

Catherine King, Member for Ballarat, moved the following Motion in the House of Representatives on 17 August 2009 and three of Polio Australia's Parliamentary Patrons were able to take part in the debate. Being in the public domain, extracts from Hansard, such as that below, are able to be freely reproduced (with the proviso that extracts are adequately cited and that they are quoted in context).

That the House recognises that:

- (1) polio survivors continue to be the single largest disability group in Australia today, numbering in the tens of thousands;
- (2) this number not only includes those who contracted polio in Australia during the epidemics last century, but also young polio survivors who have migrated from countries where polio is still prevalent or only recently eradicated;
- (3) the needs of polio survivors have been largely neglected since vaccination against the disease became a reality, and as they age with chronic disabilities this neglect must be addressed as a matter of urgency;
- (4) over the last 20 years much attention has been drawn to the development of new, previously unrecognised, symptoms which occur in people who were thought to have reached a stable level of recovery after the acute disease;
- (5) symptoms of the late effects of polio include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms and twitching, respiratory and sleep problems, swallowing and speaking difficulties, depression and anxiety;
- (6) over the last 20 years polio survivors have established state based post polio organisations to provide information and support for fellow survivors, and that these networks are run by polio volunteers who themselves are experiencing increased disability and decreased mobility; and
- (7) in the coming years it is increasingly inevitable that many state networks will cease to function as volunteers find themselves unable to continue the service, thereby creating the necessity for a central body, Polio Australia, to take over responsibility for state functions.



Catherine King

Member for:
Ballarat (Victoria)
Australian Labor Party

7:25 pm I move this motion on polio survivors to bring to the attention of the House the continuing impact that polio has on our community. Many would believe that we have managed to consign polio to the annals of medical history. Through mass immunisation we have managed to almost eradicate polio throughout the world, although there are still cases diagnosed in developing countries as immunisation coverage has been somewhat slower there. Most of us will have seen some of the awful images of children and young teenagers struck down by this disease — again, seeing these as images that are part of our historical past.

During the early to middle 20th century poliomyelitis impacted the lives of thousands of Australians. It is a very old disease where, conversely, as our hygiene standards improved, the immunisation protection passed on by mothers to their infants lessened. It is difficult to put an exact figure on the number affected as many cases did not require hospitalisation and were therefore never recorded, but many resources put the number at over 70,000.

This disease crippled not only individuals but communities in which they lived. This horrific disease terrified Australian communities as it was not known how it was transmitted, with the disease not being brought under control until the late 1950s. It struck down children — over 50 per cent of cases were children under three — and teenagers across the country and, if you look at the Polio Victoria website, there is a roll of Victorian polio survivors. It is heartbreaking to see the ages of those, from six months old to one-year-olds, to seven-year-olds, to those in their teenage years and their early 20s.

For those children and young people who survived, they recovered from polio without any, or only mild, disabilities. They thought they had left polio behind them when they exited from the hospital and treatment facilities. They were all keen to get on with their interrupted lives. They finished school, they worked. Many married and had children and grandchildren. They participated in sport, helped out at school fetes, were active in public life, and contributed alongside other members from their generations to Australia's growth.

But, as this generation has aged, for some of them the effects of that dreadful childhood illness have come back, and I refer to post-polio syndrome, a not widely known syndrome but one that, nevertheless, has come to have a significant impact on the lives of those thousands of polio survivors. We now see new symptoms striking them, with effects such as fatigue, increased pain in muscles and joints, declining strength and endurance, an inability to stay alert, weakness and muscle atrophy, muscle spasms and twitching, respiratory and sleep problems, swallowing and speaking difficulties, and depression and anxiety. It is critical that those suffering from post-polio syndrome receive early assessment and intervention.

Unfortunately, not only do many members of the community lack a sound understanding of post-polio syndrome, but many health professionals are also unaware of the condition. Survivors of post-polio syndrome report that many of them have had difficulty in getting a diagnosis, often having been subjected to many years of testing and at times wrong diagnosis, let alone then trying to get access to support services.

The advent of state based and local polio support groups is assisting, but there is clearly a need for a greater role for national bodies such as Polio Australia to provide advice to the federal government and health professionals for the development of policy and education programs to improve the lives of those impacted by the late effects of polio. Polio survivors continue to be the single largest disability group in Australia today, numbering in the tens of thousands. This disease still haunts those sufferers decades later. Many of us in parliament are aware that former member and former Labor leader Kim Beazley was a polio survivor.

On a personal note, my mum, whose 80th birthday we celebrated on the weekend, contracted polio in 1946 and spent her 17th birthday in Fairfield hospital. She emerged after a year fully recovered, but on developing muscle weakness and a limp in her 50s was diagnosed with post-polio syndrome. I know that it has affected her significantly as she has aged — not something that we as a family have always understood. I think that particularly those like my mum, who experienced such a debilitating illness in their early lives, have been determined to stay well and they certainly have a lot of pride about their being physically strong and capable. Acknowledging and coming to terms with having post-polio syndrome has been really hard for many of them. I encourage those who have members of their families who have had polio to inform themselves about the syndrome and, whilst not all survivors will be affected, I cannot stress enough the importance of an early assessment and access to appropriate services.

I thank those members who are supporting this motion this evening. I know that it does mean a lot to polio survivors to have what is happening to them recognised by this House. I certainly commend Polio Australia and the state based organisations and the local support groups such as the Ballarat Polio Support Group in my own electorate for the work that they are doing to support post-polio syndrome survivors.



Darren Chester

**Member for:
Gippsland (Victoria)
National Party**

7:30 pm In rising to speak on this important motion before the House, I congratulate the member for Ballarat for raising the issue and her personal insights particularly in the context that polio survivors continue to be the largest single disability group in Australia today. Like the previous speaker, I have met with the representatives from Polio Australia and sufferers from within my own electorate and it has given me a better insight into the challenges that many Australians face.

The epidemic of this terrible disease during the last century is certainly well known, but the continuation of suffering by those affected has largely gone unnoticed in our modern society. Indeed, it is fair to say that polio is largely seen as a disease of a previous generation. There is a lack of understanding about the late effects of polio or post-polio syndrome and the impact that the disease is having on all of our communities today.

Within our local communities the effects of the disease continue to haunt many polio survivors and immigrants who contracted the disease before they actually arrived on Australian shores. I do not suggest for a second that our medical professionals have been complacent about their recognition of the disease. I think that we would all agree that there have been several other medical issues that have perhaps attracted more attention in recent years and post-polio syndrome has not been recognised to the extent that it probably needs to be in the future. I believe that perhaps this lack of recognition has taken away the emphasis that the medical system previously had on eradicating polio but also in providing adequate care for people going forward.

It is a case that Polio Australia have made throughout their campaign and their slogan is: "*Polio forgotten, but not gone*". As I said, polio is seen as a disease of a previous generation and there is a concern that many people are actually reluctant to talk about their experience and the effects that the disease has had on them throughout their lives. Unfortunately there remains a certain stigma that surrounds this terrible disease, which we as a society, I believe, have to try to overcome and remove if we are going to provide the assistance required in the future.

I believe that the lack of communication and financial support between the polio support groups and the community has probably contributed to a lack of funding across all levels of government to investigate and resolve many of the effects and the problems associated with post-polio syndrome. Indeed, I am advised by the Parliamentary Secretary for Health that the Department of Health and Ageing does not currently provide any specific funding to support post-polio syndrome. The Department's role under the current health funding arrangements is limited to providing grants to the state and territory governments and they decide their own priorities.

The effects and the problems of post-polio syndrome are continuing to grow as the majority of the polio survivors become older and more reliant on assistance from support groups and carers. Naturally, as our polio sufferers age, their health needs will become more complex. Having met recently with Polio Australia, I understand the need for funding to assist the support groups that work with the sufferers of this disease. I was advised by the group that there are approximately 40,000 people suffering from a paralytic form of the disease and the number of people suffering from the non-paralytic form could be as high as half a million. Importantly, there are forms of the disease that show symptoms similar to other medical ailments, making it even more difficult for the medical profession. This can lead to people with the disease being misdiagnosed or undiagnosed completely and such a failure to diagnose the late effects of polio, or post-polio syndrome, can lead to an inappropriate treatment which, as Polio Australia volunteers informed me, can actually lead to a further exacerbation of the condition and an escalation of the symptoms for those sufferers.

There lies one of the most significant problems for Polio Australia. On a database at the moment they have about 1,500 people, I understand, who are regarded as being affected by the disease and are registered on their database. They need to expand that and get a better handle on the actual numbers of people involved in that, and that is going to require funding. A significant amount of work is being done on the ground by the support groups to meet the growing demand throughout regional communities, but a concern is that throughout all these support groups there is actually only one paid role in Victoria at the moment. This lack of paid support is an issue for us for a range of medical conditions, but certainly in polio it is emerging as a major concern for Polio Australia.

Polio Australia have argued — and I believe quite rightly so — that without the government's future support they will have a further impact on the volunteers who are required. The burden that is falling upon these volunteers is probably too extreme for them, particularly as many of them are directly affected by the disease themselves. They are right in saying that help is urgently required to help them support sufferers of post-polio syndrome in the future. Too much of the burden is falling on the kind-hearted volunteers in our community.

I believe it is essential that the federal government works with the polio support groups, encourages more volunteers and further assists organisations like Polio Australia in its endeavours. It is important that any services that are provided in the future are made available to people in rural and regional areas, and that we take steps to overcome that tyranny of distance which prevents people from accessing services. I commend the member for Ballarat again for bringing the matter to the House's attention.



Jill Hall

**Member for:
Shortland (NSW)
Australian Labor Party**

7:35 pm I second the motion moved by the member for Ballarat and, in doing so, I would like to stamp my contribution on this debate by thanking Peg Hatherly from Buff Point who I met with on 8 May this year. It was Peg that brought to my attention the plight of people suffering from post-polio syndrome, or late effects of polio as she likes to refer to it. Present with Peg were Neil von Schill and a local GP, all people that had suffered from polio earlier in their lives and now were experiencing symptoms associated with the late effects of polio.

It was from this meeting that I arranged for them to come and talk to the Standing Committee on Health and Ageing. On that day they were here, they met and spoke with a number of members. It was interesting to learn just how many people had relatives and friends who had actually been affected by polio. My own grandfather suffered from polio and my memories of him are of a little man that always wore callipers.

The issues associated with post-polio syndrome are quite enormous. Peg is a person who has been quite debilitated through her life because of suffering from polio at a younger age. As she has aged, the effects have become much worse and she has become much more debilitated. It took a long time for people to actually recognise what the problem was. By using Peg as an example, it emphasises the problem that sufferers of late effects of polio have.

Whilst polio is now a disease that has been virtually forgotten by our community and health professionals, it is still present but in a very different form. It was in the late 1950s that the immunisation program became widespread throughout Australia, but very few health professionals and even doctors have experience in dealing with people who have suffered from polio at that acute

stage. Just recently, as has already been stated in the House, many people that have had polio have developed symptoms later in their lives.

Whilst previously polio, it was considered that once you recover from the acute stage of polio, whatever your residual disability was, that was deemed to be the level of your recovery. What has subsequently happened is that there has been a slow degenerative process associated with it.

In a previous life, I worked as a rehabilitation counsellor for people with disabilities and that was the first time I had contact with a person who was actually suffering from post-polio syndrome as it was called at that time. The one aspect that was most debilitating for him was the fact that he suffered from really acute depression. That is one of the many symptoms that are associated with post-polio or late effect polio syndrome, along with fatigue, muscle weakness, pain and a general and rapid decline in physical ability.

I think it is time that parliaments and governments of all persuasions acknowledged the fact that more people suffer a disability from polio than from any other disease. We need to assess its impact and ensure that the right education is provided so that people can not only recognise it but also put in place the right sort of support for those suffering from the late effects of polio. Education is a key factor but we should also do everything in our power to look at supporting Polio Australia so that one body has overall responsibility. Once again I commend the member for Ballarat for bringing this important motion to the attention of the House.



Mark Coulton

Member for:

Parkes (NSW)

National Party

***Shadow Parliamentary Secretary for
Water Resources and Conservation***

7:40 pm I would also like to commend the member for Ballarat for bringing this motion on polio survivors before the House and also for relating the experience of her mother. Often the best way of getting a message across in this place is through personal experience, and I thank the member for that.

I am honoured to be here tonight. Recently, I was asked to be a patron of Polio Australia — and I suspect that others in this room have been as well — and so it is a great honour for me to speak on polio tonight. The three previous speakers have probably covered this issue pretty well. However, I think the real issue is that, since the threat of another polio epidemic was put away in the late fifties and early sixties, polio as a disease has been largely neglected. I probably did not realise the significance of lining up with other kids in my class in primary school and being administered the very sweet tasting pink liquid that was presented on a tiny plastic spoon. At the time, it was not significant but I was probably one of the first generations to be largely polio free in Australia.

Polio survivors are one of the largest disability groups in Australia. There are tens of thousands of polio sufferers living in Australia today. This group includes not only Australians but also immigrants from countries where there were no mass immunisation programs for polio. Over the last 20 years, there has been increasing concern about the victims of polio succumbing to unexpected new symptoms 40 or more years after their initial infection. People in their 40s, 50s, 60s and 70s are experiencing what is called 'post-polio syndrome'. The sinister nature of this syndrome is that it is often misdiagnosed and, hence, mistaken for other illnesses. The symptoms include fatigue, decreased strength and endurance, pain and weakness in muscles and joints, respiratory and sleep problems, swallowing and speaking difficulties, depression and anxiety. A whole raft of other illnesses would fit that description.

If post-polio syndrome is not detected early, it can lead to further complications. It is now generally agreed that, in order to minimise the severity of any new symptoms, early assessment and intervention is essential. After a full assessment, post-polio sufferers may be referred to one or all of the following: respiratory specialists, speech therapists, orthotists, physiotherapists, occupational therapists, psychologists or a pain clinic.

One thing that I do not think has been discussed tonight and that is quite dangerous is that a person suffering from post-polio syndrome must avoid using many of the common drugs. These include muscle relaxants, cholesterol reducing medicines, local anaesthetics, general anaesthetics and painkillers such as aspirin for dysphagia. Polio Australia told us that, if someone is not properly diagnosed and they are being confronted with another illness, their life can be put at risk if these drugs are administered to them.

During the past 20 years numerous state based groups have been formed by polio sufferers. These groups are run by volunteers who suffer from post-polio syndrome themselves and who aim to provide information and support to their fellow sufferers. In the minute I have left I would like to pay tribute to that brave band of Polio Warriors. They march around this place and they knock on doors. They are under-resourced and they are doing it for no other reason than to try and help their fellow man. Quite frankly, they are putting themselves through a great amount of discomfort in doing what they do.

I would also like to pay tribute to the people from Polio Australia. One of the things that I think I can do as a local member — and I have to admit to having trouble with how to word it — I hope without creating mass panic is to highlight in the newspaper that it is an issue that people need to be aware of. I am just struggling with how to do that without having all the doctors' surgeries overrun with everyone believing they have got post-polio syndrome. With the help of Polio Australia I hope to do that.