PUBLIC PETITIONS COMMITTEE

Tuesday 20 May 2008

Session 3

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PUBLIC PETITIONS COMMITTEE
9th Meeting 2008, Session 3

CONVENER

Mr Frank McAveety (Glasgow Shettleston) (Lab)

DEPUTY CONVENER

*John Farquhar Munro (Ross, Skye and Inverness West) (LD)

COMMITTEE MEMBERS

*Bashir Ahmad (Glasgow) (SNP)
*Claire Baker (Mid Scotland and Fife) (Lab)
*Angela Constance (Livingston) (SNP)
Nigel Don (North East Scotland) (SNP)
*Rhoda Grant (Highlands and Islands) (Lab)
*Robin Harper (Lothians) (Green)
*Nanette Milne (North East Scotland) (Con)

COMMITTEE SUBSTITUTES

Jim Hume (South of Scotland) (LD)
Marilyn Livingstone (Kirkcaldy) (Lab)
John Scott (Ayr) (Con)
John Wilson (Central Scotland) (SNP)

*attended

THE FOLLOWING ALSO ATTENDED:

Margaret Curran (Glasgow Baillieston) (Lab)
Peter Peacock (Highlands and Islands) (Lab)

THE FOLLOWING GAVE EVIDENCE:

George Darroch
Tina McGeever
Reg McKay

CLERK TO THE COMMITTEE

Fergus Cochrane

ASSISTANT CLERKS

Franck David
Zoé Tough

LOCATION

Committee Room 4

Scottish Parliament

Public Petitions Committee

Tuesday 20 May 2008

[THE DEPUTY CONVENER *opened the meeting at 14:03*]

Cancer Treatment Drugs Inquiry

The Deputy Convener (John Farquhar Munro): Good afternoon, everyone. I warmly welcome you to the ninth meeting in 2008 of the Public Petitions Committee. First, I have some domestic advice. Please ensure that all mobile phones and other electronic devices are switched off. We have received apologies from the convener of the committee, Frank McAveety, who has another engagement, and from Nigel Don.

Under agenda item 1, which is the main agenda item, the committee will take evidence as part of its inquiry into the availability of cancer treatment drugs on the national health service. This is the third of our planned oral evidence sessions.

We warmly welcome to the meeting Tina McGeever, George Darroch and Reg McKay. I do not need to tell them how much the committee appreciates their taking the time to be with us this afternoon. We look forward to hearing their thoughts on the issues that have been thrown up by petition PE1108 and our inquiry so far and we sincerely hope that their evidence will be beneficial to all of us.

I invite Tina McGeever to make some introductory remarks, after which members will ask questions.

Tina McGeever: Thank you for inviting us back to discuss our petition and for your good wishes. I know that Michael would have been extremely proud and delighted that the committee and the Scottish Parliament are taking the petition so seriously.

Underpinning our petition has been article 2.1 of the Charter of Fundamental Rights of the European Union, which states:

"Everyone has the right to life."

Michael was asking for the right to live, and he was asking not just for himself but for the 400 people throughout Scotland who are in a similar position and for all the other people in that position in the future.

Michael succeeded in prolonging his life, albeit for a shorter time than we had hoped, but it was still longer than expected. Up to two weeks before he died, he was still going out with his friends, including George Darroch, who is here today, and he was also working until near that time.

For us, at a cost of about £26,000, was that additional time cost effective? For some organisations that look at quality-adjusted life years and statistics and at the population and not the patient, I cannot answer that question. However, for a human being such as Michael and all the other 400 people throughout Scotland who just want to extend their life, contribute to society and have a decent quality of life for a longer time, I would say that it absolutely was cost effective.

Michael's life would have been shorter by months if he had not paid for the right to live. As such, there are some issues that we would ask the committee to consider. The first is public-private funding. The guidelines for us were very unclear. The Scottish Executive guidance talked about the discretion of the clinician: is the prescribing of drugs at the discretion of the clinician or not? Michael was lucky in that he had financial support, but other people will not be so lucky.

Another issue is what constitutes exceptional circumstances. Where are the clear, accessible and transparent guidelines for patients? When and how should they be made available to patients and families in order that they have time to take decisions on whether to follow different routes? Do all health boards follow a similar code of conduct? Why can a patient not, if they want, sit in on the decision-making process on whether they are allowed to live or die, so that they can then appeal against decisions from an informed position? With Michael, we had to unravel that information. We had to find it through research and meetings.

Another issue is equity. Are all patients who are terminally ill treated in a similar manner? Do they have to qualify for "exceptional circumstances" to stay alive? Perhaps if we had travelled an hour further north, cetuximab might have been available at an earlier stage in Michael's illness.

Finally, how do health boards and approving bodies share and compare data for future drugs approval? Those are some of our areas of concern and consideration.

Let me say lastly that we welcome the statement by NHS Grampian on the error that it made in relation to Michael. However, we would like to put on record that Michael's clinician was more than happy to prescribe the drug. He said that on several occasions, and he also wrote a letter to the chief pharmacist, Mr Downie, requesting the drug and showing evidence of cetuximab working for people. I do not accept that our clinician did not see Michael as exceptional.

The Deputy Convener: Thank you. Does George Darroch want to say a few words?

George Darroch: No, I am happy to try to answer questions.

Reg McKay: Likewise, convener.

The Deputy Convener: Other MSPs with an interest in the case are present, and they may have some questions later.

Rhoda Grant (Highlands and Islands) (Lab): Thank you very much for that helpful opening statement, which leads to my first question. You said that you feel that the clinician was happy to prescribe cetuximab. Would you argue that clinicians do not have the freedom to prescribe the drugs that they want to prescribe to patients?

Tina McGeever: Yes, I think that that is the case. Our clinician wrote to the head pharmacist in September, requesting that Michael be prescribed cetuximab and giving extra data regarding the drug. He received a letter in October, saying that his letter had been passed on to one of the other pharmacists for a decision. That makes us wonder whether they knew about the exceptional circumstances procedure in NHS Grampian. The information that we eventually received from NHS Grampian stated that a clinician had to fill in a form. Why did that not happen in September? Why did we have to wait to find out about the exceptional circumstances procedure? We are not sure whether NHS Grampian knew the proper procedure for exceptional circumstances. Certainly, the clinician was not given the opportunity to prescribe cetuximab—that was not at his discretion at all.

Rhoda Grant: You are saying that, in writing the letter, the clinician was making the case for exceptional circumstances but perhaps did not complete the proper paperwork.

Tina McGeever: Yes. The letter does not mention exceptional circumstances. Nevertheless, our clinician was willing to prescribe cetuximab. On a number of occasions, he stated to us both in writing and verbally that he was more than willing to give Michael the drug. He mentions Michael's quality of life in the letter.

Rhoda Grant: So the clinician made it quite clear to you that the drug was of benefit to Michael and should be prescribed.

Tina McGeever: Yes.

Rhoda Grant: Do you think that a lack of clarity and guidance caused the misunderstanding and the problems in Michael's case?

Tina McGeever: Yes, I do. In the past, there had been only two cases of exceptional circumstances in NHS Grampian. I do not think that the process in NHS Grampian was transparent, as we had to find out for ourselves about exceptional circumstances.

Rhoda Grant: No information was given to you—you had to seek out the information.

Tina McGeever: We had to seek it out and, eventually, at a meeting, I had to ask, "What do you mean by 'exceptional'?" George Darroch was with me. At that time, they could not tell me. They later looked into the clinical side of things, but at the time they were not sure. Eventually, we received papers regarding exceptional circumstances and what would happen but, originally, when we asked about the procedures, we were not told them—we had to wait for them.

George Darroch: As Tina McGeever has said, it took determination and effort to find out the information. Generally, we would like information to be made available at an early stage when somebody is diagnosed with terminal cancer. We also contend that the information should be supplied in hard copy—on paper—as not everybody has access to the websites. There are those of us who are not very nimble in negotiating websites, so it is essential that the information is made available early.

Tina has also talked about the impact of the decision and about a person not being ready to take in information at the appointment when they learn that they are terminally ill. We would have liked to have a package of information to take away to discuss with Michael. We are asking for consideration to be given to an early follow-up appointment with somebody who can go through the information with the patient and explain the whole system.

14:15

The kind of information that we are talking about includes information about policies and procedures, which should be made clear at that early stage, details of the professionals who will be involved and their roles and responsibilities, information about the patient's involvement in decision making about their care, and information about appeals procedures and timescales—particularly in the short term, if the patient is terminally ill.

Such issues emerged from Tina's experience with Michael. When Michael gave evidence in committee room 2, he expressed concern about the 400 people a year who face the same situation. Those people need information so that they do not go though the experience that he went through.

We had a conversation at the weekend in which we were mindful of the person who goes alone.

Reg McKay: In case there is any doubt about this, I add that, although some of our examples arise from our experience with NHS Grampian, we

looked for information, for example about exceptional circumstances procedures, across health boards more widely. We found the same pattern throughout Scotland. Wherever people are in Scotland, they will face the same difficulties that Mike and Tina faced in trying to find out what happens next and what the procedures are. There is a national problem, not just a problem in Grampian.

Robin Harper (Lothians) (Green): The Scottish medicines consortium admits that there is a lack of useful data on hospital prescribing. We know about Michael's case through the witnesses' incredible efforts, but we do not know precisely how many other people are or have been in the situation that he was in. Mr Darroch mentioned 400 people. Do you have further comments on the lack of useful data?

Reg McKay: In a previous life, I was a director of social work and I was much involved in negotiations and joint work with health authorities. At that time—it is not yesterday—a great deal of money was being spent on improving data collection systems in health authorities throughout Scotland, but we are no further forward. When I left social work more than 10 years ago, colleagues in health authorities were working hard to secure consistent systems throughout the country—never mind more sophisticated processes. Although there was very much a will on the part of health bodies to introduce proper data collection, there seemed to be small power bases in health authorities that were reluctant to make progress, for different reasons. I fear that that is why we are no further forward. It is a bit like the blindfolded leading the blind, but the trouble is that in this context the blind are seriously, and sometimes terminally, ill.

We can learn lessons from south of the border, where data collection is much improved. There are some horrific findings there that parallel what we are saying about SMC's decisions on approval for drugs and so on. Last week on television, we heard about a woman who has helped folk in exceptional circumstances appeals in England; as a result of her hard work and commitment, she found out that 50 out of 52 appeals had been successful. In Scotland, the authorities could not begin to say how many exceptional cases committees have been convened, never mind the ratio of success to failure.

I think that any reasonable person would think that, given that we are paying the SMC to do an important job, the least that it can do is put in place basic data systems that can identify whether its decisions were right. However, that has not happened.

Robin Harper: The SMC needs to bang a few heads together.

Reg McKay: Yes, but millions of pounds have been spent on improving information technology and data collection in the health service over more than a decade, as I said, so I suspect that someone else might have to bang the heads together.

Nanette Milne (North East Scotland) (Con): Thank you for your earlier comments. You have addressed questions that I intended to ask about the exceptional circumstances in your situation. As you have said clearly, and as other witnesses have indicated, there are no nationwide guidelines on exceptional circumstances procedure and how it should be initiated. I take it that you are calling for a more national approach.

Tina McGeever: Absolutely. As George Darroch said, it is not acceptable—I know that that is an emotive term—that someone who has been told that they are going to die should have to find ways and means of funding or getting a drug. Michael spoke about having to appear before 10 people in order to find out whether he would get the drug that he needed. George Darroch will say more about the process for determining exceptional circumstances, but I think that it is not acceptable. I know that every health authority is different, but there must be some standardisation of procedure across authorities. For the sake of the patient, who, I assume, is the most important person in the process, they must look into the matter.

George Darroch: When we gave evidence to the committee in January, we had little information about exceptional circumstances, because our experience was confined to NHS Grampian, which had dealt with two cases prior to Michael's. Since then, the issue has become clearer. Reg McKay alluded to the work of a woman called Kate Spall, who lives near London. Apparently, her mother was in circumstances similar to Michael's, except that she had terminal cancer of the kidney. A drug for the condition had been developed, but the National Institute for Health and Clinical Excellence had not approved it for use in the NHS. Clinical evidence suggested that the drug was capable of extending the life of a terminally ill kidney cancer patient by two to four years.

Kate Spall took up the fight on behalf of her mother and eventually won it by putting in a lot of hard work, as Tina McGeever has done. However, the victory came too late, because her mother had just died. As a tribute to her mother, she decided to take up, at her own expense, cases of individuals in similar circumstances, to try to get the health boards concerned to use the drug. Reg McKay has given the relevant figures. To date, she has been involved in 52 cases, in 50 of which the patient's request has been upheld by the exceptional circumstances board. That is relevant to Rhoda Grant's question. The only condition that

Kate Spall applies when deciding whether to take on a case is that the oncologist involved must have said that he or she thinks that the drug is required. The fact that the patient's request has been upheld in 50 out of 52 cases indicates that in those cases the oncologist was correct. For that reason, Kate Spall questions whether there is such a thing as an exceptional case and suggests that we take a hard look at what constitutes exceptional circumstances.

When we presented the petition to the committee on 15 January, we had received no feedback on people's experience of exceptional circumstances hearings. At that time, Peter Peacock MSP, who is with us today, expressed the view that there is something inhuman in the process and that it is degrading for someone to have to sit in front of a panel of 10 people to plead for what is left of their life, especially when their oncologist has said that the drug is required. We now have feedback that indicates that Peter Peacock's view corresponds to the experience of people who have had to go through the process. We need to consider the issue in human terms. Much has been said about cost effectiveness and something has been said about clinical judgment, although that seems to be sliding off the agenda, but the humanitarian aspect of the issue has already been forgotten.

Nanette Milne: If my memory serves me right, previous evidence that we have received in our inquiry has put a lot of emphasis on the importance of clinical judgment, which I think is absolutely right. I think that NHS Grampian said that patients were under no compulsion to appear in front of the exceptional circumstances committee, as the clinician or oncologist will often do that without the patient. I know that Michael wanted to appear in front of that panel, stressful though that obviously was—

George Darroch: The feedback from those who have appeared before such panels indicates their determination to be involved in a process in which decisions are made about their life. Apparently, Kate Spall ensures that people have access to feedback from others when she is trying to prepare them for the difficult experience of taking part in the hearing. It appears that the majority of people decide to go through with that.

Tina McGeever: The point is that we should not need a Kate Spall to take people through exceptional circumstances hearings. I applaud her, but we should not need someone like that. The process should be clear and transparent. It should be easy for someone who is terminally ill to choose, as George Darroch said, whether they want to attend the hearing. In our case, if we had not attended the hearing, we would not have known what we were talking about if we had to appeal. The process needs to be made as transparent as possible.

Nanette Milne: We are looking for consistency and clarity.

Tina McGeever: Absolutely. I also think that the term "exceptional" is abhorrent. It is a terrible term.

George Darroch: I should add that Michael had to request to be allowed to attend the exceptional circumstances hearing. He simultaneously requested that he be allowed to be involved in the decision-making process at the end, not so that he could make any contribution but so that he could witness the decision-making process in operation. However, that was refused. The health board was prepared to be transparent to a degree, but then the line was drawn. Michael really wanted to attend that bit so that he could understand why the decision was yes or no.

Nanette Milne: I can understand where you are coming from. Clearly, there will always be situations in which difficult decisions need to be made, but the issue is how that difficult decision is arrived at. If a patient is ultimately told no, that will clearly be devastating, but the patient probably requires to know that a clear and transparent process has been gone through.

My next question would have been about the impact of the experience of the exceptional circumstances procedure, but it is quite obvious what that impact has been, so I will not trouble you with that.

The Deputy Convener: I think that Robin Harper has another question.

Robin Harper: This question follows on from previous questions. When a patient—I will put this in general terms—is told that the required drug treatment will not be publicly funded, he or she obviously needs to consider other avenues. What do you think a patient's expectations are at that point?

Tina McGeever: Talking from personal experience, I should say that we were aware of cetuximab from the outset because Michael had been part of the clinical trial for the drug. Therefore, our case might be slightly different.

14:30

Reg McKay: After Mike and Tina took action to bring the issue with NHS Grampian before the Public Petitions Committee, I had the honour of writing a feature on Mike's situation for the *Daily Record*. More than with anything I have ever written before—I write controversial crime books—ordinary people went out of their way to share with me their life experiences of similar situations to the one that Mike Gray had to go through. None of

those people knew about exceptional cases, and none was told about other drug options and so on. I am talking about people with close relatives who had died mainly, but not solely, as a result of cancers. It seemed to me that they sought me out to say that the fight that Mike and Tina had taken on and the confrontation that they had to face in having to go through the exceptional cases procedure was news to them. They would love to have had the same dilemma—for people to have been asked how they were feeling and whether they could cope, albeit that they may have faced the horror of being told that a drug that could give extra life would not be given.

The evidence is anecdotal, but I am talking about evidence from scores of folk in a few months, and the message that came back was that members of the general public who have been affected by terminal diseases, including cancer—of which, unfortunately, there are too many—would love to have faced exceptional cases dilemmas or the other dilemmas that Mike and Tina braved. Obviously, Mike and Tina had to find out information. The picture I got was bleak: hardly anybody came to me and said, "Well, it wasn't like that for us, you know." If they did say that, their treatment was for a cancer such as breast cancer, for which there is a treatment regime—thankfully—that is entirely different from that for many other types of cancer because of the campaign work that committed people have done over the past decades.

Tina McGeever: We expected to get proper information from the start. All the appropriate information should be made available to a person from the moment they are told that their illness is terminal. That is one of the problems. I sometimes worry that people judge who or what type of person a person is from the outset, when they are told that their illness is terminal and what to expect. We knew that a drug existed and was available when we were told that Mike's treatment was not working, but someone who goes to another clinician might not be told about such drugs—they might simply be told that their treatment is not working. Perhaps no other drugs will be mentioned, and the person might not know where they can find out information about them. The issue is difficult, but all the options are not made clear from the outset to terminally ill people. People need to be clear about what options exist. Even if patients or their families do not take things in at the beginning, they need to know what is available. The drug in question was licensed and we knew about it. That is the only reason that we were able to proceed.

George Darroch: Michael was propelled to considering private care because of the position he was in. Tina talked about private and public treatment. The NHS told Michael, "I'm sorry, but there's nothing else we can do for you," but there was something that could be done, although it would cost him. Michael was a very principled individual, and Tina had a very difficult job persuading him to go down the private and public treatment route. He had two main concerns, one of which was the cost. Tina threatened to sell the house and so on, but Michael said, "You can't possibly live in a council house"—he was a son of the manse. It was obvious that he had principles, but he was eventually convinced by us that the private and public treatment route was the route that he had to go down to extend his life. Having decided to do so, he was immediately penalised because the treatment that he received when he was having chemotherapy at the expense of the NHS ceased to be delivered by it. Michael and Tina then had the entire expenses to pay. The drug in question was very cheap, according to the medical director of NHS Grampian, Dr Dijkhuizen. He told the committee that it was relatively inexpensive, but the costs of the overheads became unbearable. In a sense, the current arrangements make it impossible for somebody to benefit from a mixture of private and public treatment; worse than that, it is a violation of article 2 of the consultant contract to enter into anything that even borders on private and public treatment.

Robin Harper: So, when that decision was taken, no further support was available. That was it, and you were told that you were on your own.

Tina McGeever: Do you mean when we were told that there was no other treatment on the NHS?

Robin Harper: Yes. Was there no further advice?

Tina McGeever: The advice from the oncologist was that there was a drug called cetuximab. As I said, it was a matter of research on my part. I went back to the internet and discovered that it was the drug that was being trialled at Aberdeen, in Grampian and throughout the country for people with advanced bowel cancer, so we looked into it. The only advice that we received was when we asked our oncologist for his advice on whether Michael should take the drug. He said that he was happy to prescribe it, but there was nothing else.

From there on in, we had to find the money, set up the meetings with the chief executive and Roelf Dijkhuizen and try to unravel the procedure for exceptional circumstances. He would not go down the public-private route, although we had to go to NHS Grampian for the initial treatment. I do not quite understand the ban on public-private treatment when we were still seeing an oncologist, getting the treatment privately but going into NHS premises in Aberdeen in case there were any major problems. The ban does not sit well at all.

Such treatment happens anyway in various strands. To me, it was an easy way for NHS Grampian to say no.

Reg McKay: Mike had three treatments of cetuximab, which proved that it worked for him. Ironically, once he won the case at the exceptional circumstances committee, NHS Grampian decided to keep delivering cetuximab to him in the way that he had received it in private service because it worked out cheaper than delivering it to him in the way in which the NHS would have insisted on doing.

Rhoda Grant: You mentioned that cetuximab was being trialled in Aberdeen. Was it possible for Michael to get on that trial?

Tina McGeever: He was on the trial, but it had three strands because it was a comparative study. His name went into a computer and he did not get cetuximab at the beginning; he had another treatment—continuous chemotherapy—because the different types of treatment were being compared with cetuximab for people with advanced bowel cancer. Cetuximab was being given; it is just that Michael did not get it. That is why I knew about it. It is the only reason that Michael was asked whether he would be willing to take part in the trial, and he said yes. I remember the drug being mentioned and then our oncologist mentioned it again later. That is when I went back on to the internet and discovered that it was being trialled at the hospital.

Rhoda Grant: You say that you were aware of cetuximab before. To clarify, did Michael's oncologist say that he could benefit from its use?

Tina McGeever: In the letter to Mr Downie, our oncologist talks about Michael's relative quality of life and new data; in other e-mails, he said that he thought that Michael could benefit from cetuximab. I do not think that any clinician would say that a drug would make the patient better in such a case, nor would we have expected him to, but I assume that the fact that he was willing to prescribe it to Michael meant that he assumed that it could benefit him. However, I would never say "would"; I am sure that it is only possible to say that it could benefit a patient.

George Darroch: We were left wondering. We were confused that the letter was written to the pharmacist, because that was not the procedure. Therefore, we wondered whether the oncologist knew the procedure, or whether a procedure was followed. Once we had considered—with the chief executive, the oncologist and the medical director—the procedures for exceptional circumstances, the oncologist made the appropriate application, requesting a meeting. The case was clinically impressive. So why, if he knew the procedures, did he then write to the pharmacist? That caused a delay that then had to be remedied. It was about four weeks before information came back to Michael and Tina to tell them that he would not get the treatment. We then had to go through the whole process again of making an application—a proper application this time. By then, we knew the procedures and we had been told what had to be done.

Rhoda Grant: At what point were you told about the procedures?

Tina McGeever: We went to a meeting in early December. By that time, we had been told that Michael was not going to be prescribed the drug. We have yet to see the letter, or the minutes of the meeting, in which that was discussed. We have never seen the letter, so we are assuming that there is no letter. The only letter we have is one that says that information had been passed on.

The meeting in December was a meeting with Richard Carey—the chief executive—and with Roelf Dijkhuizen and our clinician. The exceptional circumstances were discussed at that meeting. Things had gone on since September, which is a long time in the life of someone who is terminally ill.

Rhoda Grant: We have spoken about public-private funding quite a lot. You have read the evidence that we received on public-private funding and the evidence that we received from the cabinet secretary on liabilities and responsibilities. I guess that you have worked your way through the whole system, so have you any suggestions on how such issues could be dealt with more easily?

Tina McGeever: I find it very difficult. I know Michael's principles and the way he thought, and I also know that the idea of public-private treatment is very difficult for people who cannot pay for it. The first problem that I saw was the creation of another tier. Some people will be able to pay to prove something, or to get a drug, but others will not be able to do so. That creates another tier. However, although I have mentioned principles, we did it anyway, because Michael was going to die.

I find this issue very difficult, but if a person is terminally ill and they are able to go for public-private treatment, they will do it. Public-private treatment is happening now. It happened with Michael: he was seeing the oncologist, but he was also getting private treatment at home; he was going to the NHS hospital in the first instance, but he was paying for treatment. The public and the private are tied together anyway, and I do not know how you unravel that. I find the issue a minefield, I really do. I do not know how you can avoid creating other tiers for people who cannot afford it.

George Darroch: We do not pretend that there is an easy answer. However, underpinning our petition was the right to life. We have to consider how life can be preserved and promoted, even when somebody is terminally ill with only a little time left. The right to life does not become diluted just because a person is terminally ill; it still has to be promoted.

We have to find an answer. The health boards and the legal systems contain people with skill, expertise and knowledge, and I feel that those people should be able to put their heads together and devise something that could work, with the approval of whatever authority is required to approve it. That is what we are pushing for. We do not pretend that there is an easy answer, but, as in any other situation, there will be some kind of answer because there is a question.

14:45

Tina McGeever: It was unacceptable that we had to pay the NHS privately to prove that the drug was working. It is unacceptable for patients to have to find the money to prove that a drug works. That is the job of the NHS.

Reg McKay: The oncologist, the SMC and the others involved knew fine well that three treatments with cetuximab could prove whether or not it worked for somebody. Surely that must come under the NHS's role in health assessment and its duty of care. The NHS buys in private services anyway under its duty of care and for health assessment. In this instance, it seems black or white: the drug is either approved or it is not. That applies to many other drugs, too.

The Deputy Convener: I think that that concludes the questions from committee members, but I invite other colleagues to contribute.

Peter Peacock (Highlands and Islands) (Lab): Thank you very much, convener—I will try to be brief. I respect the fact that I am not a member of the committee, and other members have been following the matter much more closely.

The witnesses have made some extremely powerful points today, and they have made them very well. I did not intend to ask about this, but I am intrigued by the point that George Darroch made about the television interview with Kate Spall, which I happened to see at breakfast time one morning recently. The point that he seemed to be making struck me at the time too. The case in question was from south of the border, and slightly different circumstances apply, but if someone who, like you, has unravelled the situation and come to understand it, and so is able to advocate on behalf of others, pursues 52 cases, 50 of which suddenly get through, that is an astonishing result.

I accept that it is difficult to extrapolate these things in an entirely scientific way, but if we consider the 400 people whose cases you have described, who are potentially in the circumstances that Michael was in, might a significant proportion of them end up getting the drug that is currently denied them if there was such a service in Scotland and if they had advocates who understood the system? Would that be your contention?

George Darroch: Absolutely. I do not see why that could not happen. The information that Kate Spall gathered dealt with the reasons that influenced exceptional circumstances committees in coming to their decisions. Kate listed such things as the amount of research that had been done, the amount of information that people were able to present, the quality of the presentations, the threat of legal involvement, the threat of requests for a judicial inquiry and the amount of media exposure that it was possible for people to obtain to give their cases as high a profile as possible. When we discussed the matter this week, Tina McGeever and I were of the view that it was doubtful that Michael would have been given the drug but for Reg McKay's efforts.

To return to your point, judging from the information that we have been able to gather, I do not see any reason why the same kind of ratio could not be achieved in Scotland.

Peter Peacock: Does it follow that, when push comes to shove, the cases that you have described are not actually exceptional? Such cases have been excluded in some way, but when the evidence is examined, one sees that they are not truly exceptional. If the statistics had been the other way round, with two cases approved out of the 52, and 50 rejected, the two cases would clearly have been exceptional. Tina McGeever touched on that point earlier. Do you think that the approved cases were exceptional, given the circumstances?

Reg McKay: Mike Gray used to say that he was not exceptional; he was just one of many. If he had been alive to hear the figures that you have just shared with us, he would have had the proof that he needed. You should remember that, in every case down south, as well as in Mike's situation, the oncologist said that, from a medical perspective, the drug should be given. Therefore, in 51 out of the 53 cases that we now know of, the doctor would have been proved right.

George Darroch: A concern was introduced through the QALY system of measurement—the quality-adjusted life year. The health economist, Dr Walker, explained the system to the committee on 29 April. More emphasis is now being placed on cost effectiveness than on clinical judgment and the humanitarian aspect, because a tool has

been discovered that can help economists to measure the cost of preserving life.

Dr Walker said that if somebody's treatment costs £20,000, the chances are that they will get it. If the cost goes up to £30,000, that will be more difficult, and if it is more than £30,000, I would question a person's prospects of getting the treatment. At the exceptional circumstances committee meeting, Michael seemed to be shocked when a health economist did an overhead projection and talked to the committee about QALYs and how much his life was worth.

Margaret Curran (Glasgow Baillieston) (Lab): I thank the witnesses for their evidence, which has been compelling. As has been said, real challenges undoubtedly arise in trying to sort out the Scottish health system to address some of the big issues that you have flagged up. If we draw international comparisons, we find that progress on cancer is more effective in other places. The issue is a big one and we need to grapple with it. The evidence that you have provided supports the case for an overhaul of the system. Somebody who is terminally ill is not exceptional in the health service, so they should be treated as a standard patient and should get all the resources and interventions that they require. Nonetheless, we need to separate out short-term improvements that could be made to the service and not let our grappling with some of the complex issues, particularly on drugs, prevent us from moving ahead on those. There are changes every day in the performance of drugs and new drugs come on the market.

The point that I have been most struck by is the time that it took you to fight your way through the system and the resilience that you needed at perhaps the most vulnerable time for your family. You needed all your emotional support for each other, but you had to mobilise that to take on a complex and resistant system that seemed not to be helping you at all. It is a great irony that, at the time when you needed the health service most, it was most confusing for you. In the short term, surely we can improve the systems and procedures throughout Scotland to help families in your circumstances, while taking into account the need to consider the longer-term and challenging big issues.

I suppose that my points are really addressed to my colleagues on the committee. I hope that we can extract something from the dreadful experience that Mike, Tina and their family went through. We could move on quickly by telling the health boards that they need to fix the short-term issues fast.

George Darroch: I just make the point that the issue is no longer about Michael Gray.

Rhoda Grant: I have a final question. From reading the evidence that we have received and from your experiences, do you have anything to add about the processes? At the end of our inquiry, we must draw up a report, which will go to the Government and will influence health boards and other bodies. Are there any points that you think we should make? Are there measures that would make the system simpler or easier for people who find themselves in the same circumstances as you were in?

Tina McGeever: I do not know who it should be, but somebody, perhaps the clinician or another person, should have training, so that, from the outset, they understand all the procedures that are in place when somebody is told that they are terminally ill. Clinicians rightly think about the health of the person and how they can get them through something, but they must also think of that person as a human being. People who are not as eloquent as Michael was and who cannot speak up for themselves are the ones who need assistance. From the outset, when someone is told that they are terminally ill, procedures must be in place to give them easy access to information.

George Darroch alluded to the internet. I am talking about simple things such as leaflets. That is going back to basics, but it is important that when somebody is told that they are terminally ill, they go away with information that they can come back to later. There should also be a key person whom the patient can trust and who can take them through the minefield as they progress with clinicians. We must start with the basics. We need stepping-stones, so that people know the road that they can take. We do not have that at present, but it is important for the patient that it is put in place.

The Deputy Convener: I thank the witnesses for their evidence. You have come through what seemed like a David and Goliath situation remarkably unscathed. Given the effort that you have put in, I am sure that the responses that you have received have given you a lot of satisfaction. On behalf of the committee, I thank each of you for coming to the Parliament and giving us your evidence in a clear, sincere and measured way. We appreciate that very much.

The committee will consider carefully what you and all the other witnesses who have appeared before us have said and we will reflect on that in our report, which is being prepared. I hope that we will publish the report early next month. We cannot specify an exact date, but the clerk has agreed to notify you of precisely when that will happen—you will get a personal notification. I know that Tina McGeever is going on vacation. I am sure that by the time she comes back, the report will be nearly complete and ready for presenting. I thank her again for being with us, and I thank Reg McKay

and George Darroch for coming along to support her.

Tina McGeever: Thank you—we appreciate it very much.

Decision on Taking Business in Private

14:57

The Deputy Convener: Under this agenda item, we must decide whether to consider the draft report of our inquiry into the availability on the NHS of cancer treatment drugs in private at future meetings. Do members agree to that?

Members *indicated agreement*.

The Deputy Convener: That concludes the meeting. Our next meeting will be on Tuesday 27 May. I ask members to stay behind for a few minutes to address some administrative issues.

Meeting closed at 14:57.

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