APPG on ME

8 July 2009

Committee Room 13, 1.30 pm

Des Turner MP (Chair): Good afternoon Ladies and Gentlemen. I'm sorry if any of you have had trouble finding the room—the room has been changed on us about four times in the last five days. I hope it was signposted so that you could find it.

I have two other apologies to make. We have not succeeded in getting a speaker for this meeting, and secondly, I personally will have to leave at 2 o'clock, but the Countess of Mar has very kindly agreed to take the Chair to complete the meeting which, given that we haven't got a speaker, I assume will be slightly shorter than normal.

The next business is the Annual General Meeting. I am happy to say that we have a quorum of parliamentarians in the room, so I propose to delay no further and get straight on with it. This part of the meeting involves only parliamentarians, so it's nice if other people approve. We have to deal with elections. To the best of my knowledge, the officers we currently have are prepared to stand again, but we need to find a new secretary because Ian Gibson is no longer an MP. He resigned.

Great. Alright. We will start with the election of Chairman. Can someone hold the ring—Peter, will you hold the ring for that? We're doing the relevant bit right now while we've got a quorum.

[Current Chair is nominated then re-elected]

We've just done Chairman, which I'm afraid is me again. I point out that I'm not standing at the next general election, so a new Chairman will have to be found at that point. There will be no alternative.

Vice-Chairman is you [and Tony?] isn't it Andrew?

[Andrew Stunell and Tony Wright nominated for re-election and elected]

For Secretary we have a problem, Peter, because of the resignation of Ian Gibson. We need to find a new Secretary. It is nominal; it doesn't actually involve any work. Would you be prepared to do it? Alternatively, the Countess will do it.

Peter Luff MP: I'd be very happy for the Countess to do it.

[Countess nominated and elected]

Chair: Who was our Treasurer? [David Ames]. In his absence, I'll nominate him.

[Vote. David Amess re-elected]

He's done too. That's the way democracy sometimes works.

Chair: Minutes of the meeting are available. Do we have any printed ones? Bear in mind that the minutes are not intended as a verbatim record; they are business minutes. Does anyone have any comments on those?

Paul Davis: I wrote to Heather last week. I made a statement in the last meeting which said that there is a road map that goes back to the CMO report, York review 1 and a certain school of psychiatry. The CMO report part was omitted.

Chair: That's a matter for the transcript of the meeting rather than the minutes.

Paul Davis: Umm—I was reading from a script.

Chair: Yes, the transcript is not the minutes. The minutes are a business record. We have in the past allowed the minutes to expand into virtually a verbatim transcript of the meeting, which is not what minutes normally are. Doing that involves a fantastic amount of work for Heather, and we decided at the last meeting that the minutes as such would be normal business minutes—the topics discussed, and the decisions taken—and that there would be a separate transcript published. So, your argument, I think, is with the transcript.

Paul Davis: The…yes, the minutes which were published, I mean, it's a small thing and it's up to you, but I said at the last meeting, "There is a road map that goes back to the CMO report, York review 1, and a certain school of psychiatry." The CMO report part was omitted.

Chair: Well, have you found that in the transcript?

Paul Davis: Yes, I mean—

Chair: Are you satisfied with the transcript?

Paul Davis: No.

Chair: Right, can you point us to where you are not happy?

Paul Davis: I don't have the full thing with me. It was on page 4, about half way through. It reads, "Chair: I hope we will pick up through our questionnaire—" Paul Davis says: "There's a road map that goes back to the CMO report, York review 1 and a certain school of psychiatry. The toothpaste is out of the tube." After that, it's "Chair: we are trying to draw a line under things, not to follow—"

Chair: I think we're on the wrong page here…okay—we can do that.

Paul Davis: Thank you very much.

Chair: Oh yes—that's an obvious error.

Jane Colby: I don't know whether this is the relevant place to say it, but you do introduce—where you gave your welcome, "The Chairman welcomed those present, and explained that the meeting was joined by people from the BBC Politics Show." I don't know whether you feel it's worth making a note as matters arising from the minutes, that that show was actually transmitted in ME awareness week, and that everybody was very grateful to the APPG for allowing it to happen. I don't know where that should go—

Chair: We will note it as a matter arising at this meeting.

Jane Colby: Oh right. Okay.

Chair: Thank you very much for that information.

Jane Colby: I am sorry. It did seem very rude that I had to rush out early, but I really was involved with them and I couldn't—

Chair: Don't worry. It's not a problem.

Is everyone else happy with the minutes? Right. I will sign this copy as a record. Today is 8 July. It is much better doing it this way because we don't spend half the meeting arguing about every word in the minutes. It's there in the transcript if anyone is concerned about what they've said.

Matters arising. We've already had that kind piece of information—thank you very much. Now, the APPG inquiry into NHS services is grinding on and evidence sessions start tomorrow. The first session will be between 2 o'clock and 4 o'clock in Committee Room 19. Members of the public are welcome to come and sit in the audience, but the only speaking players in these sessions, just as in a Select Committee hearing, are the witnesses and the interviewing panel.

The first session is tomorrow, when we will be questioning patient associations and a panel of patients. At next week's session we will have a Minister. We hope to have the Chief Medical Officer and service providers.

That's where that has got to. We have a mountain—and I mean a mountain—of paper to digest and turn into some sort of report. I'm not going to make any predictions about what the report is going to say at this point except that I doubt very much whether any of you will be surprised by our findings. The one thing we can say is that there is an inconsistent picture, which is scarcely surprising, and obviously we will formulate recommendations about what we should do about that picture. Hopefully we will be able to use the completed report as a campaigning tool to improve services for people with ME, which is the object of the exercise. That is the state of the inquiry so far.

Paul Davis: You said improve. Can I just say at this point that many people with ME in England don't really feel these services are about neurological G93.3 ME? This is a point which I've made at previous meetings. There are concerns as to whether this inquiry will be objective and based on statements made by members of the panel. I refer you to the Gibson report. It says at section 5.1—this is a report signed by yourself and Lady Mar, "The £8.5 million ring-fenced by the Department of Health was used to set up 13 new CFS/ME treatment centres nationwide. The group is extremely pleased with the advent of these centres, and we hope they will be maintained and rolled out." It also says, at section 3.2 that they were to his—Simon Wesley's—model.

Do you think you may have been precocious in signing that particular—

Chair: I think anyone who presumes to dictate a model of service for ME/CFS sufferers is kind of being precocious, because there are no recognised guaranteed therapies. There are services which are offered but, as you know, they do not necessarily have any beneficial effect for sufferers, and in some cases, they can have adverse effects. We are aware of that. That will be an issue which is covered by the inquiry.

Paul Davis: Could I just make one further point if that's alright? You said at the APPG meeting on 2 July last year that you expected that the inquiry would be taking evidence on progress made since the CMO report in January 2002.

Chair: That's why we've invited the CMO as a witness.

Paul Davis: Well, I've taken this from the minutes. The point, I believe, which many ME patients would make, is that they feel there has been regression since the CMO report.

Chair: That is the purpose of carrying out this inquiry. If there is regression, I hope we will expose it.

Peter Luff MP: This is turning into an inquiry meeting, I think.

Chair: Paul, you're trying to jump the inquiry into saying things.

Paul Davis: No, I'm not jumping it. I'm merely saying that there are concerns—

Chair: The points you raise are perfectly valid considerations, and they will be considered, I can assure you.

Paul Davis: I've simply been asked to make those points today. That is that the members of the panel have already said that—well, they've made favourable comments regarding the centres which were set up following the CMO report in 2002.

Chair: Well, I think it was in the spirit of being glad to see anything happening that might be useful.

Christine Harrison: We had the one clinic that was good in the country. Since Dr. Mitchell retired three years ago, we've lost that. We've had no care at all. We understand where the frustration comes, but we are equally frustrated. There will be some people not turning up for your hearing tomorrow because there is a very high-level meeting tomorrow up in our area. That's why we are all split up. We're getting to the consultation stage—three years we've been battling. Two years we've sat round as a service design group with three different PCTs. It's now gone to consultation stage. At the last meeting, it was quite successful. The info that has come out in the last couple of days has made us feel as if we've gone backwards yet again. It's going to be a very intense meeting again tomorrow.

If we win, what we've got set up there would be the best clinic you could find in Europe. If we're successful, we hope it can be used as a precedent for the rest of the country. We've fought so hard—everything.

Chair: If you're successful, could you submit a late piece of evidence, and we'll try and incorporate it?

Christine Harrison: I mean, we have gone absolutely everywhere. We've gone from the lowest level to the very highest level. We've gone through all the parliamentary procedures; we've gone through all the local and joint hosts—we have gone everywhere and we're still battling. To leave patients with no care for three years, you know, it's a breach of duty of care.

We welcome the report as I think it will give us a basis. We know there are a lot of problems out there, but I think it will give us a basis to draw on, so that we can then have it—as you say—as part of our tool kit, to reinforce what we're fighting for. Hopefully we can achieve it.

Janice Kent: May I just make a point? When we were setting up the Sussex service, I went to all the little independent groups to make sure I'd got a consensus of what they wanted. We then took that to mid-Sussex PCT, which eventually commissioned it. Mike Wood, who is the Chief Executive Officer, looked at the service model that was set out with the money. He said, "I agree with you Janice. This is the wrong service model for this illness; it's too early." It was then made very clear to Peter Hayward, the Director of Public Health and Mike Wood, that if the bid didn't match what was advocated, we wouldn't get the money. I put a caveat on that because we wanted to look for consultant positions, and nothing has been done about that. The caveat is still there, but it was ignored.

I'm only mentioning it so that people can see the problems we hit. Even quite specific legislation can work against you. Whatever anyone says, what we have is better than nothing.

Chair: Yes, it's the Cinderella disease.

Janice Kent: Yes, but this is when, you know, the Chief Executive, who is supposed to have the authority—this is what we're told now, "It's down to the Chief Executives"—but he was sort of overruled.

Jill Cooper: I am speaking on behalf of other people who phoned me this morning. One of the things that people have been concerned about is the fact that they haven't had any confirmation of receipt of either evidence or questionnaires.

Chair: We do not have a massive secretariat to do that sort of thing.

Jill Cooper: I'm just expressing a concern.

Chair: It's a man and a dog operation.

Jill Cooper: Yes, we guessed, but we just thought we'd mention it. I haven't had anything that's been flying back at me, so I assume that you've received what

I’ve sent. Another concern—again, these are phone calls that I’ve had today from people who are too ill to be here—there is concern about where the questionnaires for service providers are. Have they gone to all PCTs?

Chair: They have gone to all PCTs.

Jill Cooper: Okay. The actual concern is that there is a clinic which is run at George Eliot Hospital by Dr. Patel. Tracey is very concerned that he may not have had the opportunity to provide evidence as a service provider. That’s all I need to say.

Chair: Okay.

Dr Charles Shepherd: I actually dropped you an email about it a while ago as well. As far as the questionnaire is concerned, we’re reaching people who belong to the national organisations, who are pretty small in number compared to the total number of people who have got this illness. We are reaching people via some local groups, but not others, and we’re reaching people who look at the internet. But there is a whole massive group of people out there who don’t know anything about this. I know we’ve done a press release. My only further suggestion was a letter to local newspapers, which they’re not bad at printing.

Chair: Yes, it’s a bit late now.

Dr Charles Shepherd: I know it’s getting late, yes.

Chair: It’s unfortunate: we can only reach the people we know about.

Christine Harrison: Just to follow on from that—it’s gone to another level, but we have been invited to be part of the next stage Darzi review, which is quality accounts and quality standards. That’s one thing I raised. They can easily do that for heart, stroke, cancer, things like that. The thing they will have a problem with in quality account and quality standards is for the Cinderella illnesses that are out there—not just our own, but others, especially within neurology. Basically, they do things that are good for people who are going new into the service, but, as we all know, some people have been ill for decades, and they have literally dropped off the system. I'd give them that challenge, and the DoH is going to try and look at ways at how it can try and do that.

As we said, a lot of people don't have GPs, or they don't have contact with their GP anymore. It will be a very difficult system to then bring in—quality accounts and quality standards. Patients really have got no knowledge of it, and they haven't got any backup material or evidence for it. It's another challenge. As I keep saying over and over again, as Lord Darzi ended his speech in the House of Lords, where there is a national inequality in care, it needs to be identified. This is a true example of a national inequality of care.

Paul Davis: Could I just say a quick point? Several of our supporters didn't reply to the inquiry because they simply don't feel that the services are about ME again. If I could just say very quickly about your own county, Sussex, in terms of the criteria, it says that the patient is willing to have a biopsychosocial and management assessment. The point that I want to make here is that patients don't feel that the psychosocial part is really relevant. I don't know if you have any comment on that. You are the patron of the Sussex group, which supports clinics in Sussex.

Chair: Well, the Sussex group happened to have taken a particularly independent line towards the inquiry, and seemed to be quite miffed that we were doing it at all. They haven't participated, so I can't really say very much.

Janice Kent: Let me say, if I may, that there is often a psychosocial assessment of other patients. It's done with renal and chemo analysis patients; it's done with orthopaedic patients who are elderly—can they cope with the rehab? That is not novel. It is just trying to assess whether patients can go through the procedure.

Chair: But ME patients tend to be rather sensitive on that point.

Janice Kent: Well, things can be done much more subtly than blatant questionnaires. Any good doctor should be able to assess.

Chair: Yes—there aren't many of those about.

Janice Kent: There are good doctors.

Chair: Yes, but not all.

Paul Davis: Coming back on that point, people feel that the bio side of this is actually being ignored, and that the emphasis is on the psychosocial. We know that clinics are offered GET and CBT. If you take Sussex, I mean, it's based again on the CNCC at Barts in London, which says under its referral criteria, "The patient is willing to have a biopsychosocial assessment."

Chair: Paul, we have consistently said in this group, that if we stand on one thing, it is that it is a neurological condition—it is a biological condition, and not a psychological condition. While that [your point?] is helpful, and will be addressed by the report, it is not the view of this group.

Paul Davis: I think some patients would just feel that it is slightly contradictory.

Chair: I'm sorry—you've lost me there.

Paul Davis: Well, I mean, if one the one hand the parliamentary group on ME is saying that it recognises ME to be a neurological illness under G93.3 of the ICD code, but one the other, its Chairman is patron of the Sussex group which supports clinics which have this psychosocial element.

Chair: I'm sorry. I don't see the problem there. Anyway, if you will excuse me, I have to leave at this point and invite my superior to take the Chair.

[Countess of Mar takes the Chair]

Countess of Mar (Chair): Does anyone else have any brief comments about what Paul has just said?

Christine Harrison: All I wanted to say is to ask on behalf of the SHA, that people must respond to their consultation groups. We sit on PCT and SHA long-term condition panels, the neurological ones, and the more we can get ME into the psyche of everybody—we're sitting on long-term condition working groups and neurological groups. It should run off the tongue like MS and other things do. It's about pleading with patients to get involved locally.

Jane Colby: I've got one other comment about the inquiry. I've been a bit slow off the mark about this, because I've been caught up with other things. Something has been said to me—I can't remember from where in particular—but there are places round the country where the services that now exist have actually replaced previous services. People are not happy because they did have a path where they could go from their own GP to their own consultant, who was a good consultant who helped them. They are now dissatisfied. I don't have details of this, because it has only just occurred to me that these questionnaires that have gone to PCTs, and presumably the service providers and so on who are coming to next week's evidence session and so on, will be from the new services.

I was wondering how the inquiry might be able to tackle, if it can, anything to do with the fact that services that were in existence, have actually been replaced. The doctors, who were the specialists running them, have also not been allowed to take part in the new services, for whatever reason. It is a matter of concern, but I don't quite see how it will fit into the inquiry.

Chair: It could come with questions from us and members of the panel. You have alerted me to it now.

Jane Colby: Right. Thank you.

Janice Kent: It certainly should be looked at, because they are required to actually employ the best people. You mark each interview—I interviewed a new Chief Executive for a hospital trust, and we had to score very carefully. I know that at our service they actually didn't employ the best doctor who had the most experience because of those criteria that were set out by the department to get the money. They would not pay for a consultant position, so a lot of knowledge went.

Chair: That's fine. Point taken.

Jill Cooper: Quickly, I would like to support what Jane has said in that people in Warwickshire in our area—this chap actually services Leicestershire, Northampton because there isn't one of these formal services for people with ME. However, most people think he's wonderful. He's an [endochrinologist?]. They are quite concerned—they do not want that to be replaced; they'd like better services, and they'd like better services for severe cases who have no help.

Chair: Yes, I think we acknowledge the fact that there's not enough support for severe cases. That is something we will be raising. Can we go on?

Sir Peter Spencer: All the points that have been made are good ones, but I think we also have to recognise that the decision which was taken at the last meeting, to drive ahead on these timescales, was taken in the knowledge that the inquiry is not going to be as high-quality or as comprehensive as some people had aspired to—as we had all aspired to. The judgment that was taken by the parliamentarians is something which we have to listen to. We could get into a position whereby taking too long over this, we actually time-out in this Parliament, and lose a lot of time.

The concern that people have got, that the work may be of such poor quality as to be of no value, is a real one. However, the way in which these points are being put to those who are going to be on the panel to ask the questions will mitigate that. I hope that a report will come out of this which has sufficient credibility, a sufficient evidence base and sufficient authority from the parliamentarians to make it something that the Health Select Committee might want to take up, where there will be a much more thorough investigation. That is a realistic ambition.

Chair: Good. Okay, fine.

Michelle Goldberg: There's a gentleman by the name of Dr. Weir who was part of the working group for the CMO's report on ME. He was in the NHS but he's now in private practice. I think that he is one of, if not the leading expert consultant in the field. Would he—I'm not clear about how the whole thing—

Chair: I think we're a bit late now to start introducing new people into the system with the inquiry.

Michelle Goldberg: I don't understand why he would not have been a key advisor in the process.

Dr Charles Shepherd: First, I know Willie very well. I appreciate all you are saying—Willie was a consultant in infectious diseases at the Royal Free Hospital until he went into private practice in Harley Street. On behalf of the group, the inquiry itself is being run…the group that are taking evidence are parliamentarians, there is no one else. It's not an inquiry that has any other external people on the group. The charities, ourselves and AfME, are doing a small amount of administrative help in connection with that, and the rest of it is people submitting evidence.

None of us have time to chase everyone up and say individually, "Can you submit evidence?" The opportunity was there for everyone who wanted to, to submit up to 3,000 words of evidence on what they felt was right and wrong, or whatever, to do with services. I don't know whether Willie has submitted that. If he has, there is obviously an opportunity to bring him back next Thursday if the group so desires, to ask questions on his evidence.

Michelle Goldberg: Has he been approached? I just don't see how this can really be going forward effectively without somebody like him.

Janice Kent: May I interrupt? Can I just say that with his new work schedule, it would not be appropriate for him to take on this work? He is a medical advisor to my charity, so he would not be able to that with the work he's doing at the moment.

Charles Shepherd: I think the other point is that he is now purely within private practice, and this is an inquiry into NHS services. It is not an inquiry into overall services.

Chair: Thank you. I am conscious of the time so can we move on now to the statement of the West Midlands Group?

Heather Walker: Sorry Countess, it was me who asked if that could go on the agenda if that's okay. I would like to apologise formally because I tabled the wrong statement at the last meeting. Just so that you know, the correct version was circulated immediately after the meeting with my apologies. I just wanted to say, formally, especially to Jill Piggott who submitted it on behalf of the West Midlands ME Group's consortium, and those who wrote in and supported the statement, that it was my mistake. I'm very sorry. Two statements were sent to the Chair, and I stupidly downloaded and printed off the wrong one. My apologies for that.

Chair: Has anybody any comments to make on that?

Jill Cooper: I have something to say. It will be quite quick, and I am going to submit a copy. I want to say this, and I would like it minuted. I am also aware that there may be further discussion about this—or so I have heard.

First, can the secretariat confirm that copies of the statement that we are talking about have actually been sent to all attendees of the 1 April meeting?

Heather Walker: They were, yes. Straight after the meeting.

Jill Cooper: The West Midlands ME Groups consortium would like sufficient time to be allocated to discuss the key issues of appropriate training at a future APPG meeting. There is no point in people clamouring for more NHS resources if staff are being centrally "trained" to view ME/CFS as a psychosomatic illness.

The key issues outlined in the statement from the West Midland ME Groups consortium of transparency and accountability remain unresolved. While we would always advocate measured and constructive dialogue, without transcripts and/or DVDs, etc., patients cannot possibly judge whether the perceived "benefits" of being a "critical friend" as advocated by AfME and AYME, is actually supported by any tangible evidence that is benefiting patients and their families.

Dr Charles Shepherd: That is something that we could raise at our next meeting following this with the representatives of the CNCC. It is a very important point.

Sir Peter Spencer: I think the issue about whether or not a particular charity wishes to be a critical partner is one for the trustees of that charity. It is a decision which they have taken and they have explained it very openly on a website. That is a perfectly legitimate line to take. Secondly, having been present, I assure you that people are not being "trained" to treat this illness as a psychological illness.

Thirdly, so far as tangible benefits are concerned, I would argue that one of the particular benefits which accrued from this last meeting was that at my strong request, Professor Stephen Holgate came and gave the address in the afternoon. He gave a very strong pitch based on his personal experience of the frustration that ME patients have with the attitude towards the illness which was being taken by the people who are producing current treatments. The frustration was that so little was understood about the physical nature of the illness by the large majority of people present in that room, and that was why he was taking the initiative with the Medical Research Council expert group to put the focus very much on the hard science of understanding the pathology of the illness.

He put an enormous amount of emphasis on getting new research talent into the field, bringing new technology to bear and putting an emphasis on what he described as the national collections, i.e. proper analysis of the National Outcomes Database proper analysis of the findings of the ME observatory. He indicated strong support in principle to the idea of creating a tissue archive so that some really good pathology could be done in the future. All of that came as the result of Action for ME being part of that meeting.

In the context of another example, in a discussion on the collection of data for the National Outcomes Database, I was able to make a very strong input that from our perspective, the measures which were being taken on the minimum data set, were insufficient and there needed to be a much stronger emphasis on properly derived patient reported outcome measures—the sort of thing that Kirsty Haywood referred to last time.

I understand why people are concerned, but I would not agree that there was no benefit. We will continue to work very hard through our contacts with clinicians and other medical professionals, as you all do in other charitable organisations. As you will know, I had the opportunity to speak at the Royal Society of Medicine, and to be extremely candid last year about the findings from our surveys. We are critical in the sense of being very candid about what we see as shortcomings. We do it on the base of the evidence that we have collected. If you have different evidence, that is fine, and you play that in. That's why it needs to be put into the totality of what is collected, and is why I think the independent inquiry is so important, so that we can get lots of evidence and look at it.

Rather than criticise each other, we should actually find the things on which we can get real agreement. On most of the things that really matter we are absolutely in agreement on already. There is insufficient knowledge about this illness. We need to press very hard for that and meanwhile, we need to ensure that we don't have the circumstances described by Christine, where bits of the country don't have any access to treatment at all.

Chair: Can I make the point about the paragraph on Pathways to Work? At the moment, going through the House of Lords we have the Welfare Reform Bill. I have been fighting tooth and nail to have ME, and other diseases of that kind—they call them fluctuating conditions—recognised. I've been there day after day after day sitting in the Grand Committee, fighting on your behalf. I think the message is just beginning to trickle in, that perhaps they're going to have to look at people with fluctuating conditions slightly differently from others. They've tried to lump them in with people with mental illness, and I've said, "No, it's not mental illness." I keep saying, "No, it's not mental illness." I hope you'll accept that people are becoming aware of it. The Minister cannot be anything but aware of it.

Jill Cooper: I have read some of the things you've said.

Sir Peter Spencer: I think we should put on the record how much we appreciate the work that you have done, particularly in the Committee stage in the House of Lords, which is tough going.

Chair: Yes. We’ve had eight days on it so far, and I think there is still a lot to go.

Sir Peter Spencer: It is a huge, huge amount of work.

Chair: Yes. It is. Thank you. Can we go on to the future of the all-party group? Future work. Has anybody got any bright ideas? I have a feeling that things are going to be up in the air for a bit until we have an election.

Jane Colby: I would like to see if possible, as the APPG’s future work—I realise that this is just one thing—a follow-up to the presentation that was made about the child protection problems. We had another one blow up just this morning and I had to madly email somebody to deal with it before I came out. There were two very simple recommendations that we thought about quite carefully. They were put into the paper that I submitted with Joanna Smith, who was one of the mothers who came and gave evidence. I think those particular recommendations are doable. Some of the other recommendations that have come from other sources might not be, but I think that the two that we suggested are fairly simple and should be doable. If the APPG could actually consider how that might be taken forward, it might help ameliorate this problem which is still going on.

Chair: It keeps arising doesn’t it?

Jane Colby: Yes.

Chair: Is everybody happy that we consider that?

Sir Peter Spencer: What form would that take Jane? Are you going to make a specific proposal?

Jane Colby: Well, we did. In the presentation that I gave—I believe you were there, I haven't got it with me because I didn't think to bring it out—there were two simple recommendations that could be made to help simply get over the misunderstandings. As I remember, one was simply to inform…it was worded very carefully, but it was to make sure that social services departments were alerted to the fact that ME in children is a case where statistically there is a huge anomaly. In other words, the mistakes and misunderstandings that are made…when people think it's a child protection case, they don't realise that there have been so many false allegations in that area around the country, because they only deal with their own individual part of it. It is a case of some kind of alert being put out. It was worded carefully as to how that might be done.

Chair: So, we really need to get the Inspector of Social Services to come and see us.

Jane Colby: Yes. That would be very helpful. They simply don't see the wood for the trees. They see their own little tree.

Chair: Then, when I had permission from a whole lot of parents to raise the matter with the Inspector of Social Services, all she did was go back to the social services department. She didn't go to the parents to find out. I saw red I'm afraid. We really do need to take this up.

Jane Colby: There was another suggestion as well. I think it was simply the fact that parents who were about to be involved in this should be informed of their rights and given a simple leaflet with organisations that could help them and information. I remember comparing it with the PACE [Police and Criminal Evidence?] situation with the police. Before you had PACE, it was a different matter. Now, people must be informed of their rights and there is a procedure that must be followed. That was another proposal made. That kind of thing could be looked at. I realise there is a difficulty where they really suspect that they shouldn't actually be alerting the family that they're being investigated. It is difficult, but it should be doable for parents to be informed of their rights by the people who are actually investigating them.

Chair: Jane, could you write to me personally, and I'll raise some written questions in the House as well on that one? And anybody else who has suggestions.

Michelle Goldberg: The matter that's just come into view about the misuse of information on the databases where—I wish I'd brought the article now—people have access into the NHS database. It's putting not just children at risk but, you know, anybody with a medical condition or vulnerability is at risk of misuse of that information.

Chair: We have just formed an all-party group on privacy where we are very critical of the databases that are held. The bigger the database, the more leaky it is of course. There were 70,000 illegal incursions in one month into the database at Leeds General Hospital—St. James's Hospital in Leeds. So much for the security of data.

Sir Peter Spencer: The other piece of work which is outstanding in the short term is getting someone from the Care Quality Commission.

Chair: My Friend Baroness Young.

Sir Peter Spencer: Yes. I wonder if that is something which we could continue. I think when we get onto the next item, we will perhaps be thinking about some longer-term work objectives. In the time remaining—there are one or perhaps two more meetings that we'll have before end of this parliamentary term.

Chair: Yes, we need to have one meeting with Baroness Young don't we? Is everybody happy about that? Any more suggestions—remembering that we've only got a few months? With the general election, everything folds and starts again.

Christine Harrison: I think we have to keep looking at the DWP and Welfare to Work.

Chair: I'm doing my best.

Christine Harrison: Yes, I mean, we just have to keep the finger on the pulse and obviously see how the services are going in the country. Hopefully, we can have good news where we are. If we can win, that will help everybody else.

Chair: Okay, the all-party group legacy paper. Who knows about this?

(Legacy Paper (copy and paste address into browser): http://www.afme.org.uk/res/img/resources/Scottish%20CPG%20on%20ME%20Legacy%20Paper%20-%20March%202007.pdf)

Sir Peter Spencer: We got involved with the cross-party group in Scotland who provide the secretariat there. Before the last Scottish election, Members of the Scottish Parliament who formed that committee—which is very similar as it has patients and patient groups in attendance as well—decided to write down a legacy paper, which was a summary of what that group had achieved during the term of the Scottish Parliament that was coming to an end. It set out a set of objectives so that its successors would have something to look at before they picked up the reins. It didn't bind their successors to anything, but it anticipated that there would be a change in the people involved, as indeed there was.

From our perspective, that was an extremely worthwhile exercise. It focuses the mind. The suggestion on the table is that the APPG might like to do something similar, in which case it would consist of taking down and agreeing a consensus document as to what were the major items of work done by this group since this Parliament started, what were the principal outstanding concerns and what sort of main areas and objectives should be pursued by the new APPG.

Chair: I am thinking of the workload.

Dr Charles Shepherd: It's an admirable suggestion, but I'm just thinking about who's going to do it.

Sir Peter Spencer: Well, we will do the first draft, but it's important that it's not seen to be an Action for ME piece of work, so we would facilitate the work as opposed to doing it. I think the process would something along the lines of…perhaps we could agree at this meeting that within six weeks—to give people time—they should write to Heather and Charles, and we'll copy it into Des and the other parliamentarians, about what they think the key issues might be. I think it only need be three or four bullet points; it doesn't need to be an essay. We are not asking people to draft the text, but we want to get a consensus as to what the main issues would be. We would then, I guess, circulate a straw man paper that said, "The consensus coming through says that these are the main areas. Do people believe that this is how they would like the paper constructed?" We will then put together a draft. If it is too long it will be counter productive. We could circulate. We'll get agreement, but it was a public document—perhaps we could circulate it with the Scottish CPG paper.

Heather Walker: I was going to say only that the legacy paper produced by colleagues in Scotland was only two sides. It wasn't very long—

Chair: I was going to say—MPs only read two sides of A4.

Heather Walker: It was only two sides. They would have to be very short submissions.

Peter Spencer: So, if we were to circulate that to people more or less immediately, so that you would get the model, what it looked like. Then we would produce a sort of basis of what people were telling us, and it would come back to this meeting to agree. It would be an APPG paper. Our involvement here will be purely as a secretarial function.

Chair: Right. Is everybody happy? Good. That's accepted. Any other business?

Michelle Goldberg: I don't know whether anybody saw this article, but one of my neighbours gave it to me. I just find it sad that these kinds of things are still going on because of the lack of knowledge. It's very brief; it's a very short one. It's "ME mum on kill rap: mum accused of trying to kill her ME sufferer daughter yesterday admitted aiding her suicide. Kathleen Gilderdale 54, was supported by her family at Lewes Crown Court. She denies attempted murder and faces trial in January. The ex-nurse of Stonegate, East Sussex, acted as a carer for bedridden Lynn, 31, who died after 17 years battling Myalgic—" I'm not going to try and say the word—chronic fatigue syndrome. My concern there is the political, criminal element.

Chair: Unfortunately, this happens with assisted suicide, and in fact last night we had a big vote in the House that assisted suicide was not to be condoned. Each individual case will be taken on its merits. That is a horrible situation. I have huge sympathy for both the mother and the daughter. They had a horrible time for 17 years, but the law is the law, unfortunately. I know I'm a law maker, but I can't do it by myself. If I had a choice about euthanasia, if it was for me, I'd say yes, but I cannot say it for everybody else. This is where the difficulty arises.

Michelle Goldberg: I think that there is some mechanism in medicine and law, which doesn't work. It doesn't sit together. It works all the way through the system, on the bureaucratic side, the legal side and on the medical side. In all of this, I keep saying, “I’m not a point of law and I’m not a checkbox. I’m a human being.”

Chair: Yes, I know. We considered that. If you read last night’s *Hansard*, you will find some extremely good speeches on the subject, and you will see why we came to the decision we did. It is worth looking at. I’m sorry, there’s not much we can do for the moment until she goes to court.

Dr Charles Shepherd: I’ve got to be careful what I say because I’m involved in various medical and legal aspects of this case. However, one thing that has been very obvious with this—I don’t know what the general tone of the rest of that article is, but there’s been a lot of press coverage of it. It was covered on the television and the news and everything before Christmas when it first happened. Generally speaking, news coverage of this has been incredibly sympathetic towards Kay and the family. I know a number of journalists from *The Times, The Guardian*—a long list—who want to write sympathetic, helpful pieces about this when the time is right.

Chair: What is so horrible is the fact that the medical assistance was not there for both of them at the time when it was most needed. That’s what this inquiry is going to cover.

Michelle Goldberg: Exactly. I mean, how did this happen? Why were there no support services? Why were they left?

Chair: That’s what we are going to ask. That’s what we are working for. We’ve got to work towards it. I keep thinking that asbestos took 100 years to be removed. Things do take rather a long time.

Janice Kent: Can I just say that this was very much the bad old days? I am on the group now that works with the local Sussex service, and domiciliary service and cover is something that is being looked at very carefully. They have done a brief survey and found that there isn't a huge need for doctor visits to the severely affected, but it's the knock-on effect of the chronicity and the every-day caring. This has still got to be addressed. I think we have moved on a bit.

Michelle Goldberg: Can I just say something else? This is another paper that I would like to give you. In my current residence, which is council, I have for 12 years suffered persecution, discrimination and stigmatisation. Doctors' letters have been ignored. I have never been offered a support service from the council. I have struggled; I almost died. I was suffering from sleep deprivation and stress, noisy neighbours. There was a whole range of things. I never received a support service; I have been discriminated against continually. There is an article here which has just come out in the *Daily Mail* about an innocent woman given an ASBO on hearsay. She took the council to court and won, but I don't think this woman had ME. The profile of this case is very similar to what I was subjected to.

The reason I'm also bringing this up is because there's a certain mentality, which runs through this and a number of other things where discrimination is concerned by people in positions of public service who are abusing and misusing their positions. I'd like to pass this on to you because there is a link with this. There's a link, I think, with the abuse of children and the databases which are being misused. There is a link to all of this. I don't want to say anything further, I would like to give you this article to bear in mind, as I think it relates to other things.

Chair: Thank you. Any other business?

Christine Harrison: This relates to ME. It's another little thing that I have taken a campaign up on—the Disability Discrimination Act, and pets in holiday accommodation. If you book a holiday in a pet-free accommodation, whether that be a holiday cottage or caravan mobile home—a lot of people with health problems tend to have independent holidays so that they can deal with their health problems. There is now a clause at the back of most of the catalogues, which says where pets are not permitted in properties. There is a piece at the end, "Customers with allergies should be aware that we cannot guarantee that a registered guide and/or support dog has not stayed in their chosen property, nor can we accept liability for any suffering which may occur as a result of such animals having been present."

If you book a family holiday to take a loved one away who has severe health problems, it's quite an effort anyway. Suppose you went all the way to Scotland or across the water and ended up in France, and you found that a week before they'd actually had a dog in the premises. That could have fatal effects if they have severe problems, severe asthma or severe allergies. I'm calling on MPs, and the Countess of Mar has kindly taken it up in the House of Lords, for a new clause to be added to the Disability Discrimination Act to say that people who rent out such accommodation are permitted/allowed to have a policy of no pets and no smoking to allow them to offer accommodation to guests who may have health conditions and/or allergies that might be exacerbated by the presence of pets and smoke.

By not discriminating against blind and deaf people, it has meant that other people with other chronic health conditions are now discriminated against because they can't go on holiday at all. It is something that needs to be amended. Allergy UK is supporting me on this, and I'm hoping to meet with the Blind and Deaf Association next week. I don't think they would feel badly about me doing this. There is accommodation out there that does allow dogs, but it discriminates against other people with other chronic health problems.

Chair: A colleague of mine in the House of Lords has two holiday cottages. One has no animals in it, and the other—

Christine Harrison: Yes. It's just the fact that you could book up this year in good faith, plan you holiday—you know what it's like with a chronic illness, it's such an effort to go. What do you do if you get there and there is a severe reaction? It could be fatal for some people. I just think it's something that needs an amendment in there.

Sir Peter Spencer: We've slightly skipped over one item on the agenda which was the website.

Chair: Oh yes. Sorry, I missed it.

Sir Peter Spencer: Just to say that since the last meeting it's been set up. I think the intention is that it's going to last longer than the inquiry, and will therefore be the sort of central focal point of information about meetings and activity.

Chair: Everybody finished? Do we have a date for the next meeting? No—it will be in the autumn I expect.

I declare the meeting closed. Thank you all very much.