and shared time with Elinor, bed 12 to 1-ish, up 7-ish . . . and round we go again. All days are the same in plan but differ in the detail.

Over to Philippa's for dossier-marking yesterday, 6-month interview for a registrar today (and the second specialist wishing to convert to GP in a day!!) . . .

Eating at home on Tuesday night, at Neil and Jane's on Wednesday, going singing on Thursday and in J the O for a pint and chips before staying the night tonight – Friday.

And Maggie? Every day is the same for her – and different too. The routine varies (through disorganisation as much as anything else!) and the overall trend is improvement but all on an unremitting background of paralysis and frustration and helplessness.

A catalogue:

- ◆ *Eyes* – consultant came this week and explained the return of right gaze with the left eye only and the return of the diplopia (especially with distant vision). There has been an improvement in the nucleus controlling right gaze – this operates on both eyes so Maggie should have a return of conjugate gaze to the right as well as on the left. Unfortunately there are fibres of abducens passing nearby so it is likely that the return of right conjugate gaze is masked in the right eye by a VI nerve palsy! Blast! Maggie’s tendency to cross her eyes and lose fused vision is down to this it seems. A pair of glasses with the right eye misted helps her to read.
- ◆ *Ears* – no tinnitus any more!
- ◆ *Neck* – power and coordination are good enough now for Maggie to hold her head in balance for a couple of minutes, to move it in all directions on the pillow or headrest and therefore, to direct her gaze usefully wherever she wishes. She sometimes lets her head dangle forward 90° and then looks sideways and wiggles it about and looks ridiculous (!) – *just because she can.*
- ◆ *Jaw* – jaw opening is reliable and good enough for spoon feeding and teeth cleaning. Maggie can protrude her lower jaw and retract it almost far enough to make an ‘F’; she can wiggle it left and right (especially right).
- ◆ *Tongue* – improving too, moving to the right better than the left. Tip movement is nearly good enough for ‘Th’ and ‘L’ is coming occasionally. Rear movement is still poor so ‘Ch, G, K’ etc are not yet possible and voluntary swallowing by pushing food rearwards is still very hard work. A third of a pot of yoghurt today and two-thirds of a pot of crème caramel yesterday though – with minimal aspiration and excellent cough.
- ◆ *Lips* – the ‘purse’ is good and is becoming stronger on the right. The right ‘sneer’ started this week and ‘uu’ is becoming easier. Lip smacking is still difficult. However, barring laughing and coughing fits Maggie is now practically dribble-free and can initiate swallowing when she thinks about it.

Speech has begun in earnest this week – aided greatly by the change to a tiny paediatric trachy tube which doesn't irritate, doesn't allow much airflow and has a speaking valve for daytime use. The 24-hour cap (with 'sleek') has begun again and is three hours old – I foresee no problems this time as Maggie hasn't had suction for 2-3 days and has effectively been half-capped for three days.

Her breath control is coming on. Words that were intermittent can now be reliably croaked out (proper phonation is accidental at present) and articulation is now good

enough (and our ears are practised enough) for a dozen words to be reliably understood. Simple 'yes', 'no', 'thank you for coming', 'phone!', 'hello', 'bye-bye', 'I love you' have enriched our communication immeasurably. There is even scope now for repartee (provided it is one or two syllables!).

It is now possible to guess/understand about a quarter of the words needed for communication by eye and pad. This is the greatest hope for us all. Relatively normal speech, if only understandable by close family and friends, now seems not just possible but likely. A new frustration has now appeared – the endless guessing of what a particular 'erm' croak could mean. We communicate more slowly now (because eye and pad is pretty slick). However, as speech improves then speed will outweigh frustration. I hope the balance tips soon but I feel it will – the progression in two or three days has been tremendous. Jane (Pick) was able to understand several words today with no practice. Jane (Cromarty) and Aileen were in today as well and both (after 4 days and 4 weeks gaps respectively) saw great changes.

These are the important developments this week. Speech and swallowing.

Today Maggie moved her right index finger independently of the others – with ring and little finger flexion/extension, thumb flexion and ad/abduction and wrist flexion and extension this just about completes the full house for the right hand. All of the movements are too weak, limited in range and easily tired to be of practical use yet but Maggie can reliably operate a carefully-positioned switch with her ring finger so there is huge potential. Yesterday she extended and flexed her right great toe voluntarily – not sure what we can make of this though!

On the social and functional side, the new chair works well and is quite comfortable enough for 4+ hours sitting. A harness has made it secure enough for Maggie to sit alone confident that she won't fall out if she coughs and so we can now get out and about. Front door to back door last night – no problem!

The ride to The Churchill earlier in the week for the video fluoroscopy of swallowing hinted at the problems she will face once she ventures into the world again. She burst into tears and sobbed for half the journey because she saw a 'Park and Ride' bus out of the ambulance window and her old world and her old abilities came flooding back along with overwhelming hopelessness.

So this week I am determined to get her out into the street and the public eye – so that she gets used to the world and gets used to how the world looks at her – important that we do all that before next Saturday – The Creation is on!

I have booked a van, through 'Dialability' and 'Crossroads'. The ward, the physios and the OTs are briefed. Brent is booked for a hairdo on Sunday this week. We are considering clothes for the occasion. Susan is ready to help Elinor as assistant during the rehearsal. All systems go! It will be *extremely* emotional though – for us, the choir and for Maggie most of all. She will need some support and training if she is to sail through things with her customary aplomb and presence. I can hardly wait though! Planning is important – and practice – I hope we aren't doing things too soon but the occasion is so perfect for an outing that it *must* be done.

It seems likely that we will be doing it all from the ward. A nurse at Rivermead has broken her leg, two are already off sick, so they can't cope with new admissions – we are *next*. Derick Wade came and told us on Wednesday. He needs to apply for funds to replace the nurses – ridiculous! He reckons it will be a delay of days rather than weeks though.

So – *reflection*. This is my first opportunity in a week to reflect. One hour in 7×24! There is no time to be normal. If nothing adverse happens I should be OK. I get little bits of relaxation (like this)

so that's OK. I need a cuddle though – and to make love – and to cry and to let go for a bit. Trouble is I have no-one to turn to (or rather no-one whom I would open myself, my weaknesses and vulnerabilities to) – except Maggie. And she has enough trouble.

21ST MAY – Day 68

Another week over. Tomorrow is the big day, the first outing. We are all ready I think (tho' I haven't seen Maggie yet today). I have a selection of clothes in the car, Elinor can bring the jewellery tomorrow. Maggie can sit for the required length of time and can control her head well enough. The *only* problem I foresee is the emotion of the event.

What a week it has been. The trachy 'fell' out on Monday morning – aided by vigorous neck movement I understand and has stayed out successfully. So no more suction or bubbling. Normal-sounding coughing, and more comfort so less of it. Normal-looking swallowing, normal-looking neck! In fact, given Sunday's hairdo Maggie looks essentially normal to me. I don't notice the facial asymmetry any more. In her chair, with clothes, with head moving and eyes alert she looks like a bit of an invalid – no hint of the degree of her disability or of its possible (?probable) permanence. My heart aches again, especially when I see her.

I've been more tearful this week. Not sure why. Perhaps my own slow return to 'normality' is making me recognize the size of the mountain we must climb. Perhaps the chronic tiredness is at fault. Perhaps it's the loneliness. But I think the speech is the main problem. Maggie's speech has come on markedly since the trachy came out. No proper phonation so it's throaty and quiet but she can make that noise at will now – an indication of improving breath control. The 'front of the mouth' sounds are quite good. 'M' is fine and, as the week went by 'B' became distinguishable – still not quite the pressure for 'P' yet though. It's the palatal sound that are missing – although the occasional 'K' slips through by accident or design. That all means that, one word at a time, in context, we can guess at whole words fairly reliably. Communication should be speeding up but instead it's even slower and more frustrating.

The hint that speech is nearly there is enough to make Maggie

try to use it – so sentences are longer and more complex, not just a noun-verb shorthand. And she tries to comment on lots more – so there's more 'trivia' (or rather more 'normality' not more trivial!). And we spend lots of frustrating time guessing to our mutual irritation. She is increasingly reluctant to resort to good old slow reliable eye movements and seems more angry that I can't understand. It's the 'so near yet so far' problem. Paradoxically, because we can *nearly* discuss things (nearly but not quite) I feel even more isolated than before. She feels the same I'm sure.

Still – it will come. On Wednesday Maggie blew bubbles in a glass of water through a straw – and sucked it up too (but by breathing in – not much cheek and palate involvement!). On Thursday she coughed voluntarily for the first time and on *both* those days I stopped counting the number of teaspoons of puréed cauliflower cheese and baked beans she ate *without coughing!*

On Wednesday too we visited Melida in ITU. She and the other nurses who remembered us were staggered by Maggie's improvement. It was a valuable visit for all concerned – and the first set of longish conversation literally over Maggie's head. She sitting, we three, four or five standing. How did that feel for her. I must sit at her height whenever I can.

Afterwards she said, 'Melida is very attractive'. I agreed. 'I like her voice'. I agreed. Sort of soft Canadian I think. I wonder why that thought was in her mind? Melida *is* very attractive – soft voice, gentle nature, long, dark red hair and big eyes. Did I look at her? Was there something in my voice? Was it the way she said that I looked better too? Is this the beginning of future jealousies or doubts or concerns in Maggie's mind? If so – are they justified? I know I'm weak. But I know I'm in love with Maggie too – still in love, still aroused by her and still intent on being with her.

This morning I woke before the radio (again!) and half dreamily reached for her hand. I was genuinely surprised for several seconds to find no hand, no Maggie in bed. And desperately sad when I woke properly. More tears.

I went to Chipping Norton on Thursday. Lovely people, lovely practice, offered an interview before I'd even applied for the job. But it's too soon and too frightening and has made me think

about the realities again. How can I work away from Maggie if she is going to need permanent attention and care? Too early, too early, I'm minded, on reflection, to write and say no thanks. We will talk about it tonight.

23RD MAY – Day 70

Maggie isn't locked-in any more. Kathryn and I have been talking to her this afternoon. She has said, one word at a time spoken (croaked!) or one letter at a time spelt by eye and alphabet, more in an afternoon than in the previous week. Conversation isn't normal by any means but conversation is possible. The notice over her bed is obsolete. 'I just can't talk or move' is clearly nonsense now. It is difficult to remember why we made the notice – because Maggie was so flat that it was easy to think her unconscious and unable to think or feel. Now there is no doubt.

Her opening gambit today was, 'Do you want the good news or the bad news?' I opted for bad first. 'My gastrostomy burst'.

It transpires that last night's nurse didn't know how to use it (*not* uncommon but practically *all* nurses in that situation go and find someone who does) – so she gave the drugs through the retention balloon (max capacity 3ml) – bang! The tube is still in (lots of sleek!) but it seems that they have no spare (a problem I pointed out the day it was put in when I was told they would get one). It is due to be sorted 'tomorrow' – it better had be, a simple in and out change is all that's needed. If Maggie has to go back to X-ray for a reinsertion – or for a proper PEG now that she can open her mouth, I will be *very* grumpy. I will check tonight that the staff on know how to keep the stoma patent (a urinary catheter *pro tem* was suggested by Debi when the tube was first inserted) just in case.

It was only yesterday that one nurse used a 10ml syringe instead of a 50ml syringe to give sticky lactulose – no danger to the gastrostomy in that case though – she had the wrong tip so most of it went over Maggie and her clothes. Ho hum!

The good news more than compensated – abduction/adduction of the *LEFT* thumb! Powerful too and right out of the blue. I cried.

Yesterday was a busy day but worth it. The van was fine (for short journeys). Maggie was safe and secure but we couldn't attend to her while in motion – no space. I lost the mobile phone somewhere – hopefully under the seat in the van! No sign of it today in the 'Café Something' where I first missed it over breakfast.

Maggie says now that she learnt a lot – about how emotionally labile she is and about how much people think of her. She wasn't the only one in tears yesterday. I was (and couldn't sit with her while friends came to say hello – Susan and Elinor were much better at that), so were Angela, Denise, Lindsay etc etc, and most of the blokes were misty-eyed too. The rehearsal was super – loud, fun and useful and Maggie heard all but the final chorus before we had to head back. The concert was very satisfying – some loose entrances – especially 'despairing, cursed rage' but altogether (by many counts) the best rehearsed and performed concert for years.

Maggie (rightly enough) thinks of herself as the John Harvey Jones of Wendover Choral Society.

28TH MAY – Day 75

Friday again, Jude the Obscure, fish'n'chips and a pint of 'Varsity'. Elinor and Mum are feeding Maggie her supper – a selection of Susan's mousses, pâtés and purées. I am staying the night. Feeding has been this week's success I guess. We are using a dessert spoon now, not a teaspoon, and Maggie can eat half a hospital meal or more, which takes 20 minutes. Only ten days ago it was 11 teaspoons in 20 minutes with coughing and spluttering. Coughing is rare now, dribbling is lessening considerably and Maggie can suck wetness from her lips (tho' not lick them yet!). The day when she can get sufficient calories through proper feeding is in sight and heading our way. Though *real* food courtesy of Susan and also Barbara beats the endless puréed cauliflower cheese of the hospital! Drink is still a problem – there is no good way of getting reasonable quantities of fluid in by mouth without aspiration and coughing. Syringe is best (but at 3ml a go too slow). However, a baby feeding cup has promise and the speech therapists have said they have valved straws – they have not appeared yet though and won't now until we go to Rivermead. *Tuesday is the day!!*

Monday is another bank holiday – that’s three since we have been at the Radcliffe Infirmary. Another long, boring weekend potentially but we are now getting adventurous so we should be OK – a walk to the river may be in order I think. Maggie and I went to the shops on Wednesday and bought chocolate for Mum’s birthday and a penguin notebook for Elisabeth from ‘Animal Animal’. It was OK. Careful manoeuvring in shops is required but even more careful attention to Maggie’s wants. It would be so easy to push her past what she wants to look at and it is so easy to talk over her head. The most awkward thing though is her height – about 3½ feet seated! Her ‘voice’ is a whisper so conversation (by mouth and by eye) is slow and requires me to squat – this slows dealing with shop assistants to embarrassing levels (for Maggie and me) and means that we completely block aisles (big chair and squatting attendant). Important that I ignore the embarrassment and still get down to Maggie’s level and address her needs. Tesco should be OK though – big wide aisles!

The gastrostomy was eventually replaced on Tuesday morning (25th). It had arrived the day before (eventually – the wrong size had arrived!) but despite being told that replacement was in hand during the afternoon no-one was able (?willing) to do it. I got grumpy again and asked pointed questions of Maggie’s nurse but as she was from the bank and had no idea what was going on that didn’t help much. I laid off without getting too irritable though – not her fault if the whole system lacks organisation. As Mum said though – ‘given that it was their fault you’d think they’d be bending over backwards to sort things out’. Well, yes!

The JCPTGP on Tuesday, a slick, less contentious meeting than the last couple. Brian Keighley mentioned Maggie at the outset. At lunch xxx xxx and I got chatting – probably because of the announcement. We have lots of similar problems and some very important differences. We have lots of similar problems and some very important differences. His wife is terminally ill – cancer and missed diagnosis. Anger abounds – directed at him too. She attacks him if he mentions nice weather, things he has seen which she will miss in future. He looks dreadful. Tired and washed out. I told

Maggie about it. She said tonight that she spent half the night awake yesterday thinking about him. We are so lucky in some ways. We are together. Maggie is still Maggie in all the essential ways. We can look forward. We have prospects. We have no-one to blame.

This occasional journal is becoming simply a catalogue of events. I intended it as my counsellor, my memory and my mirror. So how do I *feel*? Buoyant today. Things are looking up. The sun is shining. I'm not too tired despite a couple of beers last night with the tail-enders from a dining-in at Innsworth. This morning's meeting with Paul Evans, Dennis Ferriday and others was very upbeat. The boys looking to genuinely improve and innovate not just kowtow to outdated planning methods and vague and woolly ideas from above. I actually felt hopeful about the future of the branch! Then this afternoon the flyer for Tim Huins' job came. This is it – prospect of future employment/excitement/fulfilment and money! So 'buoyant today' it is! The critical word is 'today' I guess. It takes very little to make me feel despairing and burst into tears. It doesn't last long – my natural optimism/realism/rationalism gets me on to the next thing quite quickly and my selfishness means I still look after some of my needs. –This is an indulgence for a start! Nevertheless I do recognise that I am very emotionally restrained and labile at the moment, my concentration is poor, my sleep is poor. I feel TATT. *But*, I'm surviving – perhaps at the expense of others a little (?Elinor especially) – but I'm surviving – which means that, as we approach the three month point. I *will* survive. So *we* will survive this. I guess that's why I'm buoyant. We will be OK, I now believe it!

31ST MAY – Day 78 – Bank Holiday Monday

Rivermead tomorrow, so my last pint in 'Jude the Obscure' and my last chance to reflect on the hospital phase of events.

A lot has happened. Maggie has moved, almost imperceptibly considered a day at a time, from flaccid, immobile corpse-like state to upright, responsive liveliness with a full range of emotions on display (frustration being chief!). I believe that she has moved from black, helpless terror, where death seemed like a sensible option, to active, hopeful confidence, where life seems there to

work for. She is/has been remarkable. I still sweat in bed at night, lying immobile, trying to imagine how it feels for her. She has had no choice about the things which have been done for her, and to her, in the name of care. She must have truly loathed her situation and perhaps she still does at times. No place for prudery, privacy, control or a public face in her situation. Everything laid bare for others to see – body, bodily functions, involuntary movements, coughing, dribbling, shitting. Only her thoughts have been hidden – and those hidden as perfectly as possible. At last her feelings are beginning to show. Irritation, anger, frustration (of which there must be bucket loads stored up) – but love too.

Privacy is a funny thing. Maggie has ultimate privacy, or has had, of thought (like we all try to have). She had the perfect poker face. Then she had the over-the-top laughter – still no ‘real’ emotional display, nearly always an exaggerated gross response. Now that is beginning to be tempered and other emotions are evident – more personal ‘private’ emotions which she displays under her control, as ever. Normality looms. But personal privacy is still absent. The nurses are all-powerful and can intrude upon the most private of conversations. They are also keepers of the body – attendants upon bodily functions, and sometimes controllers of bodily functions. The laxative being the prime example. Bowel opening to nurses’ convenience, not patient’s normal routine. [That problem is much less now – Maggie can strain! And so can go when she feels the need! Luxury!] Life in the ward has been life in a goldfish bowl. Eating, spitting, crying, hugging are all on display – especially to our fellow bed mates (two at a time). The curtains, when pulled, hide most of the nakedness but they are often twitched – ‘have you got the keys?’, or wafted open as others pass (problem of being in the bed by the door) – and they do nothing to prevent sounds – talk being the main culprit of course. Talk of bowels, needing cleaning, catheter changes, feeding regimes, muscle recovery – *anything*, Maggie and I have not been alone together for nearly three months. *Marital* privacy is our biggest loss. No quiet cuddles, certainly no love-making (tho’ an evening stretch can be sensual for both of us I think), but none of the even more basic things. No closed bedroom door. No front door on the house. No ‘ring

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...’ at the door and our choice what to do – just people wandering in and out. We love to see them of course but what if we wanted to just be alone? I hope Rivermead will allow us (encourage us?) to be private together. Maybe soon I will be able to dispense with this journal. The day that I can do that will be the day we have returned to a normal relationship.

1ST JUNE – Day 79

Rivermead. The girls are with Maggie while I get my supper in the Fox and Hounds – it’s ‘themed’ – not Jude the Obscure by any means – pool table, MTV, loud female soloists over the PA and plastic menus with standardised food with funny names based around Robin Hood! However, very wheelchair friendly. In fact Mark (a fellow Rivermead resident whose path we have crossed a couple of times this afternoon) is sitting by the bar chatting up the barmaid!

Tearful farewells this morning (except for xxxx who was as overbearingly incompetent as ever – that nurse is *dangerous* – justifies her every action to others (and perhaps to herself) no matter how crass. Gaily ‘informs’ the patient of what she is and is not going to do despite the ridiculous impression it gives and fails utterly to inspire any confidence. She is the worst case. Unconsciously incompetent.)

Friendly faces all round at Rivermead so far. Interest, concern and an expectation from *everyone* that things will improve. Relaxed, professional, competent, we are involved and listened to but are clearly expected to fulfil our proper role – family! – rather than be nurse and therapist too.

6TH JUNE – Day 84

Hello diary. I need somebody to talk to. We are in the middle of a big argument (I think). Maggie’s voice has been very quiet or absent for the last two days. So lots of communication frustration for all of us. I upset her somehow this morning while we were readjusting her seating position – she had been put in the chair skew-whiff with her bum about three inches from the back and

having to hold her head up at an angle to avoid the POSM switch on her headrest. So she stopped speaking for a bit. We did a choice of symbols for the SALT to make her a little chart to aid communication with the nurses, then after that things just blew. Her voice was so quiet, or absent, and I was sitting on her left – the ‘tight’ side of her face – so lip reading was difficult. I made some mistakes with the words and, after 20 minutes of crying (mutual), shouting (unintelligible) and general frustration and anger managed to get the words, ‘You both say words that don’t sound remotely like what I am saying’. I explained the difficulties and our frustrations and I know that she understands really – but that doesn’t ease the frustration.

It’s the problem really of being communicator and mode of communication. We have to remain calm, even, accurate, constant if communication by our current speech/eye system is going to work. So I end up in the weird position of calmly interpreting angry words directed at me. If I respond normally Maggie suddenly can’t speak, but me being angry or speaking at her immediately denies her the opportunity of communicating – that’s not fair. So instead, despite the fact that I’m in a mess inside, crying and frustrated and so much in love with her, and feeling for her, and angry for her too, I seem cold and detached. If I’m not she can’t tell me how she feels.

It came to a head over lunch. After tidying ourselves up we set off, Elisabeth came back from the loo, Maggie was still sobbing a bit, Elisabeth spoke to her and she shouted quite clearly, ‘Go away’. Elisabeth went, I pushed Maggie off, a nurse got involved in the corridor, further disrupting communication and by the time I got us into a private space in the corridor and worked out that Maggie had intended the ‘Go away’ for me, not Elisabeth, a few minutes had passed. So – a tearful Elisabeth has taken Maggie for lunch and I’m just sitting here lonelier than I have ever been in my life, writing it down because I can’t think of what else to do.

The week has been full – as evidenced by the lack of writing in this journal. I was at Innsworth for a night and a morning at DG’s symposium – strange to find everyone behaving normally – so I slotted in and behaved normally too – interesting that they seemed

to expect me (despite their words) to be busting a gut at work as usual. Several caring people who genuinely show concern for us though.

Elisabeth has been happy to be home I think and Elinor has equally happily headed off for her break in the sun with Neil and Jane.

The garden is a mess – grass about eight inches long! The house is a mess (and the cleaner who was to have started next Wednesday has cried off for this week). I am behind on everything – job application, tax returns, just *everything*. I sleep fitfully – fine for four+ hours then on and off for two to three hours with lots of thoughts and worries about the future. I just want to be with Maggie and for her to be with me in our own home – to be *normal, normal for us*.

I am pretty labile at the moment – crying at a moment's notice, but still not confiding how I feel anywhere but her. I will be able to hang on I think until Maggie and I can speak properly. Meanwhile – keep juggling!

11TH JUNE – Day 89

Friday night and I'm back in the pub having supper ready to stay the night. Mum arrived for the weekend an hour ago, Elinor returned from her hols a few minutes ago. Both of them seem relaxed and normal. We are both happy to see them. Neil is intent on 'helping' me 'blitz' the garden. He saw the length of the grass of course when he dropped Elinor off so over the 'phone was keen to get it all sorted. About the only relaxation I get is pottering in the garden. I like 'help' in it about as much as Maggie likes 'help' in her kitchen. The last thing I need is to sort it all out by appointment to someone else's timetable. His motives are fine of course but I will get the garden sorted to *my* satisfaction once I have a few hours at home – and now that Elinor is back I will have! Tomorrow *and* Sunday I guess. Though my CV needs sorting out as well! And the cleaner who didn't start this week is needed more than ever. Still, mum and Elinor can push the vacuum cleaner round. I have kept the kitchen clean, cooked a proper meal for myself every day and kept up to speed with the washing (including clean sheets!) and with my and Maggie's ironing – and even done

a Tesco shop and been to the dry cleaner's and kept work going and been for my OPD 'snip' appointment at Frimley Park. So I'm doing OK. In the groove. Just no spare capacity . . .

Maggie is settling in. Getting to know the good nurses and the moaners. Getting comfortable at night (eventually). Getting known – as a worker, as a pleasant person, as 'bloody-minded'! The physio, OT, ST she has all seem great and things are poised to get going. Her first 'review' is due on Thursday when assessment officially ends and rehab officially begins (although both overlap into each other of course). We are considered in most things. I get the impression we are a bit unusual in that we are, and wish to be, involved in Maggie's care, rehab, life . . . to an extent which is unusual for many of the other patients. Most of them seem alone for much of the week.

I feel fairly stable just now. If I can get the job applied for this week, keep work ticking over and spend lots of time in here I will be content. Maybe I'll contact Mary Nichol about the consultation book too (?? – too much?). I just need Maggie to keep improving – that little smile and 'guess what?' that presages an announcement of more return of muscles – another of those this week would be perfect.

15TH JUNE – Day 93

In Silverstone – stopped for a bite to eat in transit from Peterborough to Oxford. Feeling a bit tearful today – little things – I miss Maggie so much and worry about her all alone and just want to be with her. The future is looming, not just the next months and years but what about when we're 70+? Daft to consider such distant times so I'll try to limit my worry horizon. The cleaning lady who was to have come has got work closer to home so no cleaner – I rang today to see if she could start tomorrow. Her polite explanation left me almost in tears and I had to put the phone down rather quickly. So I'm a bit fragile I guess. Work worries too as the application date for Tim Huins' job approaches. I would be ideal and I would be good at it – but is Oxford or Northants *our* ideal? What about the 'quiet house by the sea with me working from

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home' idea? Is that gone now? Was it ever possible? Maggie and I still haven't really discussed these things in detail – I feel as if I'm on the roller coaster again – I wonder where it will stop?

I will apply – it's just too sensible a thing to do – daft not to. I *will* also write to Pat Lane, Steve Field and Jamie Bahrami (and probably Arthur Hibble too) to leave a calling card and an expression of interest in Associate Adviser posts which they may have coming up. Time to get on with these things. Nothing is going to drop in my lap – I'm going to have to get out there and *make* things happen.

I miss Maggie. Even when I'm with her I miss her. I'm so used now to the new Maggie – the quiet expression, rather gloomy, the maniacal one-eyed laugh which makes her seem buoyant and reckless, the general dishevelment which comes with being an immobile sack of potatoes in a chair, the occasional dribble, the very quiet, squeaky, one-word-at-a-time speech. I love that new Maggie passionately. I think the old Maggie is in there but there is so little evidence of it that sometimes I wonder. I am trying to keep the old Maggie alive – at least in appearance – *my* attention to the details of her looks and clothing, *my* insistence that she be consulted, *my* recognition of/acknowledgement of her moods! (and sometimes my provoking of them – just as before). But is she there? Is there really *actually* a new Maggie now? How has she changed?

Should I be adapting to the new rather than trying to preserve the old? If so, when do I (we?) make the jump from – this is a temporary state – to – this is a new (more or less permanent) state?

Communication is *still* the key. The family do it fairly well now I think. Maggie and I do quite well if we have the time in private. The speech therapist has a communication book in which we can all write to each other – a good and useful idea (but she hasn't put anything in it about swallowing so we and the nurses and Maggie are united in increasing feeding despite their apparent ruling that it should be decreased!). We suffer from the shift system with the

nurses so it will take a while for them to get to know Maggie and us and *vice versa*. The good, the bad, and the indifferent are already identifiable – fortunately the good are in the majority!

But there has been an opportunity missed. The first two ‘assessment’ weeks clearly run on rails so that is OK – it ensures that nothing is missed and that everyone briefs everyone else. But things could have been so much faster if they’d asked us where we were at. They have started from ground level not the ‘three months of building’ level which we are at. We could have (we *tried* to!) told the nurses etc how Maggie liked to be made comfortable, what she liked and didn’t, how the bears and the splints worked, how to best communicate, how the chair positioning worked, how swallowing had developed . . . They could then have done their assessments while *she* was well cared for and awake during the day because she was asleep at night! They are experts in their fields but we are experts in Maggie! Shades of Tuckett!!

18TH JUNE – Day 96

Another Friday evening. Elinor is off to Tesco leaving Maggie with Elisabeth, just out for exeat weekend, and Aileen – at least for the next short while. I get a few moments to think. Maggie looks awake and happy but sunburnt! – we must watch that. Pleased as Punch with her illegal pud – Lemon Tart – which was slow (due to dryness) but apparently caused no swallowing/coughing problems. She has also had a look at the bigger room, which is due to be vacated this weekend I gather. It will be nice to have some space to move and hopefully we will be able to get some air movement and reduce the heat and fetid air levels. The boots smell – mind you she has worn them for a couple of months now, and 10+ hours a day for the last month – disgusting!

I am tired again, sleep has been patchy this week and I have had difficulty prioritising properly at work. Nevertheless, I’ve got a few things done and have been only moderately grumpy about the lot at PTC. xx is coming on and seems OK, at least he’s a known quantity. xx is a breath of fresh air in the other corridor but xxx is a waste of space – worse in fact, seems to specialise in putting people’s backs up and doesn’t have a clue what he is doing. xxx

must be overburdened but seems to be coping. xx is on leave but has no people to maladminister these days. God knows what we will do about Brize, and Cosford, and Cottesmore . . . On the positive side I have started sorting out my departure. I reckon that I can take four days off when the folks are here, and two weeks in August/September and stop work finally at the Tri-Service Trainers' Conference in November. *And* I still have 35 days resettlement to fit in. Interesting! But I must keep telling myself – *not my problem.*

The biggest personal challenge of the week was getting the application in for Tim Huins' job. The last day or two was like walking across a ploughed field – the going got heavier and heavier and was filled with doubts and fears. Mainly about the commitment, the evenings and weekends, the novelty, the need to search for a practice too, the cost of housing . . . But really just doubt about should I commit at this stage? Maggie says yes. Anyhow 'tis done. If I get the job wonderful, we will have a goal and can start building our future. If not, well . . . I felt strangely excited about hearing from JB that they are going to make the Shawbury job CMP.

Most of all I just want it to be over. I'm fed up with this game now. I want to wake up tomorrow with Maggie beside me, have a cuddle, talk about the day, get up and get on with it – together. Just like Before. Of course, given that I am staying the night that is just what will happen (but not quite as Before).

24TH JUNE – Day 102

Different pub – Duke of Monmouth. Empty (practically – just an Irishman – broad Irish with an accent so thick I can barely comprehend it, and his wife and two daughters). No food, too early, so it's a beer and some crisps and that'll have to do for today. Elinor is organising getting Maggie ready for the AGM. Elisabeth and I are sitting by and doing as we are told. It's a hot and sweaty day and I am already in need of a clean shirt having picked up Elisabeth from school this morning. We didn't go home as originally planned. Maggie got very upset about my suggesting it yesterday – lots of head-shaking and 'No', 'No', 'No' – so with

Elinor supporting her and both of them telling me not to be silly I never even got to finish my thoughts. Elisabeth seems very low considering her GCSEs are over. I think she wanted to get home and unloaded among other things, as we had planned. Elinor now has to drive the Nissan home with a boot packed with stuff and the car down on its haunches.

No matter. If I let things like that affect me I'll be getting even more grumpy and even less capable of seeing things from Maggie's viewpoint.

Maggie is making progress. Wonderful, hopeful progress. External rotation of the forearm – a wheelchair joystick controlling movement!! And today, elbow flexion – both on the right of course. She is pleased – maniacal grin pleased! She's doing well, getting on well with all the therapists – who are really prepared to work hard for her as a result, and with the nurses who are beginning to deal appropriately with her. The good ones have done that from day one of course. One or two are still of dubious competence/awareness/intelligence but I think that they are patronising and irritating rather than dangerous. Generally I should feel more buoyant than at any time since the stroke. Intellectually I suppose I am. Physically I am tired – house-job tired. Emotionally I am fine, if alone with Maggie so that we can talk and share our feelings (tonight if she is not too tired after the AGM), otherwise I'm a bit of a wreck – still very labile – and certainly becoming less tolerant; *especially* of being told off by Elinor! It really must be getting to me. Like at lunchtime when I carefully pushed Maggie into the shade of the umbrella outside ready for lunch. Elinor commented about her being in the sun, I moved her a few inches and got ready to feed her her lunch. Elinor fussed about sunscreen. Maggie said something, I stopped what I was doing and started to ask what she'd said about the sunscreen. Elinor disappeared to do something else. By the time I'd got Maggie's comments I was on my tod. 'Stop fussing about sunscreen, I want my lunch'. I guess I'm going to have to just do my own common sense thing and upset Elinor occasionally instead of upsetting Maggie and myself . . .

Still, Elinor makes Maggie laugh so that's important too.

11TH JULY – Day 119

A long gap – just because of lack of time really, no other reason. The AGM, the birthday, the ball, speech day have all come and gone – and gone quite well. Mum and Dad have been to stay for four days and we managed quite well – Maggie’s menus were the lynchpin – getting us together each night, keeping us focussed and organised and feeding us *really* well! The buying of Elisabeth’s dress could have been traumatic in the extreme (the ‘trial’ day in Aylesbury certainly suggested a disaster) – as it happened, once we got to a proper ball gown shop she loved it and so did I! It’s just been one thing after another with little time to think. Perhaps that’s the best thing but perhaps not – there is a shift in the way I feel, and in the way Maggie feels too I think.

She was fine during ‘home’ day on the 4th of July – it was fun and the rain held off after a fantastic hailstorm just after I put the new gazebo up! The day after, which began with me staying the night in the chair again, was more tearful. She realised how much she has lost, physically and socially and functionally, and how far she has to go. I already knew but I had been ignoring it I guess – so since then it has become even easier to cry for no apparent reason. Even the things around the house, which I had got used to seeing, have brought me to tears again; the kitchen block, our pictures (especially those of Orkney for some reason), house adverts, magazines – it goes on . . . Speech day was dreadful, I don’t know why but I couldn’t stop my bottom lip trembling and the tears flooding out – I don’t know what the people on either side of me thought (fortunately I had empty chairs immediately on either side) – the oddest reaction to a school speech day, traditionally hot and endless, they could ever have seen.

I’m still a bit stuck about the future too. Eleven days to go to the associate adviser interviews and I’m not sure I want the job. Do I really *want* to be on the treadmill. I could just jump off and make a living as a CMP somewhere – or go Orkney and paint and fish (alright – for me that would be photograph and write). I put everything I have into the job I have it seems, so I have no time to gain expertise or influence in different areas like journalism. I can’t make the jump now – the treadmill needs money to oil its wheels

and Maggie deserves the best. Thing is, is the best me working lots and not spending time with her, or working moderately hard and spending more time, or barely working and spending lots of time? Who knows? How do we judge? Just go for the AA job I guess (for which Derek Galen is the hot tip) and then see what happens. Once we get a house *that* will give us a focus and a purpose. So the plan is:

- ◆ Go for the AA job (Oxford or Northampton)
- ◆ If I get it:
 - Look for/buy a house
 - Get it adapted
 - Look for a practice and on we go
- ◆ If I don't
 - Write to Steve Field and plan to do the same in Shropshire
- ◆ Fall back is CMPing – easy, I'm known and can stay in education
- ◆ And also talk to EMIS – working from home
- ◆ And also think about medical education via writing/journalism etc.

But heading for Orkney and locuming along with the above is still very attractive to my heart if not my head. Maggie would be loved and supported by the community in a way which she might not be down here. Isolating for her though – she would want to be the hostess all the time – we both would. Not fair. Accessibility to friends and wider family (less my folks therefore) is important.

Just got to work up the energy to go for it.

14TH JULY – Day 122

Three times 122 is 366 so we are marginally over a third of a year into our new life.

15TH JULY – Day 123

Start again! A short meeting at Innsworth today and I thought that I would lunch in the Mess but DG wouldn't stop talking so here I am at Puesdown halfway back to Oxford – with fish and chips due to arrive shortly.

Maggie seems more buoyant over the last couple of days. Last night her speech was the best I've ever heard it and we did a letter and two+ pages of the next round robin in just 45 minutes – better volume, 6–8 syllables at a time sometimes and reasonable articulation especially of 'k' and 'g'. If speech goes well *everything* goes well. She enjoyed her second hydro session on Tuesday and Mum B and I left her early yesterday for her first aromatherapy session. I am losing track of all the muscles which work now – though none of them below the neck are much use to her at the moment – they are nearly all too weak to move anything against gravity and most are unopposed. However, I feel quite confident that she will be able to move a joystick well enough to control her chair with her right hand. Sitting forward for 'pillow plumping' purposes is also becoming easier so her abdominals are definitely improving and she is going to practise spinal muscle tensing in bed too. She is still intent on walking, though (after the transfer shock at home on her birthday) she is much more willing to accept that a chair will be a major part of her life for some time to come.

I will chat with Jo about cars etc – Maggie and I have discussed the options and looked at brochures a couple of times. My analysis is that, even if she can transfer to the Volvo over the next 2–3 months it will still not do as our main means of transport – she now has a heavy powered chair which will also need transporting and we want to get out and about during the summer months. So – I think we are looking at a seven-seater conversion over the next few weeks as a replacement for the Volvo. This will give us a degree of independence which we could not get any other way and should not be hideously expensive. I want to do it before the girls go to school and university so that we can go out as a family before then – Maggie agrees with the principle. Best I get on with it.

Other things advance too. The first three days of next week are my 'career transition workshop' at Uxbridge. I was up until two last night filling in the workbook and still have lots to do. But *immediately* after it – at 0820 next Thursday – is my AA interview which I must plan and rehearse for! DMSSBGP is at 1000 in London (I must ring with a lateness apology tomorrow) and I must prepare for that too. Arghhh!

I guess I need to plan too for the 'break' which the family and psychologist's meeting inveigled me into – a long weekend during my Aug/Sept leave perhaps? Or perhaps better three days midweek so that I don't waste valuable time with Maggie over a weekend. A B&B and walk in the hills? In *August*? Main problem is I don't have time to plan it (and perhaps don't want to go anyway). I guess for everybody's benefit I ought to – Sept onwards will be different and difficult and I must be fully charged up for it.

'Onward and Upward' – the motto of the school of the speaker at speech day last week!

27TH JULY – Day 135

Another long gap but *no time*. Every day is full to overflowing and by 1030 or so, when we finish eating, I just collapse or do odd bits and pieces of home admin. Then bed and off again the following day. The biggest problem at the moment is sleep – several nights of five-in-the-morning worries over the last week or so. Nothing specific, just *everything*. Job, money, home, girls, the future – even to the extent of how will we manage when we're eighty! I could do with someone to talk to openly but, having discussed it with Maggie, it's her or nobody. I have never opened up to anyone else – and secretive bastard that I am not even to her, or perhaps not even to myself, about what I'm really like. To speak openly to anyone would be a betrayal of our relationship – someone else would know about me and she wouldn't. That's not right, not when she is fully aware of all that goes on around her. So it's her and, intermittently, this journal.

Friday nights are looking up! I have had a bed (at Q's insistence) for the last two weeks, which has given us both an even better night's sleep, has allowed us to lie and talk, to wake up and gaze at each other in the morning and to cuddle and kiss at night. She feels so good. She seems amazed that I still fancy her but she can be in no doubt that I do! She's a bit passive I must admit (!) but there are enough moving parts now to be sure that she is involved and we both know that we will make love again – and sooner rather than later. I *must* chase my snip operation!

I had a look at the Reselco Caravelle last week and I must admit I liked it. We have always been able to jump into the car and go places, especially to please ourselves on a whim or to see friends. It's an important part of our lives and must be so again. The problem is the mileage in the Volvo. I was planning to spend £6K max but say the bits (ramps, tie downs etc cost £1200 (my guesstimate)) then the bill works out at £10200-6000 = £4200 we need for the Volvo. Reselco are offering about £2800: £1400 adrift. So it looks like I'll be paying the full amount and trying to get more for the Volvo on private sale. So it goes. If this business has taught us anything it must be to take every opportunity and not to put things off!

12TH SEPT – Day 182

Why the long gap? Lazy? Tired? No need for reflection anymore? Depressed? Not time? – probably a bit of everything but I do still need to reflect and consider things.

A lot has happened in the gap – and a lot hasn't.

We have mobility via the Caravelle – and we still have an unsold Volvo – now at £3800 – and somebody has *just*, right now, rung about it! May want to look at it this afternoon!

Elisabeth is back to school with her 5 'A' and 6 'A*' GCSEs and a new suit. Elinor is getting ready to go to Sheffield. They have been walking in the Gower peninsula – self-organised entirely and successfully.

There have been a lot of milestones:

- ◆ We went shopping (at John Lewis in High Wycombe) and bought Elinor some things for university and Maggie a new frying pan!
- ◆ We have all been shopping in Oxford since.
- ◆ We have been to a concert in public in Dorchester Abbey, with attendant wheelchair access problems.
- ◆ We have had a bust-up with the physios – chiefly over communication but with an undercurrent of Maggie wanting to *do* more in a structured programme rather than get 'some stretches' because nothing else has been planned.
- ◆ Best of all we have been home properly, overnight, twice now at the weekend. Lovely. Normal. Fulfilling. Tiring.

TRANSCRIPTION OF A JOURNAL

It will get easier the more we do it. It is the best, most positive, most glorious thing which has happened in the last six months.

- ◆ We have a concrete path and a ramp up to the patio doors.
- ◆ We have a sliding door on the toilet.
- ◆ We have a cleaner on Monday mornings.
- ◆ I have applied for the CMP job at Shawbury.
- ◆ I have set up the portable and a monitor in Maggie's room and she can now type into the word processor using an on-screen keyboard (web download demo!) and a switch operated by her right thumb.
- ◆ Maggie has painted her first silk scarf!
- ◆ She has moved on steadily in all sorts of ways. Her anterior tongue movements have become much more fluid and extensive. Still no lip-licking but so what! She can articulate all the anterior tongue sounds well now and 'k' and 'g' are pretty reliable. 'j' is still difficult. The main speech problem remains volume. It's better still but still requires a quiet room and patience. Nevertheless simple 'one phrase' telephone conversation is just about possible now.
- ◆ Swallowing is better too. No need for purée really – food squashed with a fork is readily edible. The first sandwich was two weeks ago and we are now down to one slice of bread in 15–20 minutes (it was an hour plus at first!).
- ◆ Maggie drinks minimally thickened (single cream consistency) fluids through a feeder cup with excellent swallowing but a right lip dribble. The end of the gastrostomy is in sight and if it fell out tomorrow no-one would be concerned.
- ◆ The right arm is 'top limb'. Lying in bed Maggie can put it on her stomach. *This week*, sitting in the chair, she has managed to take it from her lap to the arm of the chair and the joystick. All the fingers move and index finger control is particularly good but extension remains poor so no button-pressing. Nevertheless accurate joystick steering is now possible. The main difficulty is the laugh which causes associated movement and a collision with whatever is on the left of the chair!

- ◆ Trunk control is better and is especially evident on the tilt table where extension from 20° flexion is good in the thoraco-lumbar spine. Lateral flexion/rotation is less good so the irritating lateral supports remain in the chair.
- ◆ Knee power is better on both sides and Maggie can unlock and lock each knee in turn when standing on the tilt table (but *not* both together when weight is unevenly distributed – another physio problem!) She can't really move her legs in bed though. Extension on the T-roll yes but nothing against the weight of a quilt. So no turning over in bed yet, which will require a bent knee at least to get it started.

So lots has happened and lots of milestones passed but they indicate the beginning of a long road. Basically Maggie is still quadriplegic and requires total care – there is nothing she can do for herself at the moment.

She's a bit low this week. There is a general background of gloominess for both of us and tears come easily and sometimes for no obvious reason. The argument with physio and the way that *she* was blamed for 'not speaking out', and the excuses that were made so that *she* was expected to accept and allow for the physio's deficiencies rather than the other way round – these certainly troubled her deeply – her muscle tone rose so nursing, speech therapy, everything was adversely affected for a couple of days. I was away too, at PHCSG for a couple of days. So, for the first time since this happened, I was not with her during a day – Friday. It felt most odd. Maggie missed me and I her. I'm not sure how it will be in October and November when, in each month, I've got two or three days away in one block in *busy* work weeks. It makes me sweat to think of how we could manage if she was at home. We couldn't of course – not without living-in help.

Sunday morning. I have returned from breakfast at Café Something. Maggie is showered and dressed and will shortly be ready for breakfast and the day. It is 1130. We had a lie-in! But two hours plus is the standard time to get up, wash/shower and dress. It is difficult to see how the time could be trimmed below that and with one helper it certainly could not – there is no possibility of dual-

tasking. We will try it out for real in three weeks time when Elinor is away. It is technically possible – a night in the ILU showed that – but it does require organisation and a strong back.

How am I? OK today – I've not been home for three days of course so the garden, the ironing, the tax return, the specialist paper, the general mess, have all receded in importance. They will take over my thoughts again tonight I expect. So much to do and so little time is the thread of my life. It always has been but it is now to a ludicrous degree. Maggie is here for breakfast!

14TH MARCH – Day 366

Some enforced reflection time today – on the train to Harrogate for tomorrow's GPC Conference. Time to reflect has been in short supply. Or so I can convince myself. If I keep on doing things or if, at home when reality comes closer, I find diverting things to do, then I don't have time to reflect. At the weekends when it's just the two of us at home then we reflect together a little. Or we look at each other in realisation of what the future holds. The weekend provides frightening glimpses of the future. But wonderful companionship and closeness too. We hug a lot, and cry a lot, and argue a little when our frustrations overflow. So I avoid reflecting in order to survive.

The main frustration is still over communication. If communication is poor *everything* is a trial. Generally we communicate fairly well now. If Maggie's mouth is not too dry then she can speak quietly and intelligibly – at least to us. She puts extra effort into articulation when others are present and so can speak to anyone who is patient. The only people who can't understand are those who don't wait for her to speak, don't repeat words and check understanding, and who assume far too much. The voice amplifier helps – tho' the trial version has been returned to the Mary Marlborough Centre, it worked for a few days and enabled Maggie to speak while we were working in the kitchen – no need to stop everything to listen! But then it started making a farting noise so had to be turned off. The microphone I bought is a great success. Discreet and good quality. The purchase of a voice amplifier is now down to us I gather. The microphone on its own

has a symbolic importance though. Just as people treated Maggie differently when they saw that she was driving herself in the chair and not being pushed, so they treat her with more respect if they see the microphone. As one patient said the first time she wore it in the dining room, 'Can she speak then?'

So where are we?

Physically Maggie continues to improve slowly. The physios have abandoned the idea of transferring and in fact seem to have abandoned a structured programme for improvement at all. Maggie only gets 5–6 sessions a week now – often single sessions so much of the time is spent hoisting. She desperately wants *more* physio.

Her head movement is pretty good and would be more normal if she didn't have to tip it forward around the sides of the headrest in order to turn it – this gives her a peculiar 'bob and twist' movement like a robin looking at you out of one eye rather than a simple head turn. Still, a new headrest is 'on the way' (has been for some weeks!).

Trunk power is better but still not really useful. She falls less going around corners in the car and sits more easily on the edge of the bed for drinks but she still can't sit unsupported for more than a few seconds. With arm support she can sit for minutes but with a thoracic kyphosis which she doesn't have the power to correct.

I haven't seen her standing in the standing frame for a couple of months but she can do that for 20–30 minutes. We have stood together at home – 'illegally' of course but just to prove a point and for fun. I get her sitting on the edge of the settee with her feet firmly planted, crouch before her with my knees on hers, my arms round her lower back and her arms over my shoulders. Then I lean backwards and she stands. We end up vertical and hugging each other – a position in which we are stuck! If our balance is good it takes minimal power on my part and it's lovely just to hug. The sitting down, to my pleasure and surprise is not a big flop as gravity takes over again. It's an inevitable but controlled return to a good sitting position. So there *is* power there and greater things *are* possible. If only the physios would work on it.

Maggie's legs are ISQ but we both feel that quads power has reduced since she started having her feet bound to the extended

footplates by ‘ankle huggers’ – leg restraints! Yes her inversion is cured by them but she can’t stretch her legs when she wants and can’t extend her knees as she used to. We are leaving the restraints undone at home now so that she can ease her legs for comfort and work them when she wants.

Arms are still coming on. She can’t quite lift the left from hanging onto the wheelchair tray – it internally rotates and jams. But she can do that more easily now with the right. But the greatest success is with the right hand and wrist. She can write quite legibly (but big and spidery) and can move her hand successfully over a whole piece of A4. But she can’t hold the paper or pick up a pen so independent writing is still not on. Independent driving is a different matter though. Maggie can now, thanks to wrist dorsiflexion, put her hand on the T-bar of the joystick reliably and (fairly) quickly; 10 or 20 seconds instead of the 10 minutes it used to be. She can manoeuvre quickly and reliably. It is very impressive to see how things have improved. Tesco on the Friday before Christmas? No problem! The cramped and cluttered house? No problem (occasional catching of those infernal handles which stick out so far at the back but nothing else). She can change gear fairly well using the button I fixed in the end of the T-bar but these days just leaves it on ‘5’! At last she seems to move just for fun – setting herself near people rather than expecting us to move chairs, reversing into tiny spaces in a crowded dining room – or just going the long way round. It’s so nice to see her able to do something because she can however second-best wheels are compared with legs. I have even been able to move the joystick back to its original lateral position – a bit more difficult for a week but now all sorted. We must keep pushing the boundaries all the time.

We have certainly done so with swallowing. ‘Single cream’ fluids are now a doddle and we have progressed from spout cup to Doidy cup to normal mugs and glasses. Maggie now drinks tea and wine routinely unthickened – the only problem being the occasional cough (but no more than with thickened fluids), and a tendency to dribble – she has developed the habit of tipping her head right forward to swallow – from the days when that was the only way she could do a chin tuck. So, with unthickened fluid the slightest gap in the lip closure gives a flood!

Tongue movement is improving too. Occasionally she can spurt fluid in a stream – faulty lip closure again but excellent evidence of powerful tongue movement. She tried a pistachio nut this weekend (risky!) but managed to manipulate it side-to-side and chew it – a wonderful and new accomplishment, lateral tongue movement has not been good. So we will start trying other non-sticky, manipulable things – thin ham is one but Maggie’s idea of chewing gum seems excellent. She needs to tap in to unconscious movements, reflexes and such. At the moment all movement is conscious – so the routine continuous mouth-cleaning, lip-licking movements that I make, she doesn’t. This explains the dribbling while concentrating or writing . . . Maybe chewing gum will encourage all sorts of forgotten, routine, habitual tongue, palate and lip movements. On a couple of occasions I have seen her roll her bottom lip in under her top teeth and clean it – a quick, relaxed movement. She has not noticed and has been *unable* to repeat the movement when asked! So lots can be done. We must do it though. The therapists can advise and do a little but the big, useful improvements have come from Maggie working and working and working to an end. So the trick is – as soon as power and coordination develop to the extent that they may be useful – *use* them – for something ideally which gives benefit so that the exercise is beneficial or useful or pleasant. So – the MMC slave joystick centre-mounted, then the joystick medially on the right armrest, finally the joystick laterally on the right armrest.

I have rigged up a radio-control switch for the POSM from a car alarm I bought at Maplin. That is mounted on the tray centrally close to Maggie’s body so that she can’t hit it accidentally but she does have to move the right arm from joystick to switch and back many times a day. She wouldn’t make those movements otherwise. The next things to do are a computer click-switch mounted under the computer table so that she can use the computer independently without having to get a nurse to put the switch round her hand with Velcro. Then the switch will be in a slightly different position relative to chair and tray and arm every day – increasing power and flexibility. I long for other movements to become strong enough to work on them in this way because there is no doubt that Maggie has learned to be immobile and dependent.

Only recently has she started moving about where she wants and when – *exercising* what independence she has. She sometimes now lifts her right hand to help with dressing, she always tries to sit up when clothes are put over her but at home she doesn't say, 'right, let's eat' . . . I make most or all of the 'daily living' decisions – a problem which has certainly brought me into conflict with others on occasion (the nurse, Elinor . . .). It's always me who watches the clock and plans enough time for dressing, eating and leaving on time for appointments. Maggie used to do that and will do again but she has to *learn* to again after a year of passivity.

There was an interesting issue last month. We were giving unthickened drinks but the nurses (well, one particular nurse) refused because the SALT swallowing instructions still said 'single-cream' consistency. The words used were along the lines of – 'we'll wait until Iain comes in to see if he'll take the responsibility'. Maggie was livid and so was I. She is an adult, surely *she* can take responsibility for choosing what she can drink? It seemed a very strange attitude for a rehab unit whose responsibility surely is to encourage independence – 'patients' though are easier to manage if they are kept dependent. We brought the issue up at M's review meeting. To what extent would the staff accept *her* word for what she wanted to do or have done to her? Derick Wade sorted it. 'We won't help her to take cyanide but drinks should be no problem', and a pointed notice to that effect appeared in the kitchen a couple of days later. It's a good point though and really brought home to me how much power those of us have who can act – and how little power Maggie has over her own life and actions. The challenge for me (and others but me first and particularly) is to enable her to *act* upon independent decisions. I nearly wrote, 'to give her the option to make independent decisions' – how patronising – that is a right she has – it is *not* in my gift. But I can so easily thwart any of her ideas or intentions, by ignorance and inaction and thoughtlessness as easily as by conscious choice. She has 'learned helplessness' – we must break out of that state before it becomes 'learned hopelessness'.

The computer has helped greatly (much to Maggie's irritation she has to acknowledge the lifeline it provides). Once Velcroed to her switch she is on her own. She can write her book, save it, email

it home for printing. She can listen to music using 'Juke Box' – CDs recorded onto hard disk. She can email friends and family (her mum got on email for the purpose and my folks are about to as well! I can't think of anything which would have got them onto the internet other than this!) – that is best. She is aware of things now that I'm not. With email she can read letters, reply and stamp them and send them all with the click, click, click without *any* interference from me.

What about mood? Appropriate I guess. Low and frustrated and sometimes angry, *not* resigned to her fate but more accepting of some of her limitations. Still disbelieving – as am I. It seems impossible as I lie beside her in bed watching her sleep, or gently wake and smile that she can't just roll over and hug me, or even touch me or kiss me. When she is sitting on the settee and I say, 'shall we go to bed?' why can't she say, 'Yes' and just get up? It seems crazy, unreasonable, unfair that she can be so normal and simultaneously so markedly disabled. What do I wish for most? I wish she could bend her elbow or flex her shoulder a little more. Then she could scratch her face, wipe her mouth, perhaps drink. I wish she could control her breathing. Then she could speak. That would be most valuable of all. It would be lovely to see her mixing with the other patients, chatting, letting the nurses (and others) see that she is intelligent, with firm opinions, watching her in shops and in company dealing normally with strangers and joking with friends. Instead we have near silence, whispered words and phrases and occasionally, and unfortunately only when she is angry, clear and loud retorts. I don't know how she balances out the options, would she give up all leg movement for normal speech, all left arm movement for useful right arm movement? All her movement is so bitty. Bits here, bits there and really only neck, face and right hand which are useful. But there are others in Rivermead worse off. Would she like two good arms and no coherent speech – dysphasia rather than dysarthria? We have to accept what we have. But keep working for more.

On the job front we have been more fortunate. Getting the Associate Director job was a real treat. Only three sessions a week but an indication that others thought I was worth something and an income! Then getting Swaffham. I can't believe how lucky that

was. The only part-time job in my patch that I saw in four months. A half-time job share in a training, dispensing practice with EMIS in a market town with a cottage hospital. If only Maggie was well sorted so that we could enjoy it fully and together.

The house should soon be bought. Contracts exchanged by the end of the month I hope.

What defines my life? Am I a doctor, a husband, a person, an educator, a father? Am I trying to re-establish my own definition of myself – as a GP – after a year of turmoil and uncertainty? Shouldn't I be redefining myself as a husband and carer? Maggie is so so important to me, so central to my life. I ache for her and her predicament all, no – most of the time – the intrusive thoughts of her are less problematic when I am involved in other matters. The husband vs carer problems have become prominent over the last few weekends. We will need hired carers for much of the time or I won't be able to just be husband, I'll be nurse, physio etc etc as well and there are bound to be conflicts as a result.

Finally, how am I? 'Appropriately depressed' would describe things best I think. When occupied at work or with Maggie or even just driving (and there's *lots* of that) I am fully functional and can participate normally in everything. When alone, especially at home, I feel tired, lethargic, hopeless. Getting out of bed if I have no deadline is difficult, starting any task takes palpable effort. I just go from problem to problem in my mind, thinking lots accomplishing little. I collapse in front of the TV with my supper at 10ish and often wake up there at one in the morning. My customary enthusiasm and drive and energy are gone. They flash back at times, which gives me hope but I'm not like I was. And if I sit and think realistically about us and our future and our hopes and our past I cry and cry and cry. Just great waves of helplessness and self pity and, 'why us' . . . Then it goes away and I'm left tired and weak in our new reality.

