PERSONAL EXPERIENCE

A general practitioner looks at Issels


Clacton-on-Sea

In May 1969 a 48-year-old widow called Ivy developed post-menopausal bleeding and was found to have cancer. She has always been an awkwardly independent woman, and this is immediately apparent on entering her house. Many widows have illuminating or uplifting texts on their walls, and Ivy has one too. It reads: “Why be difficult when if you tried a little harder you could be bloody impossible”. This has been her constant guide. She has always tried to bend the world to her will. She packed off her first husband, father of her only son, shortly after the war because he was a weak ineffectual man—an orphan whom she pitied. Ten years later she married a much older man who developed severe asthma and died about three years ago. Her life has had plenty of knocks which have taught her to develop a rough-and-ready fighting independence threatened only by her controlling elder sister who occasionally visits, and, in the last two years by her illness. These are the only two things, apart from her long-dead parents and a severe episode of nephritis, that have held sway over her and she has no patience with either of them.

Her illness began in May 1969 with vaginal bleeding after one year’s amenorrhoea. Four weeks later she had a hysterectomy, followed by radiotherapy, for an endocervical cancer of the uterus. There were no signs of secondary spread. She knew the diagnosis without my telling her, and talked about it in a matter-of-fact way. We were both hopeful of a cure. She returned to work as a shop assistant and managed fairly well until July 1970 when an inguinal gland and increasing backache foreshadowed the terminal stage of her illness. While working she had communicated some anxiety that her cancer was still active; she felt that her sacroiliac joint was more prominent on one side, and she had some loin pain which she described as “something bad which was trying to get out.” She was fed up at times, describing her back as “you lousy thing you” and she was angry with me for prescribing paracetamol when she discovered it was potentially harmful to kidneys. In August she was re-admitted for further palliative radiotherapy, as by this time she was developing hepatic and spinal secondaries.

She came home with a half-truth that a poison has spread from the liver to the bones, producing softening, and was promised that an injection of cyclophosphamide would relieve this. Her spirits were good so we agreed to temporize until the hospital report arrived.

On that day she looked at me and said: “Give me the news straight from the shoulder”. Not wanting to inflict such a blow I said, “You have the fighting spirit; give it to me what you know about your illness.” She paused and said, “The news is not good then, I suspected I wasn’t getting the truth, and anyway I can feel this lump in my liver.” She put her hand under her rib margin. I confirmed the enlarged liver and we acknowledged that her malignancy was advancing.

Her first reaction was to accept the implications that she was dying. She told me she would have to sort out her husband’s estate, tell her son and one or two close friends, arrange for the dog to be looked after and so on. She would stay in her own house for as long as possible with admissions to hospital when necessary.

As her sister was staying with her, I said “What shall I tell her?” Whereupon she straight away called for her sister, who, immediately on entering the room, said she knew how things were and so did her son. She wanted to take Ivy back to her home in the North where she could look after her until she died.

This was a humiliation for Ivy and I saw at first hand how hard the sisters could be with each other. She shrugged: “Anyway, they said I would die from nephritis and I recovered.” She had accepted her impending death and now she would fight and deny the inevitability of it. That weekend she got into a new trouser-suit and went to a village fête, the first time she had left the house for weeks. She visited the chiropodist, told one or two people her doctor had said she

was dying but she would show him a thing or two, and avoided talking to her son. She was now defiant and quite angry with me.

Within the following week a third reaction of marked anxiety developed. I had three emergency calls for pain in the chest and choking. During the last visit we discussed how frightening this was. She responded by asking whether she would die suddenly or whether it would be a slow run down of her powers; she was frightened that her fighting spirit might be broken. Once this was talked about things improved considerably and her sister returned home.

Then something unforeseen happened: the BBC discovered Dr Issels. To Ivy, as to thousands of people with small hope of cure, this was the promise of a 16 per cent miracle. She determined to go to Bavaria, and in the extravagantly optimistic mood existing after the programme she raised the money easily. Quite suddenly she had found a mountain of hope. What I had been offering as hope, such as a spontaneous remission led by her own fighting spirit, she put aside as molehills. Her mood was again defiant, exuberant, and aggressive: "I will show my bloody bigoted 'GP' that I can make a come back". I promised to visit her.

In December she left for Bavaria and in January I visited the clinic on two separate days.

Rottach Egen is a small prosperous lakeside holiday town with a sprinkling of rest-cure establishments for the weary wealthy. The clinic consists of a central block with outhouses or stations resembling a minor public school. The atmosphere was one of briskness and bustle, groups of doctors and staff contrasted with small groups of waiting relatives, giving an impression that many people had beaten a path to Issels' door recently.

Behind this activity I found Ivy in a cramped, shared room, depressed, weakened, isolated and hurt. Her legs paralysed, her bladder and bowel incontinent, her back ulcerated. Although depressed she hadn't lost her anger, only now it was directed at the nurses; she thought them hard and perfunctory, failing to meet her need to be cared for as well as encouraged. Alongside this resentment was the fear, acknowledged previously, that she might lose control completely, and be unable to feed or wash herself so that she would either have to provide a private nurse or leave the clinic. In the next bed was an Englishwoman in just such a predicament being cared for by a relative. Here I encountered the first paradox. Unquestionably the involvement of the family in a caring capacity as an alternative to a professional nurse had an important therapeutic aim. It countered feelings of isolation and desertion in the patients and allowed the relatives to help in a positive way. Instead of being passive helpless bystanders, guardians of knowledge they couldn't share, here they were contributors. All the relatives I spoke to felt they were an important part of the treatment, and in this rôle they received every encouragement from the staff. On the other hand it seemed unnecessarily hard that when patients became so ill that they had to be fed and washed they could not depend on the clinic nurses to do this for them. Either a relative stayed with them, at considerable additional cost, or they had to leave the clinic. This hardness was the ethos of the place. I will return to it later.

While I was with Ivy, Dr Issels and the station doctor came in. Issels greeted me warmly, sat on the bed and asked how she was and how were the Things. "What things?" said Ivy; "The legs". "No movement". "It may come". He looked at the chart above the bed, prepared with Prussian precision, tracing her temperature-reactions, blood washes, serial white blood counts and endoxana drips, spoke rapidly in German to his colleague, moved on to the other patient briefly and left. Ivy felt no contact with him, not a spark of his energy jumped across to her. Although she said "I still think he has something", she was putting herself in the 84 per cent also-ran class. My own feelings of irritation returned when she implied that I had let her down by not mentioning the extent of the tumour in her pelvis or the existence of lung secondaries. She suggested she would not have come had she known. I defended myself; she had found out what we had discussed beforehand that treatment can be more disabling, more ruinous to the quality of life remaining, than the disease itself. Then I felt guilty that I was being too hard.

At about this time I was called down to see Issels in his office. He had an open direct sincere manner. He talked positively about her case and what should be done, so that my disbelief in his methods was temporarily suspended. I shared his feelings that perhaps the next endoxana drip would produce tumour regression even though the last one had reduced her to despair. I asked to see the chest x-ray, an A.P. film showed prominent lung markings but no convincing signs of secondary growth. I thought of Hans Anderson's story about the emperor's
new clothes. He talked quickly, briefly; anecdotes about his successes, admissions of his failures.
He wasn't unrealistically optimistic but always offered hope; that he had seen such a case gain recovery
of movement, without mentioning for how long. He seemed to have little personal interest in
psychotherapy of dying patients except to say that to allow anyone to die was disgusting. After
seeing Issels I returned to Ivy. We found ourselves almost in reversed rôles with Ivy wanting to
give up and return home, while I thought that to be fair to the treatment she should stay for her
second endoxana drip. But then, was being fair to the treatment being fair to the patient?
What sort of treatment is it when you feel such a divergence between it and the overall good of
the patient? We agreed that she should return home early in February to continue her vaccines
unless she showed clear signs of improvement before then.

After leaving Ivy I spoke with a visiting American neurologist. He had visited thirty-six
countries in two years, so understandably felt rather confused and had “gotten to the stage”,
as he put it, “where he couldn’t assess anything anymore.” He had jotted down information
on odd scraps of paper, and in his view Issels cared very much about his patients in a parental
way; always found time to talk or listen despite having a full programme. In the corridor he
introduced me to a North Country woman with her husband. She had a recurrent inoperable
tumour with possibly bony secondaries in the pelvis, following a colectomy five years before.
The cause of her pain had been concealed, leaving her vaguely uneasy as to why she couldn’t get
better. After seeing the T.V. programme her husband at last broke the news and arranged her
admission to the clinic. She felt no better after treatment but could talk about her cancer
openly without fear, and still hopes “for a miracle”. Both felt relief that they could do this.
This openness was the finest thing about the clinic; there were no lies, everybody was in the same
boat, and this was liberating.

Later in the afternoon I visited two Englishmen from the West Country. Both had in-
operable carcinomas. They knew their diagnosis having met initially in a chest ward, the older
of the two telling the younger, who was admitted with similar symptoms. After radiotherapy
they kept in contact, both realizing their disease was active and both deciding to come to the
clinic after seeing the programme. Both wives were with them, also other relatives. The
patients thought the treatment hard and the nursing inadequate. They were caught between
increasing doubts of their chance of recovery, a growing mistrust of Issels, (compensated by an
excellent house doctor), and the financial strain. They were able to soften some of their aware-
ess of deterioration by shifting the cause from the illness to the treatment. Partly true, as
maximum endoxana dosage had floored their white blood counts to under five hundred per
cu. m.m. Even wanting to believe that Dr Issels was a miracle worker couldn’t conceal from
these men inconsistencies and a somewhat shallow optimism. He wouldn’t allow them to feel
so-so, they had to be either better or worse. A tumour had to be bigger or smaller. If he said
“You will be better in three days”, and you felt worse in three days, then he repeated “you will
be better in three days”. He made or unmade decisions quickly, occasionally crossing out
instructions just given. Fair enough in a man working hard under great pressures, but never-
theless noticed by people expecting miracles. One man said he preferred the pessimism (or
realism), of the house doctor. They were waiting for a sign of recovery and there was none;
“At least we have tried”.

The second time I visited the clinic, Ivy was happier but sedated. We decided that she had
had enough and should come home as soon as possible. She had climbed her mountain, found
it hard and called it cruel. This time I spoke with two of the house doctors. Her own houseman
spoke some English but wasn’t able to express himself clearly about her case. We agreed that
her chances of recovery were very small and I tried to find out the dividing line between the
possibility of cure in his eyes, and stopping the treatment. He spread his hands and said
“marasmus”. I told him that Ivy must come home before this stage was reached.

The second resident, looking after a station with several British patients, spoke excellent
English. First he had to be sure that Dr Issels knew I was in the clinic and that I had permission
to speak to him. This formality over, I asked him about the psychotherapy patients received to
help them face such serious illness. He quoted Dr Issels: “The tumour is hard with you and
you must be hard with the tumour”. He clenched his fist, “the whole intention of the treatment
is to be hard, only occasionally do we allow softness”. He stroked his hand along his forearm.
The support was that provided by the group-atmosphere and the family. He was prepared to
disagree with Dr Issels about the size of the dose of endoxana and whether to give it when
ordered; he was dubious also about white-cell infusions because of agglutination reactions, and aware of the inconsistency of using steroids when trying to enhance immunity. He didn’t use the word death, it was definitely a taboo word in the Ringberg clinic, but when talking about the fine line between the dose of cytotoxic drugs big enough to cause tumour-regression and that to cause death of the patient, he did say that treatment sometimes causes “an exitus”. This was the only time the possibility of dying was mentioned and then only as an intragenic death. In some ways everybody was acting in a charade in which everyone had cancer but no one was going to die of it.

What did these patients want from their general practitioners when they returned to England? Those I spoke with wanted an explicit understanding that treatment to alleviate suffering would continue. They were not afraid to face their illness and didn’t want their general practitioners to be afraid to face it with them openly. For me it is a question of patient and doctor deciding on the point when attempts at cure should be discontinued and the patient helped to live out his remaining life with dignity and minimal suffering. With most of the patients in Bavaria that I spoke to, the British doctors had decided that more treatment would cause greater suffering than the natural course of the disease, before the patients were ready to accept this verdict—sometimes before the patients even knew what was their disease.

Issels works in the twilight zone where doctors have given up, but not patients or their families; understandably he will retrieve some lives. He is a man who doesn’t seem able to accept death, and in denying this grim reality I believe he creates more suffering than he alleviates.

I think of him as a sincere man who doesn’t know when to stop; disgusted by death he almost makes it the patients’ responsibility for dying. His contribution is that he is among those doctors, including several in the United Kingdom, who are making their colleagues face advanced cancer patients as individuals who still need more from their doctors than a bleak turning away, implicit in the phrase “nothing more can be done”.

Ivy died eleven weeks after returning home.

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**RATES FOR COLLEGE ACCOMMODATION**

Owing to rises in costs and to decimalization, rates for College accommodation, including breakfast, will be charged as follows from 1 April 1971:

- Single room £3 per night
- Double room £5 per night
- Flatlet (Bed-sitting room for two, bathroom and dressing room) £7 per night, or £40 per week
- Self-contained flat (Double bedroom, sitting room, half kitchen and bathroom) £8 per night, or £45 per week

Members are reminded that children under the age of 12 years cannot be admitted, and dogs are not allowed.

Members and associates may, subject to approval, hire the reception rooms for meetings and social functions. The charges for these are:

- Long room (will seat 100) £30 for each occasion
- Damask room (will seat 50) £20 for each occasion
- Common room and terrace £20 for each occasion
- Dining room and kitchen £10 for each occasion

A service charge of ten per cent is added to all accounts to cover gratuities to domestic staff.

For the convenience of members, four car-ports, outside 14 Princes Gate, have been rented by the College and may be hired at a cost of 10s 6d per 24 hours.

Enquiries should be addressed to The Royal College of General Practitioners, 14 Princes Gate, London, S.W.7. (Tel. 01-584-6262). Whenever possible bookings should be made well in advance.