

NOTES ON A SON AND BROTHER

May 1985

Done for FAPA and a few others by John Foyster, 21 Shakespeare Grove, St Kilda Victoria, Australia 3182.

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The Burning of the Brain

Cordwainer Smith's short story (If, October 1958) has long been a favourite of mine. Its appearance in the first issue edited by Damon Knight (there were two other stories in the two other issues produced by Knight) was as part of a rather ad hoc "Short History of Space Travel", but it fits rather soundly into the Instrumentality series.

My admiration for the story was such that several times, for example in the December 1967 issue of Australian Science Fiction Review, I listed it as the top sf short story I had ever read: I'm by no means sure that I have changed that opinion yet. But I could not have dreamed when I first read the story, or when I publicly expressed that high opinion, that the story would ever come to have such particular personal meaning for me.

In "The Burning of the Brain" the Go-Captain Magno Taliano, captaining a jonasoidal ship whose locksheet guidance system fails, sacrifices himself to the Pinlighters, who burn slowly through the star images in his brain to guide the ship home. In the end "(h)e had the amiable smile of an idiot, and his face for the first time in more than a hundred years trembled with shy and silly love." (If, October 1958, p. 91)

My son James, of whose early life I wrote for this audience about a year ago, died on February 24 1985. When he died his brain had been burned away almost completely, though in rather different circumstances.

In June 1984, while James was still in hospital, his brain was invaded by MRSA (multiply resistant staphylococcus aureus). MRSA is to be found in hospitals (rampantly in Melbourne hospitals) and infrequently elsewhere: it is particularly difficult to deal with. In James's case the invasion took place not only at the outer casing of the brain, the meninges (giving rise to meningitis) but also inside the brain, throughout the ventricles (ventriculitis).

For the two months from the middle of June James struggled against this infection. For four weeks James had vancomycin injected directly into his head. ("Vancomycin is too toxic for routine use and should be reserved for treating infections resistant to other antibiotics." MEDICINES: A GUIDE FOR EVERYBODY, Penguin, 1977.) During this time James's doctors were checking frequently with other hospitals for advice as to whether treatment could be safely (?) continued/discontinued. Towards the end of August the infection seemed to have subsided.

In that time we could almost chart the damage being done. From week to week, day to day, James would lose control of some part of his body, only to regain control slowly while another area began to be affected. By the end of August this phase had passed and James began to grow rapidly and to develop his motor control. Everyone knew that damage had been done; no one knew how much.

Through to the middle of October James's development continued smoothly. We began to take him out of the hospital in his pram for short walks of a block or so. He visited Space Age Books a couple of times, and especially came to like the breeze on his

face - so different from the still air inside a hospital. He also liked playing with tree branches when he could reach them.

We talked with medical staff about brain damage - cerebral palsy in particular. But nothing definite could be said; the attitude was very much one of 'wait and see'. During his life James had already survived several times when the odds were very much against him, and one just couldn't tell. But there were some puzzling things.

For example, from the fact that James could reach out accurately for toys presented silently we knew that he could see. But his eyes behaved strangely: there was no blinking or turning away from bright lights, nor did his pupils dilate. But when the light was taken away James would cry.

We really wanted further investigations by the neurosurgeon, but she felt that there was nothing more to be done until James had at least four weeks of clear health.

From late October James began to have rather difficult attacks of asthma. (It was a bad spring/summer - I had my worst time in seven years.) But James was otherwise quite well, apart from an occasional cold and a never-explained rash. Probably the neurosurgeon could have continued her investigations earlier than she did. As it was, she arranged an ultrasound of James's head in mid-November, and a follow-up in mid-December.

Just after Christmas we were given the result. James's brain was severely damaged: the ventricles were very much enlarged and in places the brain-tissue was very thin indeed. The visual cortex was almost non-existent. (But recently I have seen a Yorkshire TV documentary, IS YOUR BRAIN REALLY NECESSARY?, which makes it clear that some individuals can manage quite well thank you with very little brain tissue. I suppose the star performer was a young Englishman who had just received a first-class honours degree in mathematics who had only 5% of the normal amount of brain tissue. Such cases make a mockery of the traditional assigning of functions to particular parts of the brain, since it was shown in these cases that functions are re-assigned to bits that are left. All of the cases cited involved hydrocephaly (which James has mildly) but nothing else.)

How was this possible? James could see, after a fashion, but far better than could be expected on the basis of the amount of brain tissue visible in the ultrasound. Some medical staff suggested that, because the damage has occurred slowly, over a period of more than a month, James's brain would have been able to adapt so as to manage the major functions. Certainly earlier in his life James's brain had shown itself to be fast and efficient. Now, perhaps, it had adjusted itself to maximise performance. (Rather like the examples in the television program.)

But could anything be done to improve the situation? The neuro-surgeon ordered a CT-scan which involved visiting another hospital. James very much enjoyed his ride in an ambulance on January 11. Because of holidays for medical staff we were not informed of the results for five weeks.

During that time quite a lot happened. For example, in parallel with all this activity my father was also in the hands of the medical profession. He had had a brain operation for a meningioma (a benign growth on the meninges) then another to fix up some damage done by that operation, then another to fix up the damage done by the second . . . and we certainly were not too surprised when he finished up with meningitis (less virulent bacterium than James, though - on the other hand, coping with any form of

meningitis at the age of 76 is not fun. When he could talk, my father usually asked about James so on January 25 James had a big adventure. We found out the hard way that it was possible to wheel a pram between the two hospitals in 25 minutes. James sat on his grandfather's knee, and perhaps there was some therapeutic effect so far as my father was concerned. James, however, became quite distressed on the way back. It wasn't until he was happily back in bed that we understood that he had been frightened at being away from his home for so long!

In December and January James learned quite a lot. His liking for different sounds developed through some of the toys he got for Christmas. He particularly liked squeaking sounds and 'playing' a toy piano (which meant that he hit the keys in a rather excited fashion). In association with some of these, and also when I made squeaking sounds, James smiled. This was something we had been working for all of his life.

As well as that, James's interest in the plastic tube in his neck increased. (Early in February 1984 James had had an elective tracheostomy, which left him breathing through a hole in his throat.) He knew that people made noises with their mouths: why couldn't he? During this time James and I learned to talk to each other. Occasionally when James had excess saliva in his throat he would make a noise as he breathed. In January he discovered that he could change the pitch of this sound by tightening or loosening the muscles in his throat. His total repertoire was about three sounds, but we would sometimes 'sing' together, because I could imitate one of his sounds rhythmically from time to time changing to another sound. It was a great day for me when for the first time James followed my change in pitch, keeping in time and smiling.

All of this seems rather pathetic as I write it now, but then just about my whole life was centred on this child's struggle to come to understand something about the world in which he lived. Indeed there were days when one could only just feel certain that James was aware that he existed as a distinct part of the world.

On February 15 Jennifer discussed the CT scans with the neurosurgeon, and I examined them on the two following days. They could scarcely have been worse. The ultrasound picture had been taken at a level which was less damaged than average. James's brain had been destroyed in many places, with only the cerebellum and some substantial scraps keeping him going. Vast cysts had erupted in place of brain tissue at many places.

Within nine days James was dead. On the Sunday he began to have another of the episodes of asthma, but on Tuesday, by which time James required 70% oxygen, his specialist confirmed that this was a predictable episode consistent with James's general condition. That night I had a slight altercation with the sister looking after James who was having trouble administering the correct amount of oxygen: she seemed to think you had to add air to 70% oxygen in order to get 70% oxygen.

The next day's events can mostly be covered from our diary (Jennifer's entry).

James had another episode during physio when he 'went off' when his head was tilted down. He recovered quickly and when I left he looked quite contented in his beanbag. However, while I was away - we were told - he had four cyanotic episodes requiring bagging. I raced in, followed by John,

expecting to be confronted with the choice of whether or not to provide ventilation. Dr Murnane had already been contacted and had advised that ventilation was not appropriate but that James should be made 'as comfortable as possible'. This involved giving him 100% oxygen but withdrawing all drugs including ventolin and feeds except for 10 ml of glucose and water. We were amazed that these steps had been taken without our consent. There was prolonged and turgid discussion. I nursed James for five hours, every minute expecting him to die.

He eventually made the decision for us, rallying around 6.00pm and by the time Dr Murnane arrived at 6.30pm didn't really seem to need ventilation. After discussion it was agreed to resume James's medication and feeds.

This clearly abbreviates a long day full of events. For example, I nursed James for about four hours that day. In the past James had responded very well to our presence, and this day's recovery was very much another demonstration of this. But arguments about James and his treatment continued. On the Friday I made the following entry onto James's medical record.

When I arrived at 6.55am James was receiving ventolin. The air cylinder was flowing freely at 12 l/min. When ventolin completed the sister reconnected oxygen and air cylinder at 10 l/m and 12 l/m. I challenged the addition of air. The sister indicated that this did not matter as he was, and had been getting 100% (oxygen) all night. When the sister had left I obtained an analyzer and took several successive readings at 58% (oxygen) (re) calibrating each time. I did not touch either oxygen or air supply and have not done so. I am relieved that the laws of physics have not been suspended in Ward 601 and that James can manage in 58% oxygen when the therapeutic dose was 100%.

John Foyster 7.37 am

This illustrates the kind of battle we were having. (I photographed my entry on the medical record, by the way.) In our view, if James was to die, it should be for some reason other than his brain damage.

But it was all rather one-sided, and James's death on the morning of Sunday, February 24, choking, and gasping through the mouth and nose whose use had been denied him for over a year, could easily be predicted at this point.

James stayed alive a long time: long enough to show me just how determined even a baby may be, long enough to help my father survive meningitis, and long enough to ensure that his half-sister, Jillian Miranda, was not extremely upset in the final year of her secondary schooling (she was just distressed).

I could write, as you may well believe, many more things about this son of mine, who achieved nothing for himself in his own life, who did not know good from evil and, incapable of sin, died because others believed his life was not worth living. But this narrative is already tediously long for those who never knew James - yet absurdly brief to one who loved him.

Cordwainer Smith, one of the great artists of science fiction, never hesitated to telegraph an ending, and in "The Burning of the Brain" he does just this, describing Magno Taliano's fate less than 500 words into the story. To know what is to happen may prolong art, but it cuts at the heart of life.

MAILING COMMENTS

Before turning hastily to the February 1985 mailing there are, out of the many remarks on previous mailings I ought to make, two which stand out in my memory.

The first and lesser of these concerns comments made by Jack Speer on my previous FAPA publication which cast an interesting light upon differences of a linguistic kind in the common speech of Australia and North America. Jack referred to what he saw as a rather large number of typos on the final page, but only one of those 'typos' was in fact legitimately a typo in Australian language.

When I am escorting someone to visit John Bangsund I would expect to announce, as we arrive, something like 'and this is Bangsund's place' or, less often perhaps, 'and this is the Bangsund's place' (where the 'the' implies a plural, so that since Sally has reverted to 'Sally Yeoland', I would not currently use the second form). Jack Speer, on the other hand, would say 'and this is the Bangsund place' - a purely adjectival form with no possessive overtones. Just why the variation between continents exists I don't know, in this case, but there it is. (See Jespersen on Nexus-substantives.)

I'm more concerned about a remark I made to Art Widner when he was visiting in 1983. Intended half in jest and half seriously, my remark about the length of time Art had been a college teacher was plainly ill-spoken, as Art's report of the matter makes clear. It is late to repair damage, but certainly no criticism was intended, and in fact since that date I've had plenty of time to muse upon my own restlessness. I think now that it is my own way of living which is distinctly odd, and Art's rather less so.

Mailing 190

Redd Boggs: SPIROCHETE 30 *** Here's the first of two pleasant and trivial coincidences. Your story about Chan Davis makes frequent reference to his wife and, in almost the same mail as FAPA 190 I received a current issue of The Nation which, in describing extensively a particular controversy about a book on history, refers extensively to Natalie Zemon Davis. And the next day (herewith the second coincidence) I received a similarly-dated New York Review of Books in which Oliver Sacks refers to Robert Silverberg as being a writer who made the most of a particular phenomenon. Even if all knowledge is not contained in fanzines, you at least get plenty of cross-references.

SPIROCHETE 31 *** My front garden is filled with acacias. There is a substantial variation in colour amongst the half-dozen varieties out there, and the regularity in their flowerings (and the differences between them) ensure a progression of colour over several months from June.

Bruce Gillespie: THE METAPHYSICAL REVIEW.2 *** I gather that, despite the late date at which the notice for the AUSSIECON II Actrack appeared, the response has been more than adequate. Was this circulated earlier than in your fanzine?

R. Alain Everts: Surely there are many people who weren't Lovecraft's daughter either who would be a more interesting inspiration for articles distributed to FAPA?

Harry Warner, Jr.: HORIZONS 180 *** Congratulations on your retirement! // I'm, er, many years younger than Bert Castellari and Bill Veney, but when I was at school it was still common practice to leave at age 14. Castellari and Veney both wound up with journalistic employment, as I recall, Castellari being substantially involved with the '72-'75 Labor Government. John Bangsund should be better placed to provide further details of Bert's activities in Canberra. // Although I have extensive memories of radio, it certainly isn't of the kind of Gold Age you describe. Perhaps this is due to the skill with which you are able to evoke false recollections of things which have been half-experienced.

Rosemary Hickey: COGNATE *** Why did I even suggest that all knowledge may not be found in fanzines? Here you are with the perfect solution to shoe-repair. It would be a little more expensive from Australia, but in my view still worthwhile. And think of the possibilities for Harry Warner, Jr.!

Brian Earl Brown: BROWNIAN MOTION 8 *** I've seen 2010 twice, and neither time did I see in it the delights you seem to have found. Maybe I don't think quite as much of Arthur C. as you do. (I saw it twice because the first time was free and the second time I had to escort some kids from school...)

Terry Carr: DIASPAR 23 *** The conreport - yes. I have been waiting to read a TCarr report on CORFLU. But the typos, the bad printing? Is this a new model carr? // The WHICH and THAT Show reminded me of a longish memo I once wrote while in my previous job which explained the difference between 'oral' and 'verbal'. Having made the point that you should not use 'verbal' when you want to emphasise that the information was spoken I felt I could go on to explain it better in terms of two kinds of intercourse.

Charles Burbee: BURBLINGS *** Since I have had, and occasionally still have, the difficulty you describe Frank as having, I'm not sure that he would have been any better off going to a doctor. If there's knowledge around about how to treat this problem it hasn't seeped down to Australia. I had one attack last summer, but fortunately could remember from the previous series of attacks (six years before) how to get going again. I do hope that soon there is some better understanding, because there will presumably come a day when I won't wake up in good enough condition to carry on.

Art Widner: YHOS 31 *** I strongly agree with you about the role of fanzine fans in the running and management of conventions, world and otherwise. Only once has there been a fanzine fans' convention in Australia - seven years ago.

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I found myself enjoying many of the other contributions, but almost as a stranger. It isn't as though I haven't wanted to participate in FAPA over the past year or so; every so often I would cut a couple of stencils and then Something Would Come Up. I've just found the stencils I did for the November 1984 mailing. The topic will now be well-known to you, and please feel free to avoid it.

A DARK WOOD

November 1984

Done for FAPA and a few other folks by John Foyster, 21 Shakespeare Grove, St Kilda Victoria, Australia 3181.

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Back in February I circulated, in LIFE IN SHAKESPEARE GROVE 2, a couple of pages about my son James. It is 52 weeks tonight since he was born, and he is still in hospital. At the bottom of page 3 of LISG 2 I wrote 'We hope he will come home to us early in 1984.' The correction is 'er, 1985'.

Having a child in hospital for a year isn't to be recommended. It tends to be time-consuming, and then there's the fact that the child presumably has some health problem. James has some health problem! And hence, by a circuitous path, my title.

One could, I suppose, look on the bright side. Not many citizens have as much money spent on them by a government as has James: depending upon how you count it, James has had something between a quarter of a million and a million dollars spent on him so far, with the uncertainty arising because I'm not sure of whether one should rate some expenses at a genuine rate or at the inflated rate charged by persons in the medical profession. But to give you an idea, quite apart from occupying a bed James had had about 150 X-rays. And it goes on from there.

Back in February we left our young hero with only one lung functioning properly, but otherwise in good spirits. A quick run-through of subsequent events:

- The problem of the right lung was solved by cutting out James's right hemi-diaphragm and replacing it with a piece of plastic. As a result, on the right side James will only ever breathe passively, without any drive from a diaphragm. Better than not being able to breathe at all, you might suggest, but amongst the sequelae to the operation young James had a spell of that as well, when both lungs collapsed and he spent three days breathing 100% oxygen.

- After recovery from that James managed quietly for a while, building up his strength in the children's ward, until at Easter he came down with a bad attack of pneumonia. We were awakened at about 5 in the morning of Easter Saturday and went in to look at James's future, if any. They hadn't really done much for him when we arrived, and the doctor on standby counselled us that perhaps it was time to let James go - after all, he had been quite damaged by his previous experiences, etc., etc. On the grounds that this doctor had never seen James before, and that we had seen him recover from far worse crises, we said, more or less, 'you must be joking!' And so James went down to the Intensive Care U it for a week or so to recover. I spent Easter commuting between the hospital and the SF convention being held at the Victoria Hotel. I got tired.

- With another holiday/convention coming up in June, I rather wondered what James would turn on. His health hadn't been too good in the children's ward in the interim period, largely because the staff were not used to the kind of handling James needed. Almost on schedule, a week before the holiday, James had a cardiac arrest. Early morning visit to hospital, same doctor, same advice - much more firmly advanced. Doctor Glass's belief is that the cardiac arrest has been caused by cerebral malfunction which is probably irreversible. (He is wrong - almost fatally wrong for James, as you will shortly read.)

It takes about half an hour of persuasion (with James's breathing being maintained by hand) for us to get James onto a respirator for a maximum of 24 hours.

(Time-out to fill in with some more background. At the end of January, as a precautionary measure, James had a couple of minor changes to his anatomy so that he breathes through a hole in his neck and takes food through a hole in his abdomen. Just why this is necessary would take rather a long time and interrupt the smooth narrative flow..... In any case, the key parts of this aside are that, as a consequence, James takes his air warmed and humidified, thank you (since his nose can't get into the act), and every now and then, since he can't clear his throat, he needs a little vacuum-cleaning.)

I spent the first session down with James in the Intensive Care unit and around 7.30 am I pointed out to the sister that he was breathing against the respirator (somewhat indicative of a lack of need for same). She agrees, but suggests that we let him keep going. At 8 am the regular vacuum-cleaning brings up a chunk of mucus. My analysis - people didn't bother to clean him out adequately the previous night, his trachea blocked, with the usual consequences. (Although, only ten days later, I saw the start of a similar incident, it was not until early October that this analysis was confirmed by the sister who had been looking after James that night: there had been an emergency involving another baby, and she had been working with the rest of the team, and when she returned.... but back to our story.) Doctor Glass, of course, has his theory, and to demonstrate its truth he orders a spinal tap, from which he expects to find blood-stained cerebro-spinal fluid.

Alas for Doctor Glass, the CSF is quite clear. Alas for James, this will be the last time for some months that his CSF is clear. Five days later there is some inflammation at the back of his head and ten later he is diagnosed as having meningitis. Now since the meningitis (actually also an infection of the ventricles inside the brain) turns out to be caused by golden staph, that well-known bacterial inhabitant of operating theatres, a reasonable person might be led to infer..... (And indeed, some months later a doctor at the hospital did agree with me that ... seemed a reasonable hypothesis.)

Now ventriculitis is pretty fatal for babies, and treatment is quite uncertain. What was done, in James's case, was that vancomycin ("too toxic to be used for routine use" Medicines: A Guide for Everybody, Penguin, 1977) was injected directly into the cavity between skull and brain for four weeks. He was awfully sick, and even now, late in October, he is still recovering the use of his left leg. But most babies do die, so I guess all turned out pretty well. Except, of course, that there must be some permanent damage from so violent an assault on a baby's brain.

.In summary James, as an 11 weeks' premature baby, might be expected to be slow in development, mentally and physically. Then there's the severe birth asphyxia. Another count against brain function. Finally, the ventriculitis and the drug used to cure it. Both likely to do considerable damage to brain function. The result is scarcely cheering. Yet James, although he doesn't get on very well with human beings, is still a remarkably inquisitive little boy - and, as the medicos find out whenever they handle him roughly, a quite strong one. He has muscles rather than fat on his arms, and packs a fair wallop. And he likes to cling to my beard more than anything else in the world, I sometimes think.

And that is why I regard this as the worst year of my life. To date. Stay tuned. (John Foyster, 27 October, 1984)