Brain injury rehabilitation: jaw jaw not war war

A N Bamji

In February 1995 Minerva expressed in the *BMJ* a widespread anxiety that a charity, Headway, was covering up the deficiencies of the NHS in brain injury rehabilitation. I outline here the attempted development of a brain injury rehabilitation unit in the old South East Thames Regional Health Authority—a development that seems appropriate and necessary.

"No service can be developed until the 'money follows the patients' doctrine is sidestepped."

My theorem for new service development runs as follows:

- "If you wish to develop a new service, then I am afraid that the money will have to come out of some existing service" (director of public health, commissioning authority)
- "We cannot accept responsibility for funding a new service unless commissioning authorities are prepared to underwrite the development by agreeing to use it" (regional officer)
- "We cannot commit ourselves to funding a new service out of existing resources unless we have some evidence that it is effective" (manager, commissioning authority).

Proof: Commissioners will not buy a new service until they can see what they are buying, but providers cannot provide it until commissioners put up the money, which they do not have. This is alternatively known as Catch 22.

Corollary 1: He who chairs a working party must be prepared to become a non-person.

Corollary 2: It is probably easier not to bother.

In 1989 I was asked to chair a regional working party in brain injury rehabilitation. Our remit was to examine perceived deficiencies in service provision and suggest solutions. I expressed some reservations at spending time on a project if there was to be no money to fund the conclusions, but was assured that there was the will and the money to make certain that any recommendations would be carried through.

We established a group of neurologists, rehabilitation consultants, psychologists,

therapists, and representatives of Headway. We took advice from rehabilitation specialists around Britain, met regularly over an 18 month period, and produced a 35 page report with 57 references. We concluded that basic brain injury rehabilitation services should be provided at district level, but that a regional unit should be developed to offer a specialist service for complex cases, and provide a base for education and research.

This conclusion was welcomed by the regional health authority and an option appraisal exercise was undertaken to determine where the new regional unit would be sited. Bids were received from several hospitals and the appraisal team's recommendation that Queen Mary's Hospital in Sidcup was a suitable site was not met with universal approval. Nevertheless, there was at least a commitment to proceed. So an approval in principle document was prepared, with the enthusiastic support of the hospital management, and many more hours were spent drawing up detailed plans and costings, after visits to and correspondence with established units.

The document was taken to the appropriate regional committee for ratification. It was turned down. Two related excuses were offered: firstly, that the new purchaser and provider split in the NHS meant that the whole process of contracting for regional services was under review, and, secondly, that this specific project did not adduce any evidence that commissioners would place contracts. The explanation flew in the face of the clear expression of views by those who were managing patients with brain injuries—namely, consultants in neurology, rehabilitation, and orthopaedics—that they would be making tertiary referrals. But the decision was final.

I wrote to our MP, who wrote to the secretary of state for health, who told us to submit a business plan—a pointless exercise, given the application of my theorem. So there the matter rested, and in my filing cabinets all our background research, working papers, and unit plans gathered dust. Brain injury rehabilitation continued on its ad hoc basis, with a quasiregional service offered by the department at the Queen Elizabeth Military Hospital. Other units, notably at King's College Hospital and the younger disabled units at Hither Green and Sidcup, provide perhaps a better than average deal. A unit was established at a private psychiatric hospital offering a small but excellent service.

Meanwhile there was a continuing debate on the future of neurosciences in South East Thames, based on the premise that a single site unit would have to replace the services provided at King's College Hospital and Maudsley Hospital and the Brook Hospital in Woolwich, whose future was increasingly precarious. A perturbing factor was the amalgamation of South East and South West

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Thames regions, but it came as some surprise to read the 1994 *Regional Neuroscience Review* (which, among other things, had abandoned the single site doctrine of 20 years' standing) and discover that the question of brain injury rehabilitation had been readdressed, involving the coopting of an eminent specialist from outside the region (from whom we had taken detailed advice when preparing the approval in principle document). No new conclusions were reached, except that more work was necessary to define need. No reference whatever was made to the original working party report, option appraisal, or approval in principle exercise, where the need had already been defined. It was as if they had never been. My protests on behalf of those who had put in so much work, outlining the agreed solution, were unanswered.

Meanwhile one consultant in the region with a special interest in brain injury rehabilitation has left for the private sector, despairing of the inability to make advances in service provision. The rationalisation of army medical services, which involves the closure of the Queen Elizabeth Military Hospital, has removed the rehabilitation unit there. The closure of the Brook Hospital in Woolwich casts a shadow over the Headway House (of which I am a trustee) based there. Far from things getting better, they are getting worse; the funding Catch 22 ensures that no service can be developed until the "money follows the patients" doctrine is sidestepped. It requires a politician to break the log jam. Is it any wonder that we do not bother?

As for the bleating that there is no money

... the NHS continues to throw it away. Nationally, we have seen huge sums frittered on useless information systems, and cash is being flooded into general practice fund-holding. Locally, plans in an adjacent district for a new single site hospital on a metropolitan

green belt site were turned down by the Department of the Environment. It is suggested that the plans, which had little chance of success, cost £6 million. A scanner, bought at a cost of over £400 000 for the Brook Hospital, never worked and has now been

written off. Our brain injury rehabilitation unit could have been built and run for four years with that money.

Is this really the best we can do? No one can say we did not try.—ANDREW BAMJI is a consultant rheumatologist in Sidcup

My brain stem stroke

G F Grant

I set out on the half term holiday with the family, blissfully unaware of the traumatic events that were to follow. We had borrowed a friend's weekend cottage and I went to bed early. My only medical condition was a persistent headache, but I had had headaches before as I occasionally suffered from migraine. I was aware of my wife coming to bed much later but there was nothing ominous about that. There then

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occurred the event that was to change my life for ever.

I can recall what it was like going through the stroke itself. It felt like a desperate battle to regain my balance. I remember thinking that if only I could get things on an even keel then I would be all right. There was also a constant babble of voices all speaking different languages. I was admitted to the first hospital with only my eyelids moving. According to the admissions register I was in a deep state of unconsciousness—nothing could be further from the truth. I floated in and out of consciousness. I can recall the interminable discussion the ambulancemen had about how they would get me down the stairs. I was aware of the ambulance stopping while the men tried to make me more comfortable and decide which hospital to go to. It was difficult to make me more comfortable as I was curled in a fetal position. I recall the ambulance stopping in a layby on the outskirts of the town.

I recall nothing of my arrival at the hospital but I remember the difficulty in moving me as I was examined. No one had an inkling of the cause of my rolling eyes, laboured breathing, and dark coloured discharge trickling from my mouth. I recall being wheeled through the bowels of the hospital to be given a scan. It was uncomfortable having to hold my head still while they got a good picture. They clamped my head, the nearest thing to torture I know. I came to in a freshly made bed with some flowers on the window sill. I had no idea what was wrong with me as my brain seemed to be functioning normally when I was conscious.

I recall the doctors discussing the hopelessness of my case thinking that I was unconscious and thus unable to hear. I heard

every word and what a depressing picture they painted. I wonder how many patients have given up the ghost having heard how unwell they were during one of these dialogues. Essentially the bridge between my brain and my body blew up. This left me mentally undamaged, my memory intact, my intellectual ability undiminished, and, so my family and friends assure me, my sense of humour in no way altered, but the only parts of me that could move initially were my eyelids. I was classified as tetraplegic with no speech. My right side is even more affected than my left, which leaves me more isolated as I was right handed before the stroke. I now have some movement in my left hand so I am able to write this on my computer. My memory has got much better as I can no longer write little notes to myself.

The doctors were a bit quick to write me off. After the failure of the initial scan to show anything it was repeated three days later. This time a circular area the size of a 2p piece was clearly visible right in the brain stem, the death of the nerves being caused by the constriction of a blood vessel. My family was told in quite unequivocal terms that the stroke was unsurvivable. Yet here I am three years later living at home after 16 months in hospital.

It was soon after my stroke that I was introduced to the pleasures of physiotherapy. The smell of that tweed jacket as I was transferred to that infamous tilt table will live with me for ever. On one occasion the physiotherapist tried to get me stretched out on a big orange ball without success. I also had a tracheostomy. The tracheostomy tube gave me a new weapon with which to attack all and sundry. My high velocity sputum blasted nurses and consultants alike. I had no control over when I coughed but they soon learnt to duck. The adhesions in the locality of the tracheostomy site caused contractures, which pulled my head position forward, but these problems emerged much further down the track. In the initial stages I was purely and simply fighting to live.

I remember with joy when I made my first small voluntary movement. It was three weeks after my stroke when I squeezed my wife's hand with my left hand. I had seen the visiting consultant and he had dismissed all my movements so far as being involuntary. "They need to be voluntary in response to a command," he said. In one fell swoop he had removed all our fragile hopes that recovery was starting.

In the early days I had some speech

therapy. The inactive muscles in my mouth and tongue were stimulated with ice, but a far greater response was produced with blocks made of frozen wine. It must have been difficult for either therapist to see much response but they stuck at it. I have heard a tape of me attempting to speak one year after my stroke and it was unintelligible. I have heard that all the recovery made by a patient who has had a stroke is made in the first nine

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months. What a load of rubbish. I am still progressing three years after my stroke.

The stroke has left me like a baby in that everything has to be done for me. It is the nearest analogy I can think of. Now food has to be cut up. Bodily functions can make you feel like a baby. You have to get over the very human feeling that your life is no longer private and that is difficult. I am having physiotherapy to regain what movement I can and I hope eventually to learn to stand. Speech therapy has mobilised my tongue and lips sufficiently to enable me to swallow safely and eat a normal diet. I am learning how to speak literally from scratch. I shudder to think of those patients who have been thrown on the scrap heap because they do not have the determination and family support to fight for treatment provided by the scanty resources of the NHS. I have nothing but praise for the patience and understanding of the therapists. They seem to know instinctively how far they can push me at any time.

The main difference from that of a baby is the memory of how it used to be, which is most frustrating. A non-functioning shell of a body. You have an itch but cannot scratch it. Those around you have to put up with your outbursts of sheer frustration. Speech is difficult. You know what you want to say yet all that comes out is unintelligible mumble. You try so hard, only to be met by a blank, uncomprehending stare. Yet despite this you have to keep going. Progress is not made rapidly—it is a long slow grind. You had better face it, you may not want to hear it, but it can take years of constant repetition. It is getting better ever so slowly. It is this slowness that I was unprepared for.—G F GRANT lives in Bedfordshire