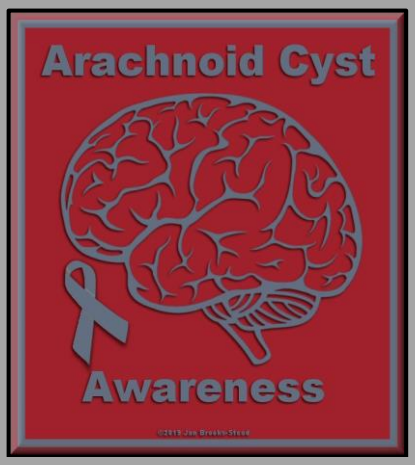
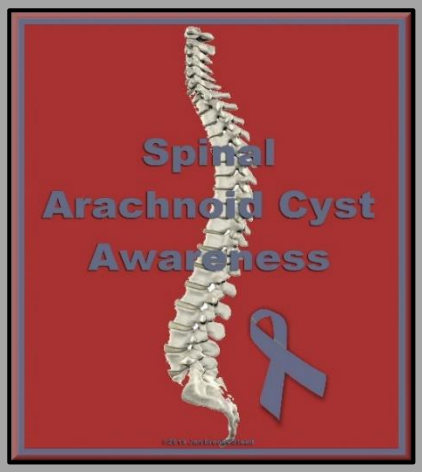
The Australian Arachnoid Cyst Awareness Support Group.

Email:acystawar@gmail.com
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Newsletter No:19 Sept/ Oct 2026: https://www.acystawareaust.com.au





Hi Everyone,

Here we are around to our ninetieth newsletter, it is wonderful how much our community has grown. I remember the very first newsletter I wrote, posted it on our overseas social media pages as I knew that would be where I would find most of our Australian patients because we did not have any support groups for Australia.

I remember thinking to myself, I wonder where this will lead to. Will Australian patients take note and read it?

The response was fabulous; within no time I

had so many of you ask to be on the mail out list for the next newsletter.

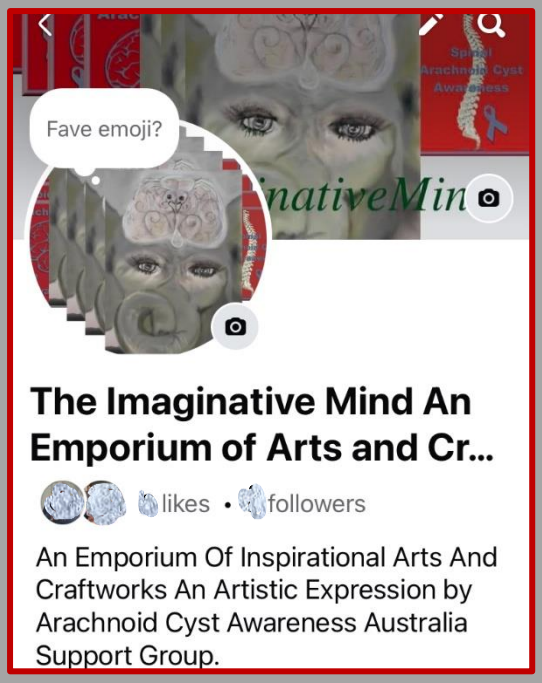
Here we are six years later with a fabulous community. Along with plenty of involvement now through our own Australian social media pages, we have our website up and running, where we have lots of information to support all of our patients and we have patients posting of their experiences so that our Australian communities can have an idea of what we are going through with this condition of Arachnoid Cysts.

Our Facebook page is also very active and along with our website we also now have members actively contributing with articles, research and their stories, on our pages all helping to keep our support group growing for our community.

We also have an online arts space page. This is where members can share their pieces of art or craft. They can also sell their piece and donate the proceeds to helping to fund our group.

If you are interested in displaying your art on our art, post your art or craft piece on our page – open your FB page then press on the link

https://www.facebook.com/theimaginativemind



I have been actively writing when I can to different organisations and governments to lobby for our need to be recognised and we have our ongoing data ase questionnaire for future information, research and studies on our progression throughout life with this condition.

The other thing you may wish to help out with is signing our ongoing petition.

The more persons we have becoming involved with our community, the more we will progress in helping to create awareness and the need for the medical community to understand the condition of symptomatic a/cs. Please go to https://www.petitions.net/please_help_us_to_receive_better_medical_and_follow_up_care_for_the_treatment_of_arachnoid_cysts.

As mentioned in our last newsletter, we now have our committee too. Which is fabulous as we now an active group representing and helping to create a better future for us all.

Where will we be in the next six years? I am excited to see. If you would like to be involved with helping to spread the news and awareness of our group you can contribute to any of the above activities I have mentioned.

You can email me - the email is at the top of our newsletter. Or follow one of our links in this newsletter.

Christmas Gift Lists

With Christmas fast approaching I thought I would bring up some of our products on our website.

Our lovely soft support beanie is so good for comfort and support for our patients dealing with ongoing bad headaches. This would be a lovely gift for a family member who has an Arachnoid Cyst to show your support.





I have just about worn out my third headache beanie out!

These lovey beanies are made of soft coral fleece,

with cuddly soft fabric linings. They are breathable and wash very well and they can be worn in the summer as well as the winter.

They come with soft pocket inserts, where if a patient has had surgery or if they need to lay down and their head is hurting while lying in that particular position, the soft pad inserts help to support the patient's head.

The adult and older children's beanie also comes with a medical grade hot /cold pack

These can also fit into the inserts inside the beanie to help ease a headache.

For the safety of the younger children and baby's we do not provide the hot and cold pack, however they are lovely and soft and still are a comfort to our paediatric patients and do come with the padded inserts.



Please note the spinal support beanies do not come with any of the inserts or hot cold packs.

You may want to team them with a soft eye mask or wheat pack all in

the same soft fabric.



Or for the littlies there is a soft cuddly support bear. We had sold a few of the bears to mums who have come back for a second and third one, as they have also become the child's security toy throughout their journey.





These little bears also come with our spinal logo on them as do our beanies and all our other support products such as t – shirts, tumblers, thermos mugs, bracelets and support bags.

To find all of our products go to https://www.

acystawareaust.com.au

You will also be helping to support and create awareness for symptomatic Arachnoid Cysts here in Australia

Changes to the NDIS

In our last newsletter I wrote about the proposed changes to the NDIS and the launch of Thriving Kids for all children under the ages of eight years.

From what I am reading on where things are now. the rollout of Thriving Kids has been launched and the from the 1st of October. There will be a gradual rollout and it is meant to all be in place by 1st of January 2027.

As mentioned in our last newsletter any children with a permanent or high support needs disability will remain on the NDIS.

Those children with autism with low delayed support needs will go onto or be transitioned onto Thriving Kids.

Services will provide-support and connections through

- peer support
- parenting groups
- facilitated playgroups specialising in these areas.

for those children needing assistance with

- speech
- occupational and physio therapy
- phycologists
- low-cost assistant technology and aids and equipment

this can also be provided.

There is now a thriving Kids Hub where you can find information and resources, go to - raisingchildren.net.au/thrivingkids

Since our last newsletter there have been more significant changes to affect members that are on the NDIS.

The future of eligibility of NDIS packages will go on the impact of the disability and how it affects the participants rather than only the diagnosis.

This will come under two areas.

General Supports – these will provide things such as

- information and resources
- peer-support groups and connecting with other people who may have similar circumstances.
- Help to build independence,
- Confidence and self-advocacy skills.
- Help community organisations become more accessible and inclusive.

This will be made available for anyone with a disability, their families and carers including people who have a NDIS plan.

Targeted foundational Supports

This will be available to people under sixty-five with lower to moderate needs who do not qualify for a NDIS plan.

Access will be on how much help you will require with everyday tasks to be able to function at home and in the community.

A medical diagnosis will not be needed and your support will be decided by a trained assessor.

The assessor will decide on a needs-based situation and look at your functional, everyday limitations. Eg of this would be

- for a child, how much trouble they have communicating.

An example for an adult would be

- how much difficulty you have maintaining your home.

From what I can make out these supports will be provided in place of a NDIS plan. Thriving Kids is included under this category.

Then the final category available for the NDIS will be those participants who are profoundly incapable of caring for themselves.

These persons plans will remain on the NDIS.

So, from October 2026 in our plans, we will also

have reductions in social, economic and community participation as well as improved daily living skills budgets. The reductions will not include supports for help with eating, drinking, education, employment and disability health related supports.

I am yet to find a clear clarification on where we will be heading? Particularly with our conditions as we can fluctuate between being really unwell and unable to care for ourselves to when we do have a patch of being somewhat partially well, but most of us still suffer our debilitating symptoms when particularly fatigued will we be able to have help for our families and ourselves to help us be somewhat independent?

Let's hope the heavy toll does not fall back on our families, adding financial burden and added stress and pressure on parents' marriages and relationships.

I have read that the disability sector strongly can see that the risk of the burden of care will be shifted back onto families and carers. There looks as though there will be a care gap that families, carers and relationships will be forced to fill.

Watch this space!

We have enough trouble with many of our members trying to access the NDIS let alone now the ones already on it. It looks as though big changes are ahead for our future plans.

Sara Hammersley is continuing her research articles on Connective Tissue Disorders associated with Arachnoid Cysts.

She plans on reposting some of these articles in our featured section on our Facebook page for newer members to find easily.

You can find them in back copies of our newsletters too, which are posted on our website.

Connective tissue disorders and the correlation with –

Arachnoid Cysts.

by Sara Hammersley

Hi there,
The topic of this article I have written is quite interesting; I have been writing these articles for our news letters to help open our eyes as to what 'maybe' a pathway to getting some help and support for AC patients.

As you know trying to get treatment is hard and trying to be heard and understood, even harder. This often stands in our way; we need an understanding of what we 'need to know" to help

advocate for either ourselves or our loved ones. It is different for everyone but I am trying to bring some ‘dots’ to help us find what might be a connection.

In the past few months, I have noticed there has been a shift in the medical community, - taking notice of some of the patterns being found. E.g. connective tissue disorders (HSD and HEDS), POTS, MCAS, CSF leaks.

It is important to know what is going on so we can get a larger view of our symptoms and possible causes.
The brain is a very complex system. “Neuro EDS” is something I am seeing being explained on a few different platforms.

It has been known for a while now that we are told our symptoms are not from our ACs more often than not... so what does that mean? Are we right in assuming our symptoms have no known cause or do we try to connect some dots and look at our whole bodies for clues to how we keep producing neurological symptoms that are very real.
Often, we are gaslit and left hanging … yet again.

So, educating our selves is what we need to do when we notice the co morbidities that can occur and why they are there. The answer to all Acs, is because our connective tissue in our arachnoid space was compromised at some point … are you showing signs of other

abnormalities? GI issues , dizziness, fatigue, head pain, sight problems, hyper mobile ligaments and joints? ADHD or ASD?… plus, others…

If the answer is yes to one or more of these then you may well have EDS, Ehlers Danlos Syndrome or a CTD (connective tissue disorder). I wrote an article explaining EDS, for our newsletter a while back and I will be posting this and my other articles to our face book group they can then be held in our featured section, we can then have easy access for us to read and maybe help new group members.

So recently, there has been a new proposed phenotype of EDS, so far, we have 13 sub types. The most common being Hypermobile, Ehlers Danlos. Currently there are “no” known genetic markers for that particular type. So, it would make sense that at this point; to assume they haven't even started to look for the genetic markers for Neuro EDS, so far, we have 13 sub types. The most common being Hypermobile, it’s quite exciting to know they are recognising some dots forming for some patients, showing up with a lot of neurological disorders and symptoms.

I think, this will have an impact on some people that have been diagnosed with FND also because it may provide clues as to where these patients symptoms originate?
I will put a list of all the different diagnosis that fit

the criteria of neuro EDS at the bottom of this page. To see what type of symptoms or abnormalities, would put you into the neuro EDS basket if any.

You may be asking yourself, what has this got to do with Arachnoid cysts? In my search for answers on other support sites like fibromyalgia. EDS and CSF Leaks these patterns keep showing up and as patients we noticed this a while back and have often discussed it amongst ourselves.

When the proposed Phenotype of neuro EDS surfaced, I noticed that they had written down Tarlov cysts as one of the symptoms or diagnosis.

It made me question, are we also part of what needs to be considered. I think it is worth considering, do we have a place on the list? Are Arachnoid Cysts a possible symptom?

I have just joined a support group for neuro EDS and posted the question “who has cysts”, especially ACs? So far, no one with an AC but plenty of other types, I have multiple types. It might take a while to get answers from the Neuro EDS support group, as it is very new but growing rapidly … if there is anything to report, I will keep you posted.

My particular CSF leak was a Venous fistula on the nerve root. I have three Meningocele,

Diverticulum, Cysts in the area of my leak.
We know there are few different types of cysts that can be in or around, the arachnoid space of the spinal cord and brain, so it only makes sense that looking into arachnoid cyst patients, they should be on the radar of the researchers if they are looking into leaks and Tarlov cysts and or other brain, spine cysts. I will also ask on my EDS site and the CSF leakers site and see what comes up.

When I asked my neuro radiographer weather the MDC were actually an arachnoid cyst, he said technically they are, but they behave differently.

A meningocele diverticulum is a close relative of the AC. This type of cyst is more of an open pouch that remains open to the flow of CSF and can occur in the Arachnoid space or the Dura Mater and can be found as a cranial meningocele also.

A Tarlov cyst also known as a perineurial cyst occurs mainly in the sacral area of the spine but can occur in any area of the spine. Tarlov cysts don't fill with CSF they are closed and contain CSF.

They occur on the nerve root and can compress the spinal cord.
They don't occur on the brain.
These cysts grow on the outer sheath of the nerve root and can contain active nerve fibres.
Tarlov cysts are already on the list of things to

look for in patients who suspect they have neuro EDS.

Ok so I hope this helps explain why I am thinking we need to be aware of neuro EDS. I know I fit snugly into this little box with multiple 'ticks' next to the criteria and I am sure if we look, we will find others who have an AC and also fit this 'proposed' criteria as a clinically recognizable neuro-prominent phenotype.

It is important that Neuro EDS is seen as 'not' a new disease or EDS subtype but a new 'proposed' Neuro predominant phenotype (set of traits of genetic code and environment) and it is being newly researched.

I am bringing attention to it because those of us with AC, need to be looked at and possibly included before we ARE EXCLUDED YET AGAIN!

This is the list of criteria being researched…

Structural, Physiological, Neurovascular & Neuroimmune.

Spinal and Cranial -

- CCI (Craniocervical instability)
- Chiari 1 malformation

- Tethered Cord syndrome
  ME/CFS
- CSF Leaks / SIH (intracranial hypotension)
- Intracranial hypertension
- Venous outflow impairment
- Eagles Syndrome (jugular compression)

Neuro – Autonomic – Inflammatory

- POTS & Dysautonomia
- Small Fibre neuropathy
- ME/CFS
- GI dysmotility
- Urinary dysfunction
- Cognitive dysfunction
- Sleep disturbance
- MALS & pelvic congestion.

Well, that's all for another newsletter.
I hope all our kids enjoyed their school holidays. I bet all our parents are enjoying them being back at school!

Until our Christmas newsletter
Take Care Everyone!

Warm Wishes
Leonie Axton- Hooper

Founder and Co-ordinator for Arachnoid Cyst Awareness Australia Support Group.



How You Can Help:

: Governing, coordinating a group and advocating a support group in your state.

: Distributing brochures to neurosurgery, neurology and Drs rooms.

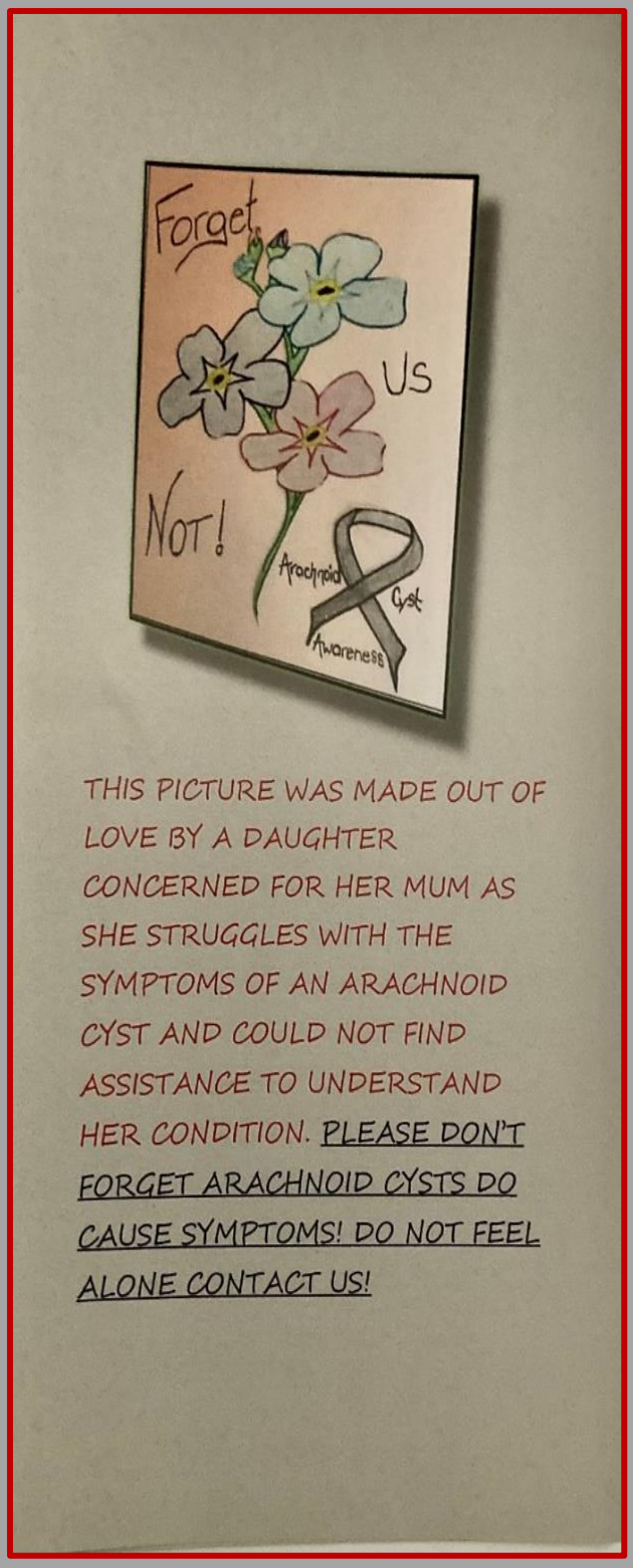
:Join the Committee

:Contribute to publications.

: Distributing brochures to neurosurgery, neurology and drs rooms.

: Contribute to our Arts and Craft Hub.

: Sign our Petition



THIS PICTURE WAS MADE OUT OF LOVE BY A DAUGHTER CONCERNED FOR HER MUM AS SHE STRUGGLES WITH THE SYMPTOMS OF AN ARACHNOID CYST AND COULD NOT FIND ASSISTANCE TO UNDERSTAND HER CONDITION. PLEASE DON'T FORGET ARACHNOID CYSTS DO CAUSE SYMPTOMS! DO NOT FEEL ALONE CONTACT US!