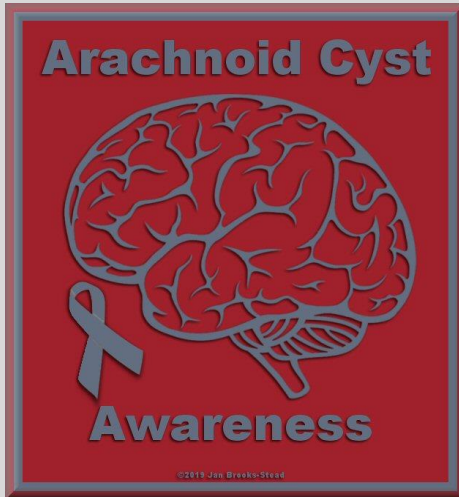


The Australian Arachnoid Cyst Awareness Support Group.

Email:
acystawaraustralia@gmail.com
<https://www.facebook.com/groups/acystawareaustsupportgroup/>

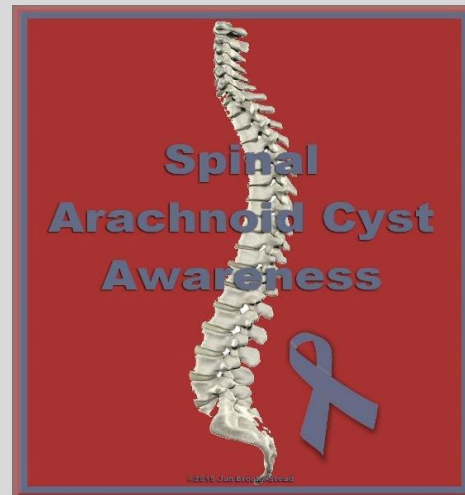


Hello Everyone,
This year is moving so quickly by.
We have just had our last lot of school holidays and before we know it, we will have the next holidays on us and its Christmas season again.

Newsletter No: 11 Sept/Oct 2223

<https://www.acystawareaustralia.com.au>

Phone: 0419 993462



I have been using my time on catching up on the many projects that have been on my white board and now that I'm feeling on top of my recovery from my surgeries earlier this year, it is a great feeling to get back into them again!

One of the to catch up with, was the Minister for Health the Hon Mark Buttlar's reply from the Ministry for Health Branch Assistant Secretary.

Unfortunately, our letter was received last year and a response was sent but I didn't receive it so a duplicate copy was sent with an updated letter of reply from their branch. Although some of us found the last letter a little bit disappointing, the duplicate copy of the previous letter that we received had some very interesting information for us which I really appreciated.

Hopefully once I explain some of the items put forward for us, I hope everyone will feel a bit more positive. A copy of both letters can be found on our Facebook page if you put in the Australian Government

Health Minister's Response in the search bar at the top of the page.

A copy of our first letter to Greg Hunt is on our website and I will post our most recent letter sent in April 2023 of this year, you will find both letters on our Who We Are - page.

One of the things bought up in both letters was that we weren't on the Australian Rare Voices Directory.

Rare Voices Australia is the national peak body for Australians living with rare diseases, it was established in 2012 and RVA has advocated for a national rare disease plan. In 2014 RVA undertook a national roadshow around Australia where discussions took place involving patients' healthcare, research, government and industry organizations. The objective was to form a national plan. RVA held its

first national summit in 2015 where almost 200 rare disease organizations and individuals formally signed and endorsed the call for a National Rare Disease Plan.

This was further developed over the next few years and in 2017 the key advocacy and policy document called Call for A National Rare Disease Framework- 6 Strategic Priorities. (Effective Rare Disease Policy Transforms Patients Lives.)

This was presented to The Minister for Health in the same year.

In 2018 the Australian Government Commissioned Rare Voices Australia to the development for The National Strategic Action Plan for Rare Diseases.

In 2020 with an investment of \$3.3million the Australian Government launched The Action Plan. (These excerpts taken from RVA website)

In our letter we received from the Australian government it explains that Rare Voices led the development of the Action plan in consultation with stakeholders. including people living with rare disease, their families and carers.

It is the first nationally coordinated effort to address rare diseases in Australia. It recognizes although statistically rare, many Australians are impacted by rare disease.

This enables different rare disease organizations such as our support network to partner with Rare Voices to further create awareness and have a voice.

One of the things desperately needed is further studies and education into our condition.

What Can happen if we Partner with Rare Voices Australia?

It means we have will RVA policy support. Advocacy and strategies, an invitation to the biennial rare disease summit, an invitation to parliamentary advents, eligibility for travel support for RVA events, a dedicated rare disease RVA speaker for events held where possible. RVA social media and e-letter promotion, we can network with the RVA closed Facebook group and other information and support.

I urge you to read the first letter we received in response to the hon Health minister and also to go to the Rare Voices Website.


www.rarevoices.org.au

I just received an email today to say we are now on the Rare Deceases Directory on the Rare Voices Website

and my plan is to organize partnering with them soon.

Our Petition

Please Everyone, help us to create much more awareness of how we as patients suffer debilitating symptoms with this condition! Please... See more



PETITIONS.NET
Please help us to receive better medical and follow up Care and Se...

We are growing steadily as a group and I would like to ask our newest members if they could sign our petition.

The more signatures we can get together helps to show how many of us are needing proper medical treatment and much more up to date evidence that Arachnoid Cyst are symptomatic.

<https://www.petitions.net/au/Please-help-us-to-receive-better-medical-and-follow-up-Care-and-Services-of->

[Arachnoid-Cysts-here-in-Australia.](#)

You can also find the link to our petition by going to our Fb page you will find it in our featured section at the top of the page.

Natural Alternate Pain Remedy's.

I have noted lots of media broadcasting the over prescribed use of pain medication here in Australia.

This does worry me as I am needing strong pain relief to manage my pain and I am concerned that I will be limited to prescribed pain relief.

Many of us are in the same situation. With this in mind I am starting to think about finding natural remedies to help with pain relief.

I been researching and have some information on natural pain remedies.

People have been using herbs, herbal remedies, spices and essential oils, homemade lotions and alternate therapies for natural pain relief for hundreds of years. Here are some of the natural herbs and spices believed to help relieve pain. If you are a keen gardener or have a sunny balcony or window sill you can grow some of these herbs mentioned below.

Lavender



Crushed Lavender and Lavender essential oil can help to relieve pain naturally.

The use of lavender can help with sleep and to ease anxiety.

Inhaling Lavender oil can help to relieve a headache.

There are a number of ways to make lavender oil or it can be distilled. But to save distilleries blowing up in your kitchen there are easier ways of making it at home.

One way is to pick your lavender first thing in the morning. With your thumb nail strip lavender away from the stalk. Crush lavender buds lightly with a

pedestal and mortar, bruise flowers lightly just to release the oil.

Transfer your lavender into a jar with a tight-fitting lid then cover with a cheap vodka and shake to release the oils.

Do this several times a day for about a week. In between shaking, leave in a sunny spot on your kitchen bench.

Strain through a mesh tea strainer or a coffee filter into a second jar, place a clean cloth or coffee filter and let your oil sit for a week while the alcohol evaporates leaving you with your essential lavender oil.

There may be some sediment in the bottom of the jar if so,

you can restrain your oil to rid of the sediment.

Store in a dark glass jar out of direct sunlight, it stores for up to a year.

Another method is to hang sprigs of lavender up to air dry preferably out of the sun. in a jar fill it ¼ full of lavender heads, storks removed cover with coconut oil.

Sit on a window sill for three weeks turning the jar and giving it a shake whenever you go by. Strain your oil through a metal strainer, muslin or coffee filter, into a bottle and store in a dark place.

You can purchase essential lavender oil on line too.

If you don't have any lavender oil

Then crushed Lavender poured into a small drawstring bag and put between a pillow and pillow slip or a sprig of lavender popped inside a cushion cover on a cushion will release an aroma while you sleep.

Rosemary



Some researches state that rosemary can help with headache, muscle and bone

pain and seizures, it boosts memory.

Rosemary oil is simpler to make as you infuse a couple of sprigs into a jar and fill with oil. This can be Olive oil, coconut oil, sweet almond or jojoba oil. All oils including essential rosemary oil can be purchased at a health food shop or online.

Peppermint



Peppermint has anti-inflammatory and pain-relieving affects. For a peppermint tea, dry peppermint the same way as you would with lavender sprigs (you can dry all herbs the same way)

Then pour a heaped teaspoon into an infuser or teabag. You can purchase empty ones online. Or tie into a square of muslin with string tied around the pulled-up corners.

Put into a teacup or mug then add boiling water and steep, add honey for a sweetener if needed.

You can purchase peppermint oil online. If you dab oil on temples this will help a headache.

Eucalyptus Oil



Mix 1 or 2 drops with coconut oil and rub on the painful area in a circular motion. (Test a small amount on your skin first and do not use on small children.)

Clove oil



Clove essential oil helps to stimulate the mind and helps with mental exhaustion and fatigue.

According to some research, Clove essential oil can help treat neurological disorders such as memory loss, anxiety and depression

(medicinenet.com.)

You can make clove oil the same way that you make Lavender or Rosemary oil.

Ginger



Ginger helps with nausea.

Try adding 1teaspoon of raw

grated ginger to smoothies, or you can try making a tea by steeping in boiling water and add a slice of lemon.

Turmeric



Turmeric is good for degenerative eye conditions and anxiety.

For pain relief boil 2 cups of water with 1 teaspoon of turmeric powder and ½ teaspoon black pepper. Let it simmer for 10 to 15 mins add lemon, honey or milk to taste.

It's best taken every day before eating for its proper affects.

The other research I looked into is Medicinal Cannabis.

Medicinal Cannabis

Medicinal Cannabis is legalized in every state of Australia.

Medical Cannabis can be prescribed by any Dr in Australia if they believe it is clinically appropriate.

If you are looking for more information and advice on Medicinal Cannabis for yourself or a family Member? Go To-

<https://www.betterhealth.vic.gov.au/health/conditionsand treatments/medicinal-cannabis>

<https://postivechoices.org.au>
[>drugs-a-z-medical-](#)
[cannabis-factsheet](#)

Earlier on in the year I posted a poll on our Facebook Page, for our older patients who were born in the 60s or 70s. I wanted to find out where we are at this stage of our lives living with a symptomatic A/C. Now I would like to have a registry of those patients.

I would like to hear where you are in your life with your symptoms and whether you have or have not had surgery.

I will contact each of you who took part in the poll. I will ask if you are happy to share your information or if you wish to remain anonymous.

Then I would like to create a poll on our children and how many are suffering

symptomatic Arachnoid Cysts, also how many of our Kids are able or not able to access correct treatment and what are their symptoms?

I feel this information on our kids, along with the other information I will be collecting, will benefit our group in having numbers and facts on our older patients and the affects later in life, then information on our children and how many have accessed early medical intervention?

This is so that we can have some up-to-date facts, so that we are able to share this information if we involve ourselves in the forums as discussed in my information on Rare Voices Australia. Also, to add these facts to any literature we produce.

You can put yourself down as anonymous if you do not

want it to be known who you or your family is.

It would be good to share this vital information.

It has been proven that the earlier our children are treated they will have a better outcome later in life.

I am really hoping if you have a child with an a/c you can all help out with this.

Well, I think that's all I have to tell so until next newsletter everyone take care!

How you can Help.

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

: Distributing brochures to Neurosurgery and Neurology rooms and hospital wards.

: Join the Committee

: Contribute to our publications.

: Contribute to our online Arts and Craft Hub.

The Arachnoid Cyst Awareness Australian Support Group.

E:

acystawaraustralia@gmail.com

W:

www.acystawareaust.com.au

F:

www.facebook.com/groups/acystawareaustralsupportgroup/



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!

Applying for the NDIS

In our Sept/Oct newsletter no 9 last year I wrote about understanding the NDIS easily.

I explained how the NDIS works and what it provides for a person needing help or assistance due to any condition that leaves them with disabilities that create difficulty functioning independently in their daily life.

I also explained the different support categories provided so that for varying people's needs these are the different areas that funding will be provided. I then explained what the different support categories are for.

In this newsletter I will now explain how to apply for the NDIS.

I have found one of the most important things to do when getting ready to apply for the NDIS is to collect copies of all your reports especially showing any deteriorating areas of your condition. I have found the easiest way to do this is to ask the specialist or Dr you are seeing to send you a copy of their report they are sending onto other drs or specialist when you are visiting them for your condition.

You are entitled to a copy of the report he or she writes. So do not be afraid or embarrassed to ask.

If you find they don't send a copy to you then most likely your general practitioner will receive the report and you can obtain it from them.

Failing that you can request your reports through the records department of the hospital or specialist you

attend. Some hospitals are now requesting that you have a letter from your general practitioner. I have recently found this in my own case and although frustrating if you persevere the hospital has to give you the record or notes you request.

The other handy thing to do is keep a journal or diary of your worst days that you are affected and what you are unable to do or achieve on those days.

Write down how this has affected or impacted on what you wanted to achieve or do on that day.

As mentioned previously all of this information you start collecting will make it easier to fill in your application.

How to get started on a NDIS application

You can access this information on the NDIS by

going to the NDIS website – <https://www.ndis.gov.au>
>how-apply

There is a **Am I eligible** page where you can complete a NDIS checklist to see if you are eligible.

You can then make a verbal application on the 1800 number but I would recommend downloading a NDIS access request form. You can google this, but double check it is from the NDIS website as other outside agencies have these forms too.

This way you can complete this form and attach the recommended paperwork such as reports and statements and then make your own photo copy (it is essential you keep photocopies of all your paperwork before sending it in. Human error can happen and in my own experience of being in the NDIS for the past five years, I have

experienced this many times.

Paperwork can get lost or is accidentally not downloaded to your NDIS application or file, so having proof of what you have sent in is essential.

There are two parts to the form –

Section 1

To be completed by you or a representative.

Section 2

To be completed by a treating professional.

On page three in the last NDIS Newsletter write up, I explained from my own experience and going on our patient symptoms with this condition that the best and most efficient reports and successful reports you will need are as follows.

A report from your Neurosurgeon (the other alternative is to make an appointment with your

neurosurgeon to fill in Section 2: of the NDIS access request form- To be Completed by the treating professional part of the form.

If you cannot obtain a N/S report, then a report from your neurologist.

If you have trouble getting an appointment with either of these professionals then you can submit the last most recent report you have.

Attach this to section 2 and explain in writing you have been unable to get an appointment with your professional.

A neuropsychologist report, I have in the past stressed on our Facebook page and in a zoom meeting we had how valuable a neuropsychologist report was for me because of my memory issues, brain fatigue and too much stimulation and noise, this can lead to

emotional outbursts and frustration and I doubt myself. As a child this led to low self-esteem.

After having a neuropsychology assessment and report done, this helped to explain to me what parts of my brain were affected and why? I was given strategies on how to manage these symptoms and stresses I was having. It also helps my specialists to understand my needs.

It was a very good report to attach to my NDIS application.

The other thing I didn't mention in my last write up was that if you are a spinal cyst patient or you are a brain cyst patient and cannot get into a neuropsychologist, then a report completed by a general psychologist on how you are coping or managing

in your day-to-day life can help too to support your application.

A letter or report from your general practitioner.

An OT report, this explains your functional Capacity.

A neuro ophthalmologist report. Many of us have pressure on our eyes.

I also submitted copies of any scans I had and visual field tests and eye scans.

Ask family or friends to write a statement on how you manage day to day living and how you cope.

I also provide my own personal statement on how I am managing and any decline I have suffered in

the last year or so. Do not forget to think of how you cope or manage on your worst days.

For our mums with young children, you would attach any hearing, early intervention assessments, speech pathologists reports and anything else that explains the problems your child is having.

If because of your symptoms you are having trouble completing your application there are agencies who can help you to apply.

If you contact a NDIA office in your area, they can help put you in touch with an early childhood partner or a Lac partner for help with applying for the NDIS.

Questions?

What is the NDIA?

What is an Early Childhood Partner?

What is a LAC?

The **NDIA** provides information, referrals and links to services and activities, it also provides information on for individualized plans and also where necessary funded supports to people over a life time. It helps to empower people and inform people with disability to be confident consumers. (Ref: NDIS website.)

*Q: What is the difference between the **NDIS** and the **NDIA**?*

The **NDIS** is the scheme that supports people with a disability, their families and their carers.

The **NDIA** is the government organization that makes decisions, plans

and agreements etc. and manages the NDIS.

An Early Childhood Partner will provide families with helpful information and connect them with the most appropriate supports in your local area and commence the NDIS application and planning process with families. (Ref: NDIS website)

A **LAC** is a Local area coordinator who can help support you to gather your information and evidence needed to support your application for the NDIS. If you are approved by the NDIS then a LAC will help to put you in touch with providers and support people, they will also help you to budget and understand your funding.

There are situations where you will not be approved the first time around or perhaps you are already in the NDIS and some of your supports have not been approved.

I do know of members of our group who have had this happen, I have also experienced this recently, it can be very frustrating but with some knowledge and empowerment on how to manage a rejection it makes the next process of managing to receive an approval a bit easier.

In our next newsletter I will discuss this process and how to put in an internal review on how hopefully to receive a good outcome.

Also, how to manage a complaint if you feel you have not been assessed fairly.

