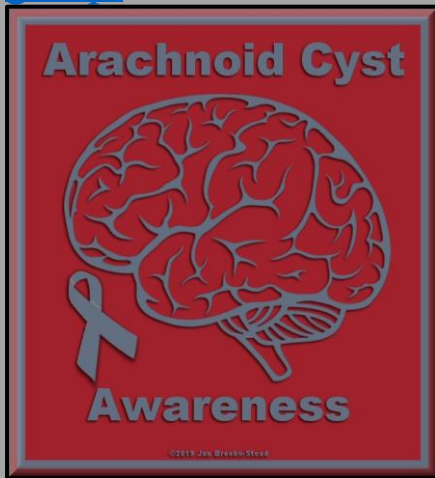
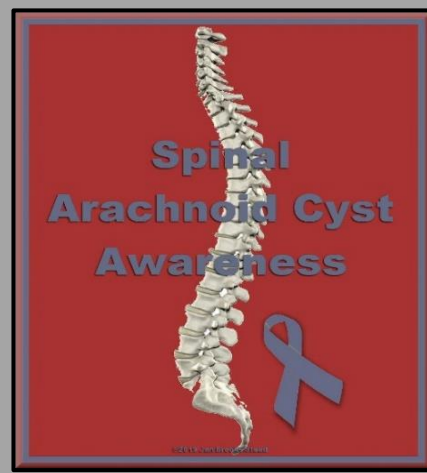


# The Australian Arachnoid Cyst Awareness Support Group.

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[www.facebook.com/groups/acystawareaust/supportgroup/](https://www.facebook.com/groups/acystawareaust/supportgroup/)



Newsletter no:10 April/May 2023  
<https://www.acystawareaust.com.au> P: 0419 993462



Hello Everyone,

Here finally is our newsletter!

We usually have a newsletter in Dec but if you have read of my journey on Facebook, you would have seen I have been recovering from being in hospital for a long period and I've had two surgeries. It has been an eventful time for some of our patients as well as myself with our condition and we had floods yet again which affected

many of us. I hope and pray for everyone things are starting to improve. Thank goodness we didn't have any major bush fires this summer.

I cannot believe how quickly Easter has come around, I imagine for all our parents, you are busy preparing for easter and having the kids home for holidays.

The best bit about easter I like is the hot cross buns. Even though they are in the shops early, I turn a blind eye and patiently wait to buy them for

good Friday and then really enjoy heating them ready to eat with a good dollop of butter and I love the smell of the spices from the traditional ones on good Friday morning throughout the house.

I hope you all have a lovely easter with your families.

I welcome all of our new patients to our Australian Group it's unfortunate that you or a family member have been diagnosed with an Arachnoid Cyst and I do know from our Facebook page many of you are having trouble with Drs telling you your symptoms are not from the Arachnoid Cyst. It can be a very frustrating and difficult time so I hope you are managing to find some much needed information and support from our website, our f/b page and by reading up to date literature explaining that the symptoms being experienced from an a/c are very real.

The reason for starting our Australian Group is from my own experiences and frustrations and I wanted there

to be much more awareness of the problems a symptomatic a/c can cause and I wanted to find and connect with other families and patients here in Australia.

I was frustrated that we were not as up to date as the medical profession are overseas on the treatment of symptomatic Arachnoid Cysts. It has been four years since our group began and I have been so lucky myself to get to know many wonderful families it really has helped my own support network.

I hope many of our new families and patients can find the same support from our group.

### **Support Group Meetings**

As I have talked about how our Australian Group began, you can see we are only very new, we did try just before covid started to organise some support group meetings in each state around Australia. This can be one strategy of helping to create that awareness we all need making it easier for other people to understand our

condition. It can also help family members and friends to become more aware of this condition too as you could bring a member along to a group meeting.

The meetings can be and a way of sharing you or your family's journey with other group members who are going through similar situations and find shared support and ideas.

I would welcome very much hearing from you if you would like to take part in one of these meetings in your state. Your group could organise to hold a meeting monthly or one every two or three months. If you are interested in taking part in a get together please email me with your details. It would be great to see these groups up and running.

### **Our letter to the Hon Minister for Health**

Last year myself and some of our members of our group helped to write a letter to our Minister for Health Greg Hunt and other government agencies.

The election was called and I guess with the change over of ministers, our letter wasn't answered so I have updated it and sent it off to Mark Butler our new Hon Minister for Health.

I hope we can hear some sort of reply from him and we can have something done to help us with more awareness and research here in Australia. If you have not read it, you will find it on our website under who we are.

### **The Australasian Shunt Registry.**

**Neurosurgical Society of Australasia.**

I received a letter from Dr Mark Dexter about The Australasian Shunt Registry. He is on our Australian good Drs File, on our website and F/b page.

Mark is also chairperson for the Neurosurgical Society of Australasia.

This is the first time I have seen any research on shunts here in Australia. Apparently, data collection commenced in 2016.

After a patient has a shunt related procedure the details of

the shunt and procedure is recorded by your Neurosurgeon.

Your n/s is required to fill in a shunt registry data collection form. This is forwarded to the Neurosurgical Society which houses the registry.

The purpose of this registry is to monitor how well shunts perform by recording information on every person having a shunt operation. The information collected will include the reason a shunt is needed, how many operations a patient may have had and their outcomes, also why a shunt may fail.

The information collected can then be used to help a n/s to improve patient outcomes and also the monitoring of shunt performance.

Having the registry can improve patient safety and quality of care for patients with shunt related conditions.

I have found this very interesting and very good news and I hope some of our patients in our group have received this letter to take part and are on the shunt registry.

I'm am sure many of our patients who have shunts and don't know about it will be happy to hear about this too.

For more information – [www.nsa.org.au](http://www.nsa.org.au)

### **Our Australian Good Drs List.**

Over the past six months there have been patients that have been able to receive treatment for their Arachnoid Cysts.

Quite a few of these patients are new to our Group or have joined our F/b page, if you feel you have had the experience of a great neurosurgeon and medical team, then we would really appreciate you sharing their name and details for our good Drs file in the announcement section at the top of our F/b page – [www.facebook.com/groups/acystawareaustsupportgroup/](http://www.facebook.com/groups/acystawareaustsupportgroup/) or by emailing me at [acystawaraustralia@gmail.com](mailto:acystawaraustralia@gmail.com).

The information you provide can help another patient to be able to find a neurosurgeon who understands the treatment of

Symptomatic Arachnoid Cysts and access correct treatment.

### **The Holiday Respite House in Victoria.**

Unfortunately, many of us suffered from our floods throughout Australia last year.

Our Floods here on the Murray were quite severe. All this took place just before I went into hospital. I arrived home from hospital to all my furniture still up on bricks and household items up high, because my husband to work and also visit me in hospital so there just wasn't time to put everything back to normal until I got home.

We were so close to going under, if it wasn't for the Army, the Country fire brigades from everywhere and residents of our community, I would have come home to a flooded and damaged house. I could hear everyone out the front of our house around the clock sandbagging leavy banks that continued to break open from the pressure of the Murray River coming straight for our house. We had

sandbags right up to our front and back doors too.

I got up one morning to see all our poor neighbours across the road inundated and flooded out, the river coming right through their paddocks destroying their houses.

One of the properties I was really saddened to hear of so much damage was my very good friend who runs her beautiful Country Bed and Breakfast.

Kerry had very kindly offered her bed and breakfast to us for a respite get away here in Victoria for patients and families recovering from the stress and recovery of surgery on their Arachnoid Cysts.

We have some photos of her beautiful historic homestead on our website.

Kerry's property had been hit the worst by the strong water's as it is adjacent to The Barmah National Park, and the banks of the Murray River in Victoria.

Both her historic home and the old bed and breakfast have received so much damage and

this has also been brought on by not being able to access her property until February when the water finally receded and dried up.

So, for now we do not have our first respite house in operation.

It remains closed until further notice.

I will make it a continued project to find more respite holidays for our patients and families around Australia.

Covid did hinder a few of our projects but now we have finally come through this, I have them up on my whiteboard to finally get them up and running.

### **Patient Stories for our Australian Website.**

I would really love to see some more patients post their story on our Australian Website of your journey and diagnoses of having an Arachnoid Cyst and how it may affect you. Or you may have a positive story to tell where you have had treatment for your Arachnoid Cyst. By doing this anyone who visits our site will have a better

understanding of what we go through and of course create more awareness and show that we are needing the right medical help here in Australia.

If you are having difficulties posting your story on the site, you can email it to me and I'm happy to post it for you.

### **Information on Applying for the NDIS.**

In our last newsletter I mentioned I would continue to try and write up some more information that is easy to understand on applying for the NDIS.

We had covered in our last newsletter the different support categories you can claim from when you have been approved for the NDIS

I also mentioned gathering some reports you may need to supply to help to be approved.

In this newsletter, I was going to explain how to apply for the NDIS and how to find organisations or support people to help you organise your NDIS plan if you are approved.

I apologise as I will have to leave it to next newsletter to continue with this because I am still recovering and tire easily.

But you can email me with any questions you may have in the meantime.

I think that's all I have to tell. I have managed to put together some easter weekend craft for the kids, I hope they can enjoy having ago or maybe some of you parents might like to get involved and surprise the kids!

Until next newsletter have a great easter weekend and stay safe and happy!

## The Arachnoid Cyst

### Awareness Australian Support Group

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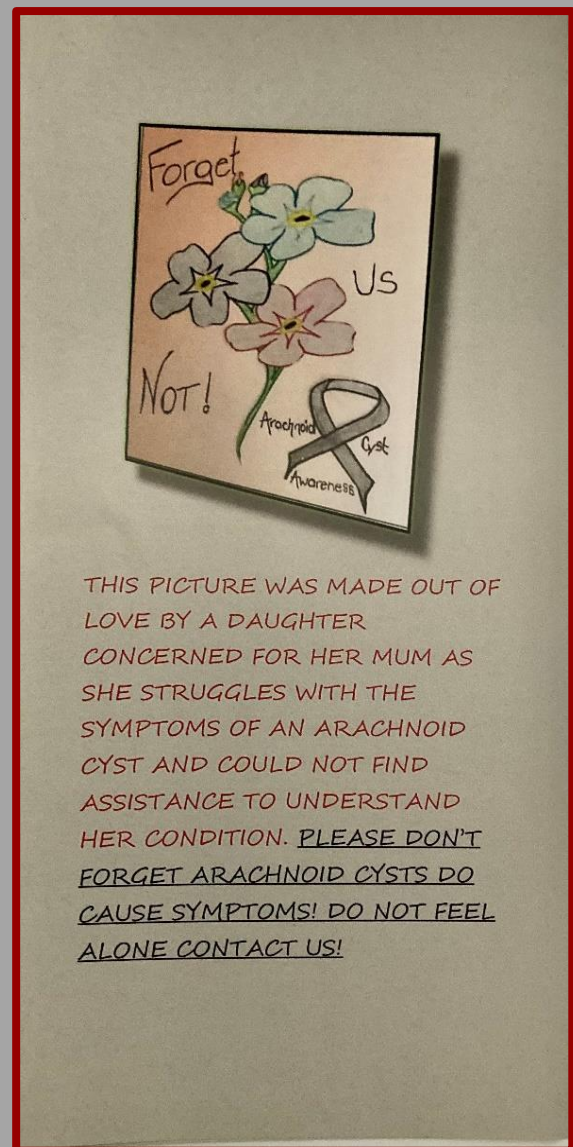
[acystawaraustralia@gmail.com](mailto:acystawaraustralia@gmail.com)

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

F.

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



### How You Can Help

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

:Join The Committee.

:Contribute to our publications.

:Contribute to our online Art and Craft Hub.

:Share your Story on our website.

# Coloured Crackled Easter Eggs and Bunny Egg Bags



These Easter Bags and eggs are lots of fun to make. You will need:

\*Some hardboiled eggs with the shells left on

\*Food Colouring

\*Some string or ribbon

\*Some small containers big enough to hold the eggs and some water.

\*Some coloured paper. You can find some in the Reject Shop or a bargain store that sells craft materials or spotlight.

\*The bunny template provided.

\*A felt tip pen

\*Some Glue

\*A stapler



*Fill your containers with cold water and add drops of your favourite colours into the water with your food colouring.*



*To hard boil eggs, carefully lower eggs into some boiling salted water and cook for six to eight minutes. Then cool them under running water.*



*This is the part the kids will like!*

*Tap the eggs on a bench and then let the kids gently crack the shell all over the egg gently pressing with their fingers.*



*Then place a crackled egg in each of the colours and let them stand for a couple of hours.*



*After a couple of hours remove each egg and carefully peel off the shell.*



*You should have some colourful patterns all over the egg.*

*Place the eggs on a plate to dry.*

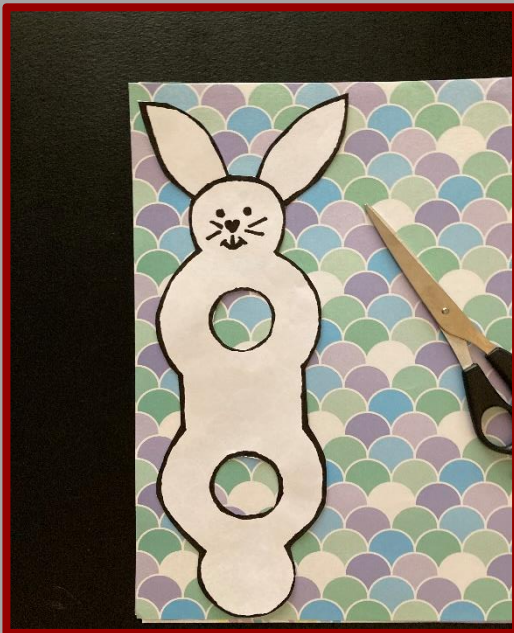


*Then place the bunny cut out and his ear insert on some coloured or printed paper and trace around it.*

*Next take your bunny template and cut it out. The kids can help with this.*



*Then cut your bunnies out.*



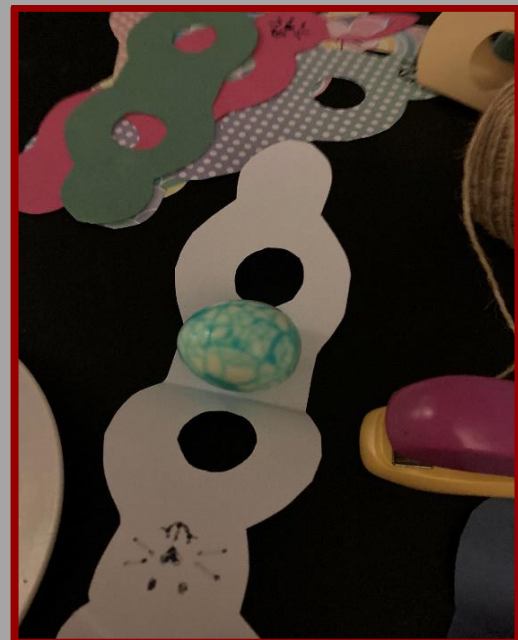
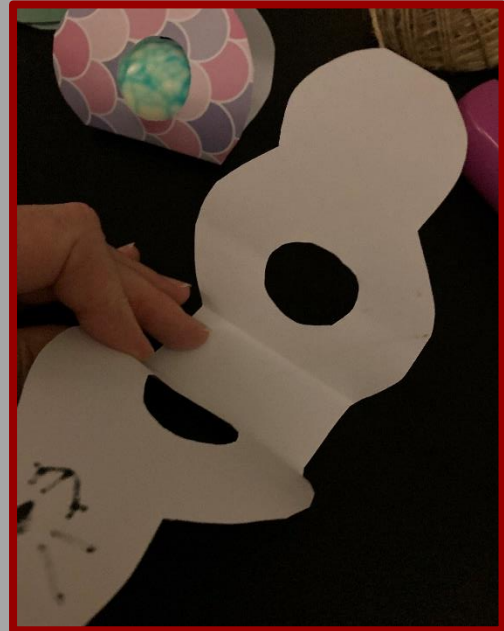
Then take a felt tip pen and draw a face on your bunny cut out.



Also don't forget to glue your bunny's ear inserts on.

I have only glued one ear insert on and folded down the other ear, but you could cut out two ear inserts and put one on both ears.

Make two folds about 3 cms apart in the middle of the template.

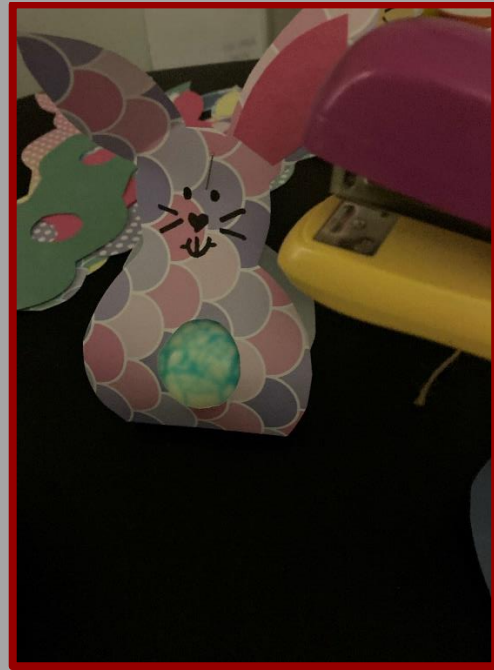


Place a crackled egg on the centre of your bag.

*I recommend putting your eggs in these bags shortly before eating them as the moisture from the egg's seeps into the paper after a couple of hours.*

*Then bring bunny's head and tail together and staple or glue shut.*

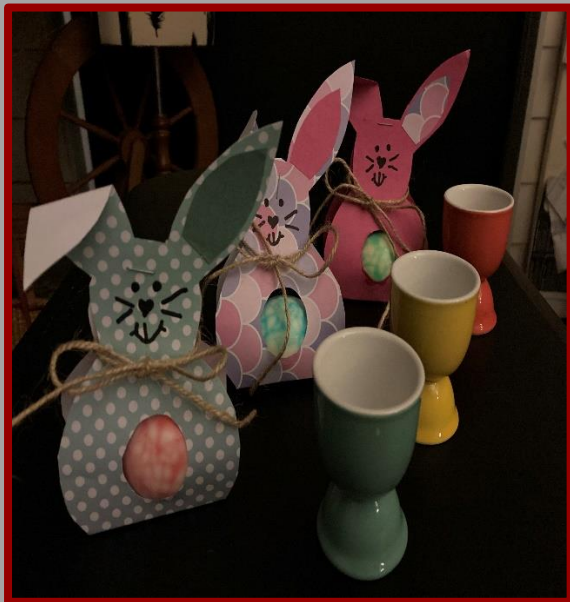
*If you glue them, I use a peg to hold the bunny bags together until they are dry.*



*Next tie a bow around the bunny's neck and you have a fun easter gift!*



*Perhaps the kids could go as far as putting the eggs in the water and colouring the night before easter morning.*



*Then mum or dad can complete the rest for a healthy easter morning surprise for their breakfast.*

*Or it can be a fun easter weekend craft to keep the kids busy!*

*Happy Easter!*

