OFFICIAL REPORT
AITHISG OIFIGEIL

Public Petitions Committee

Thursday 7 February 2019

The Scottish Parliament
Pàrlamaid na h-Alba

Session 5

Thursday 7 February 2019

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PUBLIC PETITIONS COMMITTEE

3rd Meeting 2019, Session 5

CONVENER

*Johann Lamont (Glasgow) (Lab)

DEPUTY CONVENER

*Angus MacDonald (Falkirk East) (SNP)

COMMITTEE MEMBERS

*Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con)
*David Torrance (Kirkcaldy) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

James MacLachlan (West of Scotland ILD Support Group)
Elaine Smith (Central Scotland) (Lab)
Jean Watson (West of Scotland ILD Support Group)

CLERK TO THE COMMITTEE

Sarah Robertson

LOCATION

The Robert Burns Room (CR1)

Scottish Parliament

Public Petitions Committee

Thursday 7 February 2019

[The Convener opened the meeting at 09:45]

Decision on Taking Business in Private

The Convener (Johann Lamont): I welcome everyone to the third meeting in 2019 of the Public Petitions Committee.

Agenda item 1 is to decide whether to take in private agenda item 4, which relates to our work programme. Do members agree to do so?

Members *indicated agreement.*

New Petitions

Interstitial Lung Disease and Home Management (PE1714)

09:45

The Convener: Agenda item 2 is consideration of new petitions. The first new petition is PE1714, by James MacLachlan, Jean Watson and Ivy Dodds, on interstitial lung disease and home management. The petition calls on the Scottish Government to provide funding to help to raise awareness of the condition and the development of a cohesive national policy for home management.

We have apologies from Jackson Carlaw MSP, who expressed an interest in the petition. He will attend to our conversations and discussions about it.

We will take evidence from two of the petitioners: James MacLachlan and Jean Watson. I welcome you to the meeting and invite you to provide a brief opening statement of no more than five minutes between you. After that, we will move to questions from the committee to assist our understanding of the condition and to be clear about the action that you have called for in your petition.

James MacLachlan (West of Scotland ILD Support Group): I thank you for the opportunity to expand on the issues that are raised in the petition, which aims to raise awareness of interstitial lung disease and home management.

Jean Watson, Ivy Dodds and I are all sufferers of ILD, and we are members of the west of Scotland ILD support group. Unfortunately, Ivy Dodds was unable to travel to the meeting because of health difficulties.

The thrust of the petition is that the Government should provide funding for the issues that are raised in the petition. I will not go over them, as members seem to be aware of them.

We find that one of the main problems is that there seems to be a complete lack of awareness of interstitial lung disease. In particular, the petition highlights the statistics for people who have sought their first appointment with a general practitioner. The delay of perhaps up to two or three years for a person’s first appointment is completely unacceptable and we think that the Government and others must address that by increasing public awareness.

As members can see from my nasal cannula, I am a sufferer of ILD. In hindsight, I should have visited my GP some two years before I did. That delay was down to the fact that I, like most people, was completely unaware of ILD and its effects. I put my increasing breathlessness down to age and asthma, which I was diagnosed as having some eight years prior to my ILD diagnosis. I still take asthma medication, so there was no possibility of any bad diagnosis there.

Another major problem is in the delay in ILD diagnosis. By its nature, ILD mimics many other diseases and ailments. It has no known cause—except, unfortunately, in a few industrial cases involving miners, for example—and there is no known trigger to start it.

A delay in diagnosis may be remedied by the particulars that are set out in the petition. When people go to their doctor, they should automatically get a chest examination if they are over the age of 60 or around that age, even if they have gone in with a sore toe. It takes only two minutes to lift up a person's shirt and do a chest examination. That will help to diagnose ILD and many other respiratory diseases.

Other illnesses and diseases, such as lung cancer and other cancers, presently have or have had well-funded awareness programmes. Surely such programmes for ILD and similar respiratory diseases are well within the scope of Government funding, and whatever they can come up with should be implemented. That would increase public awareness and highlight that a quality of life is expected after diagnosis. It would also bring ILD out of the shadows and increase public awareness and public acceptance of what it is. We sometimes find, not that the public avoid us, but that they find it difficult to accept that we do not have a deadly illness. If I take off my nasal cannula, I hope that I look the picture of health, but I am not. That is what we have to overcome. It should never be overlooked that ILD and idiopathic pulmonary fibrosis are insidious, incurable diseases that bring debilitating breathlessness, as you can hear.

The petition highlights the benefits of home management and says how it should be provided. Again, that is within the scope of the powers of the Government and local authorities. The provision of pulmonary rehabilitation is a mainstay with regard to maintaining the quality of life of sufferers. It gets us out and about and it keeps us mobile. The petition highlights other home management necessities—there are so many that I have not got time to go through them all. We would have to write a book or talk for a few days if we started to list and discuss all the effects of ILD, from pre-diagnosis to post-diagnosis and on to living with the condition.

We understand that a national respiratory plan for Scotland has been proposed. We feel that any delay in its formation and implementation can only cause untold suffering throughout Scotland. We therefore urge the committee to consider the petition and, thereafter, urge the Government to act responsibly.

I will not say any more. Jean Watson has a lot to say.

Jean Watson (West of Scotland ILD Support Group): My circumstances have been very similar to Jim's. I was diagnosed with idiopathic pulmonary fibrosis two and a half years ago. I had always been told that my health problems were caused by allergies and stomach problems and, like a lot of people, I used standard medication for those. I retired from work four years ago, mainly due to a recurring cough and the fact that I was feeling increasingly tired throughout the working day. An exacerbation in my condition led to me being referred to hospital and I was eventually diagnosed with IPF. I had never heard of that illness, and none of my family had, either.

On joining the west of Scotland ILD support group, I met other patients who had the same condition. Talking with fellow patients has shown me that they have had very similar problems of late diagnosis, mainly due to a lack of awareness and understanding of their conditions. The symptoms that they display may be treated, but the underlying serious condition might not be identified. Most patients have other serious health problems in addition to ILD that are classed as co-morbidities and make treatment more complex.

Interstitial lung disease affects middle-aged and older people. We feel that many people put up with their health problems due to a lack of knowledge and the idea that they are just getting a bit older. The condition causes a debilitating loss of physical activity, leading to people being unable to care for themselves. The impact on their daily life is considerable. They have difficulties with the simple activities that are involved in looking after their house, and they can experience emotional problems and feelings of social isolation. As ILD is an incurable condition, we feel that there is a considerable need to raise awareness of it to assist earlier diagnosis and create a consistent approach to care throughout Scotland.

We are happy to answer any questions.

The Convener: Thanks for that presentation. I appreciate that, when an issue affects you directly, it can be even more difficult to lodge a petition about it. The case that you made is interesting. I had certainly not heard of the condition before, or the challenges that go with it.

You have said that the condition mimics others, and that people can assume that it is something else. You suggested that GPs could carry out chest examinations as a matter of routine. Are you aware of any countries where that happens? Even if they were to conduct a chest examination, do

GPs know what they should be listening for? Is that a problem?

James MacLachlan: I think that it is a problem. That is why the petition calls for funding for extra training for GPs so that they can diagnose ILD. It is a difficult disease to diagnose, because it mimics many other chest infections and various other things. ILD itself covers about 200 or 300 degrees of illnesses, and it is difficult for GPs to isolate and identify it. In order to diagnose it, there needs to be an X-ray and, thereafter, hospital care.

We need GPs to be more aware of it. I was very fortunate when I went to the doctor—he must have had patients with it before, because he recognised it right away. However, we know that other patients, and an awful lot of people in our group, have had terrible difficulties in getting diagnosed by their GPs. They are told, “it is a chest infection, take this” or, “it is a cough, take that.” However, a simple chest examination would highlight a lot of it. There is a distinct noise—

Jean Watson: There is a crackle.

James MacLachlan: ILD gives a distinct crackle when a chest is examined. That is all that is needed for the GP to say that they need to look at it further and do an x-ray and so on. Then you are in the system.

The Convener: The issue is about routine tests and also knowing what to listen for—the distinct crackle.

James MacLachlan: They have to know what to listen for.

Jean Watson: The sounds of an ordinary chest infection and a pulmonary fibrosis are different. There is a crackling sound with the latter; it is a different type of sound. It has to be examined. It is no good just to be told that you have a cough or a sore throat, which tends to be what you get treated for. Although that clears it up a wee bit, it never clears it up totally and it keeps building up. That will happen anyway, but the diagnosis means that you can receive the proper treatment earlier.

The Convener: Treatment is delayed because the condition is not recognised and people explain away their symptoms.

Jean Watson: If you do not know what pulmonary fibrosis is, you just think that you have a cough or a chesty wheeze all the time.

James MacLachlan: I cannot hear my chest crackle.

Rachael Hamilton (Ettrick, Roxburgh and Berwickshire) (Con): You have covered the point about awareness among GPs. It seems as though people go through a long stage of misdiagnosis.

James MacLachlan: I am not sure whether it is misdiagnosis. I was not diagnosed, as opposed to being misdiagnosed. The diagnosis is missing. If you do not mind me saying so, I think that there is a difference there.

Rachael Hamilton: Sure—I am glad that you clarified that point.

What is public awareness like? Are there resources and information out there for GPs? What examples do you have of awareness among the public?

Jean Watson: There are lots of websites on pulmonary fibrosis, but if you do not know that it exists, you will not look them up. If you tell the average person that you have been diagnosed with pulmonary fibrosis, they think that you will get tablets for it and that it will be okay. They do not really understand what the condition is, because we do not hear about it.

Rachael Hamilton: Can I clarify, Jim—sorry to call you Jim, but Jean Watson did.

James MacLachlan: That is okay.

Rachael Hamilton: You spoke about a delay of two to three years in seeking your first appointment, because you thought that it was your age and then, eventually, there was the asthma.

James MacLachlan: I had been diagnosed with asthma about six or seven years earlier, but I put my increasing breathlessness down to getting older and not being as active. The asthma treatment was working for the asthma side of it, but I was still getting increasingly breathless.

Rachael Hamilton: If the proposals in your petition had been successful and funding had been made available to resource an awareness campaign, would you have realised that you had the condition and highlighted it to your GP?

James MacLachlan: I would have. However, even before that stage was reached, I am absolutely certain that my wife would have said that my cough was getting worse and worse and that I should get to the doctor; even if I was saying that it was going away and that it was just the asthma and that I was getting older.

That is public awareness—public awareness leads to the doctor’s appointment, which leads to the doctor’s diagnosis. That is the sequence that we have to follow.

Rachael Hamilton: The flu jab has a public health awareness campaign behind it. Could there be merit in considering doing the checks when people over a certain age—say people who are over 65—go for something such as the flub jab?

Jean Watson: Yes, but the flu jag tends to go along with an age profile. If you are diagnosed with ILD, you get those pneumonia and flu vaccinations from your GP at a younger age than you normally would.

10:00

Rachael Hamilton: I am thinking along the lines of a preventative agenda.

Jean Watson: If you went for your flu jag, they could do a sounding—yes, that would only take a couple of minutes. It would be very simple.

Rachael Hamilton: Do GPs currently do checks?

Jean Watson: No, not when you go for your vaccinations. Usually, you book in for your vaccination and you go to a nurse; she just asks if you are feeling all right. You do not get any soundings—at least, I have not. I can speak only for myself.

James MacLachlan: For flu jags, you get an appointment at the GP surgery for Saturday between 10 and 12, for example, and you and 200 other people queue up to get your jags, so there is no possibility of any examination.

Rachael Hamilton: Should ILD and other conditions have parity with chronic obstructive pulmonary disease and asthma in relation to levels of public awareness?

Jean Watson: Yes.

James MacLachlan: Yes. There is not the slightest doubt about that. If you speak to the average person on the street, they know what lung cancer is, they know what COPD is and they know what asthma is. If I say I have ILD, people do not know what that is. They ask me if I have stopped smoking.

Jean Watson: I think the word "disease" tends to put in people's minds the idea that you catch ILD but you do not; it just develops in you.

Angus MacDonald (Falkirk East) (SNP): In your initial submission, you provided statistics from "The British Thoracic Society Interstitial Lung Disease Registry Programme Annual Report 2015/16" that showed the elapsed times from initial onset of breathlessness to presentation. For the record, the submission says:

> "46% waited over 2 years.
>
> 25% waited 1 to 2 years.
>
> 20% waited 6 to 12 months.
>
> 8% waited less than 6 months."

Are those the most recent figures? Do they relate to the whole of the United Kingdom? Have you estimated how many sufferers there are in Scotland?

Jean Watson: As far as the statistics go, we have not been able to find any that say how many sufferers there are in Scotland. There was something in the parliamentary written answers that I looked at. Joe FitzPatrick's written answer to question S5W-21025 from Colin Smyth was about the number of people with ILD who had received pulmonary rehabilitation. That written answer referred to a table in a different written answer, which I could not quite relate to the question because the table is headed:

> "Number of patients discharged from an acute hospital with a diagnosis of interstitial lung disease, by year ... 2014-18".—[*Written Answers*, 23 January 2019; S5W-20839.]

That does not relate to pulmonary rehabilitation, and it does not really reflect the number of people who are diagnosed either because, if someone has been discharged from hospital, that means that they have been an in-patient. I have never been an in-patient—I am only an out-patient. Lots of people, including me, are not included in any of the available statistics, and we have not found any other statistics that say how many people in Scotland have ILD.

James MacLachlan: We cannot find that information anywhere. One of the things that we ask for in the petition is for the people who keep those records to record the information better rather than just putting down "respiratory illness", "respiratory disease" and so on. It would be better if they could code it properly.

Jean Watson: The information is coded, but it tends to revolve around hospital admissions and hospital discharge. Most of us just attend the respiratory clinic although it is a chronic disease—we are on their books for ever, really. I have a three-monthly appointment, and I just keep turning up every three months for the tests and so on. However, I will not be in those statistics.

James MacLachlan: In reply to Angus MacDonald's question, the figures are for the whole of the UK. They are certainly not split between Scotland, Wales, Northern Ireland and England.

Angus MacDonald: If we continue the petition, we can request a better breakdown, if one is available.

Brian Whittle (South Scotland) (Con): Further to Rachael Hamilton's question, I am interested in the suggestion that people are delaying going to their GP. I presume that people understand that something is amiss, but I want to understand why they would delay going to their GP.

Jean Watson: Initially, I was X-rayed. That must have been about six years ago. You have one X-ray and, if it is not 100 per cent clear, you wait and get another one. At the end of that, I was told that things looked okay—my blood tests were okay, my cough would probably clear up, and I just had a breathing thing. I was told to take the allergy tablets and so on.

That went on for quite a number of years. Eventually, I had what is classed as an exacerbation—things became worse. It was like getting a chest infection. I went back again, and I was diagnosed at that point, but that was only because I said that I was there because of my breathing and that there was more to it than just a chesty cough. As well as seeing a specialist, you have to go through X-rays and a computerised tomography scan before you are diagnosed. GPs cannot diagnose; they refer.

The delay is because you are left with annoying symptoms that do not quite go away. They clear up a wee bit in good weather and get worse again in the winter. You are on cough bottles and various things, as everyone else is in the winter.

James MacLachlan: And the breathlessness increases.

Jean Watson: It gets worse.

James MacLachlan: It gets worse. If you are not active and doing something a wee bit more strenuous, you do not really know that you are getting breathless. If I take off my nasal cannula, I can sit all day as long as I do not move, but as soon as I start moving, I start to get breathless. Eventually, I was cutting the grass and found that I had to rest after each time I went up and down. My wife told me that I had to do something about it. That is when you realise that you have to do something. Until then, though, unless you are pushed to the limit, you do not really know that you are breathless. When you exert yourself, the breathlessness gets worse.

Brian Whittle: Thank you for clarifying that. When you talked about not going to the doctor’s, I thought that it was a man thing, but what you are saying is that the delay is in following up on the initial diagnosis. You go to the doctor’s, get some kind of diagnosis, and accept that diagnosis for a while before returning to the doctor to say that you feel that there is something more going on.

David Torrance (Kirkcaldy) (SNP): The information that is provided in your petition appears to suggest that home management principally comes from friends, family and charities. Can you expand on that?

Jean Watson: My husband and I work things out between us in the house. If I was on my own, I would find it very difficult to do very basic things about the house. I do not have oxygen—I just have tablets—but everybody eventually gets oxygen. If you have oxygen, you need help most of the time.

James MacLachlan: You do need help. If you have a family, you find that you are unable to do the share that you used to do. You just cannot do it. When you reach the oxygen stage, it is physically impossible to get showered or even get dressed. It takes you longer—you just do not have the energy, and you have to stop and take a rest. It is debilitating, and there is nothing you can do about it. You get fatigued and cannot function properly. It is just a fact of life.

Jean Watson: Although I do not have oxygen, I would say that most people at my level cannot do a lot of very basic things, such as changing a duvet cover. With simple things such as bending over to tie your shoelaces, you feel a bit dizzy and end up sitting down again. Very simple things become difficult. Although I can walk about on the level, stairs are practically impossible for me. I always look for lifts. If I am going anywhere, I plan a route that does not have a slope up the way, although I can cope with a slope down the way. Everywhere I go, I have to watch where I go and what route to take to get there and back.

James MacLachlan: I tend to wear slip-on shoes now, because I find it very difficult to bend to do things. I can hardly blow up the car tyres at the garage—I cannot bend down for long enough without getting fatigued. I have to get somebody to do it for me or buy some attachment to do it. I cannot work when I am bending down. It exacerbates the problem, and I cannot breathe or function.

David Torrance: In your petition, you say that there is not a uniform service from local authorities across Scotland. Do you have any examples of that? How much help do you get from local authorities?

James MacLachlan: I was at a course at which I spoke to and heard from a lot of people. It is evident that a postcode lottery operates to a certain extent for a lot of things—that is just a fact of life. Whether a person gets a stair lift easily—or at all—or whether they get things such as a new bathroom with grab handles and so on depends on what area of Scotland they are in. It depends very much on their local authority and on its funding. Let us face it: not all local authorities are funded well enough to do a lot of that. It all comes back to funding. We are asking for extra funds for all those things.

Brian Whittle: I presume that what you are discussing is the situation once you have a diagnosis and specific requirements. You mentioned stair lifts; I presume that the requirements also include walk-in showers and toilets, for example. You have said that the condition is not readily recognised as a long-term one. I presume that you would say that that exacerbates your difficulty in accessing the extra items that you need. What other items would you include in your requirements? Do you want to see those things included in the cohesive national management policy that you have said you would like to see established? I am sorry—that was a lot of questions.

James MacLachlan: If I approached the local authority for assistance of that sort, I would like to think that it would send somebody out to do an assessment of my house and say yes to some things or “No, you do not need that” or “We can do this,” but as far as I am aware nobody does house assessments for such cases. Perhaps if you ask for a stair lift, someone will consider that, but somebody should come out and do a proper assessment of your house, help you to make up your mind, and provide not just what you need today but what you will need tomorrow, the next day and following that.

Brian Whittle: Is that perhaps because, as you suggested before, the condition is not recognised so, when people approach local authorities, it is not in their books, so to speak?

Jean Watson: Because it is a breathing issue, it is not seen as being on a par with mobility issues. People do not relate the breathing difficulty to why you are not mobile. They do not understand that you cannot climb stairs and walk about because your breathing is not working. They think that you should be able to do that because your arms and legs work.

Brian Whittle: It is really just a lack of knowledge.

Jean Watson: Yes, I think that it is.

The Convener: You talked about extra training for GPs and the fundamental issue that, even if they are listening, they are not hearing. They do not know what they are listening for. Who should conduct that training? Have you had any discussions with bodies that represent GPs?

James MacLachlan: I have not.

Jean Watson: No. I suppose that respiratory specialists would deal with it. We are not medically informed enough to go into that depth.

James MacLachlan: We are just people who have the disease.

Jean Watson: It must be the respiratory specialists—the people who eventually identify the condition.

10:15

The Convener: Have any of the clinicians you have come across talked about the lack of awareness on the part of those making the referrals? Is the medical profession—at the level at which there is an understanding of the condition—aware that there is a disconnect?

Jean Watson: I have never heard anything said about that, and I have not asked about it. I have never spoken to a consultant in that way.

James MacLachlan: The condition was recognised by the doctor who dealt with me, who must have encountered it previously. Doctors must have experience of the disease before they can deal with it. There seems to be a special way of sounding the chest so that the crackle can be recognised. It is not just a quick case of the doctor saying, “Breathe in, breathe out.” It has to be done in a certain way. We do not think that all GPs are fully trained in how to do that.

The Convener: Joe FitzPatrick, who is the Minister for Public Health, Sport and Wellbeing, responded to Colin Smyth’s questions. My understanding is that the minister said that this is a matter for clinicians and health boards. I assume that you think that more central direction is needed and that it cannot simply be left to the health boards to decide how much of a priority they make the condition.

James MacLachlan: I have no idea how health boards operate or how the whole system operates. We just know that there seems to be a lack of awareness and that the condition does not seem to be being dealt with. Who makes the relevant laws and arrangements is beyond us; that is above my salary scale.

The Convener: Your point about keeping people at home makes sense for the health service—people managing their condition at home relieves health service resources.

Rachael Hamilton: I imagine that the prevalence rate of ILD would have to be compared with the prevalence rate of other conditions. There is competing demand across a number of conditions when it comes to awareness raising and prioritising those conditions, so it is important that the statistics are right. There is a lack of Scottish statistics.

Have you worked with the British Lung Foundation?

James MacLachlan: I have had contact with the British Lung Foundation. It sent out something with my picture on it telling its people that they should support the petition.

Rachael Hamilton: On the convener’s point about GPs, is there any merit in considering whether other healthcare professionals, such as practice nurses, could do the check? Jean Watson said that age was not relevant to the condition, whereas James MacLachlan said that he thought that he had it because of his old age. Could a check be carried out at the same time as the flu jab? That way, more people would be reached.

Jean Watson: That could be done, but there is a problem with restricting the approach to one that is based on age. Most people will have the condition long before they are diagnosed. Lots of people will have it before they are 60. I think that, in the past, it has been shoved to the side because it has been seen as an older person's condition—the view has been that it is just people's breathing going. If it were diagnosed sooner, it would not be seen in that way. It affects younger people.

James MacLachlan: As Jean Watson said, it is when you start to walk up a hill that you find out that you cannot do it. People do not walk up hills all the time. It is something that grows and grows; it is a slow burner.

Rachael Hamilton: If you had had the opportunity to go informally to another healthcare professional, such as a practice nurse, instead of making an appointment with a GP, would you have done that?

James MacLachlan: Yes, of course I would—on the assumption that she was qualified to do such an assessment.

The Convener: There is a lack of awareness of the condition and how it is experienced and treated. Is there an issue with people who have the condition not being given the relevant support by the social security system?

James MacLachlan: I am retired, so I cannot answer that.

Jean Watson: That is a difficult one. Everyone is different. I stopped work and just took my pension, so I did not think about that issue at all.

The condition affects younger people, too. I was surprised to learn that one member of the support group that we attend is 39 years old—she is the youngest member. I think that she still works. Even so, she is entitled to claim some benefits.

We are not that knowledgeable on the benefits side of the issue.

The Convener: The petition might have flagged up an issue that the system in general should better appreciate.

We have come to the end of our questions, so we will now discuss how to take the issue forward. Angus MacDonald asked whether it would be possible to get a breakdown of statistics, so we could pursue that.

Brian Whittle: Two things jump out at me. One is data gathering, which seems to be a theme that runs through a lot of the issues that we discuss in this committee. The other is GP knowledge. It strikes me that, if I was a GP who was regularly watching the Public Petitions Committee or the Health and Sport Committee evidence sessions, I would be hiding under my desk at the thought of the number of things that the committees are calling on me to be retrained in. We discussed retraining last week in relation to myalgic encephalomyelitis, we have discussed it previously in relation to Lyme disease and now we are doing so in relation to ILD. I wonder whether there is a need for a bigger piece of work. That might be an issue for the Health and Sport Committee rather than this committee. I am just putting that out there, convener.

The Convener: We could contact the Royal College of General Practitioners about that. Of course, given the amount of pressure that GPs are under, it strikes me that very few of them will be watching our proceedings. Also, if a GP does not know about a condition or how to identify it, the issue is not the GP but that there is a gap in the system, because the GP has not been informed about the condition.

I certainly think that we should seek the Scottish Government's views. Joe FitzPatrick's response that the issue is a matter for health boards and clinicians is not sufficient, if there is a lack of awareness about the condition.

Rachael Hamilton: We could ask NHS Education Scotland what awareness-raising information it makes available. I also wonder whether we should ask ISD what reporting it does on ILD.

The Convener: ISD?

Rachael Hamilton: The Information Services Division. It could provide the statistics.

The Convener: Yes.

Angus MacDonald: The national respiratory plan was mentioned earlier. Could we have clarification on its progress? Has it been completed?

The Convener: From what I have read, I do not think that it has been started. There is an intention to do something in that regard, but I do not think that the Government has got to the point of bringing people together with terms of reference. We could ask the Government about that.

Angus MacDonald: It would be good to get an update.

The Convener: We will contact interested stakeholders who might be able to add to our information. We will write to the Scottish Government to ask for its views on the prevalence of the condition, the awareness of the condition, training for the medical profession and support for people who have the condition. Another aspect is the extent to which this issue comes under the heading of preventative medicine—that is, if people are supported to manage their condition at home, they are less likely to have to go into hospital or whatever.

I think that that approach is a good start.

Rachael Hamilton: We should write to some of the charities that are involved.

The Convener: We can identify which ones those are—the obvious ones are Chest, Heart & Stroke Scotland, the British Thoracic Society and the British Lung Foundation. If the petitioners are aware of any others, they can let us know.

Brian Whittle: The issue of what would happen if a person with the condition approached a council was raised. We could write to the Convention of Scottish Local Authorities to find out how councils deal with the issue.

Rachael Hamilton: I agree. Home management has been mentioned, and there will need to be a balance between that and treatment in a national health service setting.

The Convener: A good starting point would be to contact COSLA to ask whether it is aware of the issue and whether there is any guidance on it.

There is quite a lot to be done, but the most critical action is to contact the Scottish Government, because we are asking it to think about appropriate training for and awareness among the profession, and asking what it is doing for people in communities who might have the condition. That will be significant.

When we receive responses, the petitioners will be informed and will be able to comment further before the matter comes back to the committee. They will be able to put their stamp and give their view on the responses that we receive, which will be immensely helpful for our consideration.

We recognise the importance and significance of the petition, which is partly to do with the fact that nobody knows about the condition, which in itself tells us something. As a consequence, things will be happening that will make it more difficult for people to live with the condition, and that will end up costing the system more money.

I thank the witnesses very much for their evidence, which we have found very useful. There is a lot of useful information for us to seek. As I said, once we receive that information, the petitioners will be able to look at it and give further views.

I suspend the meeting briefly to allow the witnesses to leave.

10:26

Meeting suspended.

10:27

On resuming—

Salmon Farms (Closed Containment) (PE1715)

The Convener: The next petition is PE1715 on closed containment for salmon farms in Scotland. The petition was lodged by Mark Carter, on behalf of Marine Concern, and seeks action to ensure that the salmon farming industry in Scotland uses only a closed containment method of farming.

The note that was prepared by the clerks and the Scottish Parliament information centre outlines a number of steps that have already been taken in the area, including the separate inquiries that have been undertaken by the Environment, Climate Change and Land Reform Committee and the Rural Economy and Connectivity Committee. Those committees recommended that independent research on the benefits of closed containment farming methods be undertaken as a matter of urgency. In its response to the Rural Economy and Connectivity Committee report, the Scottish Government stated that the industry was already undertaking research in the area.

Based on the information that is set out in our meeting paper, and further to yesterday afternoon's debate on the issue, do members have any comments or suggestions for action?

Angus MacDonald: As a veteran of the bill process for the Aquaculture and Fisheries (Scotland) Act 2013, I have certainly learned more about salmon farming and wild fisheries than I ever thought I would.

During yesterday's debate in the chamber on the joint report from the REC Committee and ECCLR Committee, there was unfortunately little mention of closed containment, but it was highlighted that Norway is moving forward with it at pace. It is clear that closed containment would have a massive environmental benefit but, yesterday, there was no indication from the Cabinet Secretary for the Rural Economy that the Scottish Government is keen to move in that direction at pace—certainly not at the pace that the petitioner is looking for.

10:30

It may well be that closed containment is the answer to the majority of the environmental problems that the industry faces. I would be keen to see it move forward but, given that we did not get a lot of clarity on it from the Government in yesterday’s debate, I am keen that we write to the Government to ask exactly where it is with regard to supporting closed containment in the industry. That would allow us to decide what next steps we could take with the petition.

Brian Whittle: I agree with that. I have been on the committee only for this session and, like my colleague, I now know more about salmon fishing than I thought I could possibly know. There is certainly an interest in closed containment. The argument against it is that it is cost prohibitive at the moment. However, I would be interested to see the Norwegian model.

The Convener: Like others, I do not have a lot of expertise and experience in the area, but I am conscious that the Parliament has looked at it since the very early days. I recognise the economic significance of highly skilled jobs in remote communities. There is also the question of whether there are animal welfare issues with closed containment. It does not seem to me that salmon being in a box on land is natural or even akin to what they would normally experience. However, as I said, I do not have any experience in that area.

We can get clarification from the Scottish Government on whether it is looking at the issue. I thought that the debate and the committee’s report would have addressed the issues that have been highlighted, but we might want to look at the area a wee bit further.

Angus MacDonald: Yes. It would be good to hear from the industry as well at this stage. We could write to the Scottish Salmon Producers Organisation and possibly some of the main players, such as Mowi—which was Marine Harvest—or the Scottish Salmon Company, which may well be developing closed containment.

The problem is that the report that was conducted by SAMS Research Services Ltd and the report by the two committees were done about a year ago. Things are moving forward, and it would be interesting to see where things are now.

Rachael Hamilton: The salmon farming inquiry was quite extensive. Are you saying that you believe that technology has advanced so much that closed containment was not looked at at that point?

Angus MacDonald: No—it was looked at, and it is referred to in the report. I am saying that it was not discussed in much detail in yesterday’s chamber debate. There are certainly developments in Norway with regard to closed containment. It would be good to find out exactly where the Norwegians are with it.

The Convener: Angus MacDonald has suggested that we should write to the Scottish Government in particular, and perhaps to those in the industry that have an interest, on the specific issue of closed containment. Do members agree that we should do so?

Members *indicated agreement.*

Continued Petitions

Referendum on Scottish Independence (PE1700)

10:33

The Convener: Agenda item 3 is consideration of continued petitions. PE1700 is on the progression of the process for a section 30 order to hold a Scottish referendum on independence from the United Kingdom. The petition was lodged by Martin James Keatings on behalf of Forward as One.

We considered the petition in September last year and agreed to write to the Scottish Government for clarity on its position on a possible referendum. The Scottish Government's response states:

> "The First Minister has made clear that she will provide an update on the issue of an independence referendum when there is greater clarity about the terms of Brexit."

As recently as a day or so ago, in a speech in the USA, the First Minister confirmed:

> "I as First Minister have said I will outline my thoughts on the timing of another independence referendum in the next few weeks".

In recent days, the committee has received around half a dozen emails that urge it to support the petition.

As we have said in previous meetings, the Public Petitions Committee is a cross-party committee, so it is not expected that we will agree on the merits or otherwise of a referendum on independence.

The briefing note includes a comment on engagement with the public, as the petitioner seemed concerned that the public's views on the issue have not been adequately heard. Do members have any comments on that aspect?

Do members feel that there is anything further to be gained in keeping the petition open?

Angus MacDonald: Clearly, we do not want to get into the merits or not of a referendum. However, I cannot avoid straying into political comment here. As a member of the Scottish National Party, I fully understand the petitioner's keenness to see a section 30 order requested.

However, the petitioner will be fully aware of the stance of the First Minister and the Scottish Government, which the convener alluded to in her remarks. The petitioner will have seen the most recent utterances from the First Minister that she will be making clear her position and that of the Scottish Government in a matter of weeks.

As the Brexit saga continues and develops into what I would class as a nightmare, it is clear to me that—first and foremost—we need to see what transpires over the next few weeks, before we hear what the Scottish Government's final position is. The Scottish Government's position could not be any clearer at the moment, given the turmoil that the country is experiencing.

Brian Whittle: I will not stray into party politics here. We must respect everybody's opinion, whatever that opinion happens to be.

My issue with the petition is that it leaves it open for another petition to come in to speak against it. We would then be taking the independence debate among the wider population into our committee debates. We understand that it is the Scottish Government's responsibility to bring the issue forward, if that is its wish, and that the debate would happen then.

I completely respect the petitioner's views, but I am not sure how petitioning this Parliament forces or encourages the Scottish Government to do something that it is already considering. Let us face it, it is already the SNP's raison d'être, so I am not quite sure where the petition lies within that whole debate.

The Convener: For me, the tests on the effectiveness of the Public Petitions Committee are whether it is highlighting an issue that people are not aware of; whether it is providing the opportunity to have a debate that would not otherwise happen; or whether there is a lack of clarity on the part of those who are in authority on their position on an issue. On all of those grounds, in my view, we would not gain a lot from continuing this petition.

Clearly, the issue will be debated. People in this room will have different positions in that debate, even though we often very much agree on the impact of Brexit and so on.

The issue will be debated, whether I want it to be debated or not—it is very much part of political debate across the country. The Scottish Government has made its position very clear, which is that it will not pursue the issue until a later stage. Nevertheless, the debate will clearly continue and Scotland continues to wrestle with it. However, I do not believe that the Public Petitions Committee is where we should wrestle with it, because the debate will continue anyway. It is not that the committee is putting a block on that debate or preventing it from happening; I am conscious that it still runs like a current through Scottish politics, whether some of us like that or not. Certainly, the Scottish Government has made clear its position.

I am interested in other people's views, but my own view is that we should close the petition. That is because I am absolutely certain that it would not be the end of the debate, and that the Public Petitions Committee is not the place where the differences that we have on the question will be resolved.

David Torrance: Convener, the Scottish Government has clarified its position, and I am happy to support you in closing the petition. The debate will be carried out elsewhere and it is not for this committee to take it forward.

The Convener: Is it agreed that we close the petition on the grounds that the Scottish Government has clarified its position, that there are likely to be many opportunities for the Parliament to debate the issue and for constituents to engage with members, and that there are many channels through which the petitioner can continue to raise the issue?

I emphasise that this is not about having a view on what the petition calls for, but about whether this committee is the best place for the conversation to continue. We thank the petitioner for lodging the petition and affording us the opportunity to clarify the Scottish Government's view on the matter.

Are we agreed?

Members *indicated agreement.*

Thyroid and Adrenal Testing and Treatment (PE1463)

The Convener: The next petition is PE1463, on effective thyroid and adrenal testing, diagnosis and treatment. I welcome Elaine Smith, who is attending the committee for its consideration of the petition.

The petition was lodged in December 2012. It was first considered by the Public Petitions Committee in parliamentary session 4 and consideration has continued in session 5. On 29 March 2018, the committee published a report on the petition, and a debate on it was held in the chamber on 4 December 2018.

Several issues that we might want to consider came out of the debate. The Minister for Public Health, Sport and Wellbeing confirmed that the National Institute for Health and Care Excellence intends to develop a guideline on thyroid disease, with publication expected in November 2019. The minister highlighted that the deputy chief medical officer, Dr Gregor Smith, met representatives from NHS Education for Scotland and that an endocrine learning module has recently been produced for GPs. Dr Smith has asked the chief medical officer's specialty adviser for endocrinology to review the module in the light of the issues that have been raised through the petition.

In relation to the prescribing of triiodothyronine—or T3—the minister has undertaken to write to health boards to confirm that patients who need access to T3 under an endocrinologist can obtain it. He also asked all members to make him aware of any instances where patients cannot access T3 as a treatment.

There were also a few calls for a short inquiry to be carried out by the Health and Sport Committee. Any such inquiry would obviously be a matter for that committee, which would need to take into consideration its other work programme commitments.

The cost of T3 was raised as a possible barrier to treatment. As was mentioned in the debate, the pricing of medicines is a reserved matter.

Do members have any observations? It might be helpful to hear from Elaine Smith first, given that she participated in the debate and has pursued the issues over a significant length of time.

Elaine Smith (Central Scotland) (Lab): Thank you, convener, for allowing me to come along to the committee. I thank the committee for its work and for the debate in the chamber. The issues can be difficult to get to grips with, but I think that committee members have done that and know what the issues are.

I thank Dr Toft—I have just heard that he is retiring—who has been on a thyroid journey over the past decade, often against intransigent establishment views. He saved my life and the lives of others.

I also thank Lorraine Cleaver, who had hoped to be here today but unfortunately could not be. T3 was not really her issue, but it took over the debate to an extent because of the massive price hike, which meant that boards refused to prescribe it. When Lorraine started the petition, she wanted to help other people to avoid the horrors that she had been through, and she was hopeful that one of the outcomes might be that she could get desiccated thyroid hormone on prescription rather than having to buy it on the internet. We have not reached that stage, despite it being the only treatment to be extremely effective until thyroxine—T4—was invented and made money for the pharma industry. Desiccated thyroid hormone remains unavailable in this country, and the industry cannot make money out of it, which is unfortunate.

The committee paper is very informative, as was the way in which the convener outlined the issue. The paper highlights some of the remaining outstanding issues, one of which is the possibility of a Health and Sport Committee inquiry, which has been supported by some members of that committee. The main reason to have an inquiry is that the issue is an on-going one that directly affects the health and wellbeing of patients, who are mainly women. Although the petition has helped to raise the profile of the matter, there has not been a resolution to all the issues. We need more clarity on the guidance from Government and health organisations, as there are inconsistencies.

A Health and Sport Committee inquiry might do something like what was done with the mesh inquiry. Hearing about the issues directly from women who are suffering is really powerful, and perhaps that committee could also hear from endocrinologists who are prescribing T3 and have seen the difference that it makes. It is important to support them, because in some ways they are up against the establishment, too. However, obviously, that is up to the Health and Sport Committee. I have written to that committee and sent you all a copy of that letter.

10:45

As the convener pointed out, the minister said that he would write to health boards, which he may have done, but unfortunately nothing has changed. I sent some examples to Joe FitzPatrick and the reply that I received was rather worrying. He said:

> "it is important to emphasise that clinicians can prescribe T3, or recommend prescribing T3 for an individual patient if their symptoms are not adequately controlled with ...(T4). That decision is ultimately for the clinicians involved in the case".

However, he went on to say that the decision is also for

> "the relevant NHS Board ... to take."

Unfortunately, the three boards that I have been dealing with—NHS Tayside, NHS Grampian and NHS Ayrshire and Arran—are still refusing to prescribe T3 to patients.

I will not take much longer, as I imagine that members will want to come in, but I want to share some of the words of patients. One wrote to the convener and said:

> "The words spoken by Mr FitzPatrick gave me real hope that my fight for T3 was finally over."

However, she went on:

> "NHS Tayside have removed T3 from their formulary that is their procedure on prescribing T3. I cannot put into words how angry, disgusted, frustrated and upset I am".

She said that it was "a cruel blow" and "hard to bear". That letter was sent at the end of January, so it is recent and she is not getting her T3.

Another patient said that she has

> "been on a combination of T4/T3 for ... 10 years."

She goes on to say:

> "Without T3 I am unable to function properly. I'm struggling with my mental health at the moment as it is"

and

> "I am only just starting to plan for my future".

She says:

> "Basically if my T3 is stopped they may as well just give me a loaded gun."

That was dated late last year, after the debate, so it is another live case.

I have another letter here from a woman who could not get T3 from the NHS but who is buying it privately. She says

> "I doubled my kidney function on my own and I can breathe without inhalers and steroids".

She is having to do that on her own because she is not getting the T3.

Therefore, although the committee's work has been excellent, the debate was good and I was heartened by what the minister said, unfortunately, health boards are taking that clause in his letter saying that it is up to them to mean that they do not have to prescribe it, even when clinicians have done so.

It is essential that the Government addresses the genuine experiences and concerns of patients and sufferers. I suggest that the committee keeps the petition open for now, because there are so many outstanding factors, not least that health boards are still not prescribing T3.

There is a lot of follow-up to be done from the debate. I am going through it at the moment to pick up things of interest that I want to write about, and the committee might want to do that as well. For instance, I want to get some feedback on what has happened in relation to Dr Smith's comments. However, the most worrying thing is that health boards are basically ignoring what the minister said, they are ignoring clinicians and they are certainly ignoring women whose lives depend on the treatment.

The Convener: I have had cases in which constituents received a diagnosis and prescription from a clinician but the system then said that it did not have to prescribe T3 for them, even though it had been identified as what they needed. In the debate, I was reassured that that is not now happening but, as Elaine Smith pointed out, people are using powerful and emotive language to talk about the impact on them.

The question for the committee is not about the fact that those issues remain and are significant, but whether we can help or whether we should pass on the issue to the Health and Sport Committee, given the minister's commitment and the question of accountability. We have to think about how productive we can be and be alive to how long the petition has been on our books.

Brian Whittle: Interestingly, a lot of my information came from a man—a friend of mine, who feels that T3 has turned his life around. I know that it is predominantly women who are affected, but it is not exclusively women.

I was very hopeful, having taken part in the parliamentary debate and listened to the minister's reply, that we might be moving to a position in which the committee could step back from considering the issue. However, a couple of things still nag away at me, such as the inconsistency across health boards. I know that the Health and Sport Committee is considering doing an investigation and perhaps we should write to it to ask whether that will happen.

I would also quite like to hear from Joe FitzPatrick what the responses have been from all the health boards. If certain health boards have been highlighted as recognising that there are patients who require T3 as a treatment but are not prescribing it, why do we not just ask them directly why not? That in itself would put a bit of pressure on them.

Rachael Hamilton: It is really important to establish the reasons for not prescribing T3 because, in the debate, it was teased out that that was due to cost and supply issues. I wonder whether it is still the case that health boards are not allowing this essential drug to be prescribed due to cost and supply issues rather than for clinical reasons.

I do not know how the committee can make progress on the issue if it is a reserved matter. I think that it would be quite weak to say, “Why don't the petitioners take this forward with their local MPs, as it is a reserved matter?” Is there anything that could be added to Brian Whittle's letter to Joe FitzPatrick to find out the true reason why health boards are not releasing T3? Is it due to cost or is it due to choice and clinical reasons?

Brian Whittle: Although T3 is comparatively expensive, the overall cost—given the number of patients who are being treated—does not come to a huge amount of money. The idea that the reason could be cost nags away at me, because the actual cost to the health budget is not that high.

David Torrance: I think that the Public Petitions Committee has probably taken the petition as far as it can go, especially after having a debate in Parliament. It might be more appropriate to pass it on to the Health and Sport Committee and ask it to hold an inquiry. Brian Whittle and I are on that committee, and I think that it could take it a bit further than we can.

Angus MacDonald: I agree with other members' comments about feeling disappointed that the minister's reassurances have not been followed through at health board level. Like everyone else who was at the parliamentary debate, I left the chamber feeling quite heartened by the minister's response, but if there are still issues, they clearly have to be addressed. The best way to do that would probably be an inquiry by the Health and Sport Committee. To follow on from David Torrance's suggestion, we need to get confirmation from that committee that it will go ahead with such an inquiry before we can close the petition, out of fairness to the petitioners and to Elaine Smith, who has followed the petition from day 1. We need to get confirmation that the Health and Sport Committee would be happy with that course of action before we close the petition, because it is clear that unanswered questions remain.

The Convener: We have the option of referring the petition to the Health and Sport Committee, but I detect a bit of unease that, if we did so, we would not have any certainty that an inquiry would be conducted. However, there is a particular role for that committee in holding the minister and the health boards to account in a way that we cannot do.

My sense is that we do not want to close the petition; rather, we want to contact the Health and Sport Committee and get confirmation of its interest in doing an inquiry. The only outstanding point is whether, at this point, we want to do anything ourselves in relation to the health boards along the lines that Brian Whittle outlined.

Rachael Hamilton: In the debate, Elaine Smith was very keen on the recommendation that the Health and Sport Committee should hold an inquiry, and Miles Briggs said the same. However, I have a niggle: I think that we should speak to Joe FitzPatrick prior to referring the petition to the Health and Sport Committee. I do not know how onerous that would be for the committee, but we can say that although we have done the inquiry and had the debate, there are still unanswered questions. I do not think that matters have been properly rounded off.

The Convener: We are not suggesting that matters would be rounded off. I think that everybody recognises that there is more work to be done and, in my view, the best place for that work to happen is the Health and Sport Committee. We are saying that the work needs to be done and that, if the Health and Sport Committee is not going to do it, we do not want to let go of the petition. In any event, Joe FitzPatrick is going to appear in front of a committee, is he not?

We recognise that there are issues that we had thought had been identified and clarified in the debate on which we still have questions. The correspondence that Elaine Smith read out about the position that people feel that they have been left in would trouble anybody.

Our preferred position is that the Health and Sport Committee conduct an inquiry, but we recognise that it is outwith our gift to determine that that will happen, so we can write to it. If that is not going to be done through the Health and Sport Committee, we will need to reflect further on what we will do. That might mean that we would bring representatives of the health boards or Joe FitzPatrick back in front of us. Do members agree to that approach?

Members *indicated agreement.*

The Convener: We agree to write to the Health and Sport Committee to urge it to conduct a short inquiry to reflect on the issues in the debate and issues that seem to have emerged from it that we had not really expected.

I thank Elaine Smith for her attendance and close the formal part of the meeting. We now move into private session.

10:57

Meeting continued in private until 11:18.

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