



OFFICIAL REPORT
AITHISG OIFIGEIL

Public Petitions Committee

Thursday 7 June 2018

Session 5



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PUBLIC PETITIONS COMMITTEE

10th Meeting 2018, Session 5

CONVENER

*Johann Lamont (Glasgow) (Lab)

DEPUTY CONVENER

Angus MacDonald (Falkirk East) (SNP)

COMMITTEE MEMBERS

*Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con)

*Rona Mackay (Strathkelvin and Bearsden) (SNP)

*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Ben Macpherson (Edinburgh Northern and Leith) (SNP)

Professor Chris Ponting (University of Edinburgh)

Mark Ruskell (Mid Scotland and Fife) (Green)

Emma Shorter

David Stewart (Highlands and Islands) (Lab)

Janet Sylvester

CLERK TO THE COMMITTEE

Sarah Robertson

LOCATION

The David Livingstone Room (CR6)

Scottish Parliament

Public Petitions Committee

Thursday 7 June 2018

[The Convener opened the meeting at 09:46]

Continued Petitions

Residential Care (Severely Learning-disabled People) (PE1545)

The Convener (Johann Lamont): Welcome to the 10th meeting in 2018 of the Public Petitions Committee. I remind members and others in the room to switch phones and other devices to silent. We have received apologies from Angus MacDonald.

The first petition for consideration is PE1545 by Ann Maxwell, on behalf of the Muir Maxwell Trust, on residential care provision for the severely learning disabled. We last considered the petition at our meeting on 15 March and agreed to invite the petitioner to make a written submission; we also agreed to write to the Scottish learning disabilities observatory to ask for information about its work to address the data visibility of people with learning disabilities in Scotland. The observatory's submission provides a detailed outline of its work programme, which is included in our meeting papers.

The petitioner's written submission expresses concern that there are limited references in the work programme to epilepsy, despite 60 per cent of people with profound learning disabilities having that condition. The petitioner is of the view that residential care would resolve many of the issues that the observatory is currently researching, and suggests that the financial consequence of inadequate care for the profoundly learning disabled should be a focus of the observatory's work.

Do members have any comments?

Rona Mackay (Strathkelvin and Bearsden) (SNP): We should focus on the fact that the petitioner is saying that not enough emphasis is being put on the epilepsy question. We need to tease out some of the points that they raise about the work that is being undertaken by the observatory in order to find out in detail what is being done.

The Convener: I was quite struck by the petitioner's argument. Historically, someone with a learning disability was put into long-term care. That policy has quite rightly changed and I think that that has been a massive benefit to people

who have been able to live and work in the community and achieve their potential. However, it almost feels as if, because of that policy, there is a view that it is not appropriate to have residential care in certain circumstances.

Rona Mackay: Yes, it has gone too far.

The Convener: Although you would not want the general rule to be that people are put into residential care, the petitioner makes quite a strong case for there being a community where resources and support can be brought around about people. I agree that we should explore the issue further. Is the issue of epilepsy being considered sufficiently and, if not, why not?

Brian Whittle (South Scotland) (Con): I was going to say something similar on the question of whether the pendulum has swung too far the other way with the result that the option of residential care is now limited. That would be worth exploring. We should also explore the financial consequences of—I do not want to say inadequate care. We should explore both options, and compare the financial consequences of one with that of the other in relation to the willingness to give that care.

The Convener: The petitioner makes the case that there are financial consequences of not making this provision available in certain circumstances, because further along the line there are consequences for the individual. That could be something that we could look at.

Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con): A point was made about the Scottish Government measuring the demand for long-term residential care based on the current number of children and young people in residential care. They make the point that it is a flawed way of measuring demand and fails to capture the true need that currently exists in Scotland. Is the methodology of calculating the number of people currently taking up residential care places affecting this issue as well?

The Convener: If the facility is not available, in a sense you are ignoring demand; you are not seeking it out.

Do we agree to ask the Scottish learning disabilities observatory about its work in relation to links with profound learning disabilities and epilepsy and to look at the question of the financial consequences of what is seen as—if not inadequate—inappropriate care that is not totally supporting the person?

Members indicated agreement.

Healthcare Services (Skye, Lochalsh and South-West Ross) (PE1591)

The Convener: The next petition is PE1591 by Catriona MacDonald, on behalf of SOS-NHS, on the major redesign of healthcare services in Skye, Lochalsh and south-west Ross. Rhoda Grant MSP, Kate Forbes MSP and Edward Mountain MSP, who have attended previous meetings at which we have considered the petition, are not able to attend today but have provided some comments to which I will refer shortly.

We agreed to defer further consideration of the petition until the external review by Sir Lewis Ritchie on out-of-hours urgent care and minor-injury clinical services had reported. That report was published in May and a full copy is included in our meeting papers. The clerk's note identifies the theme and key messages within the report about the need for NHS Highland and the local communities to work together, which has been regularly highlighted during our consideration of this petition.

The petitioners have provided a written submission, in which they indicate a willingness to engage in co-production with NHS Highland and others to help to deliver some of the key recommendations in Sir Lewis Ritchie's report. Rhoda Grant has indicated that she would like the petition to remain open until the six-month review of the key themes that were identified in Sir Lewis Ritchie's report has been completed.

Edward Mountain notes that this is a long-standing petition of great importance to the people of Skye and Wester Ross, which came about as a result of the actions of NHS Highland, which he says were far from inclusive. He considers that Sir Lewis Ritchie's review has been a significant step forward, and has managed to reunite the majority of the community. He adds:

"There however remains a genuine fear that NHS Highland, although accepting the report, will revert back to their original position and will not implement all the findings. I have been asked by many to speak to this petition and to ask the committee to keep the petition open for a further six months. While I know the committee may feel the matter has been dealt with, it would give my constituents confidence in the political system to know that it was not closed."

Kate Forbes has indicated:

"I offer my apologies to the convener and to constituents watching at home for being unable to be here in person. We have made huge progress since the last meeting, with Professor Sir Lewis Ritchie's report stating unequivocally that Portree Hospital should remain open, with a resilient 24/7 emergency care and beds provided in the north end of Skye. The priority now is to ensure this happens. Until it is implemented in full, I would ask the committee to keep the petition open."

Do members have any comments?

Brian Whittle: In my constituency work, a few constituents have raised concerns about situations in which the recommendations of a review have not necessarily been implemented in full, or in which a decision has been taken that there is no need for them to be implemented in full.

I am inclined to agree with the written submissions from our colleagues. We should leave this petition open for six months and revisit it to check whether the recommendations have been implemented.

Rona Mackay: It is clear that the decision has been made on the restructuring and that that is not going to change. Edward Mountain is right to say that that has been dealt with.

It is good that progress is being made now on the collaboration between NHS Highland and the community—that is really good news—but I agree with Brian Whittle that we should keep the petition open for six months until Sir Lewis Ritchie can come back and update us with progress on the implementation of the recommendations. It is an important petition, and I think that another six months would do it justice.

Rachael Hamilton: I agree that we should keep it open for another six months, which would give us reassurance that significant progress was being made with the review.

The Convener: Do we agree to keep the petition open for a further six months and to ask the Scottish Government to provide its views on the findings of the review, particularly with regard to the recommendation that it should seek regular and robust assurance that satisfactory progress is being made, and ask how it intends to do that?

Members indicated agreement.

The Convener: That will give us an idea of whether Sir Lewis Ritchie's review is being attended to by the health board.

Mental Health Treatment (Consent) (PE1627)

The Convener: The next petition is PE1627 by Annette McKenzie. At our meeting on 29 March, we discussed a suggestion that was made by the petitioner to introduce the use of written consent forms for young people who have been prescribed antidepressants, and asked the Minister for Mental Health for her view on the suggestion. The minister is of the view that the introduction of written consent forms would undermine the whole concept of capacity and confidentiality, and could be considered discriminatory towards young people as well as creating inequity between mental and physical health.

Members will recall that, at our meeting in March, we reflected on the outcome of a survey that was conducted by the Scottish Association for Mental Health in 2014, which found that general practitioners would like more information about non-pharmaceutical treatment options for common mental health problems and that almost half of general practitioners are not aware of, or not sure if they are aware of, the Scottish intercollegiate guidelines network's guideline on non-pharmaceutical treatments for depression. We therefore asked the Minister for Mental Health to reflect on the findings of this survey and how it intends to promote the SIGN guidelines to all GP practices in Scotland.

In her written submission, the minister states that the Scottish Government is currently working with the Royal College of General Practitioners, the Royal College of Psychiatrists and the British Medical Association to provide information for GPs on training and guidance on non-pharmaceutical treatment options for common mental health problems and to promote the relevant SIGN guidelines. That information is expected to be sent to GPs by the end of June.

At our meeting in March, we agreed to ask for information about the work of the youth commission, led by Young Scot, to explore the potential for people aged 18 to 25 to continue their care within child and adolescent mental health services. We also agreed to ask Healthcare Improvement Scotland about its work to improve child and adolescent mental health services redesign with individual NHS boards. Responses have been received and that information is set out in our meeting papers.

Members will recall that we also considered the petition in private on 10 May to reflect on all the evidence that we have received to date.

Do members have any comments?

Brian Whittle: It is fair to say that this petition has exercised this committee probably more than most and has affected us more than most. It is a hugely important petition and we have recognised all along the tension around confidentiality and the need to explore the issues of somebody presenting with mental health issues and their capacity to administer medication, especially if they are under 18. It is something that I have wrestled with a lot. I indicated to you before that in the Health and Sport Committee we have been doing some work around this as well.

The issue opens up a whole can of worms for me. It would be interesting to hold some sort of inquiry and ask young people how they access mental health services and what they feel mental health services should look like. On Monday, I happened to be with a group of people who had

poor mental health. The meeting was eye opening with regard to their understanding of what mental health services should look like and their various experiences with GPs and mental health services. Hearing from such groups would hugely benefit this Parliament's understanding of how mental health services are currently being accessed. I suggest that we think about holding an inquiry into access to mental health services.

10:00

The Convener: I was disappointed in the minister's response on the question of written consent, because it is not a question of discrimination. The fact is that we are wrestling with a dilemma and a major problem. There is an issue about being confident. My understanding of best practice is that you do not offer medication in the first instance unless there is a crisis. The default position is that you would look to other therapies first. I am interested in establishing—perhaps through an inquiry—whether GPs are under such pressure that they do not have the time to go through that process and they perhaps end up feeling the need to prescribe rather than do anything else.

I also think that a person with a physical condition would routinely be told, "Make sure you get support from home." If you have had a terrible diagnosis of cancer, presumably you would be encouraged to tell your family, but somehow there seems to be an inhibition to give that advice in relation to mental health. We are almost tipping the approach in the other direction.

I think that everybody is aware of how serious this issue is for families and of the impact that it has when there are tragic circumstances involved. Perhaps it would be interesting to ensure that young people themselves are part of that conversation.

Rona Mackay: I totally agree. It is a significant and complex issue. I find the system hard to understand when trying to help constituents or families who come to me with problems. It is difficult to navigate the system and signpost people in the right direction. I think that an inquiry that could ensure that those issues are discussed, with the involvement of young people, is necessary. The process for helping young people with mental health issues is not easy.

Rachael Hamilton: I see that the commission intends to report the findings to the minister and the Scottish Government in March 2019. That is a long time to wait, because there are people out there at the moment who need treatment. If there is any way of speeding up the process, that would be fantastic. Why does it have to take so long?

Currently there are complicated pathways to receiving the right treatment. The point about helping our constituents is key because GPs currently use the CAMHS service. Are they using that to the best effect? This is a really important subject and if we could do anything to speed it up I would be behind that.

Brian Whittle: I mentioned the understanding that the point of change between CAMHS and adult services is a major issue. The petitioner's daughter sat in the age group that is affected by that change. As part of what we do, I would like us to consider how the system delivers the change from childhood treatment to adult treatment.

The Convener: That is one of the things that the commission is considering. I suggest that we agree to hold an inquiry into how young people can access mental health services and treatments, that we ask the clerks to produce a paper on what that inquiry might look like and what the timescales for that would be, and that we do the scoping work on that in private at a future meeting. Do members agree to that approach?

Members indicated agreement.

Child Welfare Hearings (PE1631)

The Convener: The next petition is PE1631, by Maureen McVey, on child welfare hearings. At our last consideration of this petition, in March, we considered a suggestion that was made by the petitioner to use fixed specialised family law courts for child welfare hearings and we sought the Scottish Government's view on that suggestion.

The Government highlights that the Lord President has the powers to determine that family cases be heard by specialist family sheriffs, but advises that a number of matters would need to be considered before making that decision, as outlined in our meeting papers. In her written submission, the petitioner asks whether there are criteria for the Lord President to determine when and in what child contact cases that happens.

Members will recall that, at our last consideration of the petition, we also considered a recommendation that was made to the Scottish Civil Justice Council, based on independent research that it had commissioned, to use note sheets to ensure that information flowed between sheriffs in situations in situations where scheduling meant that the same sheriff was not able to remain with the case. We therefore agreed to write to charities providing advocacy and support to children for their views on the current practice of recording discussions at child welfare hearings.

The Scottish Child Law Centre is supportive of the idea of note sheets, stating that they would improve the quality of decision making and

promote and safeguard the best interests of the child. However, it also highlights that note sheets should be used only to facilitate information flow between sheriffs and should not compromise judicial impartiality.

With regard to striking an appropriate balance that ensures that the recording of discussions at child welfare hearings does not make the process overly burdensome, the Scottish Child Law Centre suggests that it would improve the child welfare hearing process if sheriffs provided a written account of the basis on which they made their decision in the child welfare hearing in the form of a child welfare hearing decision note. The petitioner is supportive of this suggestion.

Members may also wish to note that there are currently two consultations underway relevant to this petition. The first is a consultation by the Scottish Civil Justice Council on a report by a subcommittee on case management of family actions. The second is a consultation by the Scottish Government on a review of part 1 of the Children (Scotland) Act 1995. Both consultations close in August 2018.

Do members have any comments on what we should now do with this petition?

Rona Mackay: I do not think that we should defer it until the close of the consultation by the Scottish Civil Justice Council because I think that there are things that we could do now. I would like to see some positive outcome from this petition as soon as possible.

We need some detail from the Lord President's office on the criteria for the decision around whether a case is heard in a family court. We need more detail around what is used to determine that and around child contact.

The Scottish Law Centre's support for child welfare hearing notes was interesting. That could be a positive development, so we should ask the Government to respond to that.

Brian Whittle: I agree.

The Convener: I thought that the idea that having a note of a discussion somehow inhibits judicial impartiality later was odd. In any walk of life, you have a set of notes about a case and you follow it through. The point in the original petition was that people should not have to keep re-telling the story and that there should not be a misrepresentation of what was discussed previously.

Rachael Hamilton: That is why it is taking such a long time to get through some of these cases.

The Convener: Yes. Do we agree to ask the Scottish Government to respond to the issues around how the Lord President's office determines

what family cases are heard in family courts, and the suggestion about child welfare hearing decision notes?

Members indicated agreement.

The Convener: I suspend the meeting briefly before we consider the next petition.

10:08

Meeting suspended.

10:10

On resuming—

New Petitions

Myalgic Encephalomyelitis (Treatment) (PE1690)

The Convener: Under the next agenda item, the first new petition for consideration is PE1690, by Emma Shorter, on behalf of #MEAction Scotland. I welcome to the table Ben Macpherson MSP and Mark Ruskell MSP. Alex Rowley MSP has also expressed an interest in the issues that are highlighted in the petition, which a constituent highlighted to him, and he has indicated that he will be interested in following the committee's deliberations.

We will take evidence on the petition from Emma Shorter and her mother, Janet Sylvester, who are volunteers with #MEAction Scotland. Professor Chris Ponting, who is chair of medical bioinformatics at the University of Edinburgh and deputy chair of the UK CFS/ME research collaborative, is also attending. I welcome you all and thank you for attending the meeting. You have the opportunity to make a brief opening statement of up to five minutes after which the committee will ask a few questions in order to help to inform our consideration of the petition.

Emma Shorter: I thank the committee for the opportunity to give evidence. I really appreciate it.

If I have difficulty speaking or trouble with comprehension or anything like that, I will deteriorate until I have trouble moving or speaking. Therefore, I have organised a time-out sign; my dad will then assist me to leave. I apologise. I am sure that Chris Ponting and Janet Sylvester will be able to answer any questions.

Our petition is about myalgic encephalomyelitis in Scotland. There are more than 20,000 people with that disease in Scotland. It turns fit and active people into ghosts. Activity for a person becomes not running and climbing, but trying to wash their hair or make a cup of tea. I know teachers who cannot teach, children who cannot play and parents who can no longer hold their children because of it. Some patients are too ill to move or to speak at all. I have a friend who has been bed-bound for over 25 years.

I got ME over five years ago when I was in my first year at the University of St Andrews. I went from hill walking and playing hockey to struggling to move my hand to lift a glass of water. I was lucky in that I was diagnosed quickly and saw a doctor who told me that he was one of the most knowledgeable doctors in Scotland. There had been recent evidence that cognitive behavioural

therapy and graded exercise therapy could help ME patients to recover. A new clinic had just opened in Edinburgh, and I was referred there right away.

The doctor said that most patients get better in two years and that the ones who do not take the illness on as part of their personalities. My parents and I could not look up anything on the internet, join any support groups or meet any patients because that could have maintained the disease.

I started at the clinic, and it started off really helpfully. There was meditation and rest. That turned into my being told, "If you're happy, you won't get better. You have to focus on nutrition and sleep, but you can't focus too much on them, or you won't get better. All the symptoms are a manifestation of your emotions, and you have to trust the therapist over your own body." I had to walk, and the walking had to increase by 10 per cent each week. As I began to get sicker, I was told, "This is the moment when you push through and get better."

10:15

When I started the clinic, I was able to walk for about four minutes each day; when I ended, I needed a wheelchair. I went back to my physiotherapist and my doctor, and they said, "Congratulations. We're so glad we helped you recover. There is no other treatment." I said, "I appreciate your help, but I have deteriorated during the treatment." My consultant's response was, "Well, did you ever think that you just didn't try hard enough?" He referred me back to the clinic.

There is objective evidence of abnormalities in ME patients from their immune, nervous, endocrine and—crucially—metabolic energy systems. Some researchers use exercise as a way to aggravate symptoms in order to study the disease. It is so distinct that it was recommended that it be named systemic exertion intolerance disease. CBT/GET remains the only recommended treatment for patients in Scotland. That is why we are here to ask for the therapies that I have mentioned to be removed—but we are also asking for more. We are asking for care, as there is only one specialist ME nurse in Fife. If ME patients are given appropriate advice and diagnosis, that may stop deterioration and give us the best chance of improvement. We are asking for the education of healthcare professionals, because becoming unwell is compounded by the disbelief and dismissiveness that we face from doctors. It is unfair to expect them to treat us without up-to-date training.

The urgency of that can be seen in the treatment of children. In a United Kingdom survey

last year, a fifth of respondents reported child protection referrals being made against them. ME is the main cause of long-term sickness absence from school but, because healthcare professionals do not understand how children can remain so sick for so long, they start to blame the parents. That is why we need to review the curriculum and update training materials.

Finally, for some of us, there is no future without biomedical research. I know that the Scottish Government has recently provided £15,000 a year for three years. That is great, but I hope that it is just the start. ME research has been underfunded worldwide for decades, and we have in Scotland world-class researchers, such as Professor Ponting, who are willing to study us. If Scotland invests in biomedical research and creates a centre for ME, we will not only change the lives of patients in Scotland; we will lead the change internationally.

Thank you for seeing us today.

The Convener: Thank you very much for that statement. The first action that is identified in your petition summary is investment in biomedical research, and your background information adds that the funding should be proportional to the disease burden. We understand that the chief scientist office has announced funding of up to £90,000 over three years towards a PhD studentship in this area, to be led by Professor Ponting.

Do you consider that that level of investment is proportional to the disease burden?

Professor Chris Ponting (University of Edinburgh): I am very grateful indeed for the £15,000 a year that will be put forward for three years for the PhD studentship. The other half of the money will come from charity. It will allow us to perform our first experiments on ME. However, as Emma has said, there are over 20,000 people living with ME in Scotland. Therefore, the amount of funding works out at about £1 per person per year for three years. I do not think that that is proportionate.

For example, ME is at least as disabling a disease as multiple sclerosis but it receives, per person, less than 20 times the amount of funding that multiple sclerosis receives. As Emma has described, people with ME have a very low quality of life compared with anyone with another disease such as rheumatoid arthritis, cancer or even congestive heart failure. People who are most severely affected get the least care, the least attention and the least funding. That marks out ME as different from anything else.

The Convener: Do you have an explanation for why that is?

Professor Ponting: We do not know what the causes are. We need to find out. There is no funding because we do not yet have hypotheses. Without hypotheses, the funders are not persuaded of the argument.

Rona Mackay: The health minister has been contacted on this issue. Was the creation of a centre of excellence raised with her at that time?

Janet Sylvester: I contacted the health minister on Emma's behalf. We did not raise the subject of a centre for excellence. We were talking then about specialist support for patients and the need for investment in research but not specifically about a centre for excellence.

Rona Mackay: If a centre of excellence was to happen, what would you like it to do?

Professor Ponting: We need to generate the hypotheses that will fire the starting gun on research. That means that we need to biobank people—their DNA and their biosamples. From that, we can determine the genetic contributions—we know that there are genetic contributions. It is a real genetic illness.

We need to have experimental medicine programmes, using the substantial enthusiasm of people with ME in Scotland to contribute to science. We need to be innovative in how we do the science, including using wearables, accelerometers and phones to allow us to measure how well or how poorly people are doing over the day.

Rona Mackay: Is it your impression that clinicians do not agree? Are there mixed opinions on diagnosis and on treatment? Is the general situation that there is no common framework or agreement on either diagnosis or treatment?

Emma Shorter: Recently, there was a meeting of international experts on care in America. They came up with an agreement on diagnosis and care and I think that they are planning to publish a paper later this year.

Rona Mackay: How can that be done without the appropriate research that you are talking about? How can it be agreed when so much is still to be learned—and should have been learned by now, in my opinion?

Janet Sylvester: They are looking at how best to support people with ME and to give them the treatment to deal with the disease, rather than anything approaching a cure for it.

Emma Shorter: They are looking at how to manage the disease.

Professor Ponting: There is an understanding of best practice in managing the disease, which is being led by the United States; we need to roll out that best practice in Scotland.

Brian Whittle: I thank Emma Shorter for bringing her petition to the Public Petitions Committee. You have provided references to a range of studies in the endnotes of the petition. You have also referred to the PACE trial, which is a pacing, graded activity, and cognitive behaviour therapy: a randomised evaluation trial. Given that one would expect research to inform training and education, can you outline what you see as the key considerations when undertaking research or evaluating studies?

Professor Ponting: I think that most people would now agree that the PACE trial does not demonstrate that there is benefit from the two treatments—CBT and graded exercise therapy—for the majority of people with ME.

That trial was not done blinded. It is very difficult to do a blinded trial—I understand that—but one must understand the limitations of an unblinded trial. The modest effects that were seen from that trial could have come about because of the unblinded nature of the trial—I am not saying that they did, but they could have.

Brian Whittle: The second point in your petition summary calls for a review to ensure that

“healthcare professionals’ training and education materials reflect the latest scientific evidence”.

Can you expand on that? For example, are you aware of international evidence that has not been considered or acknowledged within Scotland?

Emma Shorter: I am not sure. Do you mean in relation to care—the management of the disease—or in relation to research?

Brian Whittle: Probably both. You state that the care of those with ME is not adequate. We are also hearing that research is very much in its infancy.

Emma Shorter: Yes. For example, Dr VanNess from the University of the Pacific has shown that there is an abnormally early transition to anaerobic metabolism. He has worked out a system of heart rate monitoring, which gives us a best practice system to try to stay within our energy boundaries and not become more severely unwell. That is more recent research.

I brought along some of the biomedical research highlights. I think that Chris Ponting will be able to go into them in more detail. Although there is not that much research, there is some research that indicates ways in which we could be managing the disease. Does that answer your question?

Brian Whittle: I am interested in the idea of it impacting the anaerobic energy system and how that impacts on quality of life. Is the research suggesting that the early tapping into that

anaerobic energy system is what is detracting from your own ability to move?

Professor Ponting: There is evidence of metabolic dysfunction involving the mitochondrion, for example. These are observational studies. They do not say that that is a direct cause of the disease; it could be a consequence. We need to understand that it could be one or the other. We do not know yet.

I think that the most impressive research, which is yet to be published, shows that ME has an immune signature. Mark Davis at Stanford University and others have demonstrated that they can distinguish between healthy controls and people with ME by looking at their T cells and their clonal expansion. To me, that means that there is an immune component to this disorder. We know that there are many ways in which immune dysfunction can affect overall wellness and energy levels.

Brian Whittle: The endocrine system was mentioned earlier. Is it fair to say that you think that the endocrine system is being attacked as well?

Professor Ponting: I base what I say on strong evidence; I do not think that we have that evidence to date but I would be very happy to see it if there was any. We do not know enough yet.

10:30

Rachael Hamilton: Good morning, everyone. Emma Shorter spoke about the education of healthcare professionals. In the background information, it is stated:

“Care is the responsibility of GPs, who do not receive training into how best to diagnose and treat ME, and have often been badly misinformed about the disease.”

That seems to have been reflected in evidence that was given to the Health and Sport Committee in November 2017, when that committee was told that a majority of GPs were not aware of the “Scottish Good Practice Statement on ME-CFS”. What are your thoughts on that?

Emma Shorter: Are you asking for my thoughts on how bad that is?

Rachael Hamilton: I am asking for your thoughts on the fact that

“Care is the responsibility of GPs, who do not receive training into how best to diagnose and treat ME”,

and the fact that the Health and Sport Committee found that GPs were not aware of the Scottish good practice statement on the condition.

Janet Sylvester: I am not sure whether you are asking for Emma’s personal experience or people’s experience in general.

Rachael Hamilton: I would like to open it up.

Janet Sylvester: I know that, anecdotally—I have been to appointments with Emma and have heard from many other people with ME—doctors are simply not aware of the best way of supporting people with ME. Indeed, many of them still believe that it is a psychological illness and that it does not have a physical basis to it.

According to the Action for ME study, only 30 per cent of GPs said that they were aware of the Scottish good practice statement, and only half of those said that they used it. That shows how little used it is. There is a real issue, not only with GPs but with other healthcare professionals, in their understanding of the disease and the way in which they can best support people.

Professor Ponting: A doctor whom I talked to last week, who was educated in Scotland, told me that his training involved 15 minutes of ME training, as opposed to two days of training on multiple sclerosis.

Rachael Hamilton: Are you recommending that the issue should be given further consideration? I presume that that is what you are backing, but how do you think that we should go about that?

Janet Sylvester: We are still working on what the best thing to do is. At the moment, we would ask the Scottish Government to ask the royal colleges of medicine to review how ME is dealt with in the curricula, and we would like NHS Education for Scotland, the specialist health board, to explain the results of a recent review that it had carried out into the materials on adult ME and to describe its approach to ME, which is slightly different from the approach that we would like it to take.

Rachael Hamilton: Is it your ultimate objective to raise awareness among GPs of the Scottish good practice statement so that they use it, and to raise awareness of the condition more generally?

Janet Sylvester: Yes, although there are separate issues with the Scottish good practice statement. As you are probably aware, most diseases have SIGN guidelines. When the needs assessment recommendations were made in 2010, it was not believed that there was enough evidence to support producing a SIGN guideline for ME.

We have not agreed this yet, but there might now be enough evidence to produce a SIGN guideline. The Scottish good practice statement on ME is extremely rare, but there are so few Scottish good practice statements out there that it is not surprising that health professionals have not heard of it. There is an issue with how GPs and other health professionals are made aware of diseases

like ME. ME needs to be much more on the front line.

Rachael Hamilton: The statement to which I referred was supported by a patient guide. Do you have any comments about that guide?

Emma Shorter: No.

Janet Sylvester: We could come back to you on that, if that would be useful.

The Convener: You mentioned SIGN guidelines. Our briefing refers to the NICE guideline, which is being updated and is due to be published in 2020. What are your views on the NICE guideline as it currently stands?

Emma Shorter: It is not fit for purpose.

The Convener: Are you aware of what engagement or information gathering NICE is undertaking to inform its updated guideline? You believe that the current guideline is not fit for purpose. Do you think that NICE is speaking to the right people about updating it? If so, have you had the opportunity to contribute to that process, for example, through consultation? According to our briefing, the Scottish Government has indicated that it does not intend to review the Scottish good practice statement until the updated NICE guideline has been published. What do you think about that?

Emma Shorter: NICE is consulting patient groups, including #MEAction. Because we are part of a UK-wide group, we have two volunteers who go along.

NICE's feedback to us was that we were listened to, but were we heard? NICE is allowing views to be aired, but will the guideline change? It is holding consultations, inviting comments and holding meetings with patients and healthcare professionals.

There are some concerns about the harm that the NICE guideline is doing in its current state. A number of charities, including #MEAction UK, are calling for CBT and GET to be removed as soon as possible before 2020.

The Convener: So you would argue that the Scottish good practice statement must be looked at while the NICE review process is in progress rather than at the end of it.

Emma Shorter: Yes. I think that we have the opportunity to change it now. We already have the evidence, so we have the chance to stop other people being harmed by it. I think that it should be changed as soon as possible.

Janet Sylvester: There is a precedent for that, in the sense that the Scottish good practice statement was produced just after the NICE guideline, but it is considered by many patients to

be better than the NICE guideline, because the recommendations in the NICE guideline were not taken as set. There was a much more effective review process than there was for the NICE guideline.

Rona Mackay: Emma, you spoke about graded exercise therapy and what that entailed. I want to ask you about cognitive behavioural therapy. Why is it harmful?

Emma Shorter: It is definitely not the case that all cognitive behavioural therapy is harmful. People with ME and anyone with a chronic long-term illness can benefit from psychological support. I think that the form of CBT that is harmful is called directive CBT. It is based on the idea that ME is caused by fear of exercise, and deconditioning. My personal view is that it is quite manipulative. I think that the use of CBT to support patients is fine, but CBT that is based on the idea that people with ME are afraid to do anything and that they need to be persuaded to exercise more can be harmful.

Rona Mackay: Is that what happens if you go to those sessions? Is that pretty much what you are told? Are people told that it is only in the mind that they do not like exercise?

Emma Shorter: It is not explicitly like that. The point is that the healthcare professional has to gain your trust that they believe that you are sick. I have had therapy that is supportive and is about managing the symptoms, whereas with the CBT, everything came back to something that I was doing and to blaming me for the disease.

Rona Mackay: That is not helpful.

Emma Shorter: No, it was not helpful. It made me think that I was going crazy, because what the therapist was saying and what I was experiencing were so different.

Rona Mackay: Do most patients get that?

Emma Shorter: Most patients in England get that. The provision in Scotland depends on the therapist. It is possible to get a therapist who is supportive or one who follows the approach that I have described.

Brian Whittle: Our briefing refers to the healthcare needs assessment of services for people living with ME-CFS that was undertaken by the Scottish public health network, which came up with 26 recommendations—I hope that you are familiar with them. Which of those recommendations do you consider to be priorities? Is there anything missing from that list of recommendations?

Janet Sylvester: To be honest, they all look like priorities for us, but we would need to look at the list in a bit more detail and come back to you on

that. As you can see, they cover a lot of what Emma has brought to the committee in her petition. Our question is: what happened? The recommendations have not been implemented. We do not know where the work that was done in 2010 went. Could we come back to you on what our priorities would be?

Brian Whittle: That would be extremely helpful. Thank you very much.

A concern that has been identified is that recommendations can be made but not get taken forward, as you have alluded to. How many of the recommendations that were made as part of the healthcare needs assessment have come into effect or are being actively progressed? I presume that you would like to come back to us on that; I just wanted to add that in, for the sake of completeness.

Janet Sylvester: Sure.

Rachael Hamilton: We had a briefing in this morning that talked about the use of CBT not being scientifically sound. Professor Ponting, could you comment on why that is the case and why the fact that CBT and GET are the only NHS recommended therapies for ME patients in Scotland

“implies that the Scottish Government supports the CBT Model of ME”?

Professor Ponting: This comes back to the question of the PACE trial, which was investigating the benefit or otherwise of CBT and GET on patients. It comes back to the question whether there was evidence of benefit for most people from that trial, and there was not. There appeared to be benefit for some. A reanalysis of that indicates that the effect was lower than initially published and, even then, that modest effect could have been—I am not saying it was—due to the unblinded nature of the trial. People knew whether they had one type of therapy or another. Because they were being told, as we have just heard, that particular therapies were effective, that influenced their reporting of the outcomes. That is what I am saying could have led to the impression of success for a trial, which then influenced the NICE guidelines, or the retention of the NICE guidelines.

The Convener: I am going to ask our colleagues who are not members of the Public Petitions Committee but who are here for this petition if they want to ask a question or make a comment.

Mark Ruskell (Mid Scotland and Fife) (Green): I want to ask Emma about the provision of specialist nursing services across Scotland. You mentioned Fife. Did you have access to that care and support when you initially contracted your condition in St Andrews? Is it the case that NHS

boards are reluctant to put in place specialist nursing support? Is that the best kind of support and care, or should it be mainstreamed in a different way?

Emma Shorter: I did not have access to it. I know that the Fife patients support the nurse. Could you repeat what else you said? I am sorry; I have forgotten.

Mark Ruskell: It is about the provision of that specialist nursing support. Is that a model that could and should be used by other NHS boards? Is that best practice, in other words?

Emma Shorter: Yes, I think that it would be fantastic if there was a specialist nurse in every health board who could make home visits to severe ME patients. Again, it is about managing the illness early on in diagnosis for the best long-term outcome. I think that NHS boards are reluctant to invest in nurses, probably because they do not see ME as important.

Janet Sylvester: You are probably aware that the nurse in Fife is completely overwhelmed by the number of ME patients in Fife, so we are probably talking not about one specialist nurse per health board but about funding to provide more than one nurse or different types of services.

10:45

Mark Ruskell: I understand from my constituents in Fife that there is a waiting time of between 10 and 12 months to be seen by the specialist nurse. How do we go forward with this and how do we ensure that that specialist support is available across the whole of Scotland? Is that waiting time compatible with the Scottish good practice statement? My understanding is that that care pathway identifies four months as being an appropriate time to be seen, so if patients are waiting 10 to 12 months, that would suggest that specialist advice is not kicking in nearly as early as it needs to.

Emma Shorter: I know that I have already said this, but there definitely needs to be good management advice as soon as possible, for example within the four months suggested in the Scottish good practice statement. That is essential possibly to help to stop deterioration but definitely for long-term improvement. I think that the answer is probably more investment in nurses.

Professor Ponting: There is evidence that the prevalence is about one in 200 individuals. There are plenty of other disorders at that level of prevalence, so I suggest that whatever is currently in place for diseases of this severity at that level of prevalence be put in place very soon for this disorder.

Ben Macpherson (Edinburgh Northern and Leith) (SNP): I have been working with Janet Sylvester and Emma Shorter over the past two years to assist them as their constituency MSP. I have been struck not just by the leadership and courage that they have both shown as campaigners but by how widespread the campaign is in Scotland to take forward action on this disease and to overcome the stigma, discrimination and blame that Emma described. How important do you think it is that institutions such as the Scottish Parliament continue to focus more attention on ME in order to get past the stigma that there has been in the past, and to make sure that there are changes in investment, that attention is paid to healthcare provision and that there are advances in education about ME in our healthcare training systems?

Janet Sylvester: It is critically important. We have outlined the reasons why we desperately need help for people with ME in Scotland. It is clear that if the Scottish Parliament and the Scottish Government take action—we are not expecting the Scottish Parliament to do everything—other organisations will be encouraged to come in and provide support by funding research and so on. However, we need somebody to take a lead in Scotland. As the comments on Emma's petition showed clearly, this is a chance for the Scottish Government and the Scottish Parliament to take a lead by setting an example not just for Scotland but for the rest of the world. In effect, we would be saying, "Look, we have a long history of medical research and we are now going to take a lead in ME research, the education of healthcare professionals and support for patients."

Professor Ponting: Having attended a meeting in Geneva at the World Health Assembly, it is quite clear to me that many countries around the world have even worse support for individuals with ME than there is in this country and in the UK as a whole. Taking a lead would help internationally.

Ben Macpherson: I have one more question. As much as that is absolutely true in terms of giving more assistance to people with ME in Scotland now, with the film "Unrest" and the attention that it got at international film festivals, there seems to be a worldwide movement and mobilisation of those who are suffering from ME and those who know and care about ME to see action on this. I guess that I am trying to emphasise the pertinence of this issue not just for those who are suffering but as a health issue that is at the forefront of people's minds at the moment.

Professor Ponting: There is a window of opportunity but, as with all windows of opportunity,

they shut and people will forget these neglected people in time unless action is forthcoming.

The Convener: Thanks very much. I do not know whether there are any last points that you want to make before we conclude.

Emma Shorter: No, thank you.

The Convener: I found that very thought provoking and I thank you very much for your presentation. Do members have any comments on how they might to take the petition forward?

Brian Whittle: I thank the petitioners for giving us evidence today. Two things jump out at me. Obviously, I think that there is a lack of research, and research is required. There seems to be a feeling that we are talking here about attacks on the energy systems and on the endocrine system, but a biomedical approach is not happening at the moment. That is something that I want to explore.

What is worse for me is knowing that there are NICE guidelines and SIGN guidelines available. We have heard before how information is not being disseminated to the front line and we are not arming our healthcare professionals with enough knowledge of how to tackle conditions. This is one of those conditions. Until not that long ago, ME was branded as a sort of yuppie flu. We have all had casework that has moved us, which is why I am particularly glad that this petition is here. I wonder whether, in the first instance, we should write to the Government to seek its views on the actions that the petition calls for: an increase in research and the dissemination of information to healthcare professionals about the NICE guidelines.

The Convener: Specifically on the NICE guidelines, we should ask how, if it consults, it does so and whether there are things that it could do on good practice currently instead of waiting until the end of the process. Is there anything else?

Rona Mackay: I was struck by the evidence and I thank the petitioners for lodging this important petition—I am sure that the 21,000 other ME sufferers thank them as well. The thing that strikes me is that this is not a new condition and, despite all the guidelines and initiatives that have been set up, they have not worked and nothing has changed. It is just not acceptable that nothing has changed. I hope that the petition will kick-start some action from the Government and from the medical establishment. As my colleague said, we need to write to the Government to seek its views on the action that is being called for, and we need to write to a wide range of other stakeholders for their views. This has to be the start of something that makes a difference, because the petitioners have been denied that so far.

Rachael Hamilton: It seems to me that Fife is blazing a trail on this one, but I had the feeling that the funding was probably the result of fundraising—I do not know whether I am right about that. I would like to know what all the NHS boards are currently doing and what position we are in, so that we can get some sort of consistency in our understanding rather having than anecdotal evidence.

The Convener: We want to write to the Scottish Government for its views. I agree that we also want to write to health boards to ask what the provision is across the country. I am interested in the clinical view on treatment that the petitioner is arguing is harmful. What is the medical view on that? We would obviously want to write to the organisations that are closest to this, such as Action for ME. We have also been told about ME Research UK and the Scottish public health network. We can reflect with the clerks on whether there are other groups that would be worth us speaking to. If you are aware professionally of any local groups that it would be worth our while seeking submissions from, we can do that. Obviously, anybody who is interested in this field can also submit on our petitions page as well. I do not know whether there are any other suggestions. That seems to be quite a lot to be going on with.

Members indicated agreement.

The Convener: There is quite a substantial piece of work to be done. Thank you very much for your attendance and for providing such thought provoking evidence. I suspend the meeting briefly to allow the witnesses to leave the table.

10:55

Meeting suspended.

10:56

On resuming—

Access to Justice (PE1695)

The Convener: The next petition for consideration is PE1695, by Ben and Evelyn Mundell, on access to justice in Scotland. I welcome David Stewart MSP to the table for this item. This new petition was lodged without signatures or comments being collected.

The petition calls for action to be taken to ensure that people are able to access justice, including access to legal advice from appropriately trained lawyers, and financial support through legal aid. The petition asks for those to be available so that people in Scotland can pursue cases where they consider that a human rights breach has occurred.

Members will note that the background information provided for us highlights that Mr and Mrs Mundell have previously petitioned the Parliament in relation to issues arising from European Union milk quotas and related ring-fencing policies.

While the background information to the petition sets out some detail on that issue, the focus is on accessing legal advice. The petition contends that specific issues that people may face in accessing such advice include that the Law Society of Scotland's list of firms undertaking human rights cases is out of date, there is a lack of lawyers in Scotland who are willing to take on human rights cases and that the law firms that are willing to take on human rights work will do so only if paid large sums up front and will not consider such work on a legal aid basis.

Edward Mountain MSP has provided some comments on the petition and I will read them out.

"I was approached by two constituents Ben and Evelyn Mundell (as I have a background in farming I would like to refer the Committee and the Convener to my register of interests) regarding this.

The situation was that the Scottish Government took action to protect the milk industry in their area by ring-fencing their milk quota to the locale. This ensured the local milk processor stayed in business, but prevented normal trade. (The ability to lease or sell milk quota that was open to farmers in other parts of Scotland and the UK).

Mr and Mrs Mundell also believe their business was destroyed, as the processor could offer a low price for their milk knowing the quota could not be traded. The Government did consult on the "ring fencing" before it was implemented but failed to consult with individual producers who legally owned the quota and, furthermore, they took an inconsistent approach to Kintyre than they did across the rest of Scotland.

Mr and Mrs Mundell feel that their human rights have been compromised.

The issue is that due to the fact that legal advice, using legal aid, is not available for human rights violations and they cannot afford the massive costs involved thus they cannot challenge the Government's actions.

The petition, based on their experiences, is to widen legal aid to include human rights violations, which I support when the actions that caused this are undertaken by a Government.

I would ask the Committee to consider this further and perhaps write to the Government requesting comment on this potential human rights issue."

I will bring in David Stewart to indicate his involvement, then we can reflect on what we have heard.

11:00

David Stewart (Highlands and Islands) (Lab): Thank you very much, convener. I thank the committee for allowing me to support the petition from the Mundell family. I will provide a little bit of

background. I have been involved with the family for several years and I would like to thank previous MSPs who supported the family, not least Jamie McGrigor and Peter Peacock. Obviously, I also thank Edward Mountain for his work. As you know, the Mundell family is in the gallery.

This is a highly complicated case, but it is well summarised in the accompanying papers, which you have outlined. On the surface it is about the ring fencing of dairy farmers' milk quotas, particularly, but not exclusively, within the Southern Isles ring-fenced areas. The fundamental question is how an ordinary Scottish family on a modest income can seek redress and remedy for potential breaches of the European convention on human rights, and justice in general.

The simple answer is that they should seek legal representation through the civil legal aid scheme. The family has been in touch with more than 50 lawyers, either in person or by phone, and the vast majority will not deal with human rights cases. Those who will have said that they will deal only with prisoners or people who have an immigration issue.

One lawyer who agreed to take the case wanted £25,000 in up-front payment before proceeding. That sum represents double the family's disposable yearly income. Mr and Mrs Mundell met me in Parliament yesterday. They told me that many farmers in the ring-fenced areas were placed in an impossible situation with a milk price below the cost of production. That has led to the forfeit of their property—as outlined in the papers, that is a breach of article 1 protocol 1 of the European convention on human rights. Farmers have had no money to pay interest on their overdraft and have had to incinerate perfectly healthy cows at less than £500 per head. They have had no money to diversify, suffered severe stress and, in some cases, lost their home and business.

This is not about just one family—much as the Mundells are in a terribly tragic position—it is about how you right a wrong. Surely the test of any advanced democratic society is how easily and transparently you can seek legal redress at the highest level.

I will summarise three suggestions, convener. Obviously, what action the committee takes is its decision not mine, but I certainly suggest, as I think the clerk's note recommends, writing to the Scottish Government and the Law Society of Scotland to seek views on the actions called for in the petition. That seems fairly sensible.

Also, and perhaps unusually, the petition could be referred to the Equalities and Human Rights Committee so that the petitioners could provide

evidence to it, because, as you know, that committee is carrying out an inquiry on this subject.

For information only, it would probably be useful to pass the petition to the First Minister's Advisory Group on Human Rights Leadership since it is looking at that as we speak.

Finally, I thank the committee for listening to my representations. I appreciate that the issue is very complicated, but I stress that the key issue is access to human rights legal advice at a very senior level for families who have limited funding. That is the key, and I agree with Edward Mountain's point: I think that there has been a fundamental miscarriage of justice, which has in effect almost run this family into bankruptcy, along with many other farmers in the area.

The Convener: Thank you; that is very helpful. The committee has a dilemma. Given that the Equalities and Human Rights Committee is taking evidence on the subject, we could refer the petition, but if we did that, we would not then be able to take any other action. It may be that we need to think about that. I am interested in other members' comments on what we can do.

Rachael Hamilton: On that point, convener, is it permissible for the family to give evidence to that committee?

The Convener: The thing is that, as I am being informed, the evidence is now closed and the committee is considering its draft report in private today. It may be that, once we see that report, it might inform some of the action around the petition, but we will not be able to do that in the round.

Brian Whittle: This is a very good example and it does seem to highlight a gap in the law. It is my understanding that the Law Society of Scotland is reviewing its legal aid rules. I agree with writing to the Scottish Government and the Law Society of Scotland to seek their views on the actions that are called for in the petition, because I think that there is already work being done on this and, if nothing else, it may help to inform that review.

Rona Mackay: I agree with that. As a first step, we should write to the Government and the Law Society, highlighting the petition and asking for their take on it.

The Convener: We will take a note of what the report from the Equalities and Human Rights Committee says on the question.

The petition says explicitly that lawyers will not take these cases unless they are paid up front. I wonder whether we could ask the Law Society whether there are examples of good practice where people do not do that, whether that is what everybody does, whether that is what almost

everybody does, or what the balance is. That would be worth while knowing.

David Stewart: That is a good point, convener. There is a great deal of human rights expertise among the legal profession in Scotland; I am not disputing that in any way. The issue is bringing together that expertise and the provision of legal aid—that is extremely difficult. As I stressed earlier, the family went to around 50 lawyers and I gave them a very helpful Scottish Parliament information centre paper, so they went into this with their eyes open. It is extremely difficult to access justice at a high level when you are on a relatively modest income. That is the real dilemma. Anything that the Law Society could do to facilitate such access would be very useful.

The Convener: Has the Scottish Human Rights Commission done anything around this?

David Stewart: That is certainly an organisation with lots of expertise and, if the committee wanted to refer the matter to it, I would welcome that.

The Convener: It would be interesting to know what its view was.

Rona Mackay: It would, indeed, be interesting.

Rachael Hamilton: David Stewart also made the point that he wanted to ask the First Minister's advisory group on human rights leadership about this. I wonder whether we should write to it, too.

The Convener: We can flag up the issue and see whether we get a response from that group.

We recognise the strength of the representations from both Edward Mountain and David Stewart. We certainly want to explore the extent to which this is a gap in the system for people who feel that their human rights have been violated, as well as what support we have for the enforcement of people's access to human rights and justice in that regard. The petition will return to the committee. We will keep the petitioners informed of what submissions we receive and they will be able to provide a further submission once we have heard those responses.

I thank David Stewart for his attendance.

David Stewart: I thank you and the committee members for listening to me.

The Convener: I thank the petitioners for their petition. We will look at it further.

11:07

Meeting continued in private until 11:24.

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