

## **Impact of a long Hospital stay on a Humanist**

### **Introduction**

As one of my former colleagues remarked some time ago: "Life is a terminal condition". OK, so that is pretty obvious, but it underlies a somewhat soft focus view of death that for most of our lives makes it seem of no great cause for concern. However, as we grow older that focus gradually becomes sharper, and as a Humanist reminds me of the assumption that this is the only life we have, and of the need to make the best of it. When we experience a life-threatening illness the process is no longer gradual, and we are confronted with the need to review our lives and implement any desirable changes while we still have the time. This has certainly been my recent experience. In a group such as ours it is to be expected that at least a few other members have had comparable experiences, and sharing these would be interesting and potentially valuable.

### **Onset of Illness and Diagnosis**

Before the start of my problem I had been very fit and active despite being 75, with activities like climbing Ben More on the Isle of Mull at the end of May 2012 (3,189ft.), taking little more than half an hour longer than 30 years ago. This now serves to underline the traumatic change produced by my current illness. On 19 October 2012, one week after returning from a magnificent holiday in Chile, I woke up with a complete lack of energy, stiffness and aching in all my muscles and a loss of appetite (always a good indicator of some serious condition for me!). Three trips to my GP were to no avail, so I was duly dispatched to Stoke Mandeville Hospital on 24 October. Over two weeks of what appeared to be every test known to medical science eliminated all the possible ailments that were not causing the problem, but did not home on to the one that was. During this period the original symptoms subsided to be replaced by neuropathy in both hands and both feet, the right foot being completely dead to sensation below the ankle. Finally, I had a day trip to the John Radcliffe at Oxford where they had an electrical testing device that was applied to nerves and muscles and this, at last, pointed the way to my condition. A few days later, a biopsy on my right foot provided the final confirmation. And so, two and a half weeks after entering hospital, I was at last given the diagnosis of polyarteritis nodosa (PAN), an extremely rare form of the auto-immune illness vasculitis, where the arteries become inflamed and nerves bereft of blood supply die off, resulting in the neuropathy. 'Extremely rare' was quantified by the UK annual incidence rate of one in two million. What was less than encouraging was the news that PAN was a more dodgy form to have – my reaction to this is unprintable! At least my appetite had returned, so life still seemed worth living.

### **Treatment and Progress**

Treatment consisted of chemo-therapy infusions and steroids, to be followed by an immunosuppressant in pill form and other medication to minimise the possibility of iatrogenic illness from the main drugs. Progress seemed very slow, with a significant reversal in the amount of movement of my right hand after the second dose of chemo, as a result of which the amount was substantially increased. Apart from the slow and sometimes negative progress, the most frustrating aspect was that no-one seemed to know how much of an improvement, if any, could be expected, and how long it would take. In contrast, I had substantial inputs from both physio and occupational

therapists, both of which were yielding steady and measurable progress. However, although this was very encouraging, it was clearly not going to address the underlying problem. All this meant that the condition in which I would end up was uncertain, and that was a fact that I would have to live with for some time.

### **The Psychological Aspect**

So how did I cope, psychologically, with this situation? The simple answer is: 'I don't know'. Unlike many of my fellow patients, prayer was not an option, so something had to come from within. Happily it did, but how this works I cannot answer, and this is probably something one could not be confident about until such a situation has been faced. The first two weeks in hospital, prior to diagnosis, were certainly the darkest period since it was evident that no progress was being made other than to eliminate a multitude of things that I did not have. Once I had the diagnosis, progress started to be made, albeit very slowly at first, and this filled me with the optimism that my condition would improve, and all I had then to cope with was the uncertainty of how much of an improvement could be expected and how long would it take. There was one setback during which I convinced myself (wrongly) that my demise was relatively imminent, and whilst I was hoping for a few more years of life, when I looked back on the experiences and achievements of the 75 years I had been around, I felt extremely fortunate to have survived as well and for as long as I had. Somehow this made the prospect of an earlier death more acceptable.

A major factor in helping me through this difficult time was the support of my family, particularly Margaret who brought in all my food during my time in hospital. This was a huge undertaking not only in terms of quantity and quality, but she also gave considerable thought to the nutritional aspects as the steroids in my medication put me at risk of diabetes. Despite all this I lost about three stones in weight, so my chances of survival on hospital food would have been questionable. Margaret received substantial help from our three daughters despite their family and work commitments. Visits from my 8 grandchildren (6 human and 2 canine) also greatly boosted my morale.

### **Dialogue with other Patients**

During my long hospital stay I encountered a range of other patients, some of whom would clearly have been better off dead. In this category was Father Clive, a Catholic priest with pancreatic cancer. His cancer was evidently well advanced leaving him with no energy and probably significant pain. For him, suicide was obviously out of the question, but there seemed little point in enduring such a clearly terminal condition. He showed no inclination to communicate, but it is highly unlikely that we would have had anything worthwhile to say to each other. I should add that although only first names are used in this account, these have been changed to further preserve anonymity.

Not all cases where death appeared to be the preferable option were that straightforward. Alec (aged 61) was born with spina-bifida, and had suffered serious ill health throughout his life. His motivation to carry on living I found difficult to understand. Apart from having a very firm belief in Christianity (probably not quite to the fundamentalist level), which would no doubt block any consideration of suicide, he seemed an intelligent thoughtful chap with clear motivation to make the best of a life that I would have found intolerable. How he maintained such motivation I cannot imagine, but it seemed genuine enough.

Against the above were the cases where there was clear hope. I put myself into this category, since although my illness could kill me, my impression was that the chances of survival were not bad. How good a survival was open to question, but if no further improvement in my condition occurred, my brain seemed to be fully functional, and with that I could continue to lead a satisfying worthwhile life. Harry, who was opposite me in Ward 20 for a while, had an essentially similar situation. He was 47 and had burnt both his feet. Although I am not sure how this had happened, the net result was that his mobility would be significantly restricted for some months, but otherwise he was fit and healthy with an excellent ability to communicate. Harry and I had much in common, and chatted for hours on a range of subjects from gliding to dogs and extending to Indian cuisine. He was greatly missed when moved to another Ward.

One patient I found quite challenging was Den, who I encountered when moved to Ward 9. Margaret referred to this place as the old men's ward, since of the three other occupants the two opposite were best described as zombies, but at least they were quiet. Den, who was located alongside, was clearly slipping into dementia and definitely not quiet. I arrived on Ward 9 after midnight and lost much sleep listening to Den shouting at the nurses for trivial or non-existent reasons, and always in an extremely unpleasant manner. I rapidly formed the impression that he had always been a pretty dodgy character for whom dementia was merely lifting the lid of inhibition in the way that alcohol can do for some. When faced with a second sleepless night I felt justified in trying a strategy which many Humanists might find highly questionable. However, in view of the somewhat extreme situation, combined with Den's perceived character, I decided to try my own ideas on applied psychology. Legal considerations make it expedient for me not to detail these, but it proved to be an interesting excursion into an area way beyond my previous experience, and was effective. The net result was that I had a fairly good night's sleep and the nurses enjoyed a hassle free time as well.

The most interesting patient was Tom, since he was the type of character that I would have previously dismissed as a waste of space. When he first came into Ward 20, Tom was extremely unstable, - twitching, shaking and walking unsteadily. He was also reacting aggressively to perceived insults from the demented ramblings of some of the other patients. I judged him to be potentially dangerous, and treated him as a human Rottweiler by avoiding eye to eye contact. From comments by one of the nurses, it was evident that he was hallucinating due to alcoholic withdrawal. Strangely, he did seem to form a relationship with Sid, who was similar to the previously mentioned Den, but considerably less noisy and unpleasant. For the peace of the rest of us, both Sid and Tom were removed from the Ward for the night. By the next morning Tom seemed to be much more stable, and he was clearly getting on well with Sid. It seemed evident that whatever medication Tom was taking had become effective. As a result of this I started to communicate with him, and over the next few days we developed a good positive relationship. He had clearly had a very deprived background including bad company, drink, fighting, re-possession of house and what sounded like a failed marriage. Tom had a clear persecution complex, and probably with good reason. It appeared that he had received heavy handed treatment from the police in the past, which I could well believe, and even now some of the nursing staff were less than sympathetic and understanding. It was clearly all too easy to make a quick judgement of Tom based on first impressions only, and I could certainly have been guilty of this. But the fact is that it took a while to realise that beneath his off-putting first appearance, Tom had many admirable qualities. He showed a genuine concern for the welfare of other patients, and was helpful in various practical ways whenever possible. Given the

right approach he was a very friendly approachable sort of chap. But it was evident that in his past experience, the right approach had frequently not been forthcoming. He currently lived with his mother, and his future prospects certainly looked doubtful. This seemed a great pity since I really felt that he deserved better break in life. The really important thing about my experience with Tom was the huge about-turn it caused in attitude to my first impressions of a chap of his appearance. I resolved to beware of hasty initial judgements in future.

A final puzzling feature of the patients I encountered was the apparent dearth of atheists. I certainly made no secret of the fact that I am an atheist and a Humanist, but the response 'So am I' never happened. Indeed, many of the patients were well beyond the C of E – births, deaths and marriages church attenders type, being firmly committed Christians with visitors who said prayers around their bedside (with no evident influence on their medical condition!) This observation seemed at variance with the recent Census findings regarding the UK non-believing population. Margaret suggested that although many may have been ostensibly non-believers, they may have retained some nagging doubts concerning belief that prompted a little hedge-betting when faced with the prospect of their demise. This sounded a plausible hypothesis, but getting proper scientific verification could prove problematic!

One last amusing incident concerned a real believer in the bed next to me at one time. His group of visitors, no less than 4 or 5, after the customary bedside prayers introduced a new measure of medical progress by informing this patient that he had been taken off the prayer list, presumably meaning those said on his behalf by the church congregation. I suppose that this was meant to signify that his death no longer appeared imminent, and that this would make him feel much better!

### **Personality Change**

During the course of my time in hospital, I experienced a clearly observable personality change. This was not just my impression, but was confirmed by others who knew me well. So how did this manifest itself? To look at my personality as it was before requires some self-assessment for which it is not easy to be objective, but I will try. I was certainly a bit of an introverted sort of character, working best alone in my box. I could work with others to some degree, but it never came easy, and my communication and socialising skills were never good. Of the ten or so engineering papers I had published, only one was done jointly with a fellow researcher, and this I regarded as the poorest of the lot. All the rest were solo efforts, which I was much happier with. These characteristics undoubtedly got worse with age. On the positive side, I had a well-established sense of duty, which made me reliable. Along with that, my ethical position was essentially OK, but I did have difficulty in getting into other people's heads, which made seeing problems from anything other than my own perspective difficult. Margaret told me that the word 'empathy' covered that, but it was not in my vocabulary. So that was the former me, and there was clearly room for improvement.

The personality change I experienced in hospital was that I became far better and more willing to communicate with others, and generally turned into a more sociable and approachable sort of character. In fact on several occasions I was the instigator of social contact, which was very much the opposite of my former self. So what was the cause of this change? I think the main factor was the hospital environment, which gave me much time for reflection on my past life and future. This, combined with the experience of meeting a range of other people, patients and staff, opened my eyes to the differences in them and gave a better appreciation of their varied motivations. The

psychological pressure of coping with an indeterminate future resulting from my illness also played a part, and I became aware that however bad things seemed, many of those around me were in a far worse situation. Beyond this, I was aware that such changes were a possible side-effect of the steroids in my medication, and I was concerned that the change might only be short term, and a reversion to my former self could occur as this drug was reduced. Only time will tell if this is the case, but my feeling now is that although the steroids may have been influential in initiating the change, once the new behaviour pattern became established, it would endure. No-one would wish to have the illness I have experienced, but if it has resulted in my apparent positive personality change, and that it will be here to stay, then I think it will have been worth the price. There are more important things in life than good health, since although this enables one to be physically active, which can be satisfying and enjoyable, it is not essential for the achievement of other worthwhile objectives. Ultimately the only thing that needs to stay healthy and active is one's brain.

### **Dialogue with Hospital Chaplains**

My improved ability to interact with others did enable me to do quite a bit with regard to 'spreading the word' with respect to Humanism and Atheism to the extent that Margaret suggested the term 'evangelical' might be appropriate. I certainly missed few opportunities to make my position clear, and encountered a few individuals who were effectively Humanists without being aware of the term. I also engaged a few of the visiting hospital chaplains in discourses that largely comprised explaining my position while they listened. None of them showed any 'shock-horror' reaction to the disclosure that I was an atheist, which seemed to indicate a more enlightened attitude than that which would have prevailed in my youth. There were no attempts to convert me, although the Catholic chaplain did ask if I would repeat a phrase after him. I agreed in principle, depending on the phrase. So he asked me to say "God, if you exist, reveal yourself". I had no problems in repeating that, and received no blinding flashes from heaven either then or since. This strategy may conceivably work for people who, although professing to be non-believers, still retain some nagging doubts, but for me I would have to witness some pretty convincing apparition for it to stand any chance. Shortly after my transfer to Amersham Hospital, I was invited by Angela, the lady chaplain there (presumably covering all denominations), to attend a Christmas carol service. This I was happy to accept. Several members of the Chiltern Humanists seem to studiously avoid the term Christmas, Yuletide usually being the preferred option. I have no such hang-ups, and quite enjoyed singing the Christmas carols. The tunes were pleasant, and the fact that the words related to fairy stories was neither here nor there. Angela visited me in my room after the service, and we had a pleasant chat along the usual lines of me explaining the Humanist/atheist position while she listened. However, on a later visit I did try to provoke her by asking the question "I understand that in your belief it is vitally important to worship God, but doesn't that indicate that he, or she, has a rather questionable human attribute in wishing to be worshipped?" Her answer hinged on a definition of the word 'worship' that did not quite agree with mine but, if accepted, conferred an air of respectability on its use in this context. Sadly, this was the nearest I came to a satisfying argument with any of the chaplains.

### **End of Life Considerations**

My previously mentioned encounters with other patients, particularly those with clear terminal conditions, did cause me to reconsider my own views on end-of-life options and strategies.

Margaret has, for some time, held the more extreme view of preferring to go from fit and healthy to dead in the shortest time possible. Having seen the distress that terminal conditions can produce, this is a view that I am now warming to. Whatever strategy one adopts, when it comes to a conscious decision to end life, there has to be reasonably well defined criteria on which this is based. We are both agreed that any progressively declining medical condition, from which there was no realistic prospect of recovery, would be one. My view is that provided any such condition was not causing me pain or other discomfort, I would be happy to delay the decision until it did. The onset of dementia would be a definite end-of-life criteria for both of us, but again, the point at which it is reasonable to make this decision may be difficult to determine. For example, we all suffer from some degree of memory loss, which increases with age, but at what point should we regard this as insidious? The answer may not be easy, although as long as it has not reached the level at which coping with the practicalities of everyday life become problematic, then it seems acceptable.

With regard to implementation, to end one's life clearly means suicide, assisted or otherwise, which, for many of the terminal patients I met, would not have been an option due to their religious belief. For non-believers there is no such problem and the fact that suicide is currently illegal has to be regarded as academic, since provided it is successful suing a corps would not achieve much. Assisted suicide, however, is a different matter, and since many wishing to end their lives may have reached the stage where help is necessary, this is a serious problem. Using one's own resources does not seem to be a viable proposition since there are no known methods whereby life can be ended reliably and without pain or distress of any sort. Since a minority of religious people are, at present, preventing the population as a whole from legally having assisted suicide, this leaves the use of a service outside the UK as the only alternative, and the most well-known provider is Dignitas in Switzerland. This is not cheap, but from the coverage by Terry Pratchett in the TV programme of summer 2012, the service is very efficient and reliable, and is conducted with great sensitivity. The only other problem is that it is necessary to be in a condition fit enough to travel to Switzerland, and this may give pressure to make a decision earlier than one would otherwise have wished. Nothing is ever simple, and to end one's life is a huge decision. It would be like stepping into the void of nothingness which many may have difficulty in carrying through. At least for non-believers, the void is no different to that from which we effectively came before birth, and should hold no terrors such as the uncertainties concerning heaven and hell. Ultimately, the decision to end one's life does not seem that difficult in principle, but the timing of that decision would not be easy. This must be a matter of individual choice, which may vary from time to time, but it seems better to make such a decision while still able than to drift into an intolerable situation from which there is no escape.

In addition to suicide, there is also the choice of opting out of most forms of medical intervention. A speaker at the Chiltern Humanists in the summer of 2012 gave full details of the legal situation concerning this. The only problem is that it is not a completely satisfactory way to address the problem of ending one's life at the appropriate time, since declining medical intervention is no guarantee that death will be either swift or painless. It is undoubtedly better than nothing, but that is all.

### **The Aftermath – Life at Home**

I had naturally looked forward to returning home, but realised that it would pose challenges arising from my reduced mobility. In fact it proved to be almost as traumatic as the onset of my illness and

entry into hospital. The problem was that I was suddenly confronted with my limitations, which had been far less apparent in the artificial environment of hospital where there seemed to be no significant demands upon me. One of my most pleasurable activities in life had been the building of 1/72<sup>nd</sup> scale model aircraft, which demanded a very high level of fine motor control. I had been aware, since the early part of my time in hospital, that my modelling days had come to an end since any return of fine motor control was unlikely to attain the level required for that hobby. That I had accepted, particularly since it had become a bit obsessional. In terms of magnitude, however, this is probably the best example of the loss my illness had caused. The fact is that I had gone from being able to create models to a high standard of accuracy and finish to no longer daring to lift them for fear of dropping and causing damage. It was equally evident that a return to driving was unlikely to happen for some time. For now, I would be dependent on Margaret for transport, and although she was always willing to meet this need far as possible, it nevertheless represented a curtailment of my freedom. These comprised the major limitations, both of which were predictable. However, it was the numerous smaller problems that now confronted me that had a depressing effect. Simple operations like retrieving one of my larger books from the bookcase were beyond my current capability. Again, Margaret was always willing to do such things for me, but having this level of dependence was depressing.

Essentially the problem was that it took time to adjust to the limitations my condition now imposed on me, and to gain acceptance of them. My progression in this respect was aided by an awareness that my capabilities were gradually improving, albeit very slowly in some areas. The increase in my mobility was much better than expected, and this was very obvious and measurable. To her great credit, Margaret was always extremely encouraging regarding such improvements. The most tangible of these was my ability to climb Wain Hill (our nearest with a height gain of about 400ft.). At the time I left hospital I thought that with a bit of luck and some perseverance I might manage to climb it by the end of the year. At the time of writing (October 2013) I have now climbed it 24 times, and it has become fairly easy. In the main other area, which is the neuropathy in my hands, improvement seems slow, but both Margaret and the consultant at Stoke Mandeville have persuaded me that even here things are moving forward in a measurable way. All this has helped to dispel the depression I experienced, and whilst many of my practical limitations are still frustrating, I now feel more able to accept them.

## **Summary**

To summarise, my long stay in hospital has been a very life changing experience in that it has given me much cause for reflection on my own life. The contact with other patients has changed my view to a more tolerant appreciation of individual differences, and has helped to improve my communication skills. This contact, particularly in relation to terminally ill patients, has focussed my attention on end of life issues and especially on the problems relating to the timing and criteria for a decision. However bad my illness may seem, in relation to many of the patients I have met, I count myself as being extremely fortunate to have led such a full and active life and reached the age of 75 without significant problems. The experiences and achievements of my life are things I can look back on with great satisfaction and pleasure, and whatever happens to me in the future cannot take that away. My apparent personality change has been the most positive outcome of this experience, and will, hopefully, endure long after the possible influence of steroids has gone.

