

# **HEALTH AND COMMUNITY CARE COMMITTEE**

Wednesday 26 January 2000  
*(Morning)*

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### HEALTH AND COMMUNITY CARE COMMITTEE

#### 3<sup>rd</sup> Meeting 2000 (Committee Room 2)

##### CONVENER :

\*Mrs Margaret Smith (Edinburgh West) (LD)

##### DEPUTY CONVENER :

\*Malcolm Chisholm (Edinburgh North and Leith) (Lab)

##### COMMITTEE MEMBERS :

\*Dorothy-Grace Elder (Glasgow) (SNP)  
Mr Duncan Hamilton (Highlands and Islands) (SNP)  
\*Hugh Henry (Paisley South) (Lab)  
Margaret Jamieson (Kilmarnock and Loudoun) (Lab)  
\*Irene Oldfather (Cunninghame South) (Lab)  
\*Mary Scanlon (Highlands and Islands) (Con)  
\*Dr Richard Simpson (Ochil) (Lab)  
\*Kay Ullrich (West of Scotland) (SNP)  
\*Ben Wallace (North-East Scotland) (Con)

\*attended

##### THE FOLLOWING MEMBER ALSO ATTENDED:

Paul Martin (Glasgow Springburn) (Lab)

##### WITNESSES:

Iris Dewar (Parent Pressure)  
Alan Jacques (Alzheimer Scotland—Action on Dementia)  
Jan Killeen (Alzheimer Scotland—Action on Dementia)  
Pat Moir (Parent Pressure)  
Lesley Montgomery (Parent Pressure)  
Dr David Nichols (The Scottish Law Commission)  
Morag Steven (Parent Pressure)

##### CLERK TEAM LEADER :

Jennifer Smart

##### ASSISTANT CLERK:

Irene Fleming



## Scottish Parliament

### Health and Community Care Committee

*Wednesday 26 January 2000*

*(Morning)*

[THE CONVENER *opened the meeting at 09:33*]

**The Convener (Mrs Margaret Smith):** Good morning and welcome to today's Health and Community Care Committee meeting. As members know, we have a fairly packed agenda this morning—I would like to move through the earlier parts of the agenda as quickly as possible, so that we have enough time for the evidence taking on the final item.

### Subordinate Legislation

**The Convener:** The Scottish statutory instruments in front of us today are negative instruments. The first is the Contaminants in Food Amendment (Scotland) Regulations 1999 (SSI 1999/171). No motion has been lodged for annulment of the instrument. I suggest that we agree with that. Members will note that the Subordinate Legislation Committee has commented on this instrument, but we do not have to do anything. Do members agree with that course of action?

**Members indicated agreement.**

**The Convener:** Apparently, you should say, "Yes" to that question.

**Members:** Yes.

**The Convener:** Thank you.

The second instrument is the Beef Bones (Scotland) Regulations 1999 (SSI 1999/186), on which the Rural Affairs Committee did not wish to make any recommendation. The Subordinate Legislation Committee's report flags up the fact that it believes that some of the drafting makes meanings unclear, but the Executive is happy that the meanings are clear. The Subordinate Legislation Committee has drawn that point to the attention of the Parliament. However, no motion has been lodged recommending annulment of the instrument. I suggest that we agree with that. Do members agree?

**Members:** Yes.

**The Convener:** The third instrument to be considered is the National Health Service (Scotland) (Injury Benefits) Amendment (No 2)

Regulations 1999 (SSI 1999/195). No motion has been lodged recommending annulment of the instrument. Again, I suggest that we agree with that. Do members agree?

**Members indicated agreement.**

### Petitions

**The Convener:** The first petition is on behalf of the Dundee Royal Neurosurgical Unit Fund, and calls for the Scottish Parliament to conduct a debate on the subject of the proposed closure of the neurosurgical unit at Ninewells Hospital, Dundee.

**Hugh Henry (Paisley South) (Lab):** I would like to raise a general point, which covers the three petitions in front of us, and any other petitions that come before us. You might recall that I suggested at a previous meeting that we raise with the Public Petitions Committee the manner in which it is forwarding petitions not only to our committee, but to any committee. The Public Petitions Committee simply passing petitions on without indicating why does no service to this committee, the Parliament or indeed to the petitioners.

I have spoken informally to the convener of the Public Petitions Committee, but we should in future ask for a clear brief from that committee on what it thinks should happen in relation to the petitions that it passes on. That is not to say that we should be constrained, as this committee might believe that it could do more than might be suggested by the Public Petitions Committee. I do not believe that it is helpful simply to pass a petition on.

**The Convener:** I do not know whether Hugh has had a chance to read the *Official Report* of the most recent Public Petitions Committee meeting of 18 January, but those points were raised by members of that committee, against a backdrop of that committee's increasing work load. As more people become aware of the existence of that committee, more petitions will be submitted, which, as Hugh indicated, will increase the work load of the subject committees. There is some indication that some members were aware that passing petitions on without giving them extra consideration might create a logjam elsewhere in the system.

**Hugh Henry:** I would like the point that I raised to be passed formally, on behalf of this committee, to the Public Petitions Committee—which must consider my point—and to others, such as the Presiding Officer or the conveners committee. We need to address this matter in a far more structured way.

**The Convener:** I do not want to open the issue

up to too much discussion. Are members generally happy with what Hugh has said?

**Kay Ullrich (West of Scotland) (SNP):** I support Hugh.

**The Convener:** I will write to the convener of the Public Petitions Committee and copy the letter to the conveners committee. There has been some discussion in that committee about the issue, but it is right that we should continue to revisit the matter.

The first petition, on the neurosurgical unit at Ninewells Hospital in Dundee, appears to be calling on the Parliament to debate the proposed closure of the unit. From what I can tell, it seems to be a fairly localised issue, in so far as one can define a health issue as local. Perhaps the committee can write to all the Tayside members of the Parliament to find out whether they might try to debate the issue during members' business. Do members have any other suggestions?

**Malcolm Chisholm (Edinburgh North and Leith) (Lab):** John McAllion has lodged a motion on this subject. That does not negate what you suggest, convener, but I imagine that he would be interested, as he has lodged such a motion.

**The Convener:** I had not noticed that he had lodged a motion on it.

**Malcolm Chisholm:** It would be appropriate to involve him. The petition does not contain thousands of signatures, so the best course of action would be to refer it to John McAllion or to the other members from Tayside.

**Hugh Henry:** John McAllion might want to submit the petition to the Public Petitions Committee.

**Mary Scanlon (Highlands and Islands) (Con):** I have looked into the background to this matter, and I would support John McAllion were he to raise the issue as members' business. I read the acute services review, which did not recommend the closure of the neurosurgical unit at Ninewells. I also found out that a short-life working group, chaired by Sir David Carter, is reviewing neurosurgical services in Scotland. It is due to visit Ninewells hospital on 24 February. However, a concern has been raised that the short-life working committee includes neurosurgeons from Aberdeen, Edinburgh and Glasgow, but none from Dundee.

The University of Dundee has a famous medical school with an excellent reputation, and the concern is not only for neurosurgery. If parts of Ninewells hospital are closed down, that chips away at the future of the medical school. I would support discussion of this issue during members' business.

**The Convener:** I shall try to follow the best avenue for encouraging a members' business debate on Ninewells. I am not sure whether we can bring about that debate but, having considered the matter, this committee would be pleased to have a debate in the chamber on it. That would be preferable to taking up the committee's time in considering the issue.

**Dorothy-Grace Elder (Glasgow) (SNP):** By sheer bad luck we do not have a Tayside member on the committee, who would be more qualified to comment than we are. Is it possible not to confine the issue to members' business? Could we have a debate on neurosurgical facilities in Scotland, which the Tayside members might dominate in view of the circumstances? Such a debate might last for one and a half hours or so—instead of half an hour—and end in a vote. Would it be possible to leave that option open? Could we suggest that the issue be raised either as members' business or as a debate on neurosurgical services?

**The Convener:** If the matter is raised in members' business—and John McAllion has already lodged a motion—we will be able to deal with it more quickly. If we have to wait until the end of February for a short-life working group to conclude its business—which business is then in the Executive's hands for consideration—there will be some delay.

**Mary Scanlon:** The report is due in April.

**The Convener:** As Mary Scanlon says, the report is not due until April. If we want to debate the issue soon—and considerable concern has been expressed by the petitioners—pursuing a members' business debate is the best course of action.

**Kay Ullrich:** Lord Steel has made the further ruling that members' business should concern local, constituency issues. That condition would be satisfied by John McAllion's motion. I do not think that there is a case for widening the issue. After all, this petition is about Ninewells and it comes from Ninewells.

**Hugh Henry:** We also have no control over what is accepted for debate in the chamber. That decision rests with the business managers.

09:45

**The Convener:** As it would be the first time that we have referred a petition to the Parliament, rather than dealt with it ourselves in the committee, I would have to investigate what options are open to us and whether we should write to the Presiding Officer or to the Parliamentary Bureau. Members' business is probably the best place for discussion of the issue.

**Dorothy-Grace Elder:** A wider debate could

result from that, as happened in the case of domestic violence.

**The Convener:** Are members happy with that?

**Members:** Yes.

**The Convener:** The next petition comes from the west of Scotland group of the UK Haemophilia Society. It calls for the Scottish Parliament to hold an independent inquiry into hepatitis C and other infections that affect haemophiliacs.

As members might recall, I reported to the committee on 7 December that the Executive is holding an internal inquiry into some of the issues that arose from the problems in the supply of blood. We agreed that the best time to consider the matter would be when the Executive made its report on that available to us. We could examine the Executive's proposals before deciding whether they are satisfactory, both to the committee and to the people who are petitioning us. If those proposals are not satisfactory, we will have to consider whether an independent inquiry is needed.

I suggest that we hold this issue in abeyance until we receive the Executive's response to the results of its internal inquiry. This morning we received a sizeable amount of paperwork from the Haemophilia Society as background reading, which members will be able to read in the interim.

**Hugh Henry:** A motion that has been signed by approximately 60 members—not far short of half the Parliament—has been lodged. Clearly, there is a mood in Parliament to do something about this problem.

I suggest that we be more specific. We should say that, following the production of that report, we will ask the Scottish Executive to appear before this committee to discuss the details. If there is a mood in Parliament to do something about this matter, the best place to do it is in this committee. More justice would be done to the subject in that way than if it were incorporated into a wide-ranging debate that lacked focus. We should say that we will ask the Scottish Executive to appear before the Health and Community Care Committee, as it is the proper role of the committee to hold the Executive to account. If we are not satisfied, and think that the issue should be raised before the Parliament, we can help to promote a motion to that effect.

**The Convener:** I would be quite happy with that.

**Mary Scanlon:** I support that idea. What is the deadline for the Executive's report?

**The Convener:** We do not know.

**Mary Scanlon:** I would not recommend that we take action before we have seen that report.

**The Convener:** No—that is the point. The people who are concerned about the matter had a meeting with Susan Deacon, who set up the internal inquiry. However, some of the petitioners—not only those who signed this petition, but those who have petitioned the Parliament and members of this committee individually over the past few months—are unhappy with that and would have preferred an independent inquiry.

It has been agreed that, as there is an on-going internal inquiry, the committee will hold itself in abeyance until that inquiry concludes. At the conclusion of that inquiry, the Executive will write to the committee with the report on its internal inquiry. At that point we can ask the Executive to come and explain what its internal inquiry has found. We can then decide whether that allays our concerns as a committee and as members of Parliament who have shown concern about the issue, and whether it addresses the concerns of people who are suffering from haemophilia, hepatitis C, and so on.

**Mary Scanlon:** I suggest that we invite representatives of the Haemophilia Society to that meeting, to ensure that they are also satisfied.

**The Convener:** Yes. That is understood.

**Kay Ullrich:** Cannot we ask the Executive when it will be ready to report on that, so that the inquiry is not open-ended?

**The Convener:** We can provide that information to members before next week's meeting.

We move on to the next petition—which is from the Glasgow North Action Group—on the proposed siting of a secure care unit within the grounds of Stobhill general hospital. Not only has there been a great deal of local concern about this issue, but members of the Public Petitions Committee have commented on aspects of the consultation that has taken place.

**Kay Ullrich:** The way in which this matter has been handled is reminiscent of what happened at Stracathro, with doctors finding out what is happening from the newspapers rather than from the health board.

**The Convener:** There is an element of that.

The local MSP, Paul Martin, is with us today. I ask him to take a couple of minutes to set out his views and to offer suggestions as to how the committee might progress this issue. The *Official Report* of the Public Petitions Committee's meeting of 18 January indicates that members spent some time talking about the issue and that they want the Health and Community Care Committee to do something. However, members of this committee will be aware of our work load and timetable for other business. I ask Paul Martin

to set the scene for us.

**Paul Martin (Glasgow Springburn) (Lab):** The briefing paper states:

"Paul Martin MSP (Glasgow Springburn) has been active in the campaign".

In fact, thousands of local people have raised concerns about the proposal. There have been a number of petitions, including one from the local newspaper, the *Kirkintilloch, Bishopbriggs and Springburn Herald*, which was signed by 1,400 people. I want to make it clear that the other MSPs involved in this campaign and I are not alone in being concerned.

The proposal raises a number of wider issues, primarily consultation. It has been made clear that it is not good enough to take a decision before hearing the views of the local community. That is what has happened in this case: after a decision was made, the local community was advised of it through information meetings. As the petition points out, the medical staff association was consulted only after the proposal had been agreed.

I should make it clear that a large percentage of the local community—well over 90 per cent—supports the establishment of a secure unit in the Greater Glasgow Health Board area. We acknowledge that there is a need for a secure unit, but this particular proposal affects future development opportunities for Stobhill general hospital. That is the view of local members, the local community and the local medical staff association, which wants to provide an ambulatory care and diagnostic unit on the site and to give that an opportunity to develop. Our concern is that building a secure unit alongside the proposed ACAD unit would compromise the future of the ACAD unit. The proposal for an ACAD unit has been on the table for more than four years, but the proposal to build a secure unit has come forward only in the past 18 months to two years.

I appreciate that the committee cannot get stuck in a logjam of local issues, but this case raises a wider question about how health boards consult local people and medical staff on important issues that affect the future of hospitals. The Executive—as well as previous Governments that were in charge of health care in Scotland—has made it clear that clinicians have a great part to play in the development of hospitals. A local clinician, Dr Dunn, has said that medical staff have been disenfranchised during the process. The local staff have not been consulted on the proposal to locate a secure unit on the site.

We ask the Health and Community Care Committee to consider the way in which this matter has been managed, and to develop a view on whether this proposal should go ahead despite

local concerns. We would also like the committee to comment on what I regard as the mismanagement of the issue. I thank the convener for the opportunity to address the committee.

**The Convener:** I would like to check something with you. We get the impression from the Public Petitions Committee that there is a sense of urgency about this issue. That committee asked the health board to defer its decision. Because it did not, that committee has asked the chair of the health board to appear before it to explain why the decision was not held back, despite that being requested by a parliamentary committee. According to the *Official Report* of the Public Petitions Committee's meeting of 18 January,

"The board chairman says that any decision that is made today is not irreversible and that it is still open to the Parliament to consider the petitioners' requests and to make recommendations to the board."—[*Official Report*, Public Petitions Committee, 18 January 2000; c 120-21]

Obviously, the board intends to set the planning process in motion, which will create other opportunities for people to raise concerns. There is still some time. However, do you agree that we need to consider this petition urgently?

**Paul Martin:** That would be appreciated. The issue about the irreversibility of the process is important. Considerable amounts of money would be spent on producing a planning application. We must ask whether it would be better to go back to the drawing board and consider whether the proposal should go ahead. We do not want a planning application being considered at the same time as the Parliament considers issues such as whether local people have been treated fairly and whether the appraisal process was carried out properly. John McAllion, the convener of the Public Petitions Committee and I—as the local member—asked the Parliament to develop a view and issue a recommendation, on the understanding that local health boards have to make their own decisions.

**Kay Ullrich:** The committee should be aware that Susan Deacon is on record as saying that this is entirely a local matter, to be dealt with by the health board.

**Dorothy-Grace Elder:** I also have an interest in this issue, as I have an interest in the east end of Glasgow. The local public is massively opposed to this unit. Over the months, there has been a total lack of consultation. Our briefing paper states that the health board claims that it has consulted the public and held public meetings. It has, but only towards the end of last year and in January, when the heat had been on it for many months from a local public outraged by the lack of consultation. Last week, the health board once again brushed aside the views of the public and local members, who were not given a fair hearing. By going ahead



with the decision, the board is saying that it is in charge. At the same meeting, it voted to close the Auchinlea day hospital psychiatric unit in Easterhouse. The east end of Glasgow is short of mental health units, but the unit that is proposed for Stobhill is not for local people. The expenditure at the special unit would also be huge—£100,000 per patient.

The big fear is that the ambulatory care and diagnostic unit will be downgraded—already the budgets are smaller than we anticipated. We must bear in mind that Springburn is one of the six poorest constituencies in Britain, with one of the worst health records. The ACAD unit was a genuine attempt to improve local health and make things easier for people, but it is now being pushed aside. The lack of public consultation is quite disgraceful and is comparable with what happened at Stracathro.

**The Convener:** Before I attempt to get the committee's view on what we should do with this petition, do members want to raise any issues that have not been picked up already?

**Hugh Henry:** Before I make a general comment, I want to ask a specific question that might help. Paul Martin indicated that the vast majority of people involved in the campaign are not opposed to a secure unit being sited in Glasgow, only to its being on this site. Has any indication been given of where else a secure unit might be sited?

10:00

**Paul Martin:** We support having a secure unit but I do not want to suggest, before a proper appraisal is carried out, where it should be sited.

Sites that were being put up for sale at the same time were being considered within the option appraisal process. Gartnavel hospital is an example, if I remember rightly. Certainly we were appraising sites that were being actively marketed. The question of the site should be addressed through a comprehensive option appraisal process.

**Hugh Henry:** That answer helps me to formulate my general comments. The committee should not become involved in local issues. If we say that we are opposed to a specific proposal we might, in a few months' time, find that another community petitions us and says the same things about the siting of a secure unit. That is a local decision in which the committee's involvement is not appropriate. However, Paul has given the matter a wider perspective within which we have a legitimate remit. Yet again, concerns have been articulated by a local community about a health board's failure to carry out proper consultation. The Health and Community Care Committee

should ask the health board to carry out proper local consultation. We should then make no further specific comment. We should also consider telling the Scottish Executive that we are concerned about the increasing evidence of failures by health boards to carry out proper consultation on a range of issues and suggest that it undertake a review of how health boards operate and their democratic accountability.

You will recall, convener, that in a number of meetings we have expressed concern about the democratic control of health boards. At some stage we might want to look at the structure of health boards.

**Mary Scanlon:** Hugh more or less summed up what I was going to say. Without clear national guidelines on consultation we are likely to get more and more petitions. Merely publishing notice in a local newspaper that there will be a unit is not consultation. We should ask for clear guidelines—we will then be in a position to judge whether health boards follow them. With Stracathro and Stobhill, a pattern seems to be emerging.

**The Convener:** I have attended a number of meetings at which the willingness of clinical and managerial health professionals to consult more fully has been evident. Some health boards are better than others, but people want to consult, given the right guidance and assistance.

**Kay Ullrich:** Guidelines are needed as some health boards still have the old habit of secrecy. They know that they should be consulting, but I am not sure that they know how to.

What can we do regarding this petition, given that the Minister for Health and Community Care clearly sees it as a local issue and a matter for the planning authorities?

**Dr Richard Simpson (Ochil) (Lab):** The problem is that hitherto consultation has been seen as consisting of issuing a report on a decision that has been made—only at that point is there discussion with the community that is affected by the decision. There should be wider, earlier and more open consultation, at the option appraisal stage.

On Stobhill, we should ask the health board what consultation it undertook and at which stages, and decide whether we think that was satisfactory. The current conditions that are required of a consultation process might have been fulfilled. If so, that would allow the committee to consider whether health boards are being given the right instructions on consultation. As others have said, if we do not think that that is the case we should tell the Executive that we want new guidelines to be issued calling for wider and more open consultation.

**Dorothy-Grace Elder:** It is not acceptable for the Minister for Health and Community Care to dismiss this as a local issue—almost any issue can be dismissed that way. It is one of the first of a controversial type of unit. There is massive local opposition to it, including from Paul Martin, his father Michael Martin MP and all parties. Glasgow health board should be questioned by the committee or, as Richard Simpson suggested, at the very least asked to account in writing for its decision and particularly for its timing. The health board called a number of public meetings, which Paul and I and others attended, but they were all held after the decision had been made.

**The Convener:** What does the committee want to do? The first option is to take no action, but I would not want to do that. The second, as suggested by Hugh and others, is to take up the wider issue of consultation and to write to the health board asking questions about the consultation undertaken. We could then comment to the Executive on any concerns on how health boards operate and their democratic accountability that are raised by that reply, by the Stracathro inquiry and by other information that has come to us from around the country. We could also comment on the need for a clear set of guidelines with, possibly, training and back-up from the managerial executive. Another option would be to appoint a reporter who would find out what we need to know and, at the next suitable meeting, report back on the question of consultation and on the point that Paul made about appraisal of sites.

There appears to be acceptance that there is a need for a secure unit. However, it can be left to a reporter from this committee to consult staff and the wider public.

Another course of action that was suggested by Dorothy-Grace is that the committee hold an inquiry at the level of its inquiry on Stracathro. However, I do not think that that is an option. The committee will often face petitions that receive, as Dorothy-Grace put it, massive support. The Stracathro petition had 25,000 signatures; the petition on the secure unit at Stobhill has 1,400. Rarely will we receive a petition with half a dozen signatures; it will usually have several hundred. The committee cannot hold a full inquiry every time it receives a petition with hundreds of signatures on it.

However, there might be some mileage in a reporter trying to get some answers, guided by the comments made in today's meeting. Based on the results of such an inquiry—which would not take up full committee time—we could take up Hugh's suggestion of writing to the health board and to the Executive.

**Kay Ullrich:** Do we have an answer to the question I asked, about what we would do in the

light of a firm decision by the Minister for Health and Community Care that siting of the unit is a local issue and, ultimately, a planning issue?

**The Convener:** My understanding is that we can write to the health board and to the minister to express the committee's point of view. You are right: in the end it is a local decision, which will be taken by the health board. The minister's input will come after the fact. However, the committee is in a position to state its point of view. We might be in a stronger position if we have, at least, taken some kind of evidential approach, which might involve a reporter investigating some of the concerns that have been raised in committee. We can take action based on their report.

I have no reason to doubt what Paul Martin, Dorothy-Grace and others are telling us about what has happened, but, if the committee does not examine the issue, we must just take their word for it. We have not heard the health board—or any other—side of the argument. The best course of action might be to consider such points of view.

**Irene Oldfather (Cunninghame South) (Lab):** I would like clarification on a point, which might influence what action we take. Will this unit, despite being housed in Glasgow, deal with cases from anywhere in Scotland, in the way that the state hospital at Carstairs caters for people from all over the country, if they fit the right criteria? Will it be simply a unit for people who were formerly resident in Glasgow or who have a Glasgow connection? That could influence whether there is a national dimension, or whether it is a Glasgow problem.

**The Convener:** Can you pick up on that in your comments, Paul?

**Hugh Henry:** Paul might be able to answer that better than I can; however, I am aware of proposals for similar establishments in a number of areas as part of the review of service delivery. Other health board areas will face similar problems in future.

I come back to some of the points that I made earlier. We should examine the principles that affect the delivery of care across Scotland—where a legitimate political influence can be brought to bear—rather than considering local specifics. The Minister for Health and Community Care is right in that the ultimate decision rests with the health board and the planning authorities. We should not consider getting involved in that process. We need to focus on the procedures and on whether they have been applied properly.

If we find that Greater Glasgow Health Board has not carried out the procedures properly, the minister will have a legitimate concern—as will the committee. Lack of consultation is the issue, not whether there should be a secure unit. We can

make that point to the health board and ask it for a response. It is more important that we gain assurances—for every community and every MSP—that safeguards will be built into such processes and that there will be agreed procedures, which health boards must follow. We need assurances about the way in which health boards will be held accountable and it is clear that we must do something about that quickly—communities in Scotland have no confidence in the accountability of health boards.

10:15

**Paul Martin:** I would welcome the appointment of a reporter, with the caveat that the committee considers calling witnesses at a later stage. It is, however, for the committee to decide whether it wants to follow that course.

I would like to pick up on Irene Oldfather's point. My understanding is that every health board area will be required to provide a secure unit. I fully support the development of a secure unit in each area, but the proposal for siting such a unit at Stobhill causes concern.

There are many issues, not just consultation and option appraisal. I have a seven-page letter that was sent to every member of Greater Glasgow Health Board, which sets out many concerns that we do not have time to discuss in detail because of the committee's congested agenda. The committee should appoint a reporter and then consider the evidence that the reporter gathers. The reporter might make a recommendation on the operation of health boards. I am not saying that we should be taking decisions on behalf of health boards, but the Parliament should recommend the ways in which it expects health boards to go about their business.

I have raised several issues relating to the independence of the advisers to the committee, but we do not have time to go into those now.

**The Convener:** We are running short of time.

I accept Hugh's comments about the need for guidelines and the suggestions that we write to health boards and to the Executive on the matter. However, the committee must make it clear that it has considered the matters on which it is commenting—we should not assume that what we have been told by outside bodies is correct. If we appointed a reporter, they would also be able to tell us whether any of the issues on which Paul Martin has touched had wider strategic implications. That is what the committee should deal with, rather than purely localised issues.

**Mary Scanlon:** I fully support the appointment of a reporter. There are clear issues that need to be considered. Perhaps we could move on—Dr

Richard Simpson might consider being the reporter for Stobhill.

**The Convener:** Are you happy with that suggestion, Richard? What do other members think?

**Dorothy-Grace Elder:** There should be two reporters, as a lot of work will be involved.

**Hugh Henry:** That is a recipe for getting nothing done.

**Kay Ullrich:** Having two reporters would make it more difficult to co-ordinate diary dates and so on.

**The Convener:** We should leave reporting in the hands of one person. There is a sense of urgency in this matter.

**Dorothy-Grace Elder:** There is also a huge amount of work to be done.

**The Convener:** The reporter will be able to talk to any other members of the committee. All committee members will be able to give their input in advance and say what they think ought to be done. Any suggestions should include contact names, and so on. Richard Simpson probably has better contacts in the Glasgow health area than me, but I have some names that I would make known. Everybody will be able to contribute to the reporter's report, but it would be better if one person produce it. I suggest that we should have that report back on 9 February. Is that acceptable?

**Paul Martin:** I have a question about the time scale that you have announced. I appreciate the need for urgency, but Dr Simpson will be seeking evidence from several witnesses and 9 February might be an unreasonable deadline.

**The Convener:** We can expect an interim report by 9 February. We might have to extend the time scale, but an interim report will be an adequate response to the urgency with which the Public Petitions Committee is treating this matter.

**Dorothy-Grace Elder:** Can you clarify that the issue is not exclusively about Glasgow?

**The Convener:** Dorothy-Grace, I ask that you refer any other points on this issue to Richard Simpson. We must move on.

**Dr Simpson:** In my report I will not try to adjudicate on where the unit should be placed. I will examine only the processes by which the decision on siting the unit has been reached.

**The Convener:** Thank you.

## Adults with Incapacity (Scotland) Bill: Stage 2

**The Convener:** The next item is the Adults with Incapacity (Scotland) Bill. Members will recall that, at our previous meeting, we considered part 5 of the bill, which is being scrutinised by the Justice and Home Affairs Committee. We felt a need to take evidence on section 47, which had changed fundamentally from the draft that was originally sent out for consultation, and which was discussed by this committee and the Justice and Home Affairs Committee at stage 1.

Today we welcome representatives of Parent Pressure, the Scottish Law Commission and Alzheimer Scotland—Action on Dementia. I am aware that at least one committee member suggested inviting another group. However, as that would have skewed the balance of witnesses 3:1—rather than 2:1—in favour of a particular way of thinking, I decided that the organisations that we have invited this morning would be able to give us a flavour of the views of that other organisation.

We intend to focus on section 47, but at the tail-end of last week's conversation on the matter, it was pointed out that part 7 of the bill referred to the duty of care and we wondered whether reference to duty of care should be included in section 47. We might want to stray into that area in today's discussion.

Members have just been given a fairly substantial paper from Dr David Nichols of the Scottish Law Commission, who will be here in about 20 minutes. Whether members will be able to read through it in time for questioning the witness is debatable. However, we might be able to examine the paper after we have taken evidence.

I have now talked for long enough to allow the witnesses from Parent Pressure to take their seats. Good morning, ladies. All committee members—and, I think, all MSPs—have received correspondence from you, containing your views on the Adults with Incapacity (Scotland) Bill. I invite you to give us a short statement of your main concerns about the bill.

We are focusing on section 47, as the Executive's position on that section has changed. A problem that this committee has, and which it shares with the Justice and Home Affairs Committee, is that not all the Executive amendments have been lodged. What the committee and the witnesses have is an indication from the Executive—bearing in mind comments that were made by Jim Wallace to the Parliament in December—that it will make progress on the issues at hand, although we do not have the text

of its amendments. That poses a difficulty for us all.

I ask you to give the committee your view of the Adults with Incapacity (Scotland) Bill, before I open the discussion to questions.

**Lesley Montgomery (Parent Pressure):** We welcome this opportunity to explain our opposition to the proposed amendment to section 47. We hope that members have had time to read our submission. With your permission, convener, I shall expand on some of our concerns.

My daughter is 28. She is deaf-blind, quadriplegic and a wheelchair user. She has no speech and no method of communication that is intelligible to anyone except those who are closest to her. She has gastrointestinal problems that make her extremely sensitive to a range of drugs, food and drinks. Over the years, I have had, on several occasions, to argue with doctors over what they have prescribed for her. Mostly, they have listened, albeit reluctantly. If the amendment is passed, they will not have to listen.

It seems strange to me that I have been entrusted with looking after Kimberly on a daily basis for 28 years—bathing, lifting, feeding and medicating her and deciding when a doctor should be called—yet I would have no say when it comes to medication or surgery. That power will be handed over to a doctor who might never have met her. In 28 years, I have seen the often devastating effect of drugs on my daughter. I am the person closest to her in the world; the one who recognises her every change of expression and every sound of pain or pleasure. Doctors do not live with the side effects of powerful drugs—carers and their patients do.

If the committee accepts the amendment, it risks inflicting misery on the most vulnerable people in our society. For those of us who can speak, the answer is simple: we just stop taking the tablets or we go back for an alternative. That option is not open to adults with incapacity.

The way in which the proposal would be enforced is unclear. If a carer refuses to administer drugs that have been prescribed by doctors, in the genuine belief that they are harmful to the person for whom they care, what will happen? Will they be arrested? Will the person for whom they care be taken into care, or will medical staff visit every day to administer the medication? Similarly, if a carer chooses not to bring the person for whom they care to hospital for an operation, what will happen? Will that person be taken to the hospital by force?

During the debate, a view of carers has emerged that is both hurtful and frightening. At one extreme, we are people who operate on a different intellectual level from doctors—in other

words, we are stupid. At the other extreme, we are potential murderers, who would not miss a chance to kill the people for whom we care. Over the years, I have been in touch with hundreds of carers. They all have one thing in common: they want a better life and better services for their loved ones. I have not met any potential murderers. If they exist, and have been identified, I trust that steps have been taken to remove them from their caring role. I am not aware of any evidence to back up that view of carers, but there is, however, an abundance of evidence against professionals in caring situations. How many reports have there been in the media of the ill treatment of vulnerable people in hospitals, care homes and nursing homes?

All that carers want is the best possible treatment for those for whom they care. Nothing in my experience leads me to believe that they will get that if the amendment is passed.

**The Convener:** Thank you. Do any of our other witnesses want to comment at this stage?

**Lesley Montgomery:** No. I think that we are open to questions.

**Hugh Henry:** The committee should put on record its thanks for your profoundly moving statement. If this Parliament is to achieve anything, it must give people such as you the opportunity to be heard in a way that has perhaps not happened before. I thank you for that very effective statement.

10:30

**Dr Simpson:** Lesley Montgomery and I have exchanged e-mails on this subject. I am grateful for her communications.

We have a dilemma because, under the original proposal, the proxy made the decision and the doctor had to go to court. The committee has discussed that at length and has expressed concern about it. The Executive has now said that it proposes to switch the burden of going to court so that the doctor makes the decision and the proxy has to go to court. That new proposal is what you object to.

I have discussed, although I have not yet lodged, an amendment to try to reinforce the joint nature of the process. In most situations, the proxy will have to try to come to an agreement with the person who is undertaking the treatment and, if there is disagreement, find a way of allowing that treatment—as well as the partnership with the person undertaking the treatment—to continue. I am worried that we could involve the Court of Session too early. I do not think that that should or will occur, but unless we get this right we could give ourselves a lot of trouble.

I am sorry to take so long to come to my question. What does Parent Pressure feel about the introduction of a requirement for a joint agreement—a balance of power whereby both parties have to agree to a decision on treatment—and that, failing that agreement, the parties should seek a second opinion from someone who is appointed by the health board? That person would not necessarily be a doctor—they might have a training in ethics, for example—but they must have a clear understanding of treatment processes. They could help the proxy and the person undertaking the treatment to reach an agreement; they would reinforce the concept of agreement. Only if either party disagreed with the conclusion of the second opinion would it be open to either party to go to the Court of Session. I am trying to achieve balance in this.

**Lesley Montgomery:** We are unclear about the costs of going to court. If a carer has to take a doctor to court—most of us live in straitened circumstances because we have given up careers to undertake the caring role—who pays? We cannot.

**Kay Ullrich:** That is a good question.

**Lesley Montgomery:** We would prefer it if it were the doctor who had to go to court. Someone has to make the final decision, and we believe that it should be the carer who does so.

**The Convener:** Could you address Richard Simpson's question about his amendment and give us your opinion on the wider issue of a second opinion? Who would you regard as an independent second opinion? Are you concerned about the independence of that second opinion?

**Lesley Montgomery:** The problem is that the second opinion would be made by a professional who did not know the person who was being cared for—they would not know the side effects of any treatment that that person had had or understand the person's method of communication. I do not see how having a second opinion would solve the problem.

**Dr Simpson:** It would offer an alternative to the Court of Session, which does not know the patient directly either.

**Lesley Montgomery:** The carer would not have to go to the Court of Session if the amendment is not passed. Therefore, we would prefer the bill in its original form.

**Dorothy-Grace Elder:** Last week, an amendment that I had lodged fell. It referred to another section, but the principle behind it applies throughout the bill. I, too, believe that two parties are not enough to make such major decisions. I suggested that a charitable or voluntary organisation that is associated with a particular

condition should be called in. It should not necessarily be a pressure group, but it could be an organisation such as Alzheimer Scotland, from which one could get the views of lay people as well as experts. We should draw on the vast amount of expertise in the voluntary sector. A state contribution could be made to bodies that were called in. I am not at all satisfied that decisions should be left to the doctor and the carer, or to lawyers.

**The Convener:** Members may have seen the document "Adults with Incapacity (Scotland) Bill—Stage 2: Parts 2 and 3", which gives the Executive's comments on amendments. I do not know whether the Executive will reconsider Dorothy-Grace Elder's amendment. The document says:

"It is not the normal policy of the Executive to accede to amendments that are lodged by other MSPs at Stage 2."

However, the Executive is prepared to listen to arguments and regards amendments that are lodged by MSPs as

"extremely helpful in probing matters that are of concern to MSPs and those that they represent. The Executive hopes that after the detailed debate on these amendments they will generally not be pressed to a vote."

**Hugh Henry:** The document says that it is not "normal policy" for the Executive to accept amendments lodged by MSPs at stage 2. Given that there are no precedents, what does normal mean in this context?

**The Convener:** I thought that that was strange, but it is what the Executive has said to the Justice and Home Affairs Committee.

**Dr Simpson:** On a point of clarification, section 6 deals with expenses in court proceedings. In certain situations,

"the court may make an award of expenses against the adult's estate".

The court would undoubtedly take into account the circumstances of the individual making the application.

**Kay Ullrich:** Would normal legal aid law apply?

**The Convener:** I think that it would, but I do not know much about that.

**Pat Moir (Parent Pressure):** I have loved and cared for my son for almost 30 years. My son has epilepsy as well as other conditions; the doctor always asks my opinion about questions such as whether to try new drugs or whether to increase or decrease levels of drugs because, as he says, I know my son best.

**The Convener:** If I can presume to speak for the committee—without testing the water—that is how we would like things to be progressed and that is how doctors and clinical teams should work

with people, whether adults with incapacity or any other members of the public. However, when we frame legislation, we must be aware of the less perfect situations that arise and anticipate any loopholes.

**Malcolm Chisholm:** It is difficult to ask our witnesses a question, because it seems so self-evident that what they say is correct.

I was totally incredulous when, during the stage 1 debate, Jim Wallace announced the Executive's proposed change. The Executive seems to have blundered into this in order to deal with a completely different problem—the concerns that people have expressed about euthanasia.

I am of the view that the Executive will have to change its mind on this issue. In this committee, the discussion will probably alternate between the views of Parent Pressure and Richard Simpson—with whom I disagree, although on most occasions I agree with him. I want to probe Richard's position a bit more, as it seems credible, unlike the Executive's. I am sure that the Executive will agree with that when its members read the *Official Report* of this meeting.

What are your concerns about the second person? To some extent, you have answered the question by saying that they would not know anything about the son or daughter. However, I am trying to think about the practicalities—the kind of problems that would confront parents. Would the second person be someone similar to the doctor, even if they were not a doctor, as Richard is suggesting? You mentioned the courts, but I am trying to think through the practicalities of the proposal.

**Lesley Montgomery:** Pat Moir is correct when she alludes to general practitioners. Most of us have a good relationship with GPs—that is not the problem. The problems arise when someone goes into hospital and the doctors are extremely busy and harassed but have to make instant decisions. I cannot understand why we cannot leave the situation as it is now. These disputes take place very rarely, but when they do they are really important in people's lives. Some of the powerful drugs that doctors now have at their disposal, which they prescribe with the best of intentions, can cause havoc in people's lives and sometimes lasting damage.

Those are our fears. We have all experienced such situations. We propose this right only for the guardian, who will already have been scrutinised by the court. It is not for every relative, or every Tom, Dick or Harry, to tell the doctor what to do—we accept that. We propose that this power should be only for the person who is closest to the adult with incapacity. That person will have been awarded a guardianship in court, where they will

have been scrutinised by a sheriff and recognised as a fit person to look after the adult with incapacity.

**Kay Ullrich:** In many ways, you have answered the question that I was going to ask. Your statements were very poignant. As a mother, I identified immediately with the sentiment that a mother knows what is best for her child. I am glad that your experience of GPs is one of good practice. You said that, more often than not, the GP asks what you think. I noticed that the GP on my left—Richard Simpson—was nodding profusely at that.

No one knows better what is best for their children than mums—and probably dads, too, in some cases—but do you know of people who are not lucky enough to have somebody as close as a mother or a father as their carer? How would what you are proposing affect them? Do you recognise the need for a third person?

**The Convener:** Before you answer, another member wants to piggy-back on that question.

**Irene Oldfather:** I have a supplementary to Kay Ullrich's question—you may be able to answer both at once.

From the stories that we have heard this morning, and from the evidence of those who have come along as representatives of many parents in Scotland, I have no doubt whatever that parents and people in similar positions are well able to make decisions in the best interests of their children. However, when an illness is short term, such as when someone has been injured in an accident—it could be a brain injury—the person who is responsible may not be particularly close to the individual about whom they have to make a decision. Unfortunately, this bill must cover all situations. I would appreciate it if you could say whether parents have experienced such situations.

**The Convener:** The legislation has to cover the whole range of situations.

**Irene Oldfather:** Exactly.

10:45

**Lesley Montgomery:** I reiterate that we are proposing this power only for guardians who have already been to court. In the scenario that you provide—in which somebody has a sudden accident—there would be no guardian.

Most people do not argue with doctors. I would hate for you to go away with the opinion that we argue with doctors every five minutes, as we do not. We rarely see doctors, because we do all the handling and medicating, and we send for them only in life-threatening situations. Mostly, we have

no problems with GPs. However, problems arise in hospital situations where we deal with strangers who do not know the person, do not understand how to communicate, are busy and have dozens of patients to care for. I have told doctors, "You gave my daughter that drug once before. It caused a haematemesis; she had to have five units of blood and was very ill for a very long time". Even so, they have said that that was the best possible treatment, and have gone ahead and given it. It is devastating when that happens.

**Kay Ullrich:** And it is too late to say, "I told you so."

**Lesley Montgomery:** I need to be able to have the time to explain the situation to a doctor.

**Ben Wallace (North-East Scotland) (Con):** I am well aware from the submissions that you are very good carers and are very close to the people whom you look after. However, in order to support the bill, I would be concerned to tighten up the liability on carers. The see-saw is not balanced at the moment—the bill will allow carers to override doctor's decisions, which might mean that carers will not have to face the consequences of being wrong and bad carers could get away with being flippant or with not reasonably consulting medical advice. I will support your views on overriding doctors' decisions if you are prepared to take more responsibility—in terms of duty of care for individual charges—and to consult properly.

**Lesley Montgomery:** I understand that concern, but we do take more responsibility because, no matter what happens, we are left to look after our charges. We love them and would not do anything to harm them.

The duty of care has been discussed a great deal. If someone comes into my house and my daughter is bruised, starved or ill-treated in any way, I am as open to the full force of the law as anyone else. I have a duty of care—I can be charged with neglect or cruelty.

**Ben Wallace:** But, under the proposed legislation, the consequences of your decision about medical treatment—

**Lesley Montgomery:**—would be the same as the consequences of a doctor's decision. If a doctor's wrong decision about medication resulted in my daughter vomiting to death and I took that doctor to court for negligence, he or she would be able—rightly—to say that the decision was the best one for the patient at the time.

**Ben Wallace:** The difference is that the doctor is bound by duty of care.

**Lesley Montgomery:** But nothing would happen to him.

**Ben Wallace:** Under section 73, a doctor would

be punishable if he or she were found to be in contravention of duty of care.

**Lesley Montgomery:** But the doctor would not be punished because he or she could say that they made the best decision at the time.

**The Convener:** I would like to defer on that point to the committee's medical professional.

**Dr Simpson:** I do not think that Lesley Montgomery is correct to say that. Section 1(4)(b) of the bill says that account shall be taken of

"the views of the nearest relative and the primary carer of the adult in so far as it is reasonable and practicable to do so".

Section 1(4)(d) says that

"the views of any person appearing to the person responsible for authorising or effecting the intervention to have an interest in the welfare of the adult or in the proposed intervention"

must be taken into account. If a doctor fails to take that person's view into account, and if that failure amounts to negligence and has a clear consequence, that doctor would be dealt with by the General Medical Council. There is no doubt at all about that.

I do not want to go into the particulars of the case that was alluded to, but if someone came to me as the responsible person and said that the adult whom they were looking after had previously had a massive reaction to a drug, and I then went ahead and carried out treatment using that drug, I would be negligent in terms of my duty of care. Ben Wallace is making the point that that duty of care is not imposed to the same extent on the person responsible for authorising the treatment—the proxy. The advice that we have received from Sheila McLean and others—which the Executive accepted in a meeting of the Justice and Home Affairs Committee—is that we cannot appropriately impose such a duty of care on the proxy. We therefore have a problem.

**Kay Ullrich:** What Richard says about a doctor's duty and how he could be held liable is correct. However, Lesley Montgomery is saying—she will correct me if I am wrong—that a doctor, because of the nature of his skill, would be able in court to give medical examples to back up a decision to take a particular course of action, in spite of what a mum, or someone else who knew the person, had said. Is that what you said?

**Lesley Montgomery:** Yes.

**Hugh Henry:** I would like to push this discussion on negligence to a conclusion before we go on to anything else.

**The Convener:** All right—although, because of the time, we will soon have to ask the witnesses to leave us.

**Hugh Henry:** If Ben Wallace was right, and there was some suggestion of negligence, it is still possible that the doctor would go to court.

**Lesley Montgomery:** Yes.

**Hugh Henry:** You said that you still were not sure about what would happen if someone displayed negligence or wilfully made wrong decisions. However, I think that protection is built into the procedure.

This morning we have heard about the benefit of bringing common sense into the legal process. I have found the discussion extremely helpful; it has given us a better perspective. Like Malcolm Chisholm, I am inclined to put the onus on the medical profession to take action. You make powerful points about finance and people's wherewithal. However, this is not just about finance and wherewithal. We must also consider how daunting and intimidating it can be to take on the responsibility of going through the legal process. We need not only to shift the onus, but to build in safeguards, because we must ensure that the bureaucracy—if I can call it that—does not have an advantage simply because it has the money, the education and the knowledge of the system. We must ensure that some protection is built in for those who—as you rightly say—have dedicated their life, given up their career and suffered financial disadvantage.

**The Convener:** I agree. Moreover, that daunting process would come against the background of a period of great stress.

**Dorothy-Grace Elder:** Overall, the bill is very well intentioned. The evidence that we have heard today has clarified in a lot of people's minds the need for hands-on, commonsense people—the real experts—to be involved.

I feel that the legislation is being raced though at breakneck speed—legislate now, repent later. I agree with Malcolm Chisholm that the bill will have to be changed.

Hardly anyone ever really succeeds in bringing doctors and lawyers to justice. The cases brought will be civil cases, and the law remains open to everyone in the same way as Gleneagles Hotel is open to everyone—if they have the money. It is terrible once someone is involved in a civil case. I tried to lodge another amendment to ensure that cases could be pursued at public expense. We will see what happens with that. Angus MacKay is quite a sympathetic minister. He was sympathetic when another of my amendments, on the inclusion of the voluntary sector in some capacity, fell the other day. Angus said that what I proposed had not been done before and that he did not know whether it could be done legally. Well, why not? We are making up the laws and the rules. Why not bring in an expert body or someone who could be



consulted by carers or doctors?

I completely agree with Lesley Montgomery. I know about this sort of decision; I know about how the mother or father might stand in the hospital corridor arguing, "But you can't do that." Sometimes, let us face it, they are dealing with an arrogant doctor.

**The Convener:** We have come to the end of our time with Parent Pressure, but I would like to give its representatives a final opportunity to comment and to answer those points that committee members have raised that they do not feel that they have had a chance to answer.

**Iris Dewar (Parent Pressure):** We fulfil a duty of care every day. It is called conscience. My husband and I work closely together with my son. If we need a third person, why could my husband not be the one who was asked about whether drugs or an operation was to take place? He knows that I am better able to decide than anybody else—better than any professional or doctor.

**Ben Wallace:** I am sorry to come back to this, but I will try to finish the point. I do not know whether you are aware of it, Iris, but the bill lifts any duty of care from you. It says that you should incur no liability.

**Iris Dewar:** Yes, but we have a duty of care every day of our lives.

**Ben Wallace:** I recognise that, but not everybody is as thoughtful or as close to their wards as you are. In saying this, I am not directing my points at you in particular, but the bill will lift the duty of care completely—unlike what happens now, when, as you say, you have a basic duty of care if someone is bruised.

I do not expect you to have the same duty of care as a doctor, for various reasons. After hearing the evidence from Parent Pressure—and I did not previously agree that carers should have the final say—I agree with you. As Lesley Montgomery has said, doctors in hospitals are indeed very busy and very stretched, with no free resources. They are not really in a position to go to the Court of Session the next day.

The important thing is that responsibility is taken for the decision and that that is specified in the bill—Sheila McLean said that that was not possible, but other people have submitted evidence to say that it is.

**The Convener:** I bring this section of evidence to a close. I thank the representatives from Parent Pressure for coming here and for giving us their views in a clear, commonsense, but human, way. For you, and I hope for us, this should be all about human beings and how they live their lives, as well as about how you have to live your lives in dealing

with them daily. I hope that the comments of members of the committee will let you see that, as a Parliament, we are trying to take the whole issue of carers and the great work that they do seriously.

**Dr David Nichols (Scottish Law Commission):** I will talk you through section 47. I have provided the excerpt from the commission's report that deals with the equivalent of section 47 as it is proposed that it be amended.

First I should explain who I am and what I can do for you. I am a member of the legal staff of the commission, and was involved closely with the preparation of the "Report on Incapable Adults" that gave rise to this bill. I am not a medical doctor. Like Mrs Thatcher, I started off as a chemist and became a lawyer. I can only explain the commission's thinking in 1995. I cannot speak for the commission at present, because it has not reconsidered the matter. In addition, there is a limited extent to which I can answer questions because they would be personal opinions, rather than the opinions of the commission, which I regard myself as representing.

We are thinking about the scenario in which a patient is considered incapable of making a treatment decision and there is an appointed guardian or welfare attorney who has the power to make that decision. I want to lump guardians and welfare attorneys together, because the commission did so, and so does section 47.

When I talk about doctors, I include the health care team, because although decisions technically are made by the doctor or the person who is responsible, decisions usually arise from a consensus view following discussion with various people. Under the general principles in section 1 of the bill, the doctor would be bound to consider the benefit to the patient, the least restrictive option, the patient's past and present wishes, and consultations with the guardian, welfare attorney and others with an interest.

We are thinking about a scenario in which there is a conflict between the guardian and the doctor. I wish to make clear that section 47 is limited in scope. It does not apply to the whole range of medical decisions. For example, it does not deal with cases in which a guardian wants treatment, but a doctor is unwilling to provide it. It does not deal with what should happen in emergencies, as section 44(1)—and hence section 47—does not apply to them. Section 47 does not deal with cases in which there are other consent or statutory provisions, for example, the treatment of detained patients under the Mental Health (Scotland) Act 1984. The section does not deal with research, and probably does not deal with basic care, such as keeping patients clean, free of pain and so on. It was the commission's intention that no guardian or welfare attorney could refuse that sort of

treatment. That is the view that is emerging now on section 47.

I want to give the committee two examples of cases in which there have been disputes. One involved an Alzheimer patient, aged 90 but very fit and active. The doctor wanted to put her in for the new drug treatment Aricept, which, he felt, could substantially improve her quality of life. The carer said no, that she was too old and it was not worth it. In another case, someone who was terminally ill fell and broke a limb. The only way of managing the excruciating pain involved was to reset the limb in a temporary way, but the carer said that it was time to let the patient go and that they did not want the patient to undergo serious surgery at this stage. Those are examples of cases in which section 47 would come into play.

**The Convener:** Can you clarify whether those are actual cases or simply examples that you have thought up?

**Dr Nichols:** They are actual cases that I have been told about by medical friends.

The commission consulted on two options. The first was to allow doctors to proceed with treatment if there was a refusal, but for the guardian to be able to go to court to stop that. The second was for the doctors not to be able to proceed if the guardian refused, but to have to go to court. Consultation showed that there was no consensus on this issue. Most doctors and some lawyers favoured the guardian having to go to court, whereas bodies representing the mentally disabled adults, as we then called them, favoured the other option. However, the division between who supported what was not absolutely clear cut.

Faced with that, the commission consulted further with representatives of the royal colleges, to see if we could come up with a compromise solution. We came up with what I think the Minister for Justice is proposing as an Executive amendment to section 47: that if the guardian refuses consent, the doctors can get a second opinion from an independent expert. The second doctor would review the case notes, examine and interview the patient, consult the health care team and give the guardian an opportunity to make representations. That sort of second opinion is used at the Mental Welfare Commission when the treatment of detained patients is challenged, and it seems to work reasonably well there. If the second opinion is in favour of treatment, the doctors can go ahead. The guardian still has the option of getting the courts involved, but it is up to them to do that. If the second opinion is against treatment, it is up to the doctors to go to court if they still want to treat. Of course, the doctor providing the second opinion may be able to suggest a compromise that is acceptable to all.

It seemed to us that the proposal that I have outlined was a reasonable compromise between the two extreme views. As with all things, there are arguments for and against. Those are set in paragraphs 5.36 to 5.38 of our report, which you have in front of you.

One reason in favour of the proposal is that it lessens litigation. There is a feeling that doctors would not bother to go to court if they were challenged but would let matters slide, leaving the patient deprived of medically appropriate treatment. The compromise solution makes the guardian more than a consultee. It gives them a power similar to that exercised by the House of Lords, to make doctors stop, review and rethink their decisions. The proposal also recognises and gives full weight to the clinical judgment of doctors and nurses, and their understanding of the needs of patients and their duty of care.

It is recognised that the vast majority of guardians will be excellent carers who have the patient's best interests at heart. Unfortunately, some will not. Legislation cannot assume that every guardian is reasonable, and the proposed solution allows doctors to disregard the views of ill-informed and ill-advised people. Another point is that doctors are used to making these sorts of decisions, whereas the guardian may be too emotionally involved to make a sensible decision. Some of the most difficult cases are those where there is a division of opinion within the family. If the guardian had a veto, that would enable one member of the family to get himself or herself appointed and impose his or her views on everyone else.

Those are the arguments for the proposal. One argument against is that the ultimate decision is with doctors, unless the guardian goes to court. That may be seen as detracting from the powers of guardians, as the doctors may simply go through the motions of consulting and ignore the views of the guardian. The guardian might have a good non-medical reason for refusing treatment. There is also a view that second opinions would be just a rubber stamp of no real significance.

Another argument is that because guardians have been selected as suitable and may have been appointed specifically to take decisions on treatment, their views ought to be given considerable weight. The final argument is that if parents can refuse treatment for their children and a competent patient can refuse treatment for themselves, guardians should be in the same position in relation to the person to whom they have been appointed guardian.

At the end of the day, how we resolve this extremely difficult issue is a question of balance.

**Malcolm Chisholm:** The last two minutes of

your statement effectively undercut the rest of your submission, because the arguments that you gave towards the end were far stronger than those that you gave towards the beginning.

I want to pick up on four points. First, you helpfully pointed out that the bill does not allow a refusal of basic care, which undermines the reason for the Executive changing its position. As you know, I, along with many people here, support the position that is set out in section 47 at the moment. It was because of the argument about euthanasia that the Executive changed its mind, so I am very glad to hear you say that guardians cannot refuse basic care.

Secondly, you pointed out that parents have the right to refuse treatment for their children, but we are talking here about guardians who have to go to court in order to gain that right. It seems to me that if people have any concerns about guardians, they can be dealt with at that stage. I would welcome your comments on that.

Thirdly, you say that there is a feeling that doctors would not bother to go to court. Were you not persuaded at all by what the carers said about the difficulties that they would have in going to court in the situation that we are discussing?

Finally, you gave the example of a new drug called Aricept. The evidence that we have had from Alzheimer Scotland, and I hope we will hear it again in half an hour or so, was that this is precisely why it wants to keep the rights. You have picked one example, which you said was based on something that had happened, but what Alzheimer Scotland has told us is that, in many cases, people with Alzheimer's disease are being prescribed drugs with undesirable side effects, and as guardians they want to have the right to stop that. I strongly support what the previous witnesses said, but I welcome your comments on those points.

11:15

**Dr Nichols:** I find myself in a difficulty because I can only offer my personal view, and I am not sure if the committee wants to hear that.

**The Convener:** We take on board your comments at the beginning of your contribution that you are articulating a Scottish Law Commission point of view from some years ago, but you are making personal comments. We would like you to answer that question.

**Dr Nichols:** I am not sure that the parent-child analogy is a good one. Parents have a considerable and long-term interest in their children. Guardians may not have that long-term interest. A conflict of interest may develop, or they may be impersonal guardians with no real connection to the person.

**The Convener:** Does that answer your question, Malcolm?

**Malcolm Chisholm:** I disagree with that, but I understand what Dr Nichols is saying.

**Dr Nichols:** The chief social work officer may be appointed as a welfare guardian.

**Malcolm Chisholm:** We are talking about the vast majority of guardians. The image of carers that is being put about in this debate disturbs me. We would all be able to find some carers who do not treat their charges properly, but equally—I am the last person in the world to be anti the medical profession—but we have all read about examples in the papers where it has not treated patients properly. We should not deal with this according to the minority of exceptions. That problem is addressed by the fact that someone has to go to court to be a guardian. There is also the power for the doctor to go to court. It is far easier for a doctor to go to court than for a carer, who is probably on income support or less.

**Dr Nichols:** I wonder how true that is. If the doctor is going to court, presumably the carers will have to go as well, unless they are going to leave the court to make the decision. They will have to go to court and get legal representation, certainly in the Court of Session. They will have to go to considerable expense to find evidence to bolster their position.

**Hugh Henry:** I understand that point, but I think there is a difference between the carer initiating the court action and having to participate and defend an action, because the thought of taking on the establishment and the system is a daunting one for people who do not know their way around it. As the convener said, carers are often suffering from stress. They might not understand the system, owing to their educational and social background, and they might not have the financial wherewithal to take the matter to court. Despite your comments, I am still inclined to say that if anybody is going to have to take court action, it should be the medical profession and not the carers.

Listening to your comments, I wonder whether we could introduce another element into this. The responsibility still lies with the guardian, but if the medical profession wants to challenge, they can do so. Perhaps there could be conciliation as Richard Simpson suggested earlier. However, if a decision must be taken, I do not know how many decisions would be taken in a year. We all know how long courts take to make decisions. Would it be possible to establish medical tribunals, similar to social security tribunals, which would have legal effect? The tribunal would be less formal and would be chaired by a legally qualified person, but it would have a medical representative and a lay

representative on it.

**Kay Ullrich:** Would such a tribunal be similar to a social security tribunal?

**Hugh Henry:** Yes. It would have representatives from both sides and would be chaired by a legally qualified person. Ultimately, someone who was dissatisfied with the decision of the tribunal would only be able to challenge it by using judicial review procedures if the process used to arrive at the decision was found to be legally incompetent. Therefore, one could have a more informal and possibly speedier process, where both sides would have recourse to a far less legally expensive system than other kinds of court action.

**The Convener:** That is an interesting contribution.

**Dr Nichols:** We thought long and hard about where disputes under the act should be resolved. We considered the three options that had been put out for consultation: the children's hearing model, which would involve lay people; a tribunal model, which would involve an expert plus lay assessors; and the sheriff court. The majority view was that, because of the nature of the decisions that had to be made, particularly in relation to property, the sheriff court was the best option. We did not say that the sheriff court as constituted at present was the best option, but we felt that it could be made much more user friendly and it seemed to us to be the best arena for such decisions to be made.

**Irene Oldfather:** I want to take issue with the case of Aricept, which Dr Nichols mentioned as an example. If one half of an elderly couple, who had been living together for a number of years, developed Alzheimer's and the other partner felt that it was inappropriate to use Aricept, that decision should prevail over the doctor's guidance. Given the side effects of drugs such as Aricept, I have no hesitation in saying that the decision of the person who has known the ill person for their whole life should prevail.

However, I am in something of a dilemma. Earlier, I asked Parent Pressure about the role of people whom I call primary carers and that of nearest relatives in such situations. I notice that section 1 of the bill refers to the nearest relative. My difficulty is that the nearest relative may not always be closely involved in the everyday life of the incapable adult. I have no problem at all with the role of primary carers. Should we consider tightening up the legislation on that point?

**The Convener:** I advise the committee that we are now running very much over time. We still have to hear from Alzheimer Scotland and, at the end of the meeting, we will have to hold our own deliberations. I believe that our SNP colleagues have a meeting at 12:45 and this room is booked from 1 o'clock, which is the latest time that the

meeting can go on. Any member who wants to make further comments to Dr Nichols, please make them now. I will then ask him to respond to all those comments together.

**Dr Nichols:** I suppose that would be okay.

**The Convener:** Otherwise, we will run over and I do not think that we will finish our discussions. If members really need to make comments, please do so now.

**Dr Simpson:** I want to make a couple of brief comments. First, the reason I have not lodged my amendments is that I am awaiting the Executive's amendments, which may follow the lines that Dr Nichols is suggesting. Secondly, I wish to make it absolutely clear that I am not concerned about those carers, guardians or continuing welfare attorneys who have a close long-term relationship with the incapable adult. The difficulty with the bill is that it tries to cover all eventualities. As the Law Commission report says, the bill attempts to deal with the over-zealous doctor, who is trying to impose a treatment on an incapable adult in the face of a carer who does not want that treatment.

It also attempts to deal with the guardian or welfare attorney who has no significant knowledge of the individual and who may not have huge concerns about treatment, who may be more interested in the property side or who has a particular ideology. For example, if a Jehovah's Witness were appointed as guardian for a non-Jehovah's Witness, the guardian's faith would lead them to say: "No, you're not going to administer a blood transfusion. It is completely against my faith". Would that be in the interests of the incapable adult?

It is proving difficult to squeeze those issues into one section of the bill. I cannot think of a way out, beyond the option of seeking a second opinion. I accept Malcolm's point that such a second opinion could come from another doctor within the same team. Safeguards must be put in place to ensure that the second opinion comes from an individual in whom the carer has confidence that their opinion is truly independent; otherwise, there is no significant advantage in a second opinion.

**Dorothy-Grace Elder:** Dr Nichols, how would you react to the suggestion that the second opinion could come from a voluntary organisation that is experienced in such matters and that is most appropriate to an individual case, such as Alzheimer Scotland, rather than involving lawyers or another doctor?

**Dr Nichols:** May I answer that question now?

**Dorothy-Grace Elder:** Yes, please, if you are able to.

**The Convener:** Can you hold on to that question, Dr Nichols? Ben will ask the last

question and then you will be able to answer all the questions.

**Ben Wallace:** I know that you were listening to my earlier questions to the witnesses from Parent Pressure on liability. Can you comment on that matter?

**Dr Nichols:** Yes, I was hoping to be able to do so. On the second opinion, we envisaged that it would be truly independent and that it would not be given by someone from the same unit. Nevertheless, people are suspicious of second opinions. To put it bluntly, they feel that such opinions would come from the medical mafia.

**Dorothy-Grace Elder:** Or the legal mafia.

**The Convener:** Or the chemists mafia.

**Dr Nichols:** I am not sure that it would be correct for the legislation to give a voluntary organisation decision-making executive powers. Voluntary organisations have their own agendas, and I do not think that they should be asked to take on such tasks.

**Dorothy-Grace Elder:** Not even when we are asking lawyers and the courts to do so?

**Dr Nichols:** Courts exist to resolve disputes—that role has evolved over the centuries. I do not think that voluntary organisations should have that role.

I would like to say something about liability, as there are some misconceptions around that point. The guardian or welfare attorney would be criminally and civilly liable under common law for a refusal of treatment that was either negligent or decided without proper advice. If one is exercising powers on behalf of someone else, one certainly has a duty to take and consider proper advice. One would have to have strong counter-advice not to follow the advice given by doctors.

I am not sure that section 73 protects the guardian or welfare attorney who has rejected medical advice as to treatment, as they would find it difficult to fall within the provisions of section 1, general principles.

**The Convener:** May I clarify that point? Amendment 117, in the name of Phil Gallie, introduces the idea of a duty of care. It goes on to say:

“Any person who refuses or consents to treatment for and on behalf of any other person under this Act shall at all times do what is reasonable in the circumstances to safeguard or promote the physical and mental health of that other person and shall not act at any time contrary to good clinical and medical practice.”

Do you believe that there is a need to insert a duty of care section, or, bearing in mind what you said about section 73, do you think that the duty of care is implicit, because of the general principles in

section 1?

**Dr Nichols:** At the moment, the duty of care is covered under common law. Section 73 gives exceptions to liability. People who reject medical advice without good counter-advice will not escape liability; common law would apply, making them liable.

**Ben Wallace:** Could we expand section 73 to include some onus on medical treatment?

**Dr Nichols:** I would not like to express an opinion on that.

**The Convener:** That is probably a good place to stop. Thank you for giving us your time, Dr Nichols.

We will now hear from the representatives of Alzheimer Scotland—Action on Dementia. I apologise for keeping you waiting. I am sure that you were interested to hear what other people had to say. Please put forward the points that you want to raise with us, after which we will ask you some questions.

11:30

**Alan Jacques (Alzheimer Scotland—Action on Dementia):** Thank you for the opportunity to make our points. I am the convener of Alzheimer Scotland—Action on Dementia; I am also a member of the medical mafia—I am a psychiatrist with an interest in people with dementia and other mental health problems in old age. I must emphasise that I am presenting my opinion not as a doctor, but as convener of ASAD. I hope that the committee will also hear the views of the medical profession. The authority to treat gives doctors very specific powers and I hope that the views of the royal colleges of psychiatrists, physicians, surgeons, dentists and GPs will also be heard.

Our organisation represents the interests of a wide variety of groups. We recognise that drawing up the legislation requires sensitivity and a difficult balancing act. We represent people who suffer from dementia, a variety of informal carers and several professional groups. We are well used to the conflicts of ideas and interests around this subject. The new legislation must ensure that the welfare of people with dementia is enhanced and that they are protected against neglect and abuse. We must provide for both the best and worse cases and for the most simple and the most difficult—that is the great difficulty we face.

We welcome the authority to treat that is provided for in section 44 of the bill. We understand that ministers may introduce an amendment that would give a broader definition of medical treatment. We have no problem with a broader definition; to attempt to pin down a definition too closely may simply create an

opportunity for unnecessary dispute.

We see the welfare attorney or guardian as acting for the person with incapacity—agreeing or refusing consent for treatment in just the same way as that person would have done when he or she was capable. The bill includes protections to ensure that attorneys and guardians act in accordance with the principles laid down in section 1; there are ways of intervening if attorneys or guardians do not act properly. We are very pleased with those protections.

Under the current law, it would be unlawful and unethical for a doctor to act purposely to harm, kill or neglect a patient. It would not be possible for an attorney or a guardian, by their refusal of consent, to force a doctor to act unlawfully; that is a further protection. The bill contains considerable safeguards against eccentric or extreme decisions, and decisions that would not accord with what a patient would have wanted if he or she were capable.

When a competent patient refuses consent to a treatment proposed by a doctor, that decision is binding. The doctor would have to go to court to ask for authority to treat against the patient's wishes. Section 47(2), where the patient has necessarily been replaced by a proxy decision maker, is equivalent to that.

The original Scottish Law Commission proposal was that the doctor would have to seek a second medical opinion. We did not object to that proposal, but we were concerned, on behalf of carers and those with dementia, that such a second opinion might not be independent enough—it would be too weak. We want to emphasise that in cases of dispute, it is ordinary good practice for the doctor to recommend a second opinion or to agree to the proposal from the patient or their carers for a second opinion. That happens all the time. The majority of disputes are resolved through informal discussion or by informal second opinion, but the legislation must provide for situations when such informal resolution is not effective and the dispute remains.

Section 47(2) provides that the doctor would have to apply to the Court of Session if he wished to proceed. ASAD has supported that position. It is the doctor who must decide whether the treatment is necessary. When a person has been given legal authority to make proxy decisions for the adult with incapacity, it is reasonable that a court or other independent body is required in order to overturn that refusal.

We are concerned about the Scottish Executive's proposal that anyone with an interest could approach the court. In our view, it should be only for those who are directly involved in the dispute to go to the court to settle it. To provide

otherwise is to diminish the legal position of welfare attorneys and guardians who have been given explicit powers. Earlier parts of the bill make separate provision to allow those with an interest to challenge actions under the legislation.

It is important to consider the range of health care decisions. David Nichols mentioned two examples and I would be happy to come back to the Aricept one later. We want to focus on the controversial decisions, but we also want to emphasise the fact that many decisions—some quite trivial—might end in disputes. It is important that the law allows for that range of decisions. GPs have to make decisions every day, for example about simple dental procedures or whether to give a thyroxin tablet for a thyroid replacement. Such decisions might be open to dispute and are relevant to this part of the bill. We would hope that good practice would ensure that disputes about such relatively minor matters were resolved informally.

We also want to emphasise the importance of disputes about choice of treatment; other organisations have also raised that point. Sometimes the dispute can be about not whether to have treatment, but what treatment to have. The law should not mean that refusal of one treatment counts as refusal of every treatment. I do not think that it will, but it is important that that possibility is considered.

Mr Chisholm mentioned that we are concerned about excessive use of tranquillisers by some doctors and nurses in residential homes, nursing homes and, indeed, in the patient's home. We hope that decisions on the use of tranquillisers will be covered by the law as it stands.

We continue to support section 47(2) as it stands, but we would be interested in hearing about other proposals, such as the independent medical panel mentioned by Mr Henry. Some people have suggested an independent mixed panel; others have suggested that lower courts than the Court of Session could deal with decisions. It is true that neither doctors nor carers are likely to rush to the Court of Session and we would not like decision making to be avoided because of people's unwillingness to go to court. We need a system that provides the easiest possible resolution of disputes.

The Alliance for the Promotion of the Incapable Adults Bill has reminded us of the importance of allowing doctors to proceed with necessary treatment while any dispute is resolved.

**The Convener:** Richard Simpson's amendment covers that.

**Alan Jacques:** The alliance suggests that welfare attorneys or guardians who are refusing consent for a treatment would have to set down

their reasons in terms of the principles of the bill. That is a useful point.

We have provided our views on section 48 separately and we understand that the committee has heard those views. It is important that research into dementia and the causes of dementia should continue. Unfortunately, some research requires the participation of individuals who have lost the capacity to consent. Obviously, no research can be guaranteed always to benefit an individual subject. Our concerns would be met if the legislation followed the wording of the Council of Europe Convention on Human Rights and Biomedicine.

11:45

**The Convener:** You have won that argument as far as the committee is concerned. We commented on that last week and added an amendment in my name about research.

**Alan Jacques:** Thank you.

**The Convener:** We might want to pursue the issues that have been raised about medical tribunals and consultation with courts lower than the Court of Session. However, the committee probably lacks the knowledge to tell whether that would be useful.

You said that we have to have an accessible form of redress when dealing with disputes of the type we were discussing. You also said that such a form of redress should not stop people trying to find a solution at the time, which is the best option.

For the benefit of the committee, I raised the lower court argument with Jim Wallace. The Executive seems wedded to the idea that the Court of Session should make the decisions. That is because the Executive has in mind only the serious disputes that might arise, for which the Court of Session might be appropriate. What you have highlighted today is that disputes are often about not life-and-death matters, but matters of day-to-day care. The Health and Community Care Committee should flag that up to other committees.

I take it that you would not have a problem with the tribunal being made up of a mix of lay people, medical people and legal people.

**Alan Jacques:** We thought that decisions should be made by a higher body than a doctor giving a second opinion because the decision has to be seen to be independent of both parties in the dispute. The level of independence is open to debate, as is the degree to which the decision has to be judicial. The idea that a court should make the decision arises from the fact that guardians are court appointees or, in the case of welfare attorneys, have been given a legal authority. The

overturning of a legal authority can be done only by a body with considerable teeth.

**Dr Simpson:** It is important that the body should be independent and not too well known to the team that makes the initial decision. I think that Sheila McLean told us about research that had been conducted in the United States of America to test proxy decisions, albeit hypothetically. The evidence showed that the system correctly determined the wishes of the patient on only slightly more than half the occasions—that is not much better than chance. Real and hypothetical situations are different, of course, but that research raises considerable concerns about the proxy's ability to interpret properly the wishes of the patient in situations of acute care, which is different from on-going care.

**Alan Jacques:** That research raises concerns, but we are used to proxy decision making in the sense of powers of attorney; tutor dative has also been used in that sense for some years now.

The first parts of the bill indicate the amount of consultation that is necessary and the way in which the person's prior views must be taken into account. All that can be done is to include those provisions and allow for powers to challenge eccentric attorneys and guardians. The law cannot do much more than that.

**Irene Oldfather:** That picks up some of the points I made earlier. Section 1 contains the idea that the nearest relative should be consulted, but they may not always have daily involvement with the patient. Do you have experience of cases in which the nearest relative is not particularly involved?

On page 2 of your submission you say that there is often poor medical practice, with repeat prescriptions for tranquillisers being issued for life. We have not discussed that this morning, but the bill may put the onus on doctors to take careful account of that point. That is a positive point that is worth highlighting.

**Alan Jacques:** I am aware that the Scottish Law Commission has considerable difficulties with the question of the nearest relative, as we do. It is a rigid definition that has been taken from the Mental Health (Scotland) Act 1984. There are concerns about who is the best person to consult. I have not found the words to describe who that person is, but I agree that it is not always the nearest relative.

Terms such as principal carer open up just as many problems as they solve, so nearest relative was kept for want of a better phrase. The wording may have to be modified to allow for the fact that the nearest relative may not necessarily be the best person to consult in the interests of the adult with incapacity. There are ways of changing who

is named as a nearest relative, but when one is incapable it may be too late to do that.

**Irene Oldfather:** That is one of my main concerns and I am in a dilemma over this section. Although I have no difficulty with the primary carers and the parents who have dealt with incapable adults over a long period, I would be concerned about situations in which the nearest relative may not have a particular involvement. In those situations, independent medical advice would be welcome. Moving the balance in favour of someone who may not have the interests of the person at heart would be a matter for concern. I recognise that that would happen in only a very small proportion of cases, but safeguards in the form of medical opinions must be built in in such cases.

**Alan Jacques:** Allowance is made for the views of the carer who is living with the person to take precedence over the nearest blood relative, so there are some protections.

**Irene Oldfather:** If there is no primary carer and the nearest relative is not in daily contact—

**The Convener:** Yes. That is definitely an issue.

**Malcolm Chisholm:** Is not it the case that section 47 is specifically about guardians and welfare attorneys? That should address Irene Oldfather's concerns. What protections are there against eccentric or extreme decisions?

**Alan Jacques:** Under section 1, people have a duty to consult and to take into account the prior views of the person. Other sections give powers to challenge in court an attorney or guardian who is not acting in the best interests of the person.

**Jan Killeen (Alzheimer Scotland—Action on Dementia):** Writing independent advocates into section 1 might enable another independent, named interest—somebody from an approved advocacy agency—to express their views, but such people would not be legal decision makers.

**Mary Scanlon:** You said that there are already considerable safeguards against extreme decisions. For the sake of the ladies from Parent Pressure, I would like to read out a point from your submission:

"A welfare attorney or guardians may, out of over-involvement, ignorance or malice, make decisions against the best interests of the individual and busy doctors may collude and withhold treatment."

This morning we have heard from the parents of severely disabled and handicapped children. How can we balance that view to create a safeguard against potential abuse in the best interests of the patient?

**Jan Killeen:** The principle of minimum intervention should underpin how we frame our

legislation. In this country, we do not make our laws on the basis of an assumption that we are all potential murderers; we legislate to create sufficient safeguards that will allow things to progress practically.

**Dorothy-Grace Elder:** I would like to clarify a couple of points. At present, the nearest relative could be the estranged or semi-estranged spouse of the person, could it not?

**Alan Jacques:** That would be the case if there was no primary carer living with the person.

**Dorothy-Grace Elder:** Could the nearest relative also be a completely estranged spouse, provided the couple are not divorced?

**Jan Killeen:** According to the bill, that relationship would automatically fall for couples who have separated or divorced, unless otherwise stated in the power of attorney.

**Dorothy-Grace Elder:** That brings me back to the point that the nearest relative could be somebody's semi-detached, rather than formally detached, spouse. If the couple were not legally separated or divorced, the incapable adult could be in the power of that other person if there was no primary carer.

**Alan Jacques:** We must remember that we are talking only about a requirement to consult. We are not talking about a requirement to go along with what the nearest relative says. The degree of that consultation might in practice be modified by the view of the person conducting the consultation that the nearest relative did not have the interests of the incapable adult at heart.

**Dorothy-Grace Elder:** I understand; thank you. You may have heard the evidence of our previous witness, Dr David Nichols from the Scottish Law Commission. He said that the commission had considered three options: a children's hearing model, a formal tribunal, and the courts. He said that the commission had opted for the courts because it thought that the disputes were most likely to involve property. We know that such disputes could go far beyond property. What is your comment on the idea, already suggested by me and by Hugh Henry, that an appropriate charitable body should be involved?

**Alan Jacques:** We are talking about two slightly different things. What the Scottish Law Commission was discussing in relation to hearings and courts was who should make the decisions about incapacity, appointing guardians and other related matters. There was considerable discussion about which body would be best suited to that.

Our original submissions many years ago stated that we liked the idea of a hearing system. To speak personally for a moment, I am still



absolutely sold on that idea. I think that that is by far the best type of body to make decisions on welfare, health and property for vulnerable people. In our experience, people with dementia think that they are being accused of a crime when they go before the sheriff, and I am not sure that improvements in the sheriff court system will make them think otherwise.

That is my view; it is not necessarily the view of the organisation. Originally, we did think that, but we have come to agree with the Scottish Law Commission that it is acceptable for the matter to be dealt with in the sheriff court, as long as there are considerable improvements in the sheriff court system to make it more user-friendly, as David Nichols said.

12:00

We are talking today about a different matter—who resolves disputes. If there was a hearing system, things could connect to it. It might also be clearer who people should approach in disputes if there was the hearing level and then the courts above that. If there was some sort of panel of experts for dispute resolution, the hearing would not make the decisions.

We have not considered in depth the suggestion that voluntary organisations should be involved. We have not traditionally seen ourselves as part of a statutory process of consultation on individual care decisions. My guess is that we would have considerable reservations about that. We value our independence and the fact that we represent a wide range of interests. I am not sure that we would want to be involved on a statutory basis.

**Dorothy-Grace Elder:** Would you want to be consulted?

**Alan Jacques:** We want to be consulted, but the way things are framed means that people with an interest already can take an interest. Parliament may wish to consider whether the principle of advocates should be enshrined in the act.

**The Convener:** Amendments relating to independent advocates were lodged to part 1 of the bill. I supported one of them, but they were rejected. Bearing in mind what I read out earlier, the Executive's line seems to be that everything will be rejected at stage 2, but the Executive will go off and think again, so the issue may come back—it may not be completely dead in the water.

We have asked both previous sets of people to comment on the duty of care. Do you feel that there is a need to insert a more overt duty of care?

**Alan Jacques:** We do not see a particular need to do that. Under section 44, the duty on the welfare attorney or guardian is to make a decision,

not to care. If I decide to refuse treatment offered to me by a doctor, I do not have a duty of care to myself; I simply decide whether to accept the treatment and then must take the consequences. If my decision means breaking the law, I would have to obey the law, but there is no duty of care in relation to that decision. The issue is not relevant to this part of the bill.

**The Convener:** The difficulty lies in the situation that Irene Oldfather outlined. Most of us do not have a problem accepting what you say if the primary carer—the partner of 30 years, or the person who does the day-to-day on-going caring—looks out for the best interests of the adult. There is, however, an element of concern about when there is not such proximity or when the person may stand to gain financially or in other ways—for example, property. In such situations, a built-in duty of care would allay some of those concerns. The problem is covering all the options in one section.

**Alan Jacques:** The problem may have arisen because people are considering part 5 in isolation from the rest of the bill. People need to consider the duty of care in terms of the general principles in part 1. Those general principles are wide-ranging and, while they do not amount to an explicit duty of care, they amount to a duty to take care when making decisions. The principles are set out extremely well in part 1, from which everything else follows on. We are happy with part 1 and with the offences that are mentioned later on in the bill.

**The Convener:** I will bring the questions to an end. Are there any other points that you would like to make?

**Alan Jacques:** I would like to comment briefly on the Aricept example.

**The Convener:** You may comment, as long as members of the committee agree not to take you up on it. I am happy to hear your contribution, but we do not have time to hear committee members' views on it.

**Alan Jacques:** Aricept is a treatment that may temporarily help some people with Alzheimer's. It is given in the early stages of the illness. We would expect that anyone offered Aricept would be aware of their diagnosis and able to make a rational decision about whether they wanted to take the treatment. As is good practice, the doctor would take the views of relatives and carers into consideration, but the patient would take the decision. I cannot envisage many circumstances in which an incapable person would be given Aricept without their consent.

**The Convener:** Thank you for clarifying that point. Thank you also for taking the time to give us evidence and for your written submission. As far

as I know, we have the room until 1 o'clock, although I do not know members' timetables.

There are some key things for the committee to think about. Last week, we were able to pull together amendments—which we lodged in my name, as convener—that had general support across the committee. We may not be able to do that on this issue. People may prefer to take time to think about what they have heard in today's evidence and examine the written submissions and lodge amendments in their own name. We do not have to have a committee point of view, but if people feel that we are able to, we can, as we did last week.

The key issues raised by this morning's contributions are the independence of any second opinion; whether the courts are the way forward in resolving disputes; and, fundamentally, in section 47, whether the doctor or other medical professional should go to court or whether the onus should be on the guardian having recourse to the courts, which would be the situation if the Executive amendment were agreed to.

The other issue is whether the duty of care on the guardian is addressed by section 1. Is it covered by the fact that a person must be scrutinised in order to become a guardian? Is there a need for an amendment that refers to a duty of care in an overt way? Having listened to the evidence, I see those points being the main ones that we might want to discuss. Members may have other points that I have passed over. Are there any other contributions? It is not like the committee to be quiet.

**Malcolm Chisholm:** People are repeating themselves. We are beginning to realise the different views that people hold. It was interesting to hear the view of the person from the Scottish Law Commission, because presumably the competing arguments were considered by the Executive prior to publication of the bill, yet it opted for section 47 as presently drafted. It is clear that the Executive changed its mind because of the debate about euthanasia. I have seen no evidence to the contrary. All the issues that were raised about section 47 concerned the image that people had of guardians saying that people should be allowed to die.

There are issues about euthanasia in the bill, but there are many ways of dealing with them. The Executive has already sought to take action on section 44. The Executive looked at all the evidence from the Scottish Law Commission and took a contrary view. It changed its mind only because of the debate about euthanasia. There are concerns about euthanasia that are not addressed by changing section 47. We must separate out the arguments as we go along. I am prepared to look at anything that deals with

people's concerns about euthanasia, but I am happy with section 47 as presently drafted. As I said at stage 1, I will oppose the Executive amendment.

On a general point, I am concerned to see Executive notes to the Justice and Home Affairs Committee—if that is what the notes are—stating that

“the lodging of amendments is extremely helpful in probing matters which are of concern to MSPs and those they represent. The Executive hopes that after the detailed debate on these amendments they will generally not be pressed to a vote.”

A discussion on that may be for another time, but we have a new Parliament with committees that are listening to people who know the effect that these measures will have on them. We have had good examples of that today. I had quite strong views before this morning's meeting, but I have even stronger views now. We will make a mockery of the committee system of this Parliament if we do not convey in the strongest terms to the Executive the views that have been put to us this morning by Parent Pressure and Alzheimer Scotland.

**Dr Simpson:** Having sat in on all the Justice and Home Affairs Committee stage 2 meetings, I can inform the committee that, in practice, matters have been pressed to a vote on a number of occasions. If the expressed wish of the Executive was that there would be no votes, its hopes are forlorn.

**The Convener:** Good.

**Dr Simpson:** Not many amendments that have been pressed to a vote have, however, been successful. In other words, the committee has chosen not to support the amendments, including, I regret to say, the entire raft of amendments that I moved on advocacy.

My concern throughout has been to try to get modern practice into the bill. That includes advocacy and joint agreements. A balance between the treating professions and those they seek to treat is an essential part of modern practice. I am still of a mind to move an amendment, although I have shifted my view from saying that there should be a single second opinion to saying that the second opinion should come from a panel, and that the panel should be appointed by the health board. I will move what may be regarded as my compromise amendment.

However, if that amendment is not accepted by the Executive, or if a similar, acceptable arrangement is not proposed whereby the second opinion is truly independent and carers are happy and convinced that that is the case, I will adopt Malcolm Chisholm's position and vote against changing the original draft, and in favour of the

proxy having the power to refuse treatment.

The medical and other treatment professions know what to do—they are well organised and have support and legal advice from health boards and trusts. That will not be true, to the same extent, of many carers. The position I have adopted will ensure that the wishes of the incapable adult—however difficult it is to express those through the carer—are followed.

12:15

**Mary Scanlon:** I support that position, which seems very reasonable.

**The Convener:** I would be sympathetic to an amendment that encompassed the need for a truly independent second opinion, partly to try to ensure that problems are resolved outside the courts, but also to try to give a true reflection of the way in which such situations are being dealt with. More often than not, they are being dealt with by guardians and carers who know much more about the individual than the medical profession does. They are also being dealt with by clinical teams of medical professionals—nurses, doctors and psychiatrists—rather than by one practitioner. A way forward might be to find an independent second opinion, but to have safeguards as well.

However, if such a proposal is not acceptable, I agree with other members that the carers and relatives are the people who know what the person would have wanted and what would be in their best interests. I was interested in the evidence given by Alzheimer Scotland—Action on Dementia, that guardians should give reasons for their actions and for taking a contrary position to medical professionals. Carers should have to take recognisance of the medical profession, but I think that they will have the better idea of the best way forward.

**Dorothy-Grace Elder:** Whether lower or higher courts are involved is largely irrelevant because of the intimidatory nature and expense of courts. Nobody wishes to go to court and it would be inhumane to add to the stresses on carers by making court the first option. I fully support having a tribunal, or something like that.

Section 47 is intended to protect the helpless from the uncaring—not from the wonderful carers who constitute the majority. Frankly, I still do not know why guardianship by itself is not enough. Perhaps the drafters of the legislation are allowing for the fact that, years hence, guardians might themselves become ill.

The full might of the law must certainly not be the first resort. We must also be aware of how long it takes to get a hearing. Melodramatic overnight applications to judges are not on. Action

must be thought out—by more brains than that of one lawyer in a hurry.

**Irene Oldfather:** I agree with the idea of having an independent second opinion. From what I have heard today, I think that that will encourage doctors and carers to resolve disagreements earlier, and to enter into discussion.

A second independent opinion will put an onus on doctors and carers to try to work things out. The evidence from Alzheimer Scotland—Action on Dementia suggested that long-term prescribing could benefit patients, because that might force doctors to reconsider such decisions. Recourse to independent opinion will allow people to reach a resolution.

It is important to remember that some guardians are not long-term carers and that they can, at very short notice, be catapulted into stressful and emotive situations. With the best will in the world, none of us can think clearly in such situations and a second independent opinion will safeguard the interests of everyone concerned.

**Hugh Henry:** From what I have heard this morning, it seems that the onus of taking a case to court should fall on the medical profession, not on carers. Having a second independent opinion is a very sensible idea, because in many circumstances that might obviate the need for the final step. I am attracted to the idea of holding final arbitration not in a court, but in a less formal, though still legally proficient setting, such as a tribunal or a hearing, with ultimate recourse to a judicial review if that tribunal or hearing failed to exercise the law properly.

**Malcolm Chisholm:** I think that we will just have to agree to disagree on this issue. Alzheimer Scotland—Action on Dementia clearly said that there are protections against any eccentric or extreme decisions, and that the bill as drafted has the best solution to this particular problem. Dr David Nichols mentioned the problem of making sure that independent experts were actually independent, and such concerns will not command the confidence of carers.

I see no overriding reason why we cannot accept section 47 as it stands; it contains safeguards against eccentric decisions and allows doctors recourse to the courts to override any extreme decisions. I have been persuaded by the evidence from Alzheimer Scotland—Action on Dementia and Parent Pressure. Although Richard Simpson's proposal is better than the Executive amendment, I am not personally minded to support it and I will support the section as drafted.

**The Convener:** From Malcolm Chisholm's comments, it is clear that we will be unable to come to a unanimous decision on the best way to proceed. Richard Simpson will frame an

amendment that takes into account some of our concerns, and the clear mood of the committee is that, if the amendment is not accepted, the balance of support should finally rest with the bill as drafted instead of with the Executive amendment. The onus should be on the medical profession with its back-up of resources and legal advice to take legal action, rather than on carers and individuals.

Although members can examine Richard Simpson's amendment and sign up in support of it if they want to, as a committee we should make it clear that the bill as drafted is preferable to the expected Executive amendment. I hope that this morning's evidence will be as helpful to the Justice and Home Affairs Committee and to the Executive as it has been to the committee, although I will echo Malcolm's point about the Executive's attitude to amendments. Is the committee happy that that is a fair reflection of its views?

**Hugh Henry:** If you are writing to the Executive, will you ask it to consider an alternative to the courts as a legal forum for making decisions?

**The Convener:** Although we agree that the issue is worth pursuing, the committee is probably not best placed to do so. However, I am happy to make it clear that we think that the issue should be examined for a number of reasons. The committee probably speaks with as close to one voice as possible on the issue.

There is one other matter—Phil Gallie has lodged amendment 117 on duty of care, which will give the Justice and Home Affairs Committee a chance to discuss the issue. We have heard today that the bill as it stands covers the need for a duty of care. Bearing those points in mind, is the committee happy to leave that issue?

**Malcolm Chisholm:** I accept that the issue is implicit in the bill. I have no problems with the first part of Phil Gallie's amendment, although it seems as if it will not be necessary. However, the second part of the amendment opens up the argument again. For the past three hours we have been discussing what constitutes good clinical and medical practice, so it seems pointless to say that someone

"shall not act at any time contrary to good clinical and medical practice".

As that last phrase is what the disagreement is all about, I could not possibly accept that part of his amendment.

**The Convener:** Does the committee think that duty of care is implicit in the bill as it stands?

**Dorothy-Grace Elder:** We should spell it out as clearly as possible.

**The Convener:** Although we disagree on the

issue, the fact that an amendment has been lodged means that the Justice and Home Affairs Committee will be able to discuss whether this or another amendment is required to make duty of care more implicit in the bill. We hope that the information that we gleaned this morning will be helpful for any further analysis.

*Meeting closed at 12:28.*

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