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Members in attendance: Mr Georganas, Ms Hall, Mr Irons, Mr Lyons.

Terms of Reference for the Inquiry:
To inquire into and report on:
Adhesive arachnoiditis
WITNESSES

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Committee met at 09:07

Evidence was taken via teleconference—

ACTING CHAIR (Mr Irons): I now declare open this round table on adhesive arachnoiditis. Firstly, I would like to take this opportunity to welcome all participants and thank you for making the time to speak with his committee. I also welcome those who have come to observe. Adhesive arachnoiditis has been raised as a topic of interest for the committee; hence today's round table. Today's round table discussion will give the committee the opportunity to learn about adhesive arachnoiditis, including the aetiology, diagnosis, treatment and prognosis of the condition. The impact on the lives of persons with adhesive arachnoiditis and their families will also be explored. The round table format has been selected to facilitate interactive discussion. A participant paper prepared by the committee to guide discussion has been circulated.

Today's round table will comprise introductory presentations provided by Professor Marcus Stoodley, Professor of Neurosurgery at Macquarie University, and Professor Michael Cousins, Professor of Anaesthesia at the University of Sydney. Because of other commitments, both will only be able to join the round table via teleconference for a brief period this morning. This introduction will be followed by two interactive discussion sessions based on topics highlighted in the circulated papers.

Before proceeding, I would like to remind participants that the committee cannot investigate individual cases or determine questions of a legal or compensatory nature relating to adhesive arachnoiditis. Individuals seeking to pursue legal or compensatory avenues are advised to seek independent medical assessment and legal advice. All participants should have familiarised themselves with the guidelines for the conduct of the round table contained in the participant papers. The chair will provide a reminder of the format at the start of each session. Participants should be aware that today's proceedings are being webcast live on the Parliament of Australia's website and recorded by broadcasting. A Hansard transcript of today's discussion will be produced and published on the committee's website in the near future.

At this point I should also advise that although the committee does not require you to speak under oath you should all understand that this forum is a formal proceeding of the Commonwealth parliament and statements within the round table are covered. Giving false or misleading evidence is a serious matter and may be regarded as contempt of parliament. I will now hand over to our committee chair, Steven Georganas.

CHAIR (Mr S Georganas): Thank you, Steve Irons. Welcome to all of you. We have Professor Stoodley on the line. Because the professor needs to catch a plane in the next 15 minutes we will go to him first. Mr Stoodley, would you like to make an introductory statement? We will then go to questions and answers.

Prof. Stoodley: Yes. I probably have 20 minutes or so. I did think it would be useful to start with some fairly basic information to help everybody understand the issue. Is that what you are wanting me to do?

CHAIR: A brief introductory statement. That is exactly what we would like you to do.

Prof. Stoodley: I will start by bringing everyone up to date on some basic anatomy. The spinal cord runs down the spine but it does not go all the way down the spine; it stops in the upper lumbar region. The nerves from the spinal cord continue below that. The spinal cord and the spinal nerves are covered by membranes and inside those membranes is the cerebrospinal fluid or the CSF. That is very important because, in normal circumstances, spinal nerves are floating quite freely in that CSF and they are able to move as the person moves. As a person bends over or moves their legs the nerves can move up and down as the legs pull on the nerves. It does not cause any pain in the normal circumstance. Membranes around the spinal cord and the nerves are free. There is the outer dura, which is a very tough membrane, and the second membrane is the arachnoid. That is the inner membrane that encompasses the fluid. Finally, there is the pia, which is the membrane covering the spinal cord itself.

Arachnoiditis—and this is a broad definition, in terms of what we are discussing today—is a long-term scarring of that arachnoid membrane. It therefore involves the spinal fluid space and also the nerves and the spinal cord. It causes adherence of those structures to each other, whereas normally they would be freely floating and able to move. That is where the term adhesive arachnoiditis comes from. It is where there is adherence of those structures to each other.

One of the problems with this condition is that the term arachnoiditis is often misused. It is sometimes used by clinicians to describe an acute inflammatory reaction and it really ought to be perhaps called meningitis, when it is not infectious. It is sometimes used by surgeons when they see scarring around the outside of the dura, which really should be called fibrosis because it has nothing to do with the arachnoid. I think that is one of the problems: misuse of the term.
The causes of arachnoiditis are quite variable. Anything that causes inflammation in the spinal-fluid space or those membranes can lead to that long-term scarring. So infections, particularly any sort of meningitis and, in particular, chronic meningitis—such as tuberculosis, spinal injury or any sort of haemorrhage that can occur spontaneously from blood vessel abnormalities—can result in inflammation and long-term effects of scarring in the arachnoid layer. In response to the oil based contrast agents previously used in myelography it was a very potent cause of inflammation and long-term scarring. That will come up, I am sure, during the morning.

When the scarring affects the spinal nerves it tethers to them, so rather than being free floating they get stuck. It also causes blockage of the fluid space, which can result in spinal-cord damage. The scarring can be very severe and can turn into bone, which is a non-specific effect of long-term scarring and inflammation. When that happens it is called arachnoiditis ossificans. I just view that as one end of the spectrum of arachnoiditis. The clinical effects vary. Some people with arachnoiditis have no clinical effects, but others with similar degrees of scarring can have severe pain, which is probably from the tethering of the nerves, but it could be caused by blockage of blood flow to the nerves or the spinal cord. Patients can get loss of function—in particular, weakness of the legs. They can lose bladder and bowel control. They can even get spinal cord damage, which can lead to paralysis or quadriplegia. These clinical effects can occur many years after the original event. In terms of treatment, once that sort of scarring occurs there is no direct treatment available. You will hear, I am sure, from Professor Cousins about the sorts of pain management strategies, but there is no direct physical treatment for the scarring.

I would like to make a few comments about myelography, just to provide some understanding of that. Prior to MRI being used, myelography was the main mechanism for imaging spinal problems. Spinal injuries, spinal tumours and degenerative diseases of the spinal column such as bulging discs were generally imaged with myelography. A myelogram is where you inject a radiopaque dye into that fluid space in the spine and take an X-ray. If you take an X-ray without a dye, you cannot differentiate between the fluid and the spinal cord or the nerves. If you put a dye into the fluid, you get a contrast, or shadow, where the spinal cord or the nerves are. So, it allows you to see pathology of those structures. Myelography is still used, but not very often. The modern contrast agents are water based and do not cause much in the way of inflammation, but the older dyes that were developed in the early 1900s or mid-1900s were based on an oil, and that oil caused very significant inflammation and scarring. At the end of the myelogram using oil, attempts were usually made to remove that oil to prevent that from happening. Unfortunately there are many patients who have developed arachnoiditis from that myelogram technique. There are patients who have arachnoiditis where there are no clinical effects, but it can be very severe and it can affect the whole spine, including the spinal cord. The clinical effects can be devastating, with significant spinal cord damage and chronic pain. It was known, I think from at least the 1950s, that arachnoiditis was a potential complication of myelography with oil based dyes and attempts were made to prevent that from happening.

I would just like to close by saying that from my point of view the sort of concerns that I have observed are that, first, there seems to be a perception that arachnoiditis may not necessarily be a complication of oil based myelography. I think the evidence in the literature is pretty clear on this issue. It was well understood in the 1950s that it was a complication of it. It is just that because oil based myelography is not used any more that perhaps the understanding of that is fading. Second, for patients who have suffered this problem, particularly related to the oil based myelograms, there would be a concern about whether sufficient efforts were made to remove the oil. The third concern that I have identified is that patients are concerned about whether water based myelography dyes were introduced as early as they possibly could once they were developed and the oil based dyes no longer used. I hope that brief overview has been of some help and I would be happy to answer any questions.

CHAIR: Thank you very much, Professor Stoodley, for that informative introductory statement. Because I know that time is of the essence for you and you are about to board a plane, we might leap straight into questions and I would ask each committee member, if they have a question, to keep it short and precise.

Ms HALL: I am very happy with what you have had to say. I do not have any questions—I understood it all.

Mr IRONS: Just on your comment in regard to the introduction of water based dyes, when were they introduced into Australia? When were they actually developed so they were available commercially on the market, and how big a gap was there between those events?

Prof. Stoodley: The critical time period is in the mid- to late-1980s. The changeover from oil based to water based dyes was not straightforward. The original water based dyes used ionic contrast agents and they had their own particular problems. They used to cause seizures and other neurological problems so it was not completely obvious that they should replace oil based dyes. It was not until the non-ionic contrast agents were developed that those problems were solved. As I understand it, it was around about 1987 or 1988 that the changeover happened.
Certainly in the United Kingdom, oil based dyes were withdrawn from the market either in 1987 or 1988. I do not know the specific dates in Australia. I understand that you have got Professor Sage there and he may be able to answer that question more directly. But as I understand, it was the late 1980s.

**CHAIR:** We will go to Professor Sage a little bit later to clarify some of those things.

**Mr LYONS:** In terms of the diagnosis, how readily available is MRI to this particular class of people? How often is MRI used?

**Prof. Stoodley:** Nowadays?

**Mr LYONS:** Yes?

**Prof. Stoodley:** Very widely. I have to say that there are some restrictions effected by the federal government but MRI is the imaging technique of choice for most spinal conditions these days.

**Mr LYONS:** That is what I am after. What are the restrictions?

**Prof. Stoodley:** There are restrictions in place on which machines attract Medicare rebates—and we are talking currently.

**Mr LYONS:** I was thinking that there are no clinical indicators that prevent people from getting MRIs?

**Prof. Stoodley:** Sure, there are some circumstances where patients cannot have MRIs—they have got a pacemaker, for example, or other implanted metal devices that might cause problems—but that is uncommon.

**Mr IRONS:** Professor Stoodley, can you just give us a brief background on how you got involved in this particular issue—and you spoke about other people's opinions where they said that they strongly do not believe that Myodil and Pantopaque cause adhesive arachnoiditis—and why you feel that there is such a roadblock? As the former member for Throsby, Jennie George, said, there seemed to be a wall of silence with regards to this particular issue.

**Prof. Stoodley:** To answer your first question, I have a research interest in a condition called syringomyelia, which is where fluid cysts form inside the spinal cord. One of the reasons those cysts form is if there is arachnoiditis. I have a research expertise and clinical expertise in that area so I have seen a lot of patients particularly when they have developed syringomyelia. I am seeing patients particularly at the very severe end of the spectrum where the arachnoiditis has affected the spinal cord and I have to say that the most severely affected patients I have seen are ones where the arachnoiditis has been caused by Myodil. So it is that background where I have researched the literature and I have seen the animal studies that have been done and the clinical reports that has led to my view that there can be no doubt there is a connection between the use of those oil based contrast agents and the development of arachnoiditis. But as you say, that is not perhaps a widely understood connection but I think that any reasonable reading of the literature would lead to the view that there is a connection.

**Mr IRONS:** What percentage of cases of myelography procedures lead to arachnoiditis?

**Prof. Stoodley:** For people who undergo myelography now with the water based dyes, which it is not very common, it would be negligible. Even for those patients who have had the oil based myelograms, the minority develop arachnoiditis and certainly the minority who develop arachnoiditis that is clinically significant. I have read one paper from the UK from I think the 1950s or 1960s where they looked at over 100 patients who had oil based myelograms where the oil was not removed and about 10 per cent of those patients developed significant arachnoiditis. Even when the oil is not removed, it is still the minority and I think if the oil has been effectively removed it is a very low number. For all the patients who have had myelograms, which is a very large number of patients, it is a small percentage where arachnoiditis has happened.

**Mr IRONS:** Can you tell us about aspiration and the fact that sometimes it was used and sometimes it was not used. Is there any medical theory behind the use of aspiration or non-aspiration?

**Prof. Stoodley:** We are talking about quite a few decades ago, before my time in clinical practice. My understanding is that once arachnoiditis was recognised as a significant potential complication that is what led to people removing the oil dye. That was able to be done because the oil remained like a bubble inside the water CSF. CSF is essentially water. If you inject oil, it stays as an oil bubble. Because you can see it on an X-ray, you...
manipulate the patient up and down, and get the oil to sit in a certain spot and then put the needle in the oil and aspirate the oil. Once it was recognised it was a problem, I think it was standard practice.

CHAIR: Thank you very much, Professor Stoodley, for your time. We will be conducting this round table with a lot of the evidence that you have just given and others will be participating. If there is anything further that we might require, we will get in touch and vice versa—if you feel that there is something that you did not have a chance to provide for whatever reason, feel free to get in touch with the secretary.

Prof. Stoodley: Thank you. You are most welcome.
Evidence was given via teleconference—

CHAIR: Welcome. I will allow you to provide us with a short introductory statement on the issue of adhesive arachnoiditis and outline your views, and then we will go to questions.

Prof. Cousins: There is a paucity of literature on this subject, unfortunately, and I suppose that that just underlines the fact that for those suffering from this problem there has been quite a degree of frustration that often they appear to have been not believed. In my experience of seeing patients with arachnoiditis for over 40 years, they come with a story very often that there was a lot of doubt about the effects that they were describing. So this, I guess, fits into the broad problem of people with chronic pain, many of whom find that they have been stigmatised and I think this adds to the frustration of the suffering of the people involved.

I am going to draw largely upon two sources. One is a monograph entitled *Arachnoiditis: the silent epidemic*, which was written by an anaesthesiologist in the USA, JA Aldrete, and published by Futuremed Publishers, and published first edition 2000. It is quite a substantial source of information. The second is chapter 40 in the *Textbook of Pain* by Wall and Melzack, published by Churchill Livingstone which has a very good chapter by David Dubuisson on nerve root damage and arachnoiditis. So I am just going to focus on my areas of expertise, which are diagnosing the condition, the usual symptoms and signs, and some comments on the mechanisms and treatment.

Nowadays it is mainly chronic spinal arachnoiditis that we are seeing, but I should hasten to say that arachnoiditis can occur anywhere the arachnoid membrane is present, so all the way from the lumbar area to the thoracic to the neck and even up into the brain around the cranial nerves. I am going to focus on the lumbar area because it is the most frequent. Pain is usually but not invariably the first symptom and remains a very big problem, although patients can have lots of other issues, such as loss of muscle function—so weakness, even going to paraplegia, to incontinence of urine and faeces and other problems.

The other aspect that causes patients problems is that very often the symptoms and signs can be very diffuse, and this goes against, I guess, the presentations to many neurologists and other people who follow so-called dermatomal patterns—in other words, following the pattern of a single spinal nerve which is well mapped out. Suddenly, they are confronted with a patient who has pain in a patchy distribution all over their lower limbs which this week is a little bit different to what it was last week—and that certainly is a characteristic of this condition. The lower back is often an area that is also involved, and rather than being a tissue injury pain, the way a lot of back pain can present, this is a so-called neuropathic pain, a pain associated with nerve damage, which has a different sort of presentation. A lot of the pain associated with arachnoiditis is nerve damage pain, neuropathic pain, so I will say a little bit more about this.

The pain is often described as stinging, burning, gnawing, and there are often pins and needles. There can be electricity sensations, like bolts of electricity running from one area to another. The pain is often continuous, or, if it is not at the start, it becomes continuous. But it can have spikes of pain on top of that which can be triggered by movement—jarring, straining, even coughing or sneezing. In some of the most severe patients I have seen, just moving the end of the bed a little bit can be enough to trigger a paroxysm of pain. There can be cramping sensations and painful muscle spasms, and this sometimes means that, in addition to the nerve roots that go into the spinal cord that are associated with sensation, there is involvement of the nerve roots in the front of the cord that are associated with muscle function. There can be damage to the spinal cord itself that can cause changes in sensation and motor function.

Because of all these factors, the so-called straight leg raise test is used—which is usually used where there is a sign of pressure or irritation of a single nerve root. In the case of arachnoiditis, it is usually the involvement of several or many nerve roots. So the straight leg raise test is often extremely positive and, indeed, excruciatingly painful for a patient if it is tested. Taking that to a more extreme state, just flexing the neck, which is usually a sign of a meningeal infection, can be positive in patients with arachnoiditis.

Just to summarise, then, one of the problems in diagnosis and in patients being believed is the fact that the pain is so widespread, is poorly localised and can be inconsistent from week to week.

A patient can also experience what are called dysesthesias. These are unpleasant abnormal sensations. They may feel like hot water being poured over a leg or ants walking on the surface of the skin. These are due to a loss of the myelin coating on the nerve—a loss of the normal input into the spinal cord, which causes very aberrant firing of the nerve cells in the spinal cord. The end result is an error message going to the brain and the brain...
interprets what it is receiving as being one of these very abnormal sensations. That is all I am going to say about the symptoms. I could say a great deal more, because there are some very complex clinical presentations that can occur.

One of the disturbing tendencies of lumbosacral chronic arachnoiditis is that the problem can go further up the spinal canal. So if it started off involving a number of nerve roots—that is called the cauda equina, as Professor Stoodley pointed out—it can then go further up and start to involve the spinal cord itself. Also, as Professor Stoodley pointed out, you can get little loculations. There is so much inflammation that you can get cystic formation outside the spinal cord. One of the important things that has been learned, in the last 20 years that I have been working with various neurosurgeons, is that the spinal cord becomes tethered. It is meant to have a degree of movement for the normal circulation of the spinal fluid but if it becomes very strongly tethered in the one position then spinal fluid starts to enter into the centre of the spinal cord and that forms a cyst, which is called a syrinx, which can then start to press on the nerve tissue of the spinal cord.

What about the actual causes of arachnoiditis? I am very pleased to hear that Professor Stoodley is doing research on this because there has been far too little information about it. Most of the literature refers to arachnoiditis that has been triggered by the so-called older myelographic contrast media. Now that we have MRI we have got the ability to follow the progress of arachnoiditis without having contrast drugs injecting things into the spinal fluid, which can be the very cause of the problem.

In the textbook of pain that I referred to there is a table in one chapter on some of the factors that predispose to arachnoiditis. They include chronic lumbosacral nerve root compression, which is not an uncommon problem, due to things like a disc protrusion or spinal stenosis, narrowing of the spinal canal. If this becomes a chronic problem it can be the trigger in developing inflammation. The inflammation has to be in the subarachnoid space, which is deep to the dura, which is the strong membrane that contains the spinal fluid. Also, if infection develops for any reason, bacterial, fungal, viral—any of those infections—it can be enough to trigger this. It has also been found to be a potential trigger and that can occur through a bleed from a spinal vascular malformation following trauma, following a lumbar puncture and even following surgery can be enough in the presence of an inflamed nerve root to trigger this. Finally, irritant chemicals such as myelographic contrast media and some antibiotics. Amphotericin B is one and Methotrexate, which is an anticancer drug. There has been a lot of controversy around the use of steroids injected into spinal fluid. Probably the offending agent there is polyethylene glycol. Finally, the local anaesthetic 2-chloroprocaine, was thought initially to be the cause of neurological symptoms associated with possible arachnoiditis but, after careful study, it was found that the pH of the local anaesthetic solution—a very low pH in one particular preparation—was what caused the problem. So it is obviously a very, very sensitive area.

There is not a lot else I wanted to say apart from a few more comments about the sorts of changes that can occur and how they fit in with the symptoms that we see. Very often chronically compressed nerve roots become swollen and this can be associated with inflammation in the arachnoid so that starts off the process. This has to be distinguished fairly carefully from the sort of scar formation that is very common to see after a lot of surgery but is restricted to the epidural space—that is, outside the dura and well separated from the spinal fluids. That is a normal sort of thing that is often seen after surgery. Mostly it does not cause a problem but rarely it can. It is a little bit different to what we are talking about.

CHAIR: Thank you very much, Professor Cousins—

Prof. Cousins: I think I will leave it at that. I would be happy to answer questions about treatment but I will very briefly say that, sadly, the treatment is largely unsatisfactory but on the good side, because one of the major problems from a pain point of view is that we are treating a neuropathic pain, which as far as we know so far is quite similar to other neuropathic pain states. We tend to apply drugs that have been specifically developed or older drugs that are now known to be effective in neuropathic pain, and they include the old tricyclic drugs such as amitriptyline—

CHAIR: Excuse me, Professor Cousins—

Prof. Cousins: and the newer of the SNRI drugs—

CHAIR: Professor Cousins—it is obvious he cannot hear us. Could you please round it up, because we have got another eight people here who are waiting to give evidence and we have some questions.

Prof. Cousins: I will sum it up by saying that we now have some drugs that can be effective for neuropathic pain of the arachnoiditis type, and there is one particular specific treatment that can be considered—that is, spinal cord stimulation. There are still a lot of problems with matching that up with the needs of arachnoiditis. Thank you.
CHAIR: Thank you very much for that, Professor, and I am sorry if it seems as if I was hurrying you up but we have a schedule and many other witnesses. We will move to questions from the committee.

Ms HALL: Thank you very much. I am interested in the last thing that you said about spinal cord stimulation: would you like to share with the committee a little information about that, please.

Prof. Cousins: I will be very brief, because it is early days. I have not found the existing spinal cord stimulation methodology to be terribly useful in many people's arachnoiditis. I have been trying to use it for over 30 years. The news is that for the very first time we are able to measure compound action potentials from the spinal cord of people with neuropathic pain. This is being done in Australia—it is being done partly in my unit, the Pain Management Research Institute. I believe this will allow us to understand much better what are the underlying mechanisms of problems such as neuropathic pain of arachnoiditis. We are working with a federal government funded research institute called NICTA and we are well down the track in developing specific new-age technology which will be able to exploit this treatment of neuromodulation. I think this holds some hope for neuropathic pain sufferers and also arachnoiditis sufferers.

Ms HALL: Do people that have had a myelogram plus surgery have a greater frequency of arachnoiditis than those that have just had the myelogram?

Prof. Cousins: It is very difficult to answer that question in the modern context, because there are so few people now having myelogram. I think I have ordered a myelogram twice in the last 20 years. Most of those patients who used to have myelograms are now having MRIs and therefore the numbers are just not there to allow me to answer your question.

Ms HALL: I am just wondering if you have historic data.

Prof. Cousins: I do not, but if you look at the table of causes, and if you add one cause onto the top of the other, the general finding has been that if you have got more than one aetiologic factor operating, then, just by common sense, there may be a greater risk.

Ms HALL: Thank you.

Mr IRONS: With arachnoiditis what would be the most common cause? If someone came to you with symptoms that led you to believe that you would look down that road, what would be the first question you would ask them with regard to trying to diagnose someone who might potentially have arachnoiditis?

Prof. Cousins: When I first started working in the field of pain medicine, the most common cause would have been the old Myodil contrast medium. But that is right at the start. This is why the chapter is entitled 'Nerve root damage and arachnoiditis'. Damage to a nerve root, from any cause you care to name—and there are a very large number of them—can be a big enough trigger to trigger arachnoiditis. A nerve root may become compressed by a disc protrusion and then goes on to a lot of inflammation, and sometimes a lot of inflammation is generated by leakage of disc material onto the nerve root. But spinal stenosis—narrowing of the whole spinal canal—can also do it, and the presence of blood due to, for example, a lumbar puncture. That is not all that common in people with a spinal pain problem these days unless there is a question mark about infection. But a lumbar puncture can cause bleeding, and once you have blood in the subarachnoid space it can act as a trigger.

In this day and age, with much lower use of myelography and much higher use of MRI to make all the important diagnoses—and, if not, MRI/CT—we are now going back towards nerve root damage due to various causes as being most likely to be the most common presentation. Whereas in previous times there was an era where it was Myodil, basically.

Mr LYONS: I have a question about epidural anaesthetics and the potential risk of epidurals. They seem to be used in a lot of cases now, such as if you are going to have your knee arthroscoped or for women giving birth. Are there potential risks of increasing this problem?

Prof. Cousins: I think that as far as the evidence that appropriate doses of appropriately prepared solutions of local anaesthetics cause arachnoiditis, there is no evidence. There was a brief concern with the local anaesthetic 2-chloroprocaine, which never had much of a use in this country. It was one particular preparation that had not previously been present, and someone suddenly decided that they were going to add chloroprocaine to this company's range of products, and they neglected to very carefully buffer the hydrogen-iron concentration of the solution that they offered to use. It was subsequently found that the pH was extremely low. We know that that is a crucial aspect of any drug given directly into the spinal fluid. Once that was learned, that product was withdrawn and the presence of those cases virtually disappeared. The same was true for depocorticosteroids. There was quite a flurry of cases in this country and indeed there was a focus on cases in this country that did not exist elsewhere. It was found that the intrathecal—not epidural—administration of methylprednisolone acetate which contained polyethylene glycol was capable providing irritation of the arachnoid.
Apart from that, the epidural, rather than intrathecal, administration of appropriate preparations of corticosteroids continues to this day to be very valuable for patients with nerve root irritation—not for patients with spinal nerve compressions, not administered intrathecally and not for patients for whom back pain is the primary problem. There are a lot of ifs there, I know, but that is the case in all of medicine—that the correct treatment needs to be applied to the appropriate circumstances.

CHAIR: Thank you very much, Professor Cousins, for that statement. If there is anything else we want to ask, we will be in touch with you again. If you feel there is anything you need to add which was not discussed today, feel free to call us.
AHRENS, Mrs Ruth Eileen, Vice President, Australian Arachnoiditis Sufferers Association of New South Wales

BAGGOLEY, Professor Christopher, Australian Government's Chief Medical Officer, Department of Health and Ageing

CLARKE, Ms Bernadette, Private capacity

GILL, Dr Anthony John, Acting Principal Medical Adviser, Therapeutic Goods Administration

HAGEMANN, Mr Joern, Private capacity

McLEAN, Mrs Maureen, President, Secretary and Webmaster, Australian Arachnoiditis Sufferers Association

SAGE, Professor Michael, Past President, Chief Counsel and Honorary Editor, Royal Australian and New Zealand College of Radiologists

SCOTT, Mr Maxwell John, Private capacity

ZORZIT, Mrs Erika, Private capacity

[09:51]

Evidence from Mr Scott was taken via teleconference—

CHAIR: I welcome the rest of our panel to start our round table discussion. I will start by asking Joern if he would like to make an opening statement—or, perhaps, Erika?

Mrs Zorzit: Dad has asked if I could read this out for him.

CHAIR: Certainly. We will go around the room and then open up for the informal general discussion.

Mrs Zorzit: My father's statement says:

My name is Joern Hagemann. I am here in a private capacity, although I am a member of the Australian Arachnoiditis Sufferers Association of New South Wales. Whilst working as a bricklayer in Canberra in 1978, I had cause to visit my GP as I felt severe back pain. My GP referred me to a specialist who indicated that I needed to undergo a procedure to determine the cause of this pain. I underwent that procedure that involved the injection of a substance into my spinal cord. Having viewed the results, the specialist suggested that I undergo a back operation. Concerned about this, I indicated that I would prefer a second opinion, which the specialist organised.

I later visited a chiropractor who indicated to me that I had a chance to avoid the operation through chiropractic treatment, which I chose to undergo. The chiropractor had taken an X-ray of my spine for his records. After 18 years I obtained the image from my chiropractor, which clearly outlined a foreign body in my spinal cord. I have now been medically diagnosed as having oil based adhesive arachnoiditis, resulted from the injection of the toxic substance Myodil, the substance used in myelograms at the then Canberra Hospital. To this day I have not undergone any surgical procedures on my spine, and therefore my affliction with this disease is not the resultant outcome of a procedure, but the direct result of the use of the substance Myodil. Having experienced the debilitating symptoms of this disease for many years now, and having spent many years researching this topic, I am here today in the hope that I am able to assist the Standing Committee on Health and Ageing in having this condition not only formally recognised, but also acknowledged and addressed.

The impact that the inappropriate use of this substance has had on the Australian community is not only an issue for today but is one that will be an issue for the foreseeable future. I stand before you and implore you to give this incurable and insidious disease the time and attention it requires to ensure all sufferers are supported as they and their families continue a battle—

CHAIR: We can come back to you if you like.

Mrs Zorzit: Sorry, I have have had to live with the legacy that the use of this this toxic substance has had.

CHAIR: We will come back to you. Just before we go to the next witness who is here, Dr Tony Gill, can I ask Max Scott, who was on the line, who he represents.

Mr Scott: Good morning. I am representing myself. I have been in pain since 1977—

CHAIR: Thank you. We will come back to you for your statement and I apologise for not introducing it earlier.

Dr Gill: Certainly the Therapeutic Goods Administration is aware of reports of a number of Australians are suffering from the debilitating condition arachnoiditis following the use of the iophendylate dyes, Pantopaque and Myodil. These were both injectable preparations that were used in Australia and overseas as has been mentioned by previous speakers. Neither product has been supplied in Australia for many years, nor of any products
containing the iophendylate currently approved for use in Australia. Both products were available in Australia before compulsory pre-marking evaluation by the Commonwealth government was introduced in 1970, and it is believed, Myodil from at least 1959 from records and Pantopaque from at least 1961.

Myodil ceased to be supplied in Australia in 1987, and Pantopaque some time in the 1980s. The TGA is aware, from its records from the early 1970s the prescribing information for Myodil warned of the possibility of arachnoiditis and recommended that the product be removed from the end of the procedure. Similar warnings were contained in the prescriber information Pantopaque. That entire information was provided to doctors about the risks of these dyes, how to avoid them, but in the end, as has been described, for a period of time they were the only imaging agents available to look at people for many conditions.

**Prof. Baggoley:** I think it clearly most important that this round table hears from the experts in this condition, and those experts are these sufferers, their carers and today, the neurosurgeon, the anaesthetist and soon the radiologist. I think the format is very helpful and will be informative. This is for me—and I am not at all, I must stress, an expert in this field—there has been an opportunity for me to read, to learn and to talk about the condition, which obviously, as we have heard already, can be most distressing of all concerned. My background is as a specialist emergency physician, and it did not lead me into this area, not in ordering a myelogram or even an MRI, and not in spinal surgery or in the treatment of arachnoiditis, but I was frequently called upon to assess patients with back pain and for possible or actual spinal trauma.

My reading has been in a number of areas, but I will share two sources with you. The first was from Peter Day and titled *Arachnoiditis: a brief summary of the literature*, which was the New Zealand Health Technology Assessment report of November 2001; I am sure you have that. The other was in a textbook titled *Essentials of Physical Medicine and Rehabilitation*, 2nd edition, Saunders, 2008; the editor was Frontera. I am referring to the chapter by Michael Osborne on arachnoiditis, which is chapter 102. It is a succinct chapter, but it is also very helpful—it covers many of the areas that we are covering here today. My reading shows what you have heard today: the prevalence of adhesive arachnoiditis is unclear, the causes are many, presentations are not typical—that is, there is not one pattern; we have heard that there are many patterns, even within a patient—diagnosis these days is easier, treatments are not curative and prognosis is not optimistic. Research is not easy. Professor Stoodley is the most prominent Australian researcher in this area, and even there it is not necessarily directly on arachnoiditis but on this other condition of syringomyelia.

I finish by indicating that, as is my practice as Chief Medical Officer when seeking advice, I went to the Royal Australasian College of Physicians and the Royal Australian and New Zealand College of Radiologists to ask for contacts of experts in the field. They offered Professor Michael Cousins, from whom you have just heard, and Professor Michael Sage, from whom you will hear very shortly. Both of them were teachers of mine at Flinders University back in the 1970s. I spoke to each of them this week, and I think it is important that you know that.

**Prof. Sage:** I guess I am asked to give an opening statement. I did not realise; I thought I was coming in more for background, because this is an area in which I have had enormous interest since I trained.

I believe that the most common cause of chronic arachnoiditis is Myodil, and most people have been suffering for 40 years. I sit back and think: cigarettes, mesothelioma—I go through it all. These people have suffered, mainly because we were using a dye, Myodil, with no alternative. This was used until the early 1970s in the British-trained areas like Australia, New Zealand and Britain—Myodil was left in. Then there was a gradual recognition—with poor literature, I might say—that there was a problem. A needle was introduced to allow us to suck it out; the problem was that it was often impossible to suck it all out anyway. The bottom line was that, if there was some alternative, we should not have been putting it in. I was very concerned about this.

The Swedes never used it, or they banned it in the 1950s. Sadly, the only alternative was water-soluble contrast, which in those days was ionic—it was hypertonic—and they had to give a general anaesthetic, and people suffered epilepsy. It was not the answer; Myodil was probably as safe. Ahlem came up with the idea of non-ionic contrast, which could be introduced. The first paper in his research was in 1968. In the mid-1970s, I started writing to the government saying, ‘Can we do a trial of Metrizamide?’ That was eventually done in Adelaide, and Metrizamide was released in, probably, the late 1970s. After the 1970s I never used Myodil; it was sometimes, perhaps, used by neurosurgeons when they did a ventriculogram. It was thought to be inert, but in fact it was not. It was just like, if you have a child and give them penicillin, 99.9 per cent of the kids will have no problem, but 0.1 per cent will have a severe reaction. Myodil is the same.

Since that time we have gone through the possible aetiologies, and as a neuroradiologist I have not seen much new arachnoiditis due to haemorrhage or fungal infections. Michael mentioned spinal stenosis. It is so common—one of us will have it—but I do not believe it produces this chronic arachnoiditis.
In summary, I am sad that it has taken 40 years to get here for the sufferers. I strongly believe that Myodil was used in good faith and that there was no alternative at the time, until the late 1970s in Australia. Sure, the instructions were to suck it out, but in fact you could not always suck it out. Some neurosurgeons insisted on you running it up to the top to make sure that there was not a lump higher up that could go into the subarachnoid space around the brain. It could actually go into the subarachnoid space around the brain. It was done because it was thought it was inert, that it sat there in the water and did not cause any trouble.

Then you add surgery. You mention surgery. That was a problem because then: who blamed who? 'The back pain was the arachnoiditis.' 'No, it was the surgery.' It is extremely hard to do a blind trial in this sort of area, almost impossible.

I was interested to hear the story of Erika; she did not have surgery. I think that was an important one, because she did not have surgery. I guess I am overestimating it, but I do feel over these years that—the Hippocratic oath is 'First, do no harm'—I think in good faith in the early days, usually Myodil, we did it for that reason. I felt sorry for those because, as Michael pointed out, there is no cure really. Spinal cord stimulation is—I mean, that will come, but you end up with an epidural catheter up your back. It is not like taking penicillin. So I strongly believe that Myodil, arachnoiditis, chronic arachnoiditis, did and does exist. I believe that the aetiology—Depo-Medrol, we used to actually, we sucked it out and we were told to put Depo-Medrol, which Michael mentioned, around the hole to stop the leakage. In retrospect, that may have in fact compounded the problem.

**CHAIR:** Thank you very much Professor Sage. Whilst Professor Stoodley was giving his statement, I think you questioned a couple of the dates?

**Prof. Sage:** Yes, he said late 1985 or something, but the Metrizamide was released in the 1970s.

**Dr Gill:** 1976.

**Prof. Sage:** 1976. That is when the trial was done. It was probably released by the TGA by the late 70s, I think wasn't it? Since that time, I might say, Metrizamide was not holy water; you actually had to mix it up. Since then—there have been the Swedes particularly and the Germans—it gradually got safer and safer, non-ionic contrast media. So Metrizamide was not ideal. I think Metrizamide in the early days was much better that Myodil but could potentially produce arachnoiditis.

**Ms HALL:** But Myodil was still used into the 1980s.

**Prof. Sage:** It was. It was not used by me.

**Ms HALL:** Not by you, but I know in my area it was.

**Prof. Sage:** I am not being defensive. I really did see these patients, and they were moved because we didn't really—(1) they did not want to believe it; (2) we had nothing better until the 1970s. So what were we going to do? If we admitted it was not any good, what did we do with these cases? Then you added surgery on top of that.

**Ms HALL:** In another life, I worked with people who had the injection in the 1980s.

**Prof. Sage:** Certainly some of the cases we have given here were, yes—it was not removed from 1987, so legally it was thought that you could use it until 1987.

**Ms HALL:** I think it is really important to get on the record and clarify those dates.

**Prof. Sage:** 1987. Yes.

**CHAIR:** Thank you, Professor.

**Mrs McLean:** I am the President/Secretary of the Australian Arachnoiditis Sufferers Association. I started it up when I had to leave work. I could not work any longer. I have adhesive arachnoiditis. I had my first Myodil in 1971. I have had five operations. In the first one, I had broken ligaments, and there was nothing to hold the discs in. The second one was in Australia in 1981. I had a major operation after the one in 1971. I was in hospital for a month. I had little children. The orthopaedic surgeon—because there were no neuros around then—they did not know where to put the nerves. So, the way I tell it to my members is: they just threw them back in. You go to a neuro; you do not go to an orthopaedic. He said: 'Maybe I've got the hardware too close to a nerve. I'll put you in again and I'll take the hardware out.' So he put me in again and it was like having another major operation.' I was in for two weeks, and then two months later I was back there again. I said, 'I don't know what's the matter.' But I found out in 2002 when it was on the front page of the Daily Telegraph for three days. All my workmates were coming in and saying, 'Mrs Mac, look, this is what you've got.' They recognised the symptoms just from me being at work. I said to my husband, 'I'm going to go and see him and ask him.' I said to him, 'Have I got arachnoiditis?' He said, 'Bloody papers.' He said, 'No.' About two months later he called me in and said: 'I'm sorry, I shouldn't have done that. You have got arachnoiditis and I'll show you where it is.'
I find the big problem is with the GPs. They are not trained to look for arachnoiditis. They do not know what it is. We have to train the GPs as to what is when we go to them. We have to take the paperwork out. I have special printouts for new members, for family and local doctors, and websites they can look up. Three years ago we were moving up to the Central Coast and my GP said: 'Don't go. You won't get a decent doctor up there.' For a while I thought he was right. I went into this doctor and I had my paperwork, which was not really small, and I left it there. The girl over the road was on the desk and I said to her, 'I'll leave my paperwork here and come and see him at 11 o'clock tomorrow.' He was an English doctor. He called my name and I went up the corridor with all these doors but I could not see him. We walked up and looked in through one of the doors and there he was, sitting at the desk, with my paperwork in his hand. He said, 'What the hell am I supposed to do with this?' I said, 'You're supposed to read it.' He said, 'I can't put it in the computer because I can't scan it in.' I said, 'No, if you scan it in you can't work with it.' And he said, 'What the hell did you move up here for anyway?' I said, 'Why'd you come out from England?' He kept on at me. He did not want to see me. He did not want to know about arachnoiditis and I was very upset because I did not know what I was going to do. I get really bad with restless legs syndrome. I had been rushed to Westmead Hospital by ambulance several times before we moved. We did go one, but we found out that he had a mental disease. He was very nice but each time you went back to him he could not remember what you had been for the last time. The lady in the chemist said, 'They've got a new doctor down the road.' She gave me his name and I went to him, and he was honest. He was born in South Africa, had worked in Canada for 10 years and then came out to Australia. He did not know what arachnoiditis was, so I took him in some paperwork. I am a patient of Professor Cousins and Professor Cousins getting up him a couple of times really worked because he went and researched it. For anything I go in to see him with now he will help me. It is not a dirty word to him. I feel safe because I have a good GP and I have Michael Cousins.

I would like that for all my members, but they do not get it. There are other members who live in Victoria, but they do not live in Melbourne. They live in the country and they cannot get to neurosurgeons or whoever they need for help. So they ring me and I make suggestions for their GP and for any medication that might help them. But I tell them that they have to talk to their GP, because I am not a doctor. I am only there to talk to them. As my husband knows, I can spend two hours a night talking to them on the phone. My big concern is epidurals—these ladies who do not want pain when they have their babies and opt to have an epidural. They do not realise they can be in for a lifetime of pain with arachnoiditis. I would like to see epidurals in childbirth stopped.

About a week ago I had a lady from Victoria on the phone who had had an epidural. Her son was 14 years old and I would have sworn by her symptoms that she had Myodil. But she had not. She did not know what it was. She did not know what a myelogram was. But she had had cortisone into the spine—going back so far, it was the epidural. I am getting more and more of them.

Ms HALL: You have shared with us the width and breadth of how it has affected you and some of your members. We have more questions but maybe we need to—

CHAIR: Mrs Ahrens, would you like to make a statement.

Mrs Ahrens: In 1989 I sustained a back injury while working. I had ruptured a couple of disks. I tried to do some swimming and whatever in the beginning, but the pain became so intense that I saw an orthopaedic surgeon. In 1990 a myelogram was performed. In 1992 I had the surgery, which was a spinal fusion. After the surgery I was good for about 12 months. Then I developed this pain again. This time I went to a neurologist. I had had an orthopaedic surgeon in the beginning. He look at it and ordered a CT scan, and that where it showed adhesive arachnoiditis.

Probably from when I sustained the back industry, in 1989, up until 2001 I was in and out of hospital for chronic pain relief. In between that I suffered a breakdown. It has affected my life in many ways. But, with the help of my GP, I was introduced to cognitive therapy, and it has been a positive for me. It is not for everyone, but it has been for me. Today I swim and walk, but I am still on opiate medication. I can live a reasonable life, and I started my own business some years ago. I work from home.

CHAIR: Our final participant is Mr Max Scott, who is giving evidence via telephone.

Mr Scott: My problems started in July 1977, when I was employed by Lanark Trading, a one-man business selling, assembling, packing and delivering light fittings. One particular day I picked up a box of light fittings to take to a store, then I twisted and fell to the ground. Later I went to see my doctor and then a specialist, who sent me to St John of God Hospital, which is now demolished.

I was told that I was to have a special X-ray. Three straps were placed around my body to stop any movement. Three needles were then injected into my spine, into the cervical, thoracic and lumbar fluid. Lumbar fluid was extracted and Pantopaque inserted. The X-ray table was then rotated to various positions to allow the dye to flow
and to ascertain any injuries. This took about two and a quarter hours, by which time I became unconscious. I do not know for how long. The procedure started at about 1 pm, and when I awoke it was pitch black. A laminectomy operation followed, and it took me 12 months to recover. I was dismissed from work on arrival back, telling me that I was away for too long.

During my last visit to the surgeon, in 1978, I asked about my future. He said I would suffer from fibrosis, stenosis and arachnoiditis, which is the dye attacking the nerves as they leave the spinal canal. He also said I may finish up in a walking chair. Pantopaque had a devastating effect on my body, causing immense pain from my spine and legs, plus headaches, electric type shocks through my arms and fingers and clumping of the cauda equina in the lumbar region, indicating adhesive arachnoiditis. It caused me to endure two more successive surgeries. Now I am a paraplegic with titanium plates and screws on either side of my spine.

I now exist on an electric wheelchair and a bed, transferring from one to the other by means of slide-boards. My only outings now are to go shopping once a fortnight, by means of a maxi-taxi. For hygiene, ladies from Amana Living, with some help from the state government, come to shower and dress me six days a week. My wife, now in her 80th year, attends to me on Sundays and puts me to bed at night and gets me out of bed in the morning. She prepares meals and keeps the garden and the house in order. Also, she handles the very uncomfortable situation of toilet duties. These are things she did not envisage when she married me, some 54 years ago.

I have been prescribed morphine and OxyContin and it had a devastating effect. I rid myself of these as quickly as possible. I am now taking Codalgin Forte. Over the years I have written many letters to many members of parliament and government employees asking for help, but I have always been told to look elsewhere as it was not their department. I even wrote to the Ombudsman in Canberra for help. The reply was not by letter but by phone. It was a woman, who said, 'A similar case was received a couple of years ago and was turned down.' She stated that she could see no other reason that I should not receive the same fate.

I now ask this Standing Committee on Health and Ageing from the House of Representatives of the Parliament of Australia to investigate with great vigour and without fear or favour this terrible disease, which has affected thousands of Australians through the incompetence, mismanagement or greed of chemical companies. I also ask for the investigation of the Therapeutic Goods Administration for allowing the distribution of this dye throughout Australia without testing it thoroughly or advising patients of what could or would happen to them, such as death, strokes, heart attacks, meningitis and adhesive arachnoiditis. Thank you for this opportunity.

CHAIR: Thank you for sharing your views with us.

Proceedings suspended from 10:29 to 10:47

CHAIR: Thank you once again for coming to the committee today to talk to us and thank you for your stories, which we heard earlier. This session will open up to questions; the committee will ask questions in a very informal question and answer session.

Mr IRONS: Professor Sage, I was very happy to hear you talk this morning, speaking openly in the way you did. As I said earlier to one of the other witnesses, Jennie George tried to instigate an inquiry into this issue about six years ago and came up against a brick wall; in her words there was a 'conspiracy of silence'. We have heard evidence before that GSK has had a $3 billion fine by US authorities for the way they have behaved with particular drugs. We also saw the article in 2002 where Sue Dunlevy mentioned a radiologist knowing what the potential effects of Myodil were. Do you think there has been a conspiracy of silence on this particular issue at all, or why GSK would pay out so much money UK but every time I ask a question everyone says, 'We can't answer that'?

Prof. Sage: Probably, before we had CT and MR, investigation of the brain and spine was very crude. That is the wrong term, but there was nothing better. Surgeons did burr holes into the brain, but when you think about it the investigation of brain tumours prior to the 1970s was very crude—we had nothing better. This applies very much to Myodil.

I trained initially in Adelaide and Melbourne, and the idea was that you put the Myodil in and did not suck it out. Then I went to the UK, where again the same thing was done. Then in 1971 there was concern in the UK that there may be some problems with Myodil and the American study said to aspirate it out. If you take an X-ray and someone says they have the old X-ray, it stays there. It looks awful. There are clots of Myodil on your spine. So, we started trying to aspirate it, but again we had to use it, because the only alternative—certainly in the British experience—was using the ionic contrast media, which was the one we used for IVPs and which, you might remember, had a very high reaction rate even intravenously. I think one in 50,000 people potentially died, so it
was pretty toxic stuff. We knew the Swedes were not using it, but they were working hard to find a non-ionic, which they eventually did. Ahlem found that.

When I came back we were aspirating it and that remained the recommendation until we got Metrizamide released. Many of us did not use Myodil again after the late seventies; however, it was still available for use until 1987. So the only period where there was debate about whether you used Myodil or not was perhaps from the late seventies to 1987. Part of the problem, as many of the stories are compounded, is that back pain is a difficult area and back surgery has as many problems as any other area of surgery that I know. When do you operate? What operation do you do? Once you add surgery to the myelogram—whether it is Myodil or Metrizamide or the new Iopamidol, et cetera—or even MRIs, you have the problem of post-operative complications. Once you have had surgery, it is very hard to know whether it is the Myodil or the surgery, but chronic arachnoiditis, whether it is due to the Myodil or surgery, has—as Mike Cousins describes beautifully—a classic or unique pain. It is difficult to define. If you have a pure disc, pain radiates down a classic nerve route; you have an MRI and there is the big disc; that is easy. If you have that paraesthesia he spoke about, not in a dermatome—a burning pain—it is a very non-specific thing.

Mr IRONS: I have some experience of that—I have three artificial discs in my back, so I understand the process of back surgery. It was a seven-hour operation. I certainly do not have arachnoiditis from the surgery, that is for sure.

Prof. Sage: If it is a classic disc operation you should not, because a classic disc operation does not go into the thecal sac. That is a generalisation. Sometimes a disc will erode, but generally if you have a disc operation or a disc fusion you are well away from the thecal sac, or you should be—not well away from it, but you should not be entering into it.

Mr IRONS: With all the uncertainty around what causes arachnoiditis, why would GSK pay all these people that money?

Prof. Sage: I get back to the fact that prior to the late 1970s we had no alternative. Just as you get children dying from a bee sting, you will get children dying from having penicillin. There is also some discussion where someone will describe someone who felt headachy and achy as due to Myodil. I think that we have to recognise that all drugs are not totally safe. The only function of this dye is not to do anything except to pacify the CSF and you had to be sure that all the iodine was still bound to the peanut oil or whatever oil it was. It was very important that whatever oil it was had to be bound. I think they had paid out because they recognised that it may have been that it should have been removed when Ahlem introduced Metrizamide in the mid to late seventies.

Mr IRONS: I have one more question: when the Swedes stopped using it, I think it was in 1948, what did they use instead?

Prof. Sage: That is what I am saying: the water-soluble contrasts we had for IVPs, for angiography, et cetera up until the late seventies were ionic contrast media where you had to have a cation and an anion—so it was an ionic thing—because when it went into solution it was hypertonic. And there were two problems you had: one was that the carrying agent you used for your iodine, was toxic—methylglucamine or sodium; and the other one was that it was hypertonic, and if you introduce a hypertonic solution into the CSF, that has an osmotic effect on the spinal cord and the nerves and causes a very severe acute reaction.

The Swedes did two things: they would either give you a GA and use the ionic contrast media, which had a risk of producing a seizure and other things so it was quite a major operation, or they would do what was called an air myelogram, which is where, to produce the contrast with the CSF, instead of putting in something that is more dense, you put air in, like with a chest X-ray—you know how you can see the lungs? But that was terrible, because you had to put the patient upside down and suck all the CSF out and put air in, and post-operatively the patient had enormous headaches.Now they did not push this. Why the Swedes banned it, I do not know. Certainly, in the late 1960s when I trained as a radiology registrar there was no discussion about the potential toxicity of Myodil. I would have thought that their ionic contrast media would have produced arachnoiditis too. It certainly did in experimental animals.

Mr IRONS: Okay, we will have to get them here and ask them! I have one more question: Joern, I understand you have a copy of your X-ray from the initial Myodil injection, and you also have CT scans from 18 years later?

Mr Hagemann: What I have is a copy of an X-ray which was not taken in hospital; it was actually taken by a chiropractor. I was not really aware of it, but when I was diagnosed I sort of consulted my chiropractor—about 18 years later that was—and I remembered that he had taken a picture of my back and I inquired if that was still available to me. This is the one which he actually took.
Mr IRONS: Could we please pass that to the committee so they can have a look at that? And have you also got a CT scan?

Mr Hagemann: That was done a little later, when there was a new way of imaging that came on the market and I tried that out. I believe that it also showed what is actually indicated on the X-ray taken a few years earlier. See?

Mr IRONS: So does it show that it is still your system?

Mr Hagemann: Yes.

Mr IRONS: If you would like to, could we at some point ask that those scans be tabled and we can get copies?

CHAIR: Yes. We will get copies.

Prof. Sage: With that scan, Mr Irons, the thing is that that will stay—

CHAIR: Before you go on, Professor Sage, as members of the committee we would not know what we are looking at when we are looking at these scans.

Prof. Sage: I was trying to comment on the fact that that white is the Myodil. And I was going to comment on the fact that that will stay there whether you have back pain or not.

Ms HALL: So that is the Myodil.

Prof. Sage: The white is the Myodil.

Mr IRONS: So that was not aspirated?

Prof. Sage: No, as it was not general practice in Australia probably until the very early 1970s.

Ms HALL: Can I ask a question? Can it be aspirated now?

Prof. Sage: It can be, although usually it gets stuck. With arachnoiditis it can be aspirated, but I think probably you would do more harm than good. And that was another dilemma—one of the observers mentioned how she got a very severe headache the following day after the myelogram. What happens if you puncture the thecal sac too much is that the CSF leaks out and you get what is called a low pressure headache. It has nothing to do with the Myodil. But if you try to go back the next day and repuncture and you could not get the Myodil out the first day sometimes you did get them back the next day and have another go, so it was fairly crude—I am sorry—but that is all we had 50 years ago.

Mr LYONS: Is polyethylene glycol still in use? What is its use?

Prof. Sage: It is not used.

Mr LYONS: Not used?

Prof. Sage: No.

Mr LYONS: Take links with other adhesions and other things, pericarditis and getting adhesions of the heart. It happens in footballers, in shins and muscles. Is there a propensity of some people to get adhesions?

Prof. Sage: There are people getting scars, so there is, and that would be potentially a problem, I guess, but I have never seen it. Someone mentioned arachnoiditis ossificans and these sorts of things. There are people who do actually—and they are fairly rare—get reactive changes in their fibrous tissue. Someone mentioned tethered cord. You may remember that there is a group of people who get born with a tethered cord and that can cause back pain and spinal problems. That is when the cord gets stuck at the bottom of the thecal sac and when you move around it cannot move. Potentially arachnoiditis could do that.

Mr IRONS: Obviously there is a bit of concern about orthopaedic operations and the chances of them being a success, to stop pain, and probably people are not going to be helped by an operation. Is there a procedure you could put in place? It seems there are a lot more orthopaedic surgeons than neuros around. Have you got a suggestion as to a person with back pain who wants to get it fixed? I guess I am after a procedure.

Prof. Sage: When medical students used to come to me and ask what they should do and they said they wanted to do surgery, I would say, 'You've got to be careful. You've got to be in the middle. If you're a gung-ho fellow, no. If you've got a good balance in the case of the surgery, you're okay.'

What I am saying is that part of the problem we have got, as from some of the stories, is once you add surgery. Again, we do not know. Unless I could look at the X-rays I could not even give an opinion on the indications for that surgery. Some people are fusing people from the front. Some fuse from the back. The only very clear-cut back operations are those where you have a congenital slip and you have a fusion; those who have a classical disc, which does not get better and you can operate; and probably spinal canal stenosis, which quite a few of us of our
generation have if we have perhaps worked a bit more than the youngers—and I should not say that. We may have hyperchia of postural ligaments and our joints which cause the spinal canal to be narrowed. So they sometimes do a postdural anectomy, but again they should not actually enter into the thecal sac.

Mr LYONS: So?

Prof. Sage: I would not have any answer unless you gave me a thousand orthopaedic surgeon operations and asked me to review the X-rays and said, 'Would I operate?' I would love to do that but I would not be very popular.

Mr LYONS: Take the insertion of devices, screws or whatever. Does that have a potential for causing this problem?

Prof. Sage: I do not think arachnoiditis, because the surgery does not enter it. That is the problem. We do confuse postoperative pain, which I think is very common following a back operation—well, it is not uncommon; a good politician's term. Let me put it this way. I think back operations will cause back pain, which is different from arachnoiditis. Arachnoiditis pain—as beautifully described by Michael Cousins, I believe—is fairly diffuse. That is why it is ignored—because people cannot put a label on it. It is not a disc, it is not a facet joint. I have injected a lot of facet joints. People come in with back pain who have that facet joint injected and the pain goes away. You know that is causing the problem. Other people will come in and have the facet joint injection and the pain will not go away, and you do not know the cause.

CHAIR: And therefore it is something else.

Prof. Sage: Yes, it is something else.

Mr LYONS: If the standard hospital has one neuro- and 12 or 13 orthopaedic surgeons, then what do you recommend as a ratio of people with orthopaedic causes of back pain and people with nerve causes?

Prof. Sage: I would look at their training. I have some orthopaedic surgeon friends who are very good. Orthopaedics has now become very specialised, as you know. You have hips, shoulders and little fingers. Sadly, that is bad, because no-one ever looks at the whole patient anymore. And I am married to a GP, so I can say that! You go to your knee man, you go to your hip man, as long as they have the correct training. Cervical spine is probably better for neurosurgeons, but it is training; it is a label. Some neurosurgeons concentrate very much on intracranial vascular lesions.

Mr LYONS: I guess your advice is that we should be careful about doctors knowing more and more about less and less.

Prof. Sage: That is just a public comment.

Mr LYONS: Yes.

Prof. Sage: No, I think that really, if you have an accreditation system—which you should have, and most hospitals now have an accreditation system—the new federal medical board demands CPD. I would hope that at Flinders Medical Centre the surgeons accrediting people to do back operations would show that their training was adequate, whether they were a neurosurgeon or something else. So accreditation should be very rigorous. Never having been in the private sector, I am not sure that that occurs, but I think it does.

Mr LYONS: There would be more training in public hospitals than in private ones, though, wouldn't there?

Prof. Sage: Yes.

Ms HALL: Thank you so much, everybody. I know it has been really hard for some of you. I think I might start with Erika and Joern. How has it impacted on your life, and what sorts of things could have been done better to give you support and work with you along the way?

Mrs Zorzit: I think I will get my father to jump in here. I am here to represent him but I think, obviously, that he would like to speak to the committee so that they can understand what it is that he has experienced.

Ms HALL: That would be lovely.
Mr Hagemann: There have been a lot of questions asked, and a lot of answers given. I might refer back to September 2002, where Jennie George did ask all the questions repeatedly and she also got answers to the questions. But even I, as a layman, realised that those answers were not all to the point.

So the next thing which I found was that her questions were actually answered by Dr Mal Washer. I do not know what Dr Mal Washer's qualifications are, but I personally cannot ever agree with his answers. So I contacted someone who I would think is a very competent person. We contacted Dr Barton, and we wanted to know what his opinion was about this statement that was made.

Ms HALL: Dr Barton? What kind of a doctor is he?

Mr Hagemann: Dr Barton is a specialist. He is well known around the world, and in my opinion he has all the answers. Maybe not all the answers, but at least he has answers which I can understand even as a layman.

The point was that I needed to find out if that was the correct reply which Dr Washer had given. And the answer came back, 'You are right. Only one side of the story has been presented'. With what I researched I think that I can really understand what he meant by that.

Mr IRONS: Just for the record, can you tell us what the question was that Mal Washer was answering?

Mr Hagemann: All the questions raised by Jennie George.

Ms HALL: Was he speaking in the debate? I suspect that he was speaking in a debate—

Mr Hagemann: It was actually on Hansard, yes.

Ms HALL: Yes, he was speaking in a debate.

CHAIR: We would have that back on the—

Mr Hagemann: What annoyed me most was that he closed his argument with the wording, 'people did benefit from the availability of these dyes'. In my opinion, that shocked me. As a matter of fact, even today I am hearing that it was all done in good faith. I think that not even Mr Scott will agree that he benefited. And I do not think that he can accept that it has all been done in good faith, because the knowledge of the product was available ever since the forties. If it was all done in good faith, injuring all of us with that injection of Myodil, then I would like to know who was responsible and who is going to be made responsible for our suffering? That is what I would like to know.

As I said, a lot of questions were asked over the years; and again and again I read that those questions have never been answered properly. For instance, I just heard when my picture was produced and the substance was shown on the picture, the statement the gentleman made was, 'It will stay there'. That is totally incorrect. I have had many experiences in hospitals for years after; I attended hospitals and was always being released by them saying that it was an underlying problem. They have never determined what it was or never intended to determine what it was. Therefore, to the statement that the substance will stay there I would like to say: an MRI was taken and the report was given—it did not mention any substance at all. I went back to the radiologist, which I listed with you people, and said to him: 'There's something wrong here.' He said: 'What's this?' I said: 'I was injected with Myodil and I know it is still showing in the picture. Where is it in your picture?' He said: 'Oh no, mate. This is all in your head.' I said: 'Come off it; I've got proof.' 'Oh no,' he said, 'What I meant to say is that the substance over the years has travelled up your spinal cord ever so slowly and it probably will go as far as under your skull. It will come into the nerve section in your neck and it will cause a lot of damage.'

Ms HALL: Mr Hagemann, could I ask Professor Sage to comment on that from a medical perspective?

Prof. Sage: Sorry, I meant that it would not go away from—the subarachnoid space surrounds the brain: cerebrospinal fluid, CSF, is produced in cavities in the brain and circulates around down the spinal cord. What I'm saying is that Myodil will tend to stay in the subarachnoid space. It is my mobile and sometimes will go into the cervical region. I am not saying it is fixed in the lumbar region; I am just saying it does get absorbed. The research in this area is very poor, as you quite correctly say. Some people say that will one ml will be absorbed in every 10 years. Myodil is freely mobile and can—if you happen to be a diver or something and you dive—being heavier than CSF go down and into the skull. Theoretically, on the basis that it will not cause arachnoiditis. As I said, Professor Cousins or someone mentioned, arachnoiditis—we are talking very much about lumbar arachnoiditis, but it can occur anywhere. I agree: it may not stay in your lumbar region, but it is freely mobile in the CSF.

Mr IRONS: Max, have you got any experience with this issue about the Myodil and the CSF?

Mr Scott: The MRIs of my earlier X-rays showed that there were droplets of Pantopaque in my cranium as well as in different parts of the lumbar, thoracic or cervical region.
**Prof. Sage:** It is pretty mobile, like CSF.

**Mr Scott:** I must have been turned all over the place when I was on the X-ray table and they wanted the dye to move around. They put me upside down and in all sorts of silly angles to have a look. I don't know if they got it out of my spine at the finish of the X-rays. I was unconscious, so I have no idea what they did.

**Ms HALL:** Sorry to have interrupted you on that, Mr Hagemann. I thought it was really important to get that information onto the record.

**Mr Hagemann:** That's fine. If I may just continue on that point: at that time I would have liked to have had some more evidence and have been able to prove that I still had the Myodil in my spinal cord. I was advised at the time that it would have taken a very highly concentrated MRI setting and that it would probably determine droplets and all that sort of thing. But I was advised not to do that because that high MRI setting would probably have done more harm to me than anything else. In conclusion he said, straight out, 'Joern, you are lumbered with it, and that is about it.'

**Ms HALL:** Have you worked since you—

**Mr Hagemann:** I have worked. Of course I have worked. That was more or less because of my determination to raise my family. I did as much as I could. It is not very nice knowing where I am going.

**Ms HALL:** It is very hard for you.

**Mr Hagemann:** Yes. To that point, you have been asking what support is available.

**Ms HALL:** What would you like to see available?

**Mr Hagemann:** I have not had any support at all, so far. I have not even had pain management. Even so, I was listed and I made various phone calls. These people never came back to me. Now, the last thing I am trying to do in order to—

**Ms HALL:** Take your time.

**Mr Hagemann:** In order to be safe in the bathroom I meant to find out if handrails could be installed. Since I have realised that I will be relying on the wheelchair more often than I like I also inquired if I could possibly have a ramp constructed at my place. 'Of course, yes, that is all very possible. We will send you someone to inspect your premise. And we will also get someone to quote for handrails and a possible ramp. But let me tell you straight out, at the moment there are not any finances available for that sort of thing.'

**Ms HALL:** Where do you live?

**Mr Hagemann:** Out at Spence.

**CHAIR:** That is in Canberra.

**Mr Hagemann:** Quite frankly, I am quite prepared to listen to all of those sorts of excuses. It is the same when we talk about medication. Any sufferer will realise that our medication for the arachnoiditis is very expensive for us, and yet it is not listed. So I was on Lyrica for quite a while. Lyrica costs me $120-odd per month. That is, if I can stay on the low portion of it. The next portion would then cost me $300 a month, yet I have found out that apparently the question of adhesive arachnoiditis and anything attached to that has not been scientifically and medically proven. Having found out about that I ask myself, 'How come it is approved for the armed forces and not approved for us—the fellow on the street?' They can get the Lyrica for $5.80. We do not get it, because it is not approved. But how can it be scientifically and medically proven and not be on our site?

**Ms HALL:** I will ask Dr Gill to comment on that in a minute. The support you have received is basically nonexistent. You have two areas where assistance could have helped you a lot—pain management and home modifications. So if as a committee we are looking at the types of recommendations that we can make or the types of issues we can raise, one of them would be good-and-easy access to pain management. The second one would be streamlining home modifications—how people can get home modifications where they need them—and you also raised medication as an issue. Would that be a fair summation of what you said?

**Mr Hagemann:** Yes, it is.

**Ms HALL:** Maybe Dr Gill would like to comment on the issue of Lyrica?

**Dr Gill:** I do not think it is a relevant issue for the TGA; any costs and reimbursements have nothing to do with the Therapeutic Goods Administration. There are other parts of the department that are involved in that space—for example, health and ageing.

**Ms HALL:** So you cannot comment? Okay.

**CHAIR:** Maybe the Department of Health and Ageing might.
**Prof. Baggoyle:** I think this is something that needs to be followed up, as a result of this discussion, if this has been presented to the Pharmaceutical Benefits Advisory Committee: whether it has been presented and what the analysis has been. I am not familiar with the medication so I will need to make sure that we both become familiar. I think some research warrants follow up.

**Mrs Zorzit:** That particular medication was recommended to my father by Professor Lueck, from Canberra Hospital, as the medication he should be taking for his oil based arachnoiditis.

**Mr IRONS:** Mr Scott, could you also tell us what sort of medication you have been on and what sort of support or assistance you have received and where you see that the system falls down, or give us any recommendations that you think might make improvements for your situation?

**Mr Scott:** I am very lucky in regard to having Amana Living. They are a private organisation but they assist people like myself. Ladies come out and shower me and dress me in the mornings and take the responsibility off my wife. Even though we have to use slide boards to get from one thing to another, it is quite good. With regard to medication, as I said, I was on OxyContin and morphine but they tend to send you round the twist and I was happy to get myself off them. I am now only on Codalgin Forte. It is a damn good help.

**Ms HALL:** You have done really well.

**Mr Scott:** I had the hospital come to me and install ramps at the front door and the back door so I could get out in case of fire or something of that nature. I had to part-pay for concrete paths around the house and out the front. It is a fairly big block at 1,638 metres. I used to be able to get around. Not that I can do anything physically outside because I cannot even stand up. But I am quite satisfied with the help I have been getting.

**CHAIR:** I have a question for Maureen McLean—and Mrs Ahrens—about the organisation that you are president of. What sort of support does it give to other members or to people who are suffering from this illness? What else would you like to be doing if you had more resources? What other things could you offer? Is there any new member. Which specialist do you go to or can I give them your phone number? They can talk to you and you have an MRI. If they cannot get one, I have got members in all states and I ring them and say: ‘Look, I have got a new member. Which specialist do you go to or can I give them your phone number? They can talk to you and you can tell them what you think of your specialist or pain management clinic.’ I really recommend pain management clinics. Not enough people are going to pain management clinics, or they do not know that is a resource that they can go to at their public hospital.

**Mrs McLean:** We have members too that are in the country, and there is nothing out there for them in the public hospital system—and most of them are probably public hospital. Even just talking to someone can be helpful. As Maureen would tell you, we have had phone calls where people are going to commit suicide. We are
not trained. They need professional help and I do not think personally that we should have to take that bit on ourselves. If we can refer them to somebody—It becomes very stressful for us, and that stress affects our pain and emotional wellbeing too, but we want to help. If there is professional help there, we would prefer that. I believe that radiologists should play a bigger part and explain more to people. They say that the water based dye does not cause problems, but we have had many people that have had water based dyes that have got problems. These things should be explained to them when they go in to sign the form, by saying, 'This is what can possibly happen.'

**CHAIR:** That information is not there?

**Mrs Ahrens:** It is not there, no. It is frustrating.

**Mrs McLean:** I think the gentleman that is talking from Western Australia is very lucky that his wife is still there, because we have so many men where their wives have just had it—they walk out and they take the kids, or they take the house as well. We have quite a few male members like that. We have a lot of members that live on their own. My oldest one—she is my darling—lives on the South Coast. I rang her up on her 90th birthday, and at last she was moving into where she could be looked after, instead of caring for herself. Every now and again, she will send us $20 for a donation. I say to her, 'You're only on a pension, don't send it.' 'No, but I want to. I want to help out. I want to do my bit.'

**CHAIR:** That brings me to my next question: is there any funding from anywhere that your organisation receives?

**Mrs McLean:** Donations. When I started, I set it at $20 for a single member and, if the wife wanted to join, $30. I have never changed it. It is still the same. I told them I would never put it up.

**CHAIR:** Have you ever applied for any grants or government funding?

**Mrs McLean:** Community housing have funding there. Every second year, I can apply. The first year I applied, I asked for about $1,600 and they gave me $2,400, so I thought, 'This year, when I put it in, I'll put it up a bit,' so I did. I am still waiting to see if I was successful in that. But we have tried a lot of places and we get knocked back.

**Mrs Ahrens:** My husband is the treasurer. We have had a couple of big donations from private people, but most of it is run off the proverbial chook raffle—the moneys that we get in. The money is out of our pockets—not that that is a problem, but there has got to be help there, even if it is a phone call to someone.

**CHAIR:** Just before we go to Ms Clarke, Mr Scott had something to add to my original question about support in terms of the association. Do you have much to do with the association, Mr Scott?

**Mr Scott:** No, nothing at all. A long, long time ago I was in contact with a fellow that lives up at Woy Woy that started Redback, but that became too much. I know of a lot of people in Western Australia who are not getting any support whatsoever. Some of those are living very much on a knife edge, thinking of suicide and marriages breaking up and all that sort of thing. There is no support group in Western Australia that I know of.

**Mrs McLean:** We have got members in Western Australia. I know we have got New South Wales and...
onto him. He is my local GP, 600 or 700 kilometres away. I pay $180 to $200 every six weeks. I have tried every form of medication possible. I am on 90 milligram of MS-Contin per day. It costs me $180 to $200 every six weeks for my phone consultation. Because it is a phone consultation, I cannot claim a cent back. I have been doing that for 10 years. I even, in desperation, went to Perth to try radio wave therapy, which can help cancer patients for pain. Unfortunately, that did not do any good; they did not guarantee me anything but, when you are desperate, you try anything. That was another $15,000.

In the middle of all this I was nursing my husband, who was dying of cancer. There was no support or help for that. There is no support whatsoever in Gunnedah, as with a lot of people who live in the country. I spoke to two different people only last week who have had myelograms and do not know anything about it. So I just find it very hard. I look big and strong. I do not have any outwardly visible effects. People just think, 'What's wrong with her? She's got this and that'— blah, blah, blah. I try and put on some colour and a smile and go out, although I feel dreadful while I am out, and have a laugh; then go home and sit and cry by myself, which I do very regularly. It is just so depressing. And I have not had a back operation.

Ms HALL: That is what I wanted to ask.

Ms Clarke: My memory is getting so dreadful. I am so worried about my memory. I even did a living will recently. If I have to go into care, apart from having done an enduring guardianship, and cannot account for myself, I feel the first thing that would happen would be that I would be taken off my morphine—'Why is this lady, with no visible effects, on morphine?' So no medical practitioner is to take me off major pain-killing medication.

CHAIR: So you actually have that in your enduring—

Ms Clarke: I have done that recently, yes, through a solicitor, who has my will and my enduring guardianship. So that is how I feel it is affecting me. It is my whole body now, and this is what is getting so relentless. But thank you for including me and listening to me.

CHAIR: No, it has been our privilege.

Ms Clarke: I have been part of the association's committee—

CHAIR: Are you all members of the association?

Ms Clarke: Yes.

CHAIR: And Mr Scott?

Mrs Zorzit: No, Joern is.

Ms HALL: I have another question, but I just want to make sure that this is all expended and everybody is okay. I am very keen in knowing about the support services, and access to pain management and medication. If anyone else wants to come in on that, please do so. But the other thing that has struck me a little this morning is the difficulty in diagnosis, the lack of knowledge among GPs and health professionals. I was wondering whether you believe this is something that we should look at raising the awareness of. Maybe we could do it through urban divisions of GPs, or the new Medicare Local system. The two things I was interested in are what sort of support you need and the diagnostic issue.

Mrs Zorzit: This is going to be a problem for a long time to come. My father was not diagnosed for many, many years down the track, as you are aware, and as he said before, there were always underlying issues because nobody actually wanted to talk about it or knew about it. Now that he has been diagnosed, he is a pensioner and that also makes quite a difference to what his doctor has access to or can afford. Some people have probably got it but are unaware of it and are going to surface with it years down the track and if there is no education given now, or it is not at least accepted that this is a major issue, it is going to be a problem for a lot of people for a long time. They need to address it and pay some attention.

Mrs McLean: We need to start with GPs because that is where we go first.

CHAIR: The first people we contact.

Ms HALL: Awareness for GPs.

Mrs Ahrens: But I still think radiologists need that.

Prof. Sage: I really do not know, being married to a GP. I mean basically what I would like this committee to admit is that the disease does exist and secondly that in the past Myodil did cause it whether it was in good faith or not I do not know. All right? I agree that water-soluble contrast media can cause it and the use is much less now anyway. But my feeling is that a lot of people, after investigations of the back, go to surgery. Once you put surgery into the equation it complicates the picture. If you go back to the GP with your back pain after you have
had surgery the GP is very loath to say you have arachnoiditis due to the surgery. But my worry is that if we recognise that it does exist, I think it is not an orthopaedic problem. If there is not a surgical thing to cure it is actually a pain management issue. So I believe that we should be able to educate and make people aware that it does exist but GPs really do not have access to MRI anyway. The diagnosis is the clinical picture. You have had Myodil, a myelogram or back surgery and it requires someone like Michael Cousins to actually work out if this pain is due to arachnoiditis or related to something else. GPs do not have that skill. I would suggest that MRIs remove the need for myelography. If a myelogram is done now it may be that you have radio-opaque stuff here and there. I just feel that the condition does exist but the problem with it is it is compounded by surgery and people will then fudge it. They will say, 'Oh no, it is arachnoiditis' but we need the experts in the pain area to make the diagnosis. Once the diagnosis is made the person can have help which they need. Secondly it recognises that Michael Cousins clearly said there is currently no real help. They need support because there is no real cure. There is no operation; there is no magic bullet. I feel fiddling around with orthopods and neurosurgeons, et cetera, is a bit of a waste of time once the diagnosis is made.

Ms HALL: It is pain management.

Prof. Sage: It is pain management and support.

Ms HALL: What is the availability of pain management like? Do you come from Canberra?

Prof. Sage: No, I come from Adelaide. Michael Cousins initially started it in Adelaide.

Ms HALL: All right. Maybe you could just give us a bit of an overview of pain management services in your area of Adelaide and nationwide?

Prof. Sage: I cannot, really. Basically it was pioneered by Michael Cousins in Australia back in the seventies at Flinders Medical Centre. There was a pain management clinic at Flinders and also at Royal Adelaide. There are people—

Ms HALL: There is one in the Hunter.

Prof. Sage: Yes. The real problem is diagnosis. This is why the group I have built is based, as I said, on the Hippocratic oath—first do no harm. This group is a group of people who have, as Michael has beautifully described, such a variation in neurological symptoms and signs that they need someone with great experience to sort out if it is due to chronic arachnoiditis and give them a label. Then they need support—ramps, pain relief, et cetera—or they have somebody else do the operation and it is cured. I think there should be not so much emphasis on the College of Radiologists—because we are aware of the risks—but the public system should be supporting pain relief. A lot of pain units have not recognised that there is a great number of people out there with chronic arachnoiditis, which we now should recognise, and they need help. It is a cow—for the patients I see we have had the description. Once you add surgery it complicates the problem, and that is when you need Michael Cousins to say, 'I don't think your pain is due to the surgery; I think it's due to the arachnoiditis.'

CHAIR: We will come up with a discussion paper and a report, and from what I am hearing recognition and assistance to manage are basically—I will not say they are non-existent, but no-one tells you about it and you do not know where to go.

Prof. Sage: People get to chronic pain because it is not radicular pain and it is not facet joint pain but it is the result of iatrogenic misdemeanour which produces this fibrotic change. This can produce a spectrum of symptoms that need a Michael Cousins or someone of that skill to work out. Once they are labelled then they need help.

Mr Scott: I would like to know if there are other people who suffer from involuntary leg movement. My legs from time to time—left or right—jump up and move anywhere. There is no way I can tell it is coming, it just happens; my legs will go anywhere. It is particularly annoying when it is all day, or when you spend half the night trying to get off to sleep and your legs start to want to move everywhere. A lot of people have never approached this, but surely most of us would need some compensation for the injection of this dye. It paid out money all over the world into the millions, particularly in America and also in England. There was even a Western Australian woman some three or four years ago living in England who received something like 440,000 pounds. I have not heard of anybody in Australia receiving any compensation whatsoever.

Ms HALL: On that, is there any sort of class action case taking place in relation to that in Australia?

Mrs McLean: Yes. Litigation.

Mr Scott: Nothing in Western Australia.

Ms HALL: But not a class action.

Mrs McLean: We cannot have class action because we are all different. But there is litigation happening.
Mrs Ahrens: We cannot enter into that litigation because it is before the courts, but we can enter into lots of other stuff. A lot of the things that have been said today are things that can be—

Mrs McLean: The problem a lot of our members have is that they want to go for litigation and they cannot because they cannot prove to the solicitor that they have arachnoiditis—no-one will admit it.

Mr Scott: If you ask a solicitor in Western Australia about arachnoiditis they look like you have come from a foreign country.

Mr IRONS: But didn't you find with doctors as well that you could not find any GPs or even specialists who could help with diagnosing arachnoiditis?

Mr Scott: No. Only the two: the radiologist on MRI reports or CTs, or something of that nature.

Prof. Sage: That applies to every medical thing. That is why we concentrate our litigation on something that was done in the 1950s, the 1960s and the 1970s. Money is not going to cure the pain; support is. By that I mean, sure, you can litigate, and certain people will win and other people will lose. Let us agree that there is a problem here. We must get the diagnosis. If it is done by pain clinics you remove the litigation.

I do not like medical legal work, actually. If I do it I do not charge for it because I think it is a case of, 'There but for the grace of God go I.' That is what doctors think about medical legal problems. If we recognise that there is a problem—I am not saying people cannot litigate, but you will get certain people who will get payouts: some will get £400,000; other people get £7,000—and we support the people with it with diagnosis and support, like ramps et cetera, and pain relief and treatment—

CHAIR: And education.

Prof. Sage: we will have progressed somewhere in 40 years. Myodil is what worries me more, I guess, as a person who is old enough to have used it.

Mr Hagemann: Can I just add to that. As far as litigation is concerned, we were invited to go down to Sydney, at great expense, to talk to the lawyer who is now fighting the case for us. To our great disappointment—we were supposed to talk to the barrister at the time—the barrister did not make himself available. I presented my case, which is that I personally will always say that it is not the arachnoiditis that should be fought in courts any longer, because it has been fought for many years. If you were to go through my file, you would realise that even if a case has been settled—it is always settled out of court—it will then come to a point where the amounts that have been set aside for those cases that have been recognised have been divided into unequal parts. It has been divided into, 'You have that much; the other one had so much, and so forth.' It is proven that in some cases people have walked out of the court with $1,000 in their hands, because, as soon as they are going to get a settlement as far as a court is concerned, in comes Medibank and takes back all those charges which were related to the sickness of a condition which is not even recognised yet.

Coming back to the point with the lawyer, I said to him: 'If you were to represent me, please do not fight my case on arachnoiditis. I would like you to fight my case of having been injected with a toxic substance.' Do you know what the answer was? 'We can't do that.' I said, 'Why not?' because, to me, it is a fact. He said, 'No, we can't do that because we would open up a tin of worms.' Think about it. He is right, because there are about 60,000 sufferers in Australia. Can you sort them out by degrees of what sort of arachnoiditis they have? It will never be sorted. There is only one point that you can sort, and that is that they have been injected. If they have been injected with the toxic Myodil, then they have a case, in my opinion.

For that reason alone, I wanted some answers a few years back. We contacted, through email—and there is a file of emails—in the first instance Kate Lundy, and we asked Kate Lundy to take this case up for us, with a particular question, just one question. That question was going backwards and forwards for two long years, and we still have not got an answer. All I wanted to find out was: was I injected in Canberra? Point No. 1: was Canberra—if they would have answered my question—part of the experimental selection as far as distribution of Myodil was concerned? That is what I meant to find out. I never got that answer. We know a lot about the distribution of Myodil, which was all illegal anyhow, but it has never been followed up. Those are the real problems we have. We do not get any answers. We have been waiting for answers for years and years, and still, if we were to get an answer, I can assure you, all those answers are in here. It might have been Mr Butler, it might have been the health minister or it might have been anybody else in the system and they always in the end got the same question—and you cannot do anything with it.

That is our problem. As was just said, we are supposed to prove that we are suffering, but, if we cannot get any answers from those people who are supposed to support us, how can we prove our point? We cannot. That is the point I am making.
CHAIR: That is a very good point.

Prof. Baggoley: Can I follow up on your question earlier about the medication that Mr Hagemann spoke of—Lyrica; the generic name is pregabalin. You might note its use is described in the chapter on arachnoiditis by Michael Osborne; you now have a copy of that. The Pharmaceutical Benefits Advisory Committee gave pregabalin a positive recommendation in March this year for an authority required listing for neuropathic pain, when other treatments had failed, I think. Tony Gill was able to find that for me. This is a high-cost medicine and is subject to the memorandum of understanding with Medicines Australia. The government is committed to use its best endeavours for a six-month consideration and decision by the cabinet after pricing is agreed between the department and the sponsors.

CHAIR: So there are negotiations about the pricing at the moment?

Prof. Baggoley: Apparently the price has been agreed, so it is pending a cabinet decision.

CHAIR: Let us hope that happens soon.

Prof. Baggoley: I thought that would be important to advise you of.

Ms HALL: Thanks, that great.

CHAIR: The cabinet decision could take six months or three months; I do not know.

Prof. Baggoley: It is up to cabinet.

CHAIR: It has been approved and is before cabinet, which now has to make the decision to tick it off.

Prof. Baggoley: It has been recommended by PBAC.

CHAIR: Recommended, sorry.

Mr Hagemann: When you say it is in the stages of being approved, is that a result of the statement of principle which is dated 31 August? The armed forces personnel are suffering exactly the same as we are suffering, and now all of a sudden you hear about approvals. This is what I would like to find out. It even says it is a disease. All of a sudden we are going to get approval that it is a disease. We have been fighting for years to have it recognised as a disease.

CHAIR: It is before cabinet, so we do not know what the result will be.

Mr Hagemann: But this is already stated. These people are suffering exactly the same. May I add, as a layman, if I read these statements of principle, those people are going to be sorted just as much as we will be sorted all the time. It is written here, it is in black and white and anybody with a little bit of understanding will realise that half of these people will not be covered—I repeat: they will not be covered. If anybody wants to prove me wrong in the long run, I will accept it, but I am reading into this that they are not covered.

Ms HALL: It is the way the approval process takes place. The doctors could probably describe the approval process better than me, but basically the drug companies have to prove a case.

Mr Hagemann: Yes, I realise that.

Ms HALL: It sounds like the drug companies have proved their case and now—

Mr Hagemann: But this is compensation as well.

CHAIR: Yes, it is a separate thing.

Mr Hagemann: People are going to be compensated, provided they can prove their point.

CHAIR: We need to wrap it up. Ms Clarke.

Ms Clarke: I would just like to say that I had been to three pain clinics, but, as wonderful as they were, in our situation I feel they are trying to get us off the opiates and what have you and get out and do all the rehabilitation. Okay, it is important to keep active and keep going as much as we can. Are there any rebates I can get for this money that I am paying out every six weeks? There is $10,000 just in that alone—rebates from having to send to somewhere where I can get treatment.

CHAIR: I cannot give you that answer off the top of my head

Ms HALL: We will look into it.

Ms Clarke: Is there any compensation that I can get for that?

CHAIR: Who is your local MP?

Ms Clarke: Kevin Anderson is now. I have been to Peter Draper but, unfortunately, he got me the Hansard from parliament of Jenny George's—
CHAIR: What you need to do is go to your federal member—ring him—and ask him and they will investigate it for you.

Ms Clarke: Now that arachnoiditis is acknowledged through Myodil when I have not had a back operation and it is in the medical dictionary, why have we got to prove it as far as litigation goes for the likes of our two cases?

CHAIR: We cannot comment on the litigation side.

Mrs Ahrens: I can quickly say something about the litigation I was involved in some years ago: when I worked I received a workers comp claim, but in 1996 we had the insurers turn up at our door at home. They said, 'We want to help you. We want to put you in another house and we want to build all these ramps and put things in the ceiling and we want to look after you.' Then they said, 'Also, we would like to take you out and see this other gentleman and what we have done for him at Valentine,' which they did. He was 24/7 nursing care. My husband said, 'No, not unless you do it to the existing house and you add on.'

CHAIR: Sorry, this was an insurance company, did you say?

Mrs Ahrens: This is an insurance company, yes.

Ms HALL: Can I ask where you live?

Mrs Ahrens: Yes. I live in Maitland.

Ms HALL: I think I know the person in Valentine you are referring to.

Mrs Ahrens: Yes.

Ms HALL: That is in my electorate.

Mrs Ahrens: So you would know the coast quite well. I was taken out there, and yes they did on the room and I was compensated but I have not got better. It is not about the money—

CHAIR: It is about getting better.

Mrs Ahrens: It is. When I was really sick, my husband was doing four jobs to get my kids through university and things like that.

CHAIR: There is no doubt that one thing we have understood is the difficulties that people are going through. It is very hard. Before I formally close today's round table, I thank each and every one of you for your participation and for sharing your stories as hard as it was for some of you. It is important that we hear these things. Your contributions are extremely valuable as are your thoughts and insights for us to get an understanding of what is taking place. Thank you very much.

We will be coming up with a report. As I have said to all the other witnesses that were on the phone earlier, if there is anything for whatever reason that we did not get time for or you would have liked to have raised and we have not today—in discussions or questions—feel free to contact the secretariat to make sure that we get that information; and vice versa, if there is something that we think we might be able to assist with or want to ask you, we will be in touch with you.

I envisage a report towards the end of the year. That report will then be tabled in the parliament. There is no requirement of the ministers or government to respond to that report; however, what we have undertaken is ensure that we have raised this issue and that there is a better understanding of this particular issue. It will then be entirely up to the minister to take on recommendations—or not take them on—as the government of the day. We will have a small paper with a bit of research on it that will be here on the record for parliament for other people to access, read and learn more about your insights.

On that note, I would like to thank all of you for attending, the committee members and the secretariat for their organisation today and of course broadcasting for ensuring that we could contact the people on the phones and have the discussions with them and for keeping a record of everything that was said today. That will all be on the Hansard record in the next few days.

Before I declare the meeting adjourned, I ask that we form a subcommittee of Jill Hall and Steve Irons just in case we go over time at the next hearing and I have to leave. There being no objection, it is so ordered.

Resolved (on motion by Mr Irons):

That this committee authorises publication, including publication on the parliamentary database, of the transcript of the evidence given before it at public hearing this day.

Committee adjourned at 12:10