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House debates

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Committees

Health and Ageing Committee; Report

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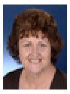

Jill Hall *(Shortland, Australian Labor Party) Share this | | Hansard source*

It gives me great pleasure to speak to the report, *Discussion paper on late effects of polio/post-polio syndrome*, which was tabled in the House on Monday. I see some of my colleagues from the House of Representatives Standing Committee on Health and Ageing here. This was an issue that we all felt very passionate about. We met with a group of people who, for a long time, had had their needs ignored and their voices not heard.

I hope that, as a result of the roundtable we had and the discussion paper we have issued, this will lead to them having a more powerful voice and their issues being considered by government.

This issue was first brought to my attention when I visited a constituent who was suffering the effects of postpolio syndrome, or the late effects of polio—either of those descriptions are used in relation to it. As she had aged, the impacts of the polio she had had when she was younger had resurfaced and become a lot greater. She had muscle weakness, and the normal ageing process of having a little bit of arthritis was extenuated. She was finding it really difficult to function around the house, and it was only because she had a very supportive environment within the home that she was able to do so.

I want to acknowledge the member for Parkes. He and I are both patrons and have been very involved in this issue over a period of time. It became really obvious to us that there was a large group of people who had suffered from polio, who had been victims of the virus that swept across our country right up until the 1960s. They had had treatment and had gone on with their lives but, as they had aged, the effects of it came back. It was also very obvious that GPs and other health professionals were not aware of the impact of it. Some of the medication given to people who have similar sorts of symptoms, even anaesthetics given to people with postpolio syndrome, can actually be fatal. There was this great lack of knowledge about the impact of the late effects of polio.

We held a roundtable in Melbourne, and I particularly want to acknowledge a couple of people who were involved in that. Firstly, I want to acknowledge Dr John Tierney OAM, National Patron of Polio Australia and former Liberal Party senator of this parliament. He has really shown to me his great concerns about this issue. In fact, he is a sufferer of the late effects of polio. He is very passionate about this issue. Secondly, I want to acknowledge Gillian Thomas, President, Polio Australia, who is confined to a wheelchair and has a number of side effects of the late onset of polio. As she has aged, she had found it more difficult but is still a very vital, dynamic woman who is out there arguing for polio and its effects to be recognised. You suffer the acute stage and then, later in life, you suffer the effects, to a lesser degree but in a very debilitating way. I think that, as a nation, we need to look at this issue and at getting some evidence on the table in relation to it.

The committee made three recommendations, and I will come to them a bit later. One of the things that I thought were overwhelming was the lack of information about polio and the number of people who are affected by it. I learned that, when medical students are being trained, they learn nothing about the late effects of polio.

This matter needs to be addressed at a medical level. I would encourage urban divisions, Medicare Locals to actually get the information out to medical practitioners—and this is mentioned in our recommendations—so they know it exists and that there are appropriate supports and treatments that need to be put in place and that it is not just a normal part of the ageing process. It is not a normal part of the ageing process and that needs to be recognised.

Not only do doctors need to be educated but the whole of the community. There needs to be information given to community organisations that there is this group of people who need special assistance. There are issues that relate to employment, because somebody who contracted polio in the early 1960s is a person we would hope would still be able to be gainfully engaged in the workforce. In a previous life, when I was a rehabilitation counsellor, I actually had a client who was suffering from the late effects of polio. He had come from a South American country. Whilst we do not have to deal with polio in Australia, there are many nations in the world where polio is still rampant in communities. People from those areas do come to Australia. So it is going to be an ongoing issue.

This person with whom I was working had worked in a manual area. He developed a weakness in his arm and could no longer undertake the work that he did in the past. We tried to organise some retraining for him and get him into a job, which we subsequently did.

Other things are associated with the late effects of polio and symptoms that not everybody understands. One of those is depression. Depression really accompanies the late effects of polio, as well as the physical debilitation. These are the types of issues that need to be raised and is the type of education that needs to be provided to doctors and health professionals, and people working in the community. Employers need to be aware that, as with anyone with a disability, a person may not have the physical strength or capabilities in a certain area, but they have a got a lot of other abilities. They need to be mindful of the fact that, if you give a person with a disability an opportunity to work, you will be well and truly repaid.

There are enormous costs associated with disability and with not dealing with it. The committee felt that dealing with the disability and the effects of the disability would be of great benefit from a cost perspective to the country, as well as from the perspective of providing a benefit to the person who is suffering from the late effects of polio. Of course, there are social and emotional impacts. Just having to struggle with those everyday activities that people without a disability can do without even thinking about it really creates problems.

I would like to turn to the recommendations in relation to the late effects of polio. Recommendation 1 is for the ABS or the Australian Institute of Health and Welfare to look at some sort of mechanism to ask appropriate questions in the health disability survey to ascertain how many people in the community are suffering the late effects of polio so that we can get some feeling for the numbers that are out there and the numbers of people that this is impacting on. We felt that it was vitally important that we get some sort of knowledge base, and we thought that the ABS or the Australia Institute of Health and Welfare would be an appropriate body to collect this information. It is important to mention here that, when we had the polio epidemic in Australia, there were the people that had acute effects of polio and my grandfather was actually one of those. They ended up with quite severe disabilities, but there are other people who had polio that was nearly like the flu, and it is only by having proper tests that it can now be identified whether a person actually did contract polio when they were younger. So it is very important that we get this information base.

Our second recommendation is that relevant national boards consult with the key stakeholders, and that is looking at peak professional bodies and educators to ensure that students learn that there is such a debilitating disease as the late effects of polio so that they can develop best practice for the treatment and management of people that have the late effects of polio. We also recommended that Medicare Locals engage with Polio Australia and the state-based polio associations to raise awareness of the late effects of post-polio syndrome, and that was looking at health professionals and working with communities through education and for people that are in that group of people that have the late effects of polio. It was a discussion paper with some recommendations that I think are achievable. There is one area that I think we also should touch on, which is that we need to do a tiny bit more research into the late effects of polio, looking at how they have impacted on people's lives and if there is a way or a treatment that can be used to lessen the effects of the late effects of polio.

In conclusion, I would like say that as a society we are very lucky that we have managed to eradicate polio. We are very lucky that we will not have future generations suffering from the late effects of polio. We need to be vigilant as a country to ensure that all children are immunised and that polio does not re-emerge in Australia, and we also need to show compassion for those people that did contract polio back in the forties, fifties and sixties. I recommend the discussion paper to the House.

10:19 am

Steve Irons *(Swan, Liberal Party) Share this | | Hansard source*

I rise to speak on the discussion paper on the late effects of post-polio syndrome, and I also endorse the remarks made by the member for Shortland. I have spoken on this in the other chamber but would like to add some other areas to this particular effect, because I feel they are important and should be put on the record. I would also like to congratulate the member for Parkes, who is in the chamber and who, with the member for Shortland, initiated this discussion paper through the House of Representatives Standing Committee on Health and Ageing. It was their efforts that made sure that we now have a discussion paper which the Australian polio association feel that they can take forward with them and use to help further their cause.

The member for Shortland touched on the recommendations and also the employment aspect of the discussion paper, but there are a couple of areas that I want to highlight that I did not have time to mention the other day—that is, the physical aspects. We as members in this place take for granted that we can exercise and go out and use the gym and the swimming pool, and I see many members in this place who obviously do that.

An honourable member: The supreme athletes

Supreme athletes, as you say. We take those things for granted. We do not understand that the people who suffer from post-polio syndrome have difficulty just in exercising and that it can actually have a detrimental effect unless handled carefully. I would like to quote from part 2.99 of the discussion paper, which says:

As noted earlier physical therapies which alleviate symptoms of other chronic conditions, if used to treat people with LEOP/PPS may actually be detrimental. In particular participants commented on the need to carefully manage muscle strengthening and exercise programs to ensure that additional muscular damage does not occur. As Dr Tierney explained:

You should not overstress the muscles. If you exercise, it has to be very gentle. Obviously, with hydrotherapy you are in water and it is very gentle. That is the way to keep yourself fit. But if people start doing weightlifting or going to the gym those very poor connections into the muscles then start collapsing at a faster rate, and you get muscle weakness moving towards paralysis if you undertake the wrong exercise regime.

Part 2.101 of the discussion paper says:

While noting that many people with LEOP/PPS ultimately manage much of their own physical therapy, Mr Doran—

one of the witnesses—

cautioned that polio survivors first had to overcome a tendency to strive to achieve over and above what is required. In this regard Mr Doran noted:

... polio survivors have incredible mental stamina. What they do with that mental stamina is override the signs that things might be going wrong, because they have been used to doing that for most of their life. In particular, they override the fact that they might be feeling a little bit weak, they override the fact that they are absolutely exhausted, and they override the fact that they are in pain, because they have been told to shut up and get on with it for so long.

Another area I want to refer to is diagnosis, which I touched on in my speech the other day. The time it takes for post-polio syndrome diagnosis can be, on average, up to six years. Research has not been mentioned yet here, but it is briefly mentioned in the discussion paper. Part 2.137 of the discussion paper says:

While recognising the need for more research into LEOP/PPS in Australia, Dr Peel indicated that there are key centres of research in North America and Europe, noting:

The research, as we have already indicated, might be inadequate [in Australia] but, nonetheless, research does occur in North America, particularly in Canada at the Montreal Post-Polio Clinic, and also in Europe. As I have already mentioned, there is the Karolinska Institute in Sweden. Also, a lot of the research comes from the Academic Medical Centre in Amsterdam. The Danish Society of Polio and Accident Victims is another source of considerable research.

The other day when we had a hearing of the health and ageing committee, as mentioned by the member for Shortland, Dr Tierney, Julian Thomas, President of Polio Australia, and Mary-ann Liethof, the National Program Manager, and Peter Guard, from Polio New South Wales, spoke to us about the discussion paper. They endorsed the recommendations that the member for Shortland has just spoken about. As individuals we said to them: 'Keep up the good work. You're doing a fantastic job. You've taken it this far and have been working for a long time.' But this is an area where we need more focus, more research and, obviously, more resources for people who are suffering from post-polio syndrome. I would like to say, 'Keep up the fight.' The resources are needed and, along with the other members of the health and ageing committee, I commend this discussion paper to the House.

10:24 am

Bruce Scott *(Maranoa, National Party)* *Share this* | | *Hansard source*

The question is that the document be noted. As someone who contracted polio as a child I am most interested in the recommendations.

Mark Coulton *(Parkes, National Party)* *Share this* | | *Hansard source*

I too rise to make some brief comments on this discussion paper. Indeed sometimes in this job as a member of parliament you get to a point where you think you have done something worthwhile as part of a team, and today is one of those occasions.

One of the great honours that I have had since I have come to this place is to have been asked by Polio Australia to be one of their patrons. It is a job that I am very proud to have and one that I take very seriously. I would like to, firstly, compliment the people from Polio Australia, led by Dr John Tierney and Gillian Thomas, for their tireless efforts. I think I met them not long after I was elected, probably early 2008, and they have been coming from all over Australia to Canberra on a regular basis, and they have mainly funded this from their own resources. Because of their own disabilities this is quite difficult for them to do, but they have just kept coming here, doing the rounds and spreading the word.

I would like to thank the Standing Committee on Health and Ageing for adopting the idea of a roundtable and for this discussion paper. Before I go any further, I should recognise the secretariat, because I think they have done an excellent job in compiling information and putting into a nutshell what this issue is about, and in a minute I will talk about the three recommendations. They have done an excellent job on that. I also recognise the previous speakers, the member for Shortland and the member for Swan, for their contributions and indeed the entire committee for their efforts.

Basically what has happened—and a lot of people do not realise this—is that many people who are suffering from the late onset effects of polio may not have even known that they had polio as a child. They may have had polio in the family; they might have had a sibling with polio. They may have had a bit of fever and so a very mild dose of polio. Largely, they got on with their lives. With all the publicity in probably the last 10 years about polio pretty well being eradicated in most of the world, I think there was a mind-set not only in the community but also in the medical profession that this job had been done. People were not looking at polio. One of the great frustrations for these sufferers is that they have been misdiagnosed with depression, chronic fatigue syndrome and a whole range of other ailments. In some cases the treatment that they received for these ailments actually exacerbated their condition. So it has been a big issue.

I will just paraphrase the three main points of the report—and here I would like to acknowledge my fellow members on the committee, led in particular by the member for Shortland—that we need to have some recommendations to come out of this report. Basically, the three recommendations are that, as a society, as a country, we need to recognise the extent of this syndrome within our society. Maybe we can gather that information through the ABS from the next census. That is the first point. The second point is that we need to educate our medical practitioners that this is a real and very debilitating syndrome. So we need the medical colleges and the universities to put in some more work on this, and we also need to disseminate information through practising general practitioners. The third point is that we need to educate the wider public about this condition. If people are feeling lethargic, if they are having problems with movement or if they are having aches and pains, they may think back and ask whether there is polio in the family. The recommendation that the Medicare locals might be a vehicle for that is, I think, a good one.

This is a good report. I commend everyone involved in it. It will be presented to the Minister for Health. From the reports of people in Polio Australia who have been speaking to the bureaucracy in the Department of Health in recent days, I think we are already starting to see a more enlightened approach to this issue.

I will finish by saying that I am one of the lucky ones. I can still remember as a child in the mid-sixties being at primary school and lining up with the entire school to have our dose of the oral vaccine. Indeed, we are a privileged generation. I thoroughly endorse this discussion paper. I truly believe this is the beginning of a process and not the end and welcome this report.

Debate adjourned.