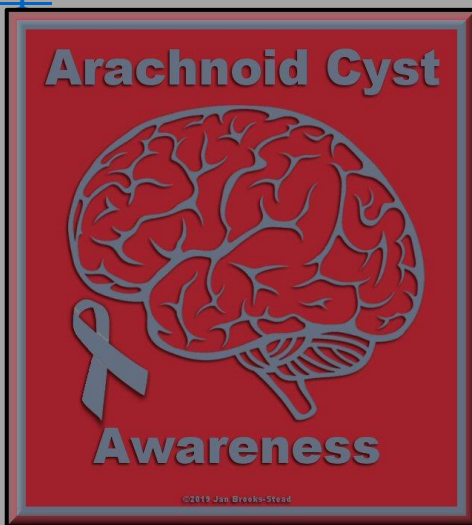


# The Australian Arachnoid Cyst Awareness Support Group.

Email: [acystawaraustralia@gmail.com](mailto:acystawaraustralia@gmail.com)

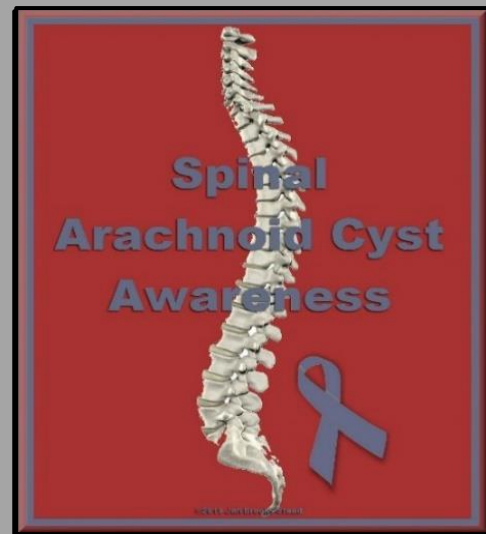
<http://www.facebook.com/groups/acystawareaustsupportgroup/>



Newsletter No: 9 Sept/Oct 2022

[www.acystawareaust.com.au](http://www.acystawareaust.com.au)

Phone: 0419 993462



Welcome everyone to our very late news letter.

For those of you that know me, I have been waiting for surgery to have my shunt replaced as well as I need related spinal surgery.

It has been a long wait as I was on the waiting list before

covid ceased all surgeries apart from emergency surgeries at the main hospital. I have my surgeries done in Melbourne. I've been waiting three years so unfortunately; I'm slowing down at the moment.

But on a good note, this week I am having my pre admission booking for my surgery finally! So, I'm

expecting a surgery date any day now.

It's been great to have many new fb members joining our page, we are really starting to grow as a group! I hope we have been able to help with support and information from both our fb page and our website.

If there are more numbers of symptomatic patients, it shows there is definitely a need that our medical professionals need to take note that there needs to be further development in how we are treated medically here in Australia.

So many members complain how hard it is to find treatment. This in turn affects our families and our daily lives as we have to look for ways to relieve our debilitating symptoms to be able to function as normally as we can.

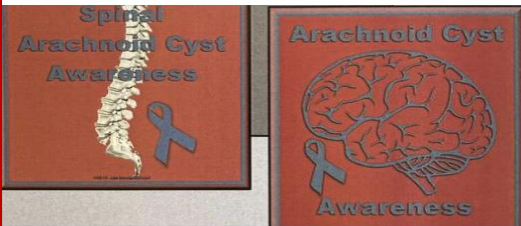
I don't know how many new patients have read our online petition, but I do urge you to sign, the more signatures we have the more affective our letter to the Minister for Health will be.

We also have a petition page you can print out and circulate amongst family and friends, some of our families have done this to collect more signatures, we will collate all of the signatures on line and on paper when we finalise the petition. To sign go to

[https://www.petitions.net/please\\_help\\_us\\_to\\_recieve\\_better\\_medical\\_and\\_follow\\_up\\_care\\_and\\_services\\_for\\_the\\_treatment\\_of\\_arachnoid\\_cysts](https://www.petitions.net/please_help_us_to_recieve_better_medical_and_follow_up_care_and_services_for_the_treatment_of_arachnoid_cysts).

Then type Arachnoid Cysts in the search bar at the top of the page.

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...**

As mentioned in our last newsletter we sent a letter to our last Minister for Health Greg Hunt but as the elections were announced just after it was sent and we didn't hear anything so I will be resending it to our new Minister for Health Mark Butler so the more signatures we can show the better.

Sharing some good news!

In September we had one lovely family who were under a lot of worry and pressure due to mum finding out her little bubs had a rather large cyst on his brain during her pregnancy. As

the weeks went by the Arachnoid Cyst was growing rapidly. Her baby boy was brought into the world by c-section and he had surgery to release the pressure a week later.

Those of you that are on f/b would have seen this mum's story.

I am really pleased and happy to have contacted the family and mum reports that they are home and bubs is doing really well.

Myself along with most of you would be very happy and relieved to hear that this family did have a good medical team and that bubs is doing really well.

On behalf of all of our group I'd like to extend our love and best wishes to the family and pray that your little boy continues to thrive really well and happily.



For those of you that are new to our f/b page or to our Support Group we do have resources available if you are needing assistance or have questions about your condition.

If you are needing some information or support you can email us.

[acystawareaustralia@gmail.com](mailto:acystawareaustralia@gmail.com)

Also, if you have been exploring our f/b pages or our website, we do have an arts hub available to our patients. If you are creative and find that the arts or crafts help to create a relaxing atmosphere for you and take you away from feeling unwell even just for a little while.

We would love for you to share your creations on our Emporium, The Imaginative Mind an Emporium of Arts and Craftworks.



You might like to just display your artworks on this f/b page or you may wish to donate a piece of your art for sale on the site with the proceeds to help maintain our support group.

We would very much appreciate it if you decide to donate your works as there are many areas of the group that need maintaining to keep us going. These are as follows-

- \* Office supplies for administration.
- \* Printing of booklets brochures and t-shirts and support bags, drink bottles and beanies.
- \* Supplies to purchase materials to make up our

our hospital bags e.g.:  
teddies, wheat packs, patient  
beanies.

- \* Purchase of nonspil drink  
bottles and thermo mugs for  
families in hospital.

- \* Funds to maintain our  
website.

- \* Postage

We have been very fortunate  
to have the organisation  
Hireup support us with the  
NDIS Zoom meetings they  
have been conducting on  
line. These meetings are for  
those already on the NDIS  
to help navigate and  
understand your approved  
funding package and make  
the most out of your  
supports. However, it also  
worthwhile for those  
patients or families who are  
considering applying for the  
NDIS as you will have a  
better understanding of how  
to use your supports and  
funding.

These meetings are held  
monthly on the first  
Tuesday of the month. I will  
supply the links on  
Facebook.

I am also planning to add to  
the next few newsletters an  
easier understanding of the  
NDIS how to apply and how  
it all works and what  
supports are available. This  
is for new patients needing  
extra supports for their  
condition.

With Christmas approaching  
fast, don't forget to visit The  
Kids Develop Store. Elena  
the owner is an occupational  
therapist and specialises in  
lots of wonderful products  
to stretch our children's  
cognitive abilities and  
imagination.



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

I was watching the news one morning and one interesting book I wanted to mention is by a fellow who is now a physiatrist called memoir of a recovered patient by Dr Ben Bravery.

Ben tells his story of how he was been treated in hospital for a diagnosis of Bowel Cancer. Although his treatment was world class, he was struck by the way he was treated as a patient, referring to himself just being a number and found he couldn't find empathy or support within the hospital system. Or have his questions answered. He says

he says shocked to find this and so went about to make a difference becoming a Dr and advocate and writing his book.

I found an interview with Laura Turner and Dr Ben Bravery on Great Australian lives. At -

[player.whooshkaa.com](http://player.whooshkaa.com)

His book Memoir of a recovered patient is sold through Booktopia.

I have mentioned this on Facebook and I will mention it again in our newsletter, we are wanting to form a committee of members to help out with things in our group.

So far, I have two people willing to help but to run efficiently and share responsibilities I would really appreciate some more patients or family members or carers interested in helping out.

- You might be handy with helping to write newsletters
- Help with emails and letters.
- Be a good at sewing to help make our bears and beanies and wheat packs for our hospital bags.
- Be good at arts and crafts or cooking for our children's page on the website or in our newsletter.
- You may be good at fundraising; you may have good technical skills for our website.

Or just come on board to share ideas. We would have a monthly zoom meeting to co-ordinate things that need doing.

If you are interested, can you please email me [\*\*acystawaraustralia@gmail.com\*\*](mailto:acystawaraustralia@gmail.com).

Well, I think that's all I have for this newsletter.

Apologies that my newsletter is a bit shorter than usual, I do hope to be chugging along well once I get this long-awaited surgery and recovery over with.

I hope those of you waiting for treatment can manage to find a good dr who can help you or your family member and I really hope with more of us coming forward with symptoms our medical professionals start to take a different approach and bring themselves more up to date with the treatment of Arachnoid Cysts.

I hope all of our kids are enjoying great school holidays this year, it's so good to be back to normal and no lockdowns!

Take Care Everyone!

## How You Can Also Help

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

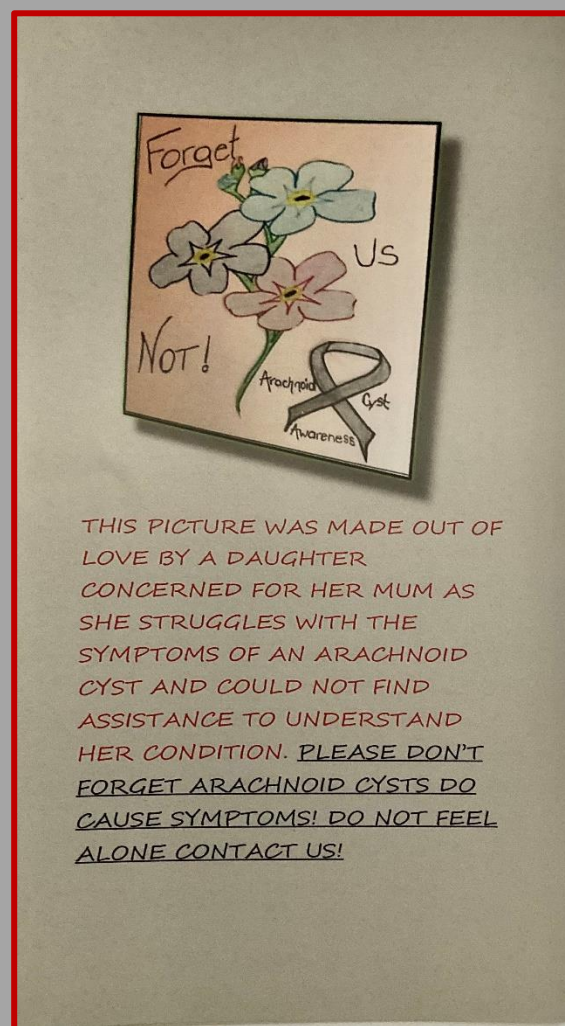
:Distributing brochures to Neurosurgery and neurology rooms and hospital wards.

: 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](mailto:acystawaraustralia@gmail.com)

W.  
[www.acystawareaust.com.au](http://www.acystawareaust.com.au)

F.  
[www.facebook.com/groups/acystawareaustsupportgroup/](https://www.facebook.com/groups/acystawareaustsupportgroup/)



**There are many of us that are diagnosed with an Arachnoid Cyst who can have enjoyable productive and fulfilling lifestyle involving education and employment, but some of us have quite debilitating symptoms and may require the help of the NDIS.**

## UNDERSTANDING NDIS EASILY

When applying for the NDIS, you will find you will be given a mountain of paperwork which can all be VERY confusing. In our future newsletters, I will include an information page and I will try to make it as easy as possible to understand.

If you look on the NDIS website for the NDIS scheme act, section 34.

Its sets out the 6 areas that all supports you have, must be met to be eligible for you to pay funding to these support networks from your NDIS plan once you have applied and are eligible for a NDIS package.

i.e., By supports, they are meaning any Support carer that helps you doing and achieving everyday activities or self-care in your house or in the community e.g., help take you to outings, shopping, community groups, sporting events,

things you enjoy doing such as going to concerts, the cinema, out to a café etc.

If you are participating in education or are able to work it could be supports around helping you with your education requirements or in the workforce to make things easier around a/c symptoms you may be suffering.

It could be the use of a builder for essential home modifications needed by you that is passed by the NDIS for helping you with access to help you around your home.

It may be that you are needing to access Occupational or Physio Therapy needs.

You may find the need for ongoing Psychology to help with cognitive abilities, memory or mood changes or unload our frustrations and depression due to our a/cs and trying to find and receive ongoing treatment.

Above is an example of some of the supports you may be needing.

These support people or networks need to meet the following criteria to meet the NDIS requirements.

I have tried to rewrite the criteria in terms we can understand, I hope this can be of help.

1. The Support will assist you the participant to pursue your goals, objectives and your aspirations.

2. The support will assist the participant to be able to access any social activities or work/education needs.

3. The support represents value for money in that the cost of the supports are reasonable – It means the amount of money spent needs to be appropriate given the outcomes your expected to achieve in having received that support. This is about you being to achieve your GOALS. E.g., Being able to go the theatre, a day out shopping, Going to Tai chi or the Gym, out for lunch or a drive in the country – anything social. You may want to undertake work or Education but cannot due to your condition these supports are to help you meet these goals. E.g., A personal Assistant to help you around your place of education, take notes in class for you and help with any other needs.

4. The support needs to be affective and beneficial to you!! This is where it would be good for you to submit as part of your paperwork How you are affected in Daily Life in terms of mobility, fatigue, personal living skills and cognitive function, memory or anything that will affect you with your daily Living. The things you WOULD like to be achieving in life and your GOALS. If this is a personal statement from you this will help show why you need these supports and value for money.

5. To take account of what is reasonable to expect families, carers and the community to provide. E.g., It means the support is not replacing what is reasonable to expect families, carers etc to provide. Every person is unique so will vary from person to person.

6. The support is appropriately funded or provided through the NDIS and NO other agencies.

The NDIS will only provide funding and supports for NON-MEDICAL requirements and support.

MEDICAL SUPPORTS are provided through the public system or your Private Health.

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You will be required to put in a number of reports and statements showing your condition. For us I have found the best and most efficient and successful reports you will need are:

- Neurosurgeons Report
- Neurologist Report (if you can't see your Neurosurgeon)
- Neuro Psychologist report (Very Important)
- GP Report
- OT Report (Very Important) as this explains your Functioning Capacity
- Neuro Ophthalmologist Report

Statements from Family and Friends explaining your day to day living and how you cope. Also, if you provide your own Personal Statement as mentioned above.

You will be given a list of Questions on all of your Day-to-Day living. It is good to have a family member or support worker help you fill this in.

You are best reporting on you Worst Days – Don't Sugar coat it...

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In your plan you are given areas in which to be able to claim the different needs that arise while you are on the NDIS.

These areas are: - called **Support Categories**. There are three types of support categories you would claim your approved funding from for your needs. These are –

### 1. **CORE**

In your Core Category this is what you would put if you were claiming from NDIS in your funding –

**Consumables**. An Example of Consumables are Continence products, Hen (Home Enteral Nutritional) e.g., Feeding tubes, feed bags, Ostomy Bag.

Also, in the Core is what's called

**Daily Activities** An example of this would be some assistance with Self Care, Personal Care or Cooking, Shared Living arrangements or Shared Supported accommodation – overnight Respite Care, Household cleaning and/or Yard Maintenance, assistance Dogs. This

all comes under Daily Activities in your Core Budget.

Also, in Core is

### **Social Community and Civic**

**Participation** Is community, social and recreational activities, this category includes one to one individual support and group-based supports often group based supports means a day program or day activities. It also can include overnight respite such as assistance on a holiday overnight or a group activity.

Also

**Transport** This would include general and specialised transport for attending school, employment or the community.

## **2 CAPITAL**

In your capital you would claim for things like –

**Assistive Technology** These would be items for mobility, personal care and communication and recreational inclusion such as wheelchairs, pressure mattresses, standing frames bathing and toileting equipment. Personal readers and vision equipment. Vehicle modifications.

**Home Modifications** e.g., would be grab rails, ramps, stair lifts and climbers, home adaptations (as long as any structural work is not required) home modifications (structural work to the home required) home modification consultation and project management. Certified approval of home modifications.

## **CAPACITY BUILDING**

In your Capacity Building category, you would claim for things like

**Support Coordination** – With the Support Coordination you would claim from your funding from an agency some support to get you started with your NDIS plan they will explain how your plan works and how to find supports for yourself and how to budget your funding for your different categories you need help with.

You may also be need to have someone organise all of the above on an ongoing basis and help to strengthen your support network of people helping you.

Or you may choose to do this yourself so the support coordination will help to get you started as stated above.

### **Capacity Building Choice and**

**Control-** Financial Intermediary Supports. This could be an individual or organisation who can look after your plan i.e., finding supports paying your invoices, generally by co-ordinating your ndis plan on your behalf.

Or you may choose to have control over your NDIS plan therefore you may choose and find your own agency (there are quite a few to choose from on the internet) who would provide support workers and other trades and or people to help around your home or your day to day living. You may want to choose outside trades and cleaners for your home.

If they have an abn (Australian business number)you can use them provided they have a contract or quote for the job they will be doing and they need to be approved. In order to do it this way will need a Local area co-ordinator (LAC) who overseas and gets improvement from the NDIS for your plan and you will need a plan manager who pays your invoices from your funding with the NDIS. This will be explained in better detail later on.

### **Capacity Building Daily Activity –**

this area is what you would claim for, if you were needing therapeutic supports, early childhood

interventions, individual assessment/therapy and training, group therapy, carer/parent training in strategies prescribed by therapists. Individual skills development.

### **Capacity Building Employment-**

individual employment support, assistance in specialised supports, leaving school supports, assessments and counselling related to employment.

### **Capacity Health and Wellbeing –**

Funding for Dietary supports, if you are unable to access mainstream exercise programs due to your physical needs, personal exercise supports.

### **Capacity Building Home Living –**

Funding to help with accommodation and tenancy obligations

### **Capacity Building Life Long**

**Learning-**This is funding to help a participant after school.

### **Capacity Building Relationships-**

This funding would help with Behavioural interventions and management plans and social skills development.

### **Capacity Building Social**

### **Community and Civic Participation-**

Participating in community activities focussing on building skills. Also, skills and development and training.

Transition with life planning e.g.,  
mentoring and peer support.

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All of these support categories are designed to provide funding in these areas for individualised and varying support for people requiring this help in their daily lives to be able to live as fulfilling life as they deem possible and to reach their potential and goals.

When you are needing help for any of the above areas each category area has a code that your support people or the organisation looking after your plan would use to have the NDIS pay your invoice(bill) for that support area you have used.

Next newsletter I will explain how to apply for the NDIS and how to find the organisation or support people to help you to organise your NDIS plan.

