

TEN YEARS ON!

I am pleased to be able to report that after ten very long and frustrating years, payment has now been made (almost) in full for my late mother's care - some interest is still outstanding.

Readers may not know that for much of my life I have lived abroad, working in the entertainment industry. Until the 1990s there was no internet, no e-mail and fax machines were not available to all, consequently all contact then was by letter or phone, which years ago had to be routed through the long-distance operator. Information was not as easy to come by as it is today. As an only child I wrote to my mother weekly, even from before she was widowed in 1977 and visited on every holiday, a time when there were far fewer flights available. I mention this because it might appear as if I had no interest in what was happening at home. As luck would have it, I did invest in a computer and was able in 1998 to access what web sites there were, and had it not been for the information available, I might never have started this long and tortuous journey.

To distill the decade involved, as far as is possible, in November 1997 my mother celebrated her 90th birthday and I stayed with her for a fortnight. Although relatives had said she was very irritable and her letters to me were frequently unkind, she had managed to cope with living - just. During my stay I discovered that she was in a very bad state mentally - no memory, poor personal hygiene, bizarre behaviour and very much more, all concealed from what few relatives she had. So disturbed was I by this that I met with her GP, only to be told "nothing can be done". The suggestion was made that she should enter some kind of "alternate accommodation" and so immediately I returned to my work I wrote to Reading Social Services to ask if there had been any change in the law concerning payment for potential care in a "home"; there was no reply. In a phone conversation with the same office I asked specifically if my mother would lose her house, to which I was told 'no'. Shortly thereafter a home visit was arranged with a Geriatric Consultant who diagnosed her with Alzheimer's Disease; her condition and behaviour worsened so much that she was taken home by a policeman. This triggered a formal Mental Health Assessment, held early in 1998, to which I was not invited, but in a phone conversation with her GP immediately following the assessment, I was told that the two social workers present prevailed upon the Consultant not to admit her to a mental hospital under Section 3 of the Mental Health Act. It was during this meeting that it was later discovered that they omitted to mention anything about the possibility of her losing her home since "it might have upset her to know." Following a distressing phone call in which she pleaded with me to come home and "sort it all out" I returned to discuss the matter with her doctor whom I met, along with the Case Manager for Reading Social Services. I was handed a Financial Assessment form to be completed. The end result was that the day following I was obliged to literally force her from her house to a waiting ambulance which was to take her to a mental hospital. Having phoned the Case Manager to tell her of this development, she first thing I was asked was "Was she sectioned?". Because I had filled in the form which I had been given, I was asked to take it to the psychiatric hospital and "just have her sign it." Since she was without capacity, I did take the document, but she was in no state to read or sign anything, as I noted on the document itself. In fact the request was for a fraudulent act. Without the benefit of a 'section', she was held in a locked ward for 13 weeks, an action which was later criticised by the Mental Health Act Commission in its report "Placed Amongst Strangers". During her long confinement to the ward, she fell badly on numerous occasions, and it was decided that specialist

nursing care was required, not merely “residential”, those words (in writing) from Reading Social Services. Although I was fortunate to be able to visit her frequently (I flew back and forth every ten weeks) without consultation or any kind of discussion with regard to fees, social services transferred her to an EMI Nursing Home, for which I assumed the state would pay. Imagine my surprise when I received a letter to say the council would fund her care “while the house is on the market”. Shortly thereafter invoices arrived, invoices which I promptly redirected to the health authority. They in turn sent them back to me, and so a long correspondence ensued about who was responsible for the payment of her care. Because the bills went unpaid, Reading Borough Council filed an Application to Register a Charge with the Land Registry, by which time I had been appointed Receiver and was able to make a formal Objection. With regard to that, some years later, the Registry ordered the Council to sue me in the Chancery Division of the High Court to decide whether or not the Charge should be registered. At my request, a copy of the Criteria then in force was sent to me which underscored my view that the health authority/NHS should be funding the care. After going through all the local procedures, culminating in the request for an Independent Panel to be convened, which was denied me because the lay Convenor was of the opinion that the Authority had acted correctly, I made a series of complaints to the Ombudsman with regard to the (former) Berkshire Health Authority. Meanwhile my mother was coming to the end of her life and I requested funding for palliative care, only to be told that “another unit” would have to be approached. She died in December 2000 with no funding in place.

Concurrently the Health Service Ombudsman had taken my complaints on board. After a lengthy investigation, during which there were four Investigators involved, the complaints were upheld in November 2002; ironically it was stated that “as a matter of urgency” the case should be reviewed by the new Thames Valley Strategic Health Authority. Subsequently the report was published in February 2003 as Annex D of the Ombudsman’s Special Report to Parliament. By that time there had been changes in the system and it was now the new SHA who became the responsible party. A series of reviews was made and on 25 February 2005, a panel agreed that all but six months of her care should be funded by the NHS. Nevertheless, reimbursement to Reading Council (who had paid the fees) was not made until 25 November 2005, a delay of nine months. Because I considered that the period from admission to the period which had been approved should have been funded, I made a secondary complaint to the Ombudsman which was upheld in August 2005. In a letter to the Ombudsman (November 2005) further restitution was refused by the PCT. This triggered another dialogue with the successor SHA, South Central. Meanwhile, because I had a malignant tumour removed from my abdomen, and unsure of my own mortality, I decided that to free up my mother’s property in order that her estate could be wound up, I would pay off the outstanding amount, which I did in June of 2006. Only then did the Council withdraw their Application to Register a Charge and the action against me in the High Court. However, there was still the matter of the remaining six months! After a protracted negotiation with the Ombudsman, in March of 2007 the SHA agreed that the previous decision was unreasonable and restitution was promised. It was only this past week (March 2008) that it was received - a year between promise and action! Even so, the interest was not included, but I thought it best to accept what there was while reminding them that I expected interest to be paid at the County Court rate - a bird in the hand still worth two in the bush. The sum included the fees I had paid personally, legal fees which arose because of the court action (which was a direct result of the SHA declining to fund) and a token amount for inconvenience.

There are many details omitted from this narrative, but what there is demonstrates how far both local and NHS bodies will go to deny funding - and how important it is to not to give up. The downside of all this was that although I managed to keep my mental health for many years, eventually the distress and pressure caught up and antidepressants were prescribed for me, the cause being attributed to a decade of worry, anxiety and stress. I would not wish anyone else to be subjected to such a lengthy fight, but persistence does pay off. However, had it been explained to me back in November 1997 when I first enquired about changes in the responsibility for paying care home fees, then it is quite possible, as with the procedure in other countries, that I would have thought it not unreasonable that the "client" should contribute to the care. But there was never a response, deliberately so I believe, since it could have been thought that the ownership of the property might be changed or even sold. That was never a thought in my mind because it was then a consideration to move back permanently to the UK, living in the same house. Nevertheless, although the council recouped (without interest) the fees they had paid, they were seriously out-of-pocket when their time and legal costs are taken into consideration, as were the three health authorities. Needless to say, the substantial cost of flying back and forth, air couriers and simple postage was not paid for - I simply never kept the records of all of them, but demonstrable legal fees connected with the case were and it must be made clear that these were not for assistance with reviews, but for advice with regard to the property about which I was being sued in the High Court.

Since I began ten years ago the system has changed, not always for the better, and I expect it to change even more in the foreseeable future. The forthcoming Green Paper will no doubt lead to new primary legislation which will set out the conditions for the state funding of long-term-care. If the present Government makes partial self-funding mandatory (which seems most likely except for the truly indigent) and the Conservatives are returned to power, I do not expect them to change it, just as Labour did not repeal the relevant former Acts of the Thatcher and Major years. For myself, in the words of the song: "and now the end is near" since the remaining interest remains due, but the long fight for what my mother deserved is over and, as the same song says, "I did it my way."

David
16 March 2008