Case conference

Retreat from death? ¹

The case of Terry Jenkins, a 15-year-old boy, who was found to have a sarcoma of bone, was discussed on television under the title of 'Inside Medicine'. The discussion revolved, not so much on the clinical details of the case or even of cancer of bone in a young person, as on the emotional disturbance that followed when the boy's mother refused to allow her son to be told about the nature of his illness or the proposed treatment. With hindsight, as is made clear in the discussion, the case should have been handled quite differently, with the general practitioner acting as the lychn pin and a psychiatrist and a social worker being brought into the emotional 'treatment' of the boy and his mother. As it was the boy was so disturbed about what he had guessed about his condition that he attempted suicide: fortunately he was rescued in time, and Terry is now stable, working, and mobile on his artificial leg.

The programme was filmed and the case history was enacted by professional actors.

Those taking part in the discussion were: Dr Joan Baker, consultant radiotherapist, Royal Marsden Hospital, London; Dr Philip Boyd, consultant in adolescent psychiatry, St Luke's Woodsite Hospital, Middlesex Hospital, London; Dr Alastair Campbell, Editor of the Journal of medical ethics and lecturer in the Faculty of Divinity in the University of Edinburgh; Mr David Christie, lecturer in law, University of Edinburgh, Miss Carole Harris, medical social worker, Oxford County; and Dr Roger Higgs, general practitioner, London.

The case history of Terry Jenkins

Terry Jenkins was a sensitive, athletic 15-year-old, an extremely keen footballer and captain of his school XI: he had hopes of becoming a professional. In his summer holidays, on a school journey, his right knee became painful, and, by the time he had returned home, was swollen. He could not remem-

¹We are grateful to the producer of Inside Medicine, Mr John Mansfield, and his staff for their skilled and tactful handling of the whole discussion. This is an edited version of the programme as it was recorded; some parts which were televised are omitted and some which were not are included.
large, hard lump in her breast, which was a cancer: this had already spread beyond the breast, and in spite of hormone treatment, she rapidly lost weight and died in the spring. Terry had been very fond of his granny and had been greatly distressed by her death. Mrs Jenkins insisted that Terry would immediately connect his own and his granny's illness, and forbade the doctor to tell him that he had cancer.

The registrar agreed with Mrs Jenkins, and Terry was told that his knee was inflamed, needed rest and a course of ray treatment. He was very upset that he could not play football the next season, but did not appear to question the diagnosis.

Mrs Jenkins, tense and voluble, avoided contact with Terry's hospital doctors or the social worker, but consulted her general practitioner, Dr Scott, on a number of occasions in the following two months. She was extremely depressed, but refused to examine or change her decision not to allow Terry to know his diagnosis, in spite of the reminder that an explanation for the amputation would have to be given. She was angry with Dr Scott's partner for not diagnosing the condition at once, but blamed herself both for her son's illness, as she used to beat his thighs when he was naughty as a child, and for her mother's cancer, which she believed had been brought on by the family stresses when Mrs Jenkins was in hospital. Dr Scott tried to change these ideas, which were mistaken, but to no avail. She also refused to allow any approach to the estranged husband, who still did not know of Terry's illness. He did not visit regularly, although the children were still very fond of him. Dr Scott knew him to be a kind but weak man, whose career as a long-distance lorry driver had been spoiled by drink 10 years before: he had had a number of affairs, had caught gonorrhoea and had left home to live with another woman in another city. This had deeply disturbed Terry who had previously been doing well at school: his grandmother's death had added to it, but luckily his prowess at football, and the responsibility of taking over in his father's shoes, had drawn him out again. The other children, aged 7, 9 and 11, appeared less affected but had also been disturbed: after Terry's illness, however, Mrs Jenkins brought all of them to Dr Scott at various times with minor aches and pains in the limbs.

Terry was quite unwell but brave during his radiotherapy treatment, but did not question the diagnosis until suddenly after two months he blurted out to the radiotherapy doctor; 'Most people who come here have cancer don't they?' The radiotherapist knew of Mrs Jenkins's veto, but had not been able to contact her recently and felt he had to use this as a cue to explain, as gently as he could, that Terry's condition was a form of cancer but curable; the ultimate cure might, however, involve him losing his leg. Terry appeared to take the news calmly, and left after his brief discussion without further comment.

The radiotherapy doctor rang Dr Scott, but before Dr Scott finished his evening surgery he had a call from Mrs Jenkins in panic, saying that Terry had left a suicide note, and was nowhere to be found. Eventually that evening he was discovered at his football club, looking very ill and vomiting in the shower room. He had taken an overdose of his paracetamol pain-killing drugs, which was a potentially lethal dose: he was admitted to the local hospital and then transferred at once to a specialist hospital, where he narrowly escaped death from liver failure.

Mrs Jenkins was unable to understand the radiotherapist's action, and threatened to sue him and the hospital for misconduct. When eventually Terry had recovered from his overdose, and was found to be free from secondary spread of tumour, she refused to allow him to be transferred to the original hospital, and initially also refused to give consent for his operation. However, after long discussions with the social workers, Dr Scott and the new orthopaedic surgeon, both she and Terry agreed to the operation. Terry was still withdrawn and apathetic, but the operation was a success, he became mobile on an artificial leg, and is now stable and working. Mrs Jenkins remains bitter, very depressed and feels that the hospital acted wrongly. Dr Scott is puzzled as to how this situation could have been avoided.

A web of difficult choices

DR CAMPBELL
I think we'd agree that there are very few situations in medicine where decisions are easy and this is certainly so where there is imminent death or disabili-ity. In this case we have people caught in a web of difficult choices. There are the patient himself, the patient's mother, several different hospital doctors, the family doctor and several social workers all involved with Terry. A number of questions seem to arise from this. How could these people have worked together to save Terry from unnecessary distress? Did Terry's mother have a right to demand that the information should be kept from him at the beginning? Was she right to refuse to allow Terry's father to be involved? Was the radiotherapist right in revealing the information to Terry at a later stage? Would it have been possible to predict Terry's suicide attempt? Would it have been possible or desirable to try to avert it?

Dr Baker, as a consultant radiotherapist you may have had experience with a patient of this kind. Can you tell us how you would have tried to deal with Terry?

DR BAKER
When you have to discuss a possibly lethal disease with anybody, the relatives or the patient, it is always difficult. The first thing with this particular
case was that the registrar was left to tell the mother and the patient. I feel very strongly that the most senior person involved with the patient should do this. It's a very difficult thing to do and it needs somebody who's had a considerable amount of experience in dealing with people to be able to put it over in the right way. The mother is always very emotionally involved with her child and when you come to tell her something of this sort she will have an emotional reaction to it right away. A doctor, who knows what the situation is for the future, should try and guide the mother, and not, as in this case, ask the mother what she thinks the child should be told.

DR CAMPBELL
She seemed to be dominating the situation at this stage.

DR BAKER
Very much so. And because she was obviously emotionally distressed in any case, and was feeling extremely guilty, she was having very great difficulty in coming to terms with this sudden diagnosis of a cancer, which, to her, probably meant instant death. Most people, if you mention the word 'cancer' to them, immediately think of people whom they've known who have died of it, and it means instant death: whereas cancer is really a family word for a great many different diseases, and this has to be explained to the relatives and to the patient. Because each type of cancer is different, it reacts differently to treatment, it responds differently and it has a different outcome over the years. I think that this could have been got over to Terry regarding his grandmother's cancer, which was a totally different sort of disease.

I think that as far as amputation is concerned, you should not discuss this with the patient until you know you are actually going to do it. I think it's quite wrong to subject a teenager to the thought that he might lose a limb some time in the future.

DR HIGGS
We often talk about preparing people for loss, and surely there is a case for preparing someone who is to lose a limb, especially a young footballer about to lose a leg? Should this information not be introduced some time before the operation, or do you think you would simply ask permission right before the operation?

DR BAKER
No, I think two or three days beforehand one would discuss it with him, but I don't think the day you tell him he's got cancer is the day you should tell him he might have to have his leg off. He's already got one hurdle to get over.

DR BOYD
I'm concerned that psychiatry plays so little part here. It's my experience in certain hospitals, both in Britain and in the United States of America, that where you bring various professional departments together you can achieve a better end result. When a 15-year-old boy is taken into hospital and treated in any way, someone should have been discussing with him some of his feelings about it from the very beginning. This is where a great deal could have been done to help young Terry to develop his ideas about being ill - not necessarily giving him all the information at once. But there must be an appropriate time to tell him both the facts; one that it isn't an inflammation - that's telling him a lie, and you never tell a young person a lie if you can help it; secondly, he's got a very dreadful alternative in front of him, as he's either going to lose his leg, as the best event that can be looked for or the cancer is going to spread, in which case he doesn't even need to lose his leg, he's going to die. Now he's got to go through all this, and I feel very strongly that he should be helped from the very beginning to understand, rather like a woman having a child is helped to understand what child-birth is all about.

A lynch pin was lacking

DR HIGGS
This is where I'm critical of the part the general practitioner played, even if he wanted to play another part. He knew Terry, and he knew the family; he'd originally seen Terry with the problem, and he had referred him to hospital. The whole family should have come back to discuss the situation, and if anyone could have helped Terry through that point, I think in this particular family it could have been the general practitioner.

DR BOYD
It could have been, yes. But then the lack of liaison here is terrible. Let's take Terry's mother. She had a psychiatrist in the hospital she was going to. He wasn't brought into this at all. He might have helped her considerably to understand the thing in a different way. The general practitioner, as we all know, in the National Health Service is the centre of the pivot of the whole wheel. Here he wasn't pulling in the various doctors and trying to create a whole family situation which could be dealt with properly.

MR CHRISTIE
Especially so in this case, because it seems that the general practitioner was about the only doctor with whom Terry's mother had a good relationship. To her, hospitals were not happy places. They were not associated with getting better and getting well. She had a bad relationship with Terry's doctor.
which, I think, led to the change in the surgeon at a later stage. Because of these factors the general practitioner was in a crucial role.

DR CAMPBELL
I think we can be very unrealistic about this, and speak in ideal terms. Dr Higgs, you are a general practitioner in a busy London practice. I wonder how realistic it is to speak of the kind of role that’s been suggested, of bringing everyone together and keeping in communication with hospitals?

DR HIGGS
The first thing that strikes one about communications is that it’s a simple line between two people and it’s a triangle when it’s three, but as soon as you’ve got four it’s not just four communications, it’s six communications. I’ve just gone through a similar problem with a teenage pregnancy, where there is a headmistress, a social worker, someone in charge of a baby home, etc, and one is desperately trying to hold these all together. You can spend your whole time on the phone. But another problem is that people don’t expect the general practitioner to make a fuss in this way. The specialist feels that it is over to him. Michael Balint actually called this situation ‘the collusion of anonymity’. He saw the general practitioner handing over to a series of specialists in hospital, none of whom actually felt themselves to have the final responsibility. The general practitioner himself felt in too low a status to insist that he was actually the person who knew. General practitioners should actually write carefully in their letters exactly what they want.

DR BAKER
Certainly sometimes we don’t allow a feedback of what we’ve actually told the patients and their relatives. We may send the family doctor a letter which tells him what we’ve actually done to the patient, but not what we’ve said to the patient. Often what we’ve said to the patient is far more important, when he is out of hospital, than what we’ve actually done.

DR CAMPBELL
There must be a social work angle to this as well.

MISS HARRIS
Certainly there was a social work contribution to be made here. A social worker, if brought in at the time that the doctor at the orthopaedic hospital told Mrs Jenkins the diagnosis and hinted at the prognosis, could have begun to help Mrs Jenkins with her immediate feelings of sheer helplessness and anger, guilt – all the feelings that we know that people have when they are told something as shattering as this. Also, a social worker might have been able to help her to work back through her life, because from the social work point of view this case doesn’t just begin at the point of Terry’s illness. This was undoubtedly a very vulnerable family unit, even before Terry became ill. Mrs Jenkins was left with four children all under 14, as a mum who was trying to be both father and mother to this family. The marriage had lasted for 15 or 16 years, but it had been 15 or 16 years of considerable insecurity and tension within the family. One wonders just how she managed to cope with all the losses. We know enough about the kind of economic problems of one-parent families to realize that not only was this family facing considerable emotional strain but also economic hardship.

DR HIGGS
Terry’s father’s drinking must have made holes in the family purse.

MISS HARRIS
I’m sure it must have done. Also we know that he had a number of extramarital affairs. The one good thing is that the relationships between the children and the parents do seem to have been, in Winnicott’s terms, good enough.

DR BOYD
Nobody has said that we ought to find out what Terry wanted. I insist that we must start with Terry.

DR HIGGS
I think from this story, he knows a great deal more than he ever lets on. He is quite a bright kid. He’s told it’s inflammation and that he’s got to go to radiotherapy. I am sure these thoughts about cancer have been mulling in his mind for some time.

DR CAMPBELL
When the mother says Terry must not be told, for some reason or other the doctor accepts this. It would be interesting perhaps to discuss what these reasons were that made him accept this prohibition so readily.

DR HIGGS
I think it was because it’s a horrible thing to have to say. One is often tempted to accept the possibility of a way out.

DR BAKER
It is a traumatic experience telling a youngster that he’s got cancer. You’ve got to do it, you’ve got to tell him the truth. But you can tell him the truth in such a way that you don’t shatter him completely.

Not a child but not an adult

DR CAMPBELL
Now let’s try to work out the legal side of it because there is perhaps a confusion in some people’s minds about the age of consent. Terry is 15, an age which
is, we think, still below the normal age of consent. Mr Christie, can you put us right from the legal standpoint?

MR CHRISTIE

Had Terry been 16, then he would have been able to give full and quite effective consent in the same way as an adult. But of course he’s not quite 16. Now it does seem that though the normal age is 16 it is possible for a person under 16 to give full and effective consent. This does seem to depend, as the lawyers always say, on the facts and circumstances of each case. In this particular case it’s worth stressing that Terry was nearly 16. He was almost put in the position of an adult by being the eldest boy in a one-parent family; he was just about to leave school; no doubt he had some responsibility in connexion with his football activities. I really think that he was treated as a child, when he was not in fact a child. What would have happened if Terry’s mother had refused her consent to the amputation? If Terry, having discovered what it was all about, gave his consent to the amputation, what would the doctors have done? I think that so far as the law is concerned the surgeon would have been quite justified in going ahead on the basis of Terry’s consent.

MISS HARRIS

The very sad thing about this is that no one actually listens to Terry. He’s hovering between childhood and adulthood and he’s being pushed in so many different directions: he’s forward one minute taking responsibility as head of the family — replacement husband — the next minute he’s pushed back into the dependence of childhood again. If only someone could have focused on where he was in his thinking it would have been very helpful indeed.

DR HIGGS

As a general practitioner I have been upset that adolescents do have reservations about going to their own family doctor. They’ve grown up with the doctor and the doctor is associated with parents. It’s desperately important that the relationship one makes with the child, because it’s just then in adolescence that the relationship is proven one way or the other, for example, when a 14-year-old wants to go on the pill. In general practice every consultation is a confidential consultation between the person consulting and the doctor.

DR BOYD

It’s very difficult for the adolescent to understand that, because there is always the belief that the doctor will go behind his back to his parents.

I would like to ask Dr Baker here whether she would agree in general that perhaps in all spheres of hospital activity there should be greater team work involving the psychiatrist? I remember doing this in a hospital in the States, in a children’s department, where I was pulled in constantly to come and talk to the children who were undergoing these kind of experiences. I was then left to see that child right the way through — he might be in three months in hospital and I would visit once a week to see that child. I wonder if enough of this really goes on in our own hospitals?

DR BAKER

No, enough of it doesn’t go on in our own hospitals and we could do with a great deal more of this. Certainly in our hospital we call in our psychiatrists as often as we can but unfortunately he is not on the staff full time. But if he were he could be used a day every day.

DR CAMPBELL

I don’t think it’s only a shortage of staff. I think we’re still in a kind of retreat from death here in this country.

DR BOYD

It is a question of a professional craft and art to learn how to get for instance a 15-year-old to talk about himself without causing trauma, without shattering him, enabling him to grow through this experience. Now that’s no kid’s stuff — it’s working with kids but it’s not kid’s stuff.

MR CHRISTIE

You seem to me to be almost hinting that an experience like this could be very helpful to a person like Terry. He could learn a lot about himself in the process.

DR BOYD

He really could have worked through the whole of the rest of his adolescence.

DR HIGGS

Seeing him now, how would you expect things to turn out for him? If I were his general practitioner what would you warn me to watch out for?

DR BOYD

Your first task as a general practitioner is to make an adult relationship with Terry, so that he sees you as someone whom he can trust, independently of his family, and with whom he can talk. From this will stem a much greater appreciation of what he’s going through and he will probably come to you of his own accord if he is worried. When he does come to you for minor matters, perhaps to do with the leg or the prosthetic limb, you can always check on other things. How is he getting on? Is he finding things all right? What kind of a social life is he having? And so on. You pick up the truth and then you can work with him in this way.
Talking to patients about cancer

DR CAMPBELL
If I'd been in Terry's shoes I would have begun to feel I'd been conned all the way along the line when finally I got information that I hadn't had before. But can you communicate with people about cancer in a way that doesn't cause such terror and how much is suicide a danger?

DR BAKER
I think you can communicate with patients about cancer. It's so important that the doctor should be the person who has told the patient, so the relationship between the doctor and the patient is a truthful relationship. With Terry, he couldn't trust his doctors. He was conned right from the start, because somebody who was not really very experienced was given the job of trying to tell him and his mother.

DR HIGGS
What would you have actually said to Terry at that first interview?

DR BAKER
I would have told him that he had a serious condition of his leg in which there were some cancer cells; that it would need treatment and the treatment would be effective, that it would take probably six or seven weeks for that treatment to begin to take effect, that at the end of that time he would have a somewhat sore leg but this would be associated with the treatment and not with the disease and that the pain in his leg that he had initially would have been cured. After that we would keep an eye on him to see how he got on, but at that stage I wouldn't have mentioned that he might have to have an amputation because he might not have come to it.

DR HIGGS
And if he'd said, 'Cancer, that's what my granny died from . . . ?

DR BAKER
Then I would have explained to him that cancer as a word is a family name for a great many different diseases, that the cancer that his grandmother had was something quite different to the cancer that he had: and that cancer of the breast is a totally different disease to cancer of the bones; that it behaves in a totally different way. And I would have told him that cancer was not catching, that he didn't catch it from his grandmother and that nobody would catch it from him, so that some of the fears that tend to be there would I hope have been allayed. That would have been on seeing him the first time. But I would be seeing him regularly as a radiotherapist while he's on treatment, once or twice a week over this period of about six or seven weeks and during that time I would get to know him quite well and have a chance to talk to him more about the whole situation, and one would hope to try and find out how he was feeling about it.

DR BOYD
I'm terribly glad to hear you say this but I wonder if all your colleagues in fact do follow that principle. I suspect they don't, and I'm sorry about that. The other thing is that a youngster can take something in intellectually but it's a very much greater problem to take it in emotionally. It's working through the emotional side that I think is very important. As you have pointed out, you would want to hear how he felt about it and so on, and I think this is already halfway there. I still think that perhaps other people had to come in as part of the team to help in this.

MISS HARRIS
I'm very interested in the role of the psychiatrist here. In most situations it's the team on the ward - the doctor, the nurse, the social worker - who are really having to cope with difficult emotional problems. Rather than the psychiatrist always needing to see the patient, is his role perhaps not more one of helping the staff with their feelings?

DR BOYD
I think frankly it's both. We are dealing with a 15-year-old boy, and a person who had no experience of dealing with adolescent children is at a disadvantage. Therefore the psychiatrist has a direct role to play with patients. On the basis of your argument, you could push the psychiatrist away so that he simply advises all other members of the team but doesn't take part himself. On the other hand, he must be there to support and to help the team of whatever medical kind it is, to look at its own actions - in this case to help the registrar to understand more clearly his own reactions to cancer and his own fears that caused him to mishandle this case.

DR CAMPBELL
Mr Christie, in law did the mother have a right to insist that information was not released?

MR CHRISTIE
I wouldn't say there was a legal right which could be enforced but it's very difficult in these cases to override the wishes of a parent.

DR CAMPBELL
I think that information which a doctor has about a patient, whether the patient is young or old, is information about that individual, and although the parent's wishes about the information are relevant, I think we have to reiterate the point that it is the patient whose body is being discussed, whose life is
being discussed, whose potential death is being discussed. There must be very good reasons for withholding such information, and these reasons must always be reasons that are clearly for the benefit of the patient.

MISS HARRIS
I feel very strongly for Terry's mum in this situation. Here is the boy who is just maturing, not grown away from his family. Her feelings of protectiveness towards the child must have been tremendously strong, and in a sense he must still be seen as an extension of herself. Just the thought of giving this lad over to the doctors is a kind of disappearance of a part of her. I do agree with what you said, but the feelings of the mother are to be considered.

DR HIGGS
Can we say that Terry was actually depressed at the time he took his overdose? If I'd been the registrar or the houseman taking in Terry with his overdose, and we didn't yet know whether he had secondary spread of this otherwise lethal disease, I wonder whether I would have thought, shall I treat this young boy? Is this someone who is emigrating from this world and simply wants to go?

MR CHRISTIE
But would you as a doctor feel that you had a right not to treat somebody whom you could treat - in the case of a drugs overdose?

DR HIGGS
I have never done that. My wife has often said to me, what are you doing, keeping this person alive who wants to go?

DR BOYD
This is a very complex story and one has got to recognize that people who actually intended to die, having accidentally recovered because somebody intervened, are glad that those people did intervene. So I don't think we can preempt this issue for the individual at all. There's rather a lot of woolly thinking here about people having the right to die. Of course they have the right to die. And if they succeed, then they enjoy that right. If they fail, it is, after all possible for them to try again. We mustn't strive too hard to keep alive, but on the other hand, I think we have a natural instinct as caring professionals to try and see if there isn't a better way of living so that life is worthwhile. In Terry's case I would have thought it would have been a very complicating factor if the casualty doctor had started to try and treat the depression.

DR CAMPBELL
You must always assume that it's better to save that life if you can, and then look into what led up to the crisis.

DR HIGGS
A terrible paradox of this whole story is that we have a boy of 15, who 30 years ago would not have survived because there wouldn't have been the radiation treatment of his tumour, but all the advances in treatment were nearly wiped out by him going to the chemist and buying a bottle of paracetamol.