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Case conference

Where there's no will there's no way

Case

If the better part of valour is discretion, then the Gregorys were very brave. All events were to prove them so. Yet, because of their quiet and withdrawn way of life, no-one would have known of the suffering or of the bravery had its intensity not burst into public conflagration with dramatic violence early in 1980.

I took on the cases of the elderly Mrs Gregory and her late middle-aged daughter in 1976. The old lady, seventy-six then, was extremely frail but very charming. She had lost her husband, a local jeweller, almost thirty years before, yet she still seemed to live with him at her side. She had a warmth and assurance that made her a pleasure to meet. Physically, however, she was in poor condition. She had heart failure kept at bay by drug therapy, a recurrent mysterious and severe anaemia that had been the cause of many hospital admissions and tests, without clear conclusions, and worst of all, from her point of view, a generalised immobilising arthritis that prevented her caring for herself in any way. She could just about walk a few steps, bent double, with the help of a special walking aid. Luckily she did not have to walk far, as her life was bounded by the dark walls of a late Victorian block of flats. She lived at the top of a series of stone steps exhausting even for a fit young doctor, and totally preventing any excursion for the old lady. She had not been out of the flat since the 1960s, when her arthritis developed, and her only lifeline to the outside world was her daughter Dorah.

Dorah was a different sort of person, and very much more difficult to know. A personal secretary to a large commercial firm in the City, she walked with pride, and was very clear about the type of life she wanted to lead. Everything must be sorted out and in its place, and there was no place for anything second rate. She must have been formidable, in her quiet way, in the office; she was certainly so in the surgery. The best of everything was preserved for her mother, and it was the failure of district nurses, home helps and aids of all sorts that led to her giving up her job suddenly in 1977 to devote herself to caring for Mrs Gregory with characteristic efficiency. However, not being a very maternal person she found the nursing duties difficult to cope with, and constantly tried to find ways for herself and her mother to change their style of life.

The flat, consisting as it did of three small rooms, was clearly unsuitable for them both. No-one among their neighbours knew them although they had lived in the same block for most of Dorah's life. The one outside contact that remained, Dorah's brother, had left home and was living in a city in the Midlands. He had been asked to look after his mother for a while, having never contributed much to her care once she had become a cripple. He refused, and Dorah did not write or speak to him again. They were alone.

The only answer seemed to be to find an alternative place to live, a bungalow or sheltered house for her mother and herself. Dorah herself had had a mastectomy for breast cancer in 1971, although there had never been any sign of recurrence since, and she was fit; for some reason, with many authorities, this seemed to be a hindrance not a help. As their general practitioner I wrote dozens of letters supporting or introducing their request for special housing around London or in the new towns. This never succeeded.

One day Dorah reported that she had found two small lumps under the skin of her back. They were not painful, but we decided that she should see the specialist who was following her up. For some reason she delayed following this suggestion. When I visited to find out what had happened, as I had not heard from them or the hospital, it was a long time before Dorah came to the door, supported by her mother's walking frame. She was clearly in great pain, and in a small space of time had lost weight. Examining her, I found a liver mass, almost certainly cancerous. She asked me to try to find a hospital place for her and her mother as soon as possible, as she wanted 'to get herself well again'. It proved impossible to find two places in any hospital, as I had expected – besides, Mrs Gregory was not in need of medical care, but required help with daily living tasks. With some difficulty I persuaded Dorah to let her mother go to one of the local old people's homes run by the Borough as a temporary measure, while we sorted things out. Dorah was clear in her mind that she was not going to be able to look after her mother for some time. She sent a desperate letter to break the silence with her brother, telling him that she was

going into hospital and asking whether he and his wife could care for Mrs Gregory.

The old lady was not deceived, and went bravely to the home knowing, I think, that her daughter would not recover. Dorah took a different view, and became quite impatient with the doctors in the hospital for not initiating therapy. Unable to believe that this was really her view, I visited and approached the theme of death and dying from every direction without actually quoting baldly her desperate progress. She was not interested in discussing any of these possibilities, and spoke bitterly of the letter her brother had sent saying that he was suffering from throat cancer, and could not come and see her or look after the old lady.

Faced with this dogged unreality, we discussed at the surgery what should be done, and arranged for Dorah to come home for a day to 'put the house straight' so that she could sort things out if she wished to, without admitting it. She did not particularly want to do this, however, and so Mrs Gregory was brought to her bedside. This was a satisfactory visit, but only afterwards did Dorah mention to a member of staff that she had no will, but that of course there was 'enough in the flat' to look after her mother in a private home for a considerable while. In a few days she was in a critical state; I 'phoned the brother, but they were unable to travel. The old lady was told of the desperate situation and Dorah died peacefully.

The speed of Dorah's dying was a shock, but less than the speed of her brother's arrival in London after the death. The day after, he and his wife were in London, claimed Dorah's keys and her belongings from the hospital, and went straight to the flat. Two days later they visited Mrs Gregory nearby. They had seen a lot of London, bought a lot of new clothes, and had arranged the funeral. It was to be a small affair, only they were going, and Mrs Gregory was to be excluded, in spite of her protests.

Mrs Gregory asked me to visit and expressed her desperation. The flat had been cleared, the furniture sold without her knowing, and she was sure that there was a lot of money kept there, saved in suitcases for the purchase of a bungalow 'if the Council did not come up with anything' – about £25,000 she thought. Her daughter-in-law had tried to persuade the old lady to let the younger couple handle all their financial affairs, but Mrs Gregory had refused, and suddenly became very anxious and suspicious. Her attitude and mood changed from one of sadness and resignation to bitter paranoia.

Since there was no will there was no immediate way of sorting out what money was whose, and when her son offered to take her back to his home, there was a terrible scene in the main sitting-room of the Home, and the old lady utterly refused to go. It seemed impossible to reconcile their interests, or, now, see where the rights lay. The old lady, in spite of much discussion, became more and more depressed.

The day after the funeral, a small fire broke out in one of the rooms of the Old People's Home. Mrs Gregory was found dead, a pile of burnt papers and matches beside her charred chair.

I was left with the horrible certainty that a frank discussion with Dorah and her writing a will would have prevented this tragedy.

Discussion

MRS JOSEPHS, SOCIAL SERVICES

There is almost an orderly progression of events in this family, which, apart from the final tragedy, could be predicted and which it seems the presenter foresaw to some degree. The crucial issue for him lay at the point of Dorah's final few days, when she seemed to be giving hints that she understood her future, and was at the same time denying it. I feel the frustration of this ambivalence even in the account presented. Dorah agrees she will not be able to look after her mother again, yet it is not clear on what basis she feels this – how surely she does, though, comes across in her desperate appeal to her brother which we can guess would have been made against some very powerful contrary and inhibiting emotions. As an intelligent woman, facing the appearance of lumps even those years after a cancer operation it is extraordinary that she did not reach her own conclusions as to the disease and did not follow through her thoughts with the doctors involved. I think this gives us the clue. I am sure that a woman of this temperament would only behave in this way – creating rather than decreasing uncertainty – if she herself were facing a truth that she was trying to escape. Her delay in presenting to the specialist could just indicate concern about her mother's future, but I suspect it also hides her understanding of her real future.

DR GAGE, GENERAL PRACTITIONER

Her behaviour here fits with the stage of denial that is quoted in literature on terminal care and is so often part of the initial reaction in practice to an unpleasant prediction. 'The need for denial exists in every patient at times, at the beginning of a serious illness more so than towards the end of life' writes Elizabeth Kubler-Ross. It is important to allow patients to maintain their own defensive walls against the rising tide – we should not break them down. Later on the two ideas – that of life persisting and life ending – can exist side by side fairly comfortably, isolated from each other but useful and used on different occasions. I do not see this as a difficult concept. So much of what we do contains this duality or tension, where two ideas, incompatible in themselves are nevertheless compatible within the mind of man. Ancient religions

were obsessed by the paradox – good and evil, light and darkness, fire and water – of unmixable mixtures: and the modern religions of sexology contain the same problems – witness the extraordinary necessity of tenderness and violence that seems to be necessary for 'normal' sexual behaviour, or the need for firmness and flexibility in good parenting. If we see these as behaviour patterns, they need time to develop, or be learned, and cannot spring fully formed from the head like Athene. Rushing people to put on attitudes that they do not easily wear and which do not fit them at the time is clearly counter-productive. Dorah was moving to an understanding – and whatever was said, the speed of her journey could not have been increased. She would have applied the brakes had anyone tried – and I think she did, as obviously the presenter had been very frank with her.

MR FRANKLIN, SURGEON

I cannot agree with you. There are principles that we can apply to our actions, but these have to be taken in context, and trying to help people to come to terms with their death over weeks when they clearly have only days left is a logical and practical nonsense. We are, if you like, faced with an emergency – not an emergency to save the patient's life, but to salvage his identity and to put him in touch with truth. This emergency calls for a response from the doctors, nurses and social workers looking after the patient that is of a different quality from their normal behaviour, just like any emergency. It requires decisive, speedy action to alter the situation just like snatching a child out of the path of an oncoming lorry. Faced with the consequences of her indecision, Dorah surely would have seen what she should do – and it is no kindness to her memory to imagine otherwise.

Just as I was sent this case I came across an account in *The Guardian* of the death of the Member for Liverpool at the opening of the original Liverpool to Manchester railway by the Duke of Wellington and his entourage. The MP was hit and mortally wounded by a passing train, and was rushed to a local vicarage, where he was attended by a surgeon. He asked what was going to happen to him, and he was told, not that things looked grave, or any such nonsense, but that he was going to *die*. He asked how long he had left, and he was told 'about six hours'. So, he called a priest, made a confession, made an up-to-date will, said goodbye to his family, and died. No slow transitions, no gradual drawing out of understanding, no helping to conceptualise – but the truth. Why can't we do that sort of thing nowadays? It almost seems that this type of honesty, like mediaeval blue glass, just can't be produced any more. In its place we have, excuse me, sociological countefeit cant!

DR PHILPOTT, HISTORIAN

Strong words! Yet if we follow you, we have now to ask, why can't we produce true-blue truth? Many people feel that we are in a culture which generally denies death. It fails to celebrate it in any acceptable ritual. It fails to find any satisfactory philosophy to explain it, and it uses every way possible, to avoid talking about it directly. Some people have seen sexual pornography replaced in our culture by such taboos on discussion of death that this has become a new pornography.

Given this background, physicians, nurses and social workers are no different from anyone else – they share the views, in general, of the society in which they live. Yet familiarity with death should not breed contempt or superstition. We should, as professionals, be able to give a good example in our talk and thinking, because we can show that there is nothing to fear by doing so.

MR FRANKLIN

Once the issue had been ducked however, and Mrs Gregory was left alone without secure finances, could anything have been done to rescue the situation? Once again I believe that swift action would have helped. A lawyer, arriving at anyone's instigation to deal with the old lady's rights, would have satisfactorily created balance in the situation before psychological and practical events got out of hand. There was no plenty in delay here for Mrs Gregory. This is the other type of will that was lacking – the will to act decisively to forestall problems.

CHAIRMAN

How far can a professional act out his own feelings as if he were an active participant in the drama? Must he continue to assume that he is a professional there to be consulted, and speak only when spoken to, or should he involve himself in the centre of the plot to secure the outcome that he sees to be desirable from his professional viewpoint? There are examples where society expects a health professional to intervene – such as when a health visitor enters a house to save a baby from injury. I do not think professionals or society are clear what role they wish to see adopted, and the response is usually to try to keep it as a professional debate taken behind closed doors rather than accepting the political nature of such discussions. A professional who becomes too involved is by definition now in a new role – perhaps that of close friend, foster-parent, or trustee – and as such must abandon the attitudes and forfeit the respect that his profession has given to him. This is frequently portrayed as an indication of major weakness or failure. Yet perhaps sometimes society needs not the mandate but the man, not commentary but commitment.