

DATE: 1 April 1, 2022

The Hon Greg Hunt – Minister for Health

The Australian Commission on Safety Quality and Healthcare Standards

The Healthcare Complaints Commissioner

The Australian Government Department of Health

Dear Sir/Madam

RE: Treatment of Arachnoid Cysts

My name is Leonie Axton – Hooper, I am asking for your help.

We are very behind here in Australia in regards to treatment of patients suffering with Symptomatic Arachnoid Cysts. It is always difficult to receive treatment as many Doctors are led to believe arachnoid cysts are Asymptomatic and not the cause of the patients' symptoms. Due to this, many patients have found they have not been informed of findings of an Arachnoid Cyst on their brain because when undergoing a brain scan for symptoms, many radiologists pass them off as incidental findings. Our brains are compromised whether the cyst is left untouched or removed and yet the patients suffering with this condition are overlooked.

Here in Australia, in our Medical System, there is so much conflicting information. We appear to only ever have a handful of neurosurgeons who familiarize themselves with how to treat Arachnoid Cysts, but even though we have these few surgeons available they will only take on a handful of cases, turning the majority of our patients away. It has always been a highly debated issue on how to treat this condition and so it is extremely difficult to find a Neuro Surgeon who will decide to treat the Arachnoid Cyst. Following surgery there is no follow up support and advice for the lifelong issues laying ahead for so many of us. This is a complex condition with very little research being done and current literature is outdated.

Daily on our support pages online, we have adult and pediatric patients and families experiencing an ongoing lack of empathy, support and medical intervention, they are continually coming away from appointments feeling they are not believed of their symptoms, as a result of our patients trying to advocate strongly for themselves for help and understanding, they are turned away from any suggestion they make, that their Arachnoid Cysts are causing their symptoms. When a patient or family becomes distressed because of this, quite often the Dr will recommend the patient see a psychologist. Without the physical cause of their symptoms being investigated.

For many years this situation has not improved for patients with this condition and I would like to know why?

I am a patient and the founder and coordinator of the Arachnoid Cyst Awareness Australian Support Group. Our website is <https://www.acystawareaust.com.au> Arachnoid Cyst Awareness Australian Support Group

There are many other patients with this condition all over Australia and unfortunately we suffer with many debilitating symptoms and side effects as well as ongoing surgeries and it is very difficult for us, as unlike other illnesses and diseases, we go unrecognized. It is very stressful for families with young children and newly diagnosed patients who cannot get the appropriate treatment needed, as already mentioned, not all of the medical profession understands our condition.

Usually, we are sent to so many specialists non related to our condition, or told we are not symptomatic when we are. A lot of our children miss a lot of school due to debilitating headaches as the csf (cerebrospinal) fluid on our brains and spinal cords build up in a balloon in one of the three layers of tissue that surround the brain or spinal cord and cause massive pressure on these areas.

Symptoms

We have hearing and eyesight issues, seizures, chronic pain throughout our bodies, memory loss, some of our children are mentally or physically delayed. Some adults and children are unable to walk or walk with a stagger or are unsteady from constantly being dizzy when standing and other cognitive issues. We have bladder and bowel dysfunction. We also have change in mood, depression and debilitating anxiety associated with acquired brain injury or cranial nerves being displaced. (Doctors at the mental Health Hospitals will tell you they have many patients suffering with chronic acute mental health and they have arachnoid cysts in their brain, but they don't believe it is a symptom} We all suffer with fatigue and exhaustion and pressure headaches. Patients with spinal cysts or a spinal Arachnoid Web suffer blocked spinal canals and pressure resulting in blocked csf fluid traveling to the brain leading to acute deviation of spinal nerves fatigue myelopathy/weakness from compression causing extreme back and leg pain also bladder/ bowel dysfunction, temperature and sensation defects, paralysis, Arachnoiditis, sciatica and these webs and cysts lead also to headaches, fogginess and dizziness with the result of focal Arachnoiditis and cord displacement with Caude Equine progression.

Most of these families have no idea that they will need to have the correct diagnoses and not be gaslighted due to many of our doctors not understanding or knowing about this condition.

If our children are not diagnosed and treated correctly with early intervention, then they will go on to have many of these problems and complex medical issues resulting from acquired brain injury because of delayed intervention.

This in turn has a future effect on our welfare and disability support services.

For the parents of our children, they have the continual stress and worry of helplessly watching their child deteriorating and developing further issues, such as daily pain, developmental delays, anxiety and communication problems and these children are easily fatigued leading to the child's own confusion and frustrations, thus leading to outbursts and personality changes. They can miss out on normal activities in their daily lives, older children can miss out on many important activities such as sport and socializing with friends and they have trouble with their schooling, due to changes in their memory, information processing and cognitive abilities.

These families spend lot of time and energy going to continual appointments because they are trying to navigate their child's health needs without any ongoing support or advocacy.

MY STORY

I have a 4x11x16cm Arachnoid Cyst on my brain I am 58 but I was diagnosed in 1988 at age 26 due to headaches and seizures, memory loss and other debilitating symptoms. I was given three surgeries to relieve the pressure of my brain two at the Royal Adelaide hospital and one at the Royal Melbourne eventually resulting in a shunt being inserted to drain the large csf fluid filled cyst away from my brain. In the early eighties the drs did take note of my a/c because of the size, however even the smaller a/cs can cause pressure on brain structures and ventricles in the brain, just as any other neurological mass or tumor on the brain depending where these cysts are situated.

Throughout my life since first being diagnosed, I have had lots of difficulty receiving further medical assistance or follow up. I have developed severe depression from having to fight to receive medical attention when my shunt has malfunctioned and debilitating and further medical symptoms have returned.

These shunts break down due to scaring developing around the catheters or the catheters kink or the valve eventually malfunctions. In fact, the brand that I have put in at the Royal Melbourne is a Medtronic, these have been recalled at times over the years, yet they continue to use this brand for my procedures when I have finally been able to receive assistance for a shunt replacement or revision.

My surgeries were absolutely necessary, but it has been so very difficult to receive surgery intervention. I have had relief from these surgeries, but then unfortunately unlike other neurological diseases and other types of brain tumors that are recognized, I was left to go home to recover without any follow up support or understanding of the changes in my brain from surgery.

To add to my story, I now have arachnoiditis from having to have lumber punctures, I have needed to have these tests even though I would know I had a malfunctioning shunt and had all the symptoms to go with it. I would be sent home from regional hospitals where I would be told that I

was wrong and there was nothing wrong with me. Then because I've used persistence, I would be put through a barrage of tests and scrutiny from not being believed I am symptomatic.

My spine is now compromised and I have to have surgery to relieve the symptoms of terrible spinal pain, I have lost the use of my bladder and have a supra pubic catheter and my bowels are going. I worry if I don't have my surgery soon I will eventually go the same way needing another incontinence bag. My eyesight is diminishing and I suffer daily head pain and chronic nerve pain. I walk with a walker as I cannot walk far, I cannot take too many phone calls and I cannot socialize with friends and family as this is very difficult. I cannot manage well with bright lights including afternoon light, I have to draw the blinds after lunch for the day from fatigue and pain, I cannot deal with a lot of noise stimulation after lunch, so I try to manage what I am needing to do for myself including bathroom needs, main daily meal, administration tasks with the help of carer support before midday. However, it has also become difficult to find carers as I am in regional Victoria and the covid pandemic has affected what carers there are available. I have to use support devices around the home such as a chair and hospital bed and bathroom equipment to be able to function and for support of my daily pain. I have had to fight strongly to receive the disability pension and the Ndis for these items as I have had to retire from the work force earlier than I had ever anticipated. I am due also for a shunt replacement in my brain and both surgeries have been held up for three years due to covid. Every day is a challenge.

I want to note that after advocating for myself strongly which was a challenge because of my brain fatigue and symptoms, I managed to get the Ndis, but many of our patients who are needing carer support and home help are really struggling to be excepted as there drs just are not recognizing our condition..

There are other patients in Australia who are my age, and have struggled for medical intervention and follow up support all their lives too and are now facing the same or similar outcomes as myself. As of the 8th March this year I have been turned away for surgery yet again at the Royal Melbourne Hospital. My last admission was in July last year where tests revealed I needed my surgeries, before I decline further.

Since 2020 I have been struck off the neurosurgical clinics list at The Royal Melbourne without reason three times requiring a new referral and even though I have been promised surgery from the neurosurgical team and had confirmation in writing from the hospital. My surgery has been cancelled, twice during my admission in July 2021 and the last time receiving notice on 8th of March informing me the hospital has removed me from the neurosurgical operating list and I have been given no explanation once again.

I understand as do all our patients the pressures on the hospital system at the moment due to the covid outbreak, but this has been an ongoing issue way before covid commenced not just for me, but the many patients suffering around Australia.

I read in your NSQHS standards under Recognizing and Responding to Acute Deterioration Standard.

The intention of the Standard is to Recognize and respond to a patient acute deterioration such as physiological changes as well as acute changes in cognition and mental state. It states early identification of deterioration may improve outcomes and lessen the intervention required to stabilize patients whose condition deteriorates in a health service organization.

Symptoms for Arachnoid cysts around the brain listed according to The National Institute of Neurological Disorders are,

Headache

Nausea and vomiting

Seizures

Hearing and visual disturbances

Vertigo

And difficulties with balance and walking.

Arachnoid cysts around the spinal cord compress the spinal cord or nerve roots and cause symptoms such as,

Progressive back and leg pain

Tingling and numbness in the leg or arms.

According to NINDS, Untreated, Arachnoid Cysts may cause permanent severe neurological damage when progressive expansion of the cysts or bleeding into the cyst injures the brain or spinal cord. NINDS go on to read-

Symptoms usually resolve or improve with treatment.

NORD Rare Disease Data base reports

Neurological Findings may include

Developmental delays,

Behavioral changes,

An inability to control voluntary movements (ataxia)

Difficulties with balance and walking

Cognitive impairment

Weakness or Paralysis on one side of the body (hemiparesis)

In addition to this they report

Hydrocephalus and cysts located in the suprasellar region may be associated with

continuous bobbing of the head and abnormalities affecting certain hormone producing glands that help the rate of growth, sexual development and certain metabolic functions. (Endocrine System)

My question to your organization is:

-Why are we not recognized and supported such as other neurological conditions?

-Why is there no recent figures or research on our patients who are symptomatic here in Australia?

-There are many patients coming forward each day and things just don't seem to be as advanced and there isn't the same awareness as overseas and the studies these countries have.

Our patients are seeking out Facebook support groups and are needing to find a supportive organization for appropriate support services. But I have found many of our neurological services have no idea what an Arachnoid Cyst is or the complications from them. Teachers at our children's schools do not understand the child's needs and the support they may be needing. Many general practitioners and nurses have no idea of what an Arachnoid Cyst is here in Australia.

The last research I can find in Australia was Prof Geoffrey Kluge and Professor Rosvelt in the eighties, Dr Michael Levy is head of Neurosurgery at Radys Children's Hospital San Diego. Pub Med shows all his publications, he does surgery on many patients and pediatrics. He apparently travels to other countries training surgeons on Arachnoid Cysts. There is also a Dr Kristopher Kahle in America doing genetic Studies on Arachnoid Cyst patients. He is at Yale School of medicine. There are two most up to Date books edited by Knut Webster at the university of Bergen Norway, Bergen, Haukland University Hospital, Bergen, Norway. They are (Arachnoid Cysts Epidemiology, Biology, and Neuroimaging.) Also (Arachnoid Cysts Clinical Management) both these books prove we are needing treatment and ongoing care.

Our condition has always been a debated issue in the medical sector amongst many specialists over many years, but this does not help our current and long standing situation of a declining population of symptomatic patients.

We do not receive the correct care under the Australian Commission on Safety and Quality Healthcare particularly when I read The Australian Charter of healthcare Rights, latest edition and fact sheet 3: The Partnering with Consumers Standards.

The Arachnoid Cyst Awareness Support Group will be participating in an online Petition to ask for your help and support of this prevailing situation of non-medical support and services needed. This is just as important as the intervention and services other neurological conditions and brain diseases here in Australia.

We would really respect and appreciate it if the Hon Greg Hunt, The Healthcare Complaints Commissioner and The Australian Commission in Quality and Healthcare and the Australian Government Department of Health take the time to look into this.

I look forward to receiving a reply

With Regards

Leonie Axton- Hooper

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