

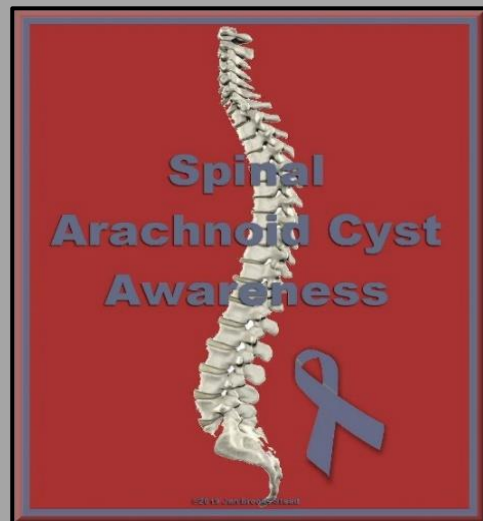
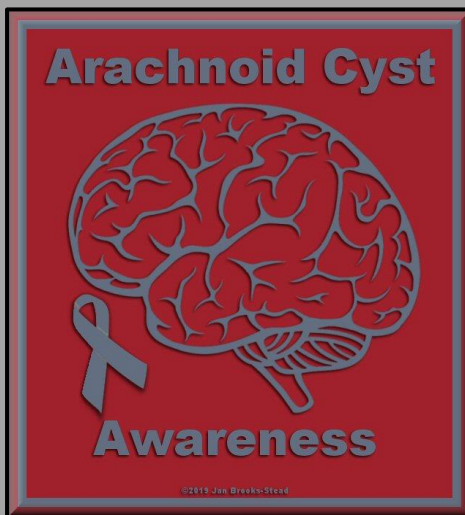
The Australian Arachnoid Cyst Awareness Support Group.

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

Newsletter No: 12 Dec
2023

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

Phone: 0419 993462.



Hi Everyone,

I cannot believe we are once again around to Christmas.

This is our fourth Christmas, third Christmas newsletter

since our group began and I'm so excited to be able to celebrate Christmas this year.

For our newest group members, I was too sick last year and missed Christmas as I was in hospital. I'm making the most of enjoying Crissy

this year so I am really getting into the Christmas spirit. Only three days to go.

I have a few Christmas things I have made for our newsletter.

I want to show you how to make an Aussie Christmas wreath out of our own native trees shrubs and whatever you have in your garden. If you don't have a wreath on your front door yet you might like to make this one.

Then I also thought it would be fun to show our kids and grandkids how to make an Arachnoid Cyst Awareness Australian koala Christmas badge or necklace.

I have not included any Christmas recipes but if you go on our website in our 2021 Christmas Newsletter you will find some healthy Christmas Recipes and there are some recipes for the kids too. I've also posted these recipes on our facebook page.

Questionnaire for our Australian Database.

I have been emailing our older patients with our questionnaire for our database so I'm hoping to receive back lots of information on where we are now with our symptoms and other important questions.

If you have received it, I know it be a busy time in our households at this

time of year, so once Christmas is over – if you could find the time to grab yourself a cuppa and fill in the form and email it back to me you will be really contributing and helping to create awareness of what we go through with symptomatic a/cs. If you would like to participate in this questionnaire please either email me or pm me on facebook.

It would be good also for me to know any success stories, perhaps you have had surgery and have gone on to lead a pain free and pretty healthy lifestyle.

All this information will help to create a story relating to our needs. I can then bring these statistics up during any

meeting or conference we are invited to with Rare Voices Australia.

Just recently one of our young people and her mum from Victoria had to travel to Sydney to have a revision of her shunt.

This young lady underwent surgery with Dr Mark Dexter and mum has indicated how happy she is with him.

I wish them both so very well, I am pleased to hear they are both home now, and this mum's lovely daughter has soldiered through with such strength.

I hope to hear of a good recovery and that you both enjoy a lovely Christmas.

It would have been a long trip traveling there for surgery and then home again. I hope eventually patients will not need to travel long distances for treatment.

I hope we find more neurosurgeons with a comprehensive up to date understanding of symptomatic Arachnoid Cysts in each of our states.

WA will be one of our States I will be focusing on in the new year. I will be re writing to Mark Buttler our health minister and also to the WA health minister.

Over the last two years we have had so many W.A patients come forward and say how they are desperately trying to

find a neurosurgeon who can treat them.

I am quite concerned how many of our patients are turned away from treatment in W.A and its such a long way for them to travel to any of our Neurosurgeons on our good drs list.

Northern Queensland Cyclone and Floods and WA fires.

For those families who live in Cairnes and surrounding and outer areas that have been affected by this disaster, please know that myself and I'm sure many of our group members from other states will feel the same, you are in our thoughts and prayers and I hope things are starting

to improve going forward and that you will get the support needed to help you through this stressful situation and help to get your homes cleaned up and return your lives back to some normality very soon.

For our WA families affected by the fires please also know we are thinking of you too and this devastation of fire is also so very sad and stressful for you and just as we hope Northern Queensland families are getting the support they need, I hope our WA families are accessing much needed support too. I am so sorry you are all dealing with this devastation right on Christmas.

I hope you are safe and are ok.

Holiday Emergency Plans

Given that our weather is so unpredictable, our summers are getting hotter and we have the threat of fire or floods or other unpredictable weather events. I thought I would talk about emergency plans and are you prepared?

One of the biggest things we need to think about is do you have all your health records together and medication and health fund details in one spot ready to access if you need to in a hurry?

Do you have an emergency plan put in place with neighbours, friends and if you are

needing assistance to be evacuated?

Have you thought about what happens if the power goes out and phones go down?

This happens often to me as I live in a regional town. But in a bad weather event this can happen to anyone anywhere in Australia.

Have you got your drs and emergency phone numbers written down in a booklet or a small writing pad that can be kept in a pocket or your bag? For families a laminated poster with all of your important numbers written down can be helpful. Perhaps for families you could make your young and older children aware of where these phone

numbers are in an emergency if there is no phone or internet access.

After last year's floods that affected us. I have a list on my notice board of what we need to have and where they are stored in case of an emergency or evacuation such as the things mentioned above re- medication, scrips, medical files, all our paperwork i.e. medical fund, insurance birth certificates etc. Also, phone chargers, batteries, a packed bag of clothing, radio and torches and drinking water.

It is something we all need to think about particularly if you are affected by our condition of symptomatic Arachnoid Cysts.

Children coping with the Festive season.

I wanted to also talk about our children and how overwhelmed they can become with too much stimulation because of the pressure in their brains.

Particularly during hot and humid days or stormy weather, we experience a rise in pressure in our brains and if we are tired and experience too much stimulation at once it can affect us and this can cause your child to have a meltdown.

Too much stimulation can be loud music or TVs, too many children at once with their excited chatter, yelling and squealing in a party situation. Having to

answer questions or talk to people when they are tired and overwhelmed and then forgetful. Bright lights, loud traffic, noisy restaurants, shopping malls or any loud noise or loud computer games in a room. All of these things affect us.

Sometimes your child might just need some time out in a relaxing quiet atmosphere so they can have time to recharge and reprocess. We get fatigued easily.

Especially those children that are dealing with being on the spectrum with autism or ADHD and have hyperactivity.

I am finding many families have a connection to these conditions within the

family unit of those of us with a/cs.

Having the light in the room they are in darkened, maybe just the Christmas tree lights on and the room dimmed using soft lamp light can also help to calm their surroundings while they are resting.

If they want to play or listen to music or watch their iPad or TV, if this is helping them to be comfortable and relaxed, that will help them to recharge and cope with the busy festive season.

I hope all our families can enjoy the festive season.

*How to make an
Australian
Native and
Garden
Christmas
Wreath.*



Every year I make my Christmas wreath for my front door out of the native shrubs and plants growing in my garden.

I love the decorations in the shops but very rarely do I see Australian decorations. So I try to decorate with an Australian theme in mind.

**This is how I make my
christmas wreath.**

I look for gum trees with extra long spindly branches to make the base of my wreath and I leave the gum leaves attached.



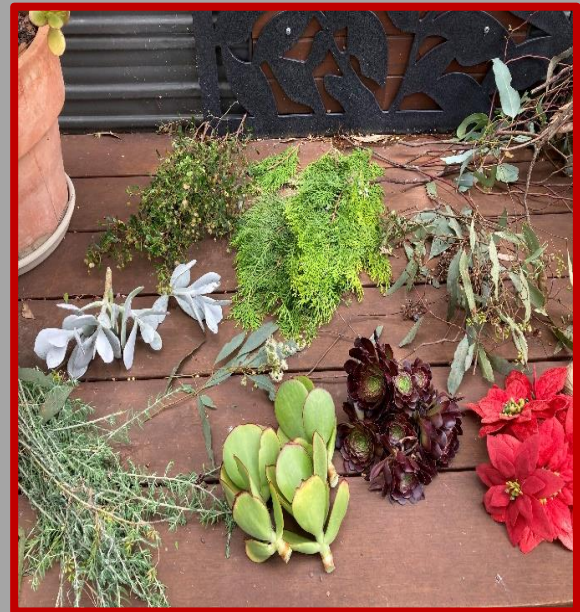
This year because Ive just busted outside in my new powered motorised wheelchair, I have my carer who is a good mate helping me.



You can see from our pictures we have cuttings

from various shubs on my road and my garden. I even use succulents.

All these different textures work well in my wreath.



Once I have all of my cuttings. I lay them out in bunches so I can see clearly what I have.

The first thing I do is take the long spindly gum tree branches (you can find and use other spindly tree or bush branches too) and twist them together.



Once you have a bit of length you can twist the two ends together.



If you have the help of someone else like one of the kids perhaps or a friend, I wind one way and the other person twists the opposite way.

Then I take a ball of kitchen string or jute and twist it around your wreath and secure it by tying the ends together.

You can make your wreath as big or small as you want. If I make a small one I can usually wind the branches myself.



Now comes the fun part!
You can start poking
your cuttings into your
wreath until you are
satisfied with your
design.

I then wind more kitchen
string around to secure
the cuttings on the my
wreath.



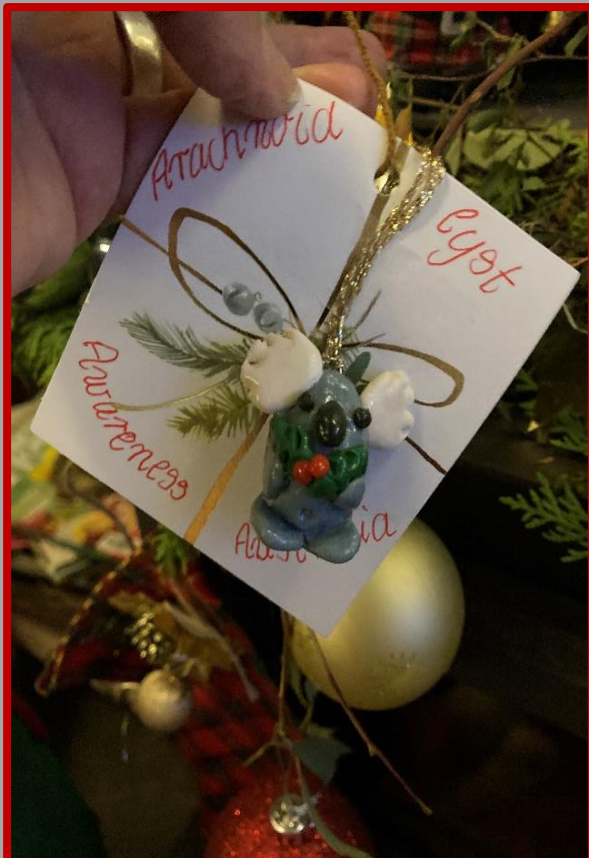
When I am finished I tie
on a bow and some
baubles or a christmas
decoration. Some years I

have wound christmas
ribbon or lights around
my wreath. Then make a
loop out of my string or
do a slip knot and tie it to
the top of my wreath
ready to hang on my
front door.



I hope you have fun
making this Australian
Christmas Wreath for
your front door!

*How to make a
Christmas
Arachnoid Cyst
Koala Bear
Necklace or
Badge.*

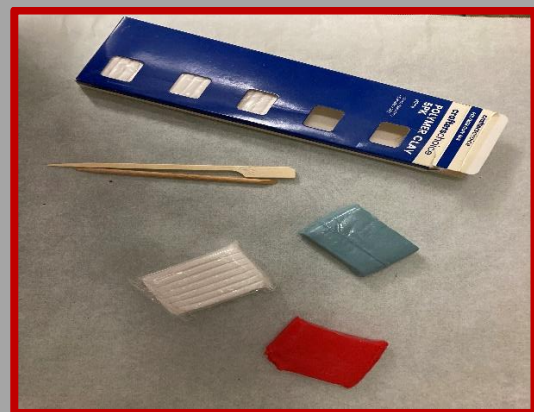


This little Koala Bear can be made by the kids

or an adult can have fun making some of these for last minute little gifts to create awareness for our group **Arachnoid Cyst Awareness Australia.**

You need some polymer clay. You can purchase this quite cheaply at spotlight stores or craft shop. For tiny tots you could help them make one out of play dough.

You will need wire cutters, one or two safety pins and a skewer or toothpick to help you with shaping and creating textures in your clay.



You will need colours red, grey, green, white and black.

Roll the clay into balls such as in the picture below using the different colours.

You need

4 little grey balls for the hands and feet.

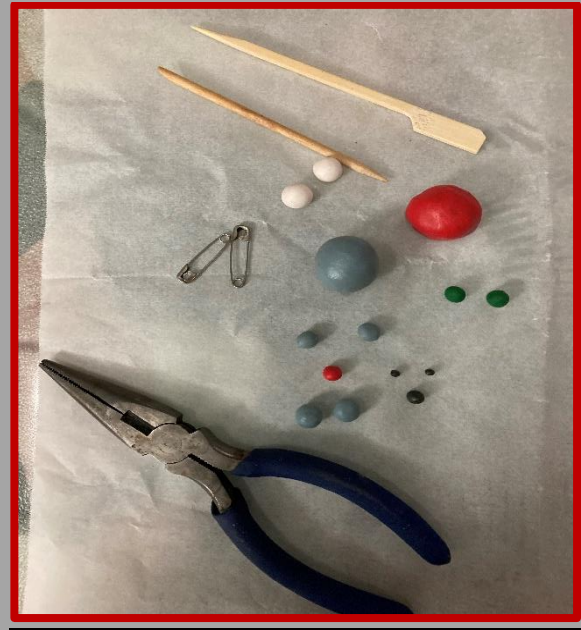
1 larger ball for koalas body.

Two white balls for the ears.

Three tiny black balls for the eyes and nose.

Two green balls for the holly.

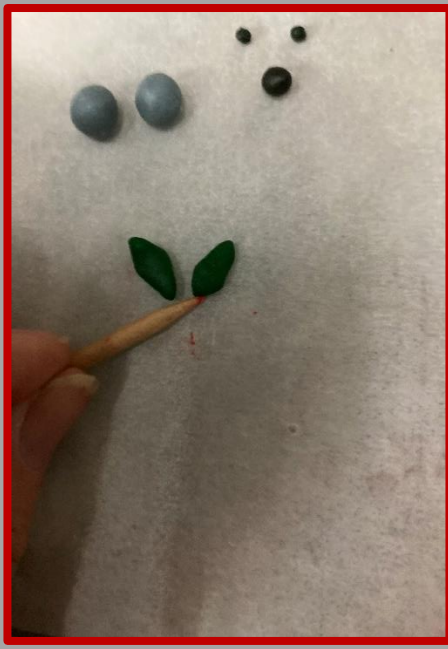
Two tiny red balls for the berries on the holly.



Shape your grey ball into a sphere to make your koala bears body.



Then take your green balls you have rolled and shape them into leaves and using your skewer or toothpick add the indents to make your leaves look like holly.



Then add the little red berrys to the leaves and place them on the body of the koala.



Then take two of the rolled pieces of the grey and shape them for his feet and add them to the bottom of your koala.



Take the pieces of the white you have rolled into balls and then flatten the pieces and shape into your koalas ears.



Also shape and add your koalas arms.



Attach the ears to your Koala.



Shape and add his eyes and nose.

My computer is misbehaving and Im having trouble downloading my photos.

Unfortunately I'm missing my photos to show you how to cut the safety pin - so what you are needing to do is take your wire cutters and chop one of your safety pins in half.



Then squeeze the ends in closer so your hook is thinner to be able to insert into the top of your koala.

Then poke your hanger into the top of your bear.



You can also place a safety pin onto the back of your bear to make a badge instead of a necklace.

You then need to sit your koala on a piece of baking paper and bake your koala at 135 degrees celsius for 15 to 20 mins until hard. Check every ten mins as ovens can vary.

Let your koala cool and once cooled you can paint some clear lacquer on your bear with some clear nail polish or there is craft lacquer you can buy at spotlight or craft shops.



If you are making your little koala into a necklace, add a long piece of christmas string or ribbon



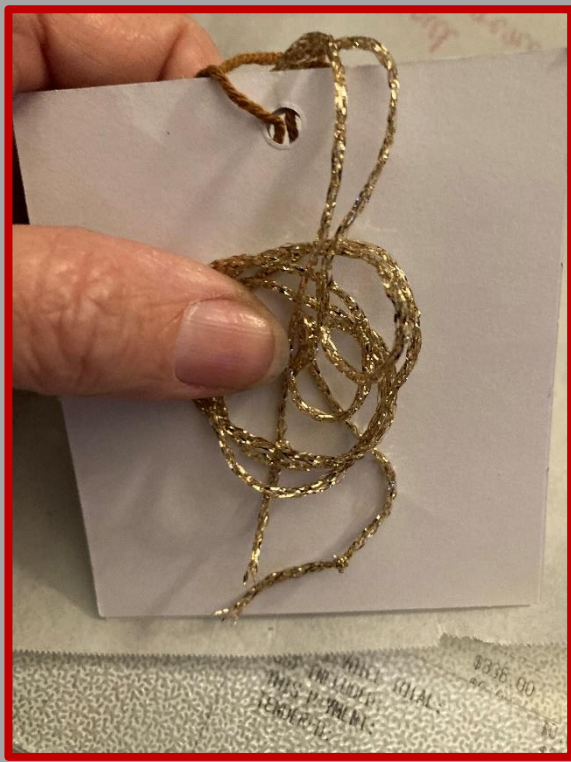
The next thing you can do if you want to give your koala necklace as a gift, or badge, is cut out a square piece of cardboard. (I used an Australian decorated christmas gift tag)

Then tape or pin your koala bear to your tag or square piece of cardboard



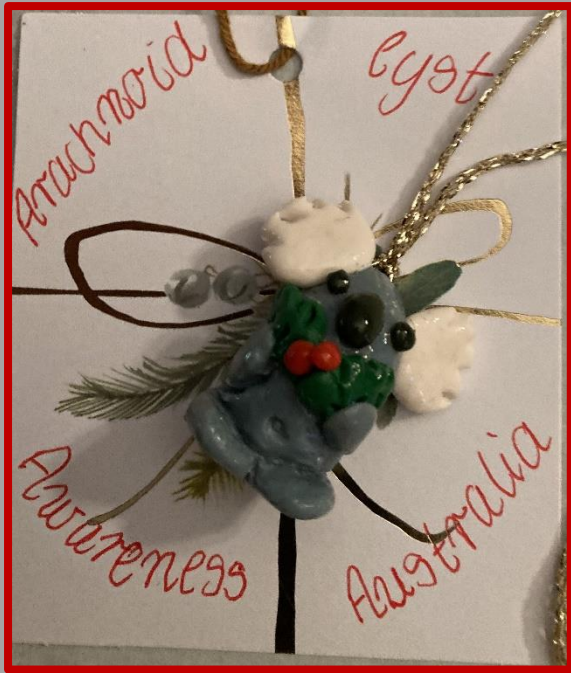
Then curl the string up and tape it to the back of the cardboard.

Ive written Arachnoid Cyst Awareness Australa on my tag as the Koala bear is our childrens soft cuddly comfort bear we have for sale on our website.



You can help to create awareness of our condition, or you can put a name or another design on your tag.

The kids might like to personalise their card with some of their own creativity such as their own little drawings. I hope you have fun making this cute little bear!



I hope everyone has a lovely Christmas and New Year.

I look forward to better things in 2024 for us all!

Well I think that's all from me. I'm looking forward to sending our newsletter off and then I have some presents to wrap and help pack our van as we are taking our first holiday in years.

Then I'm looking forward to winding down and really enjoying this Christmas.



How you can Help.

: Governing, co-ordinating a group and advocating a support group in your state.

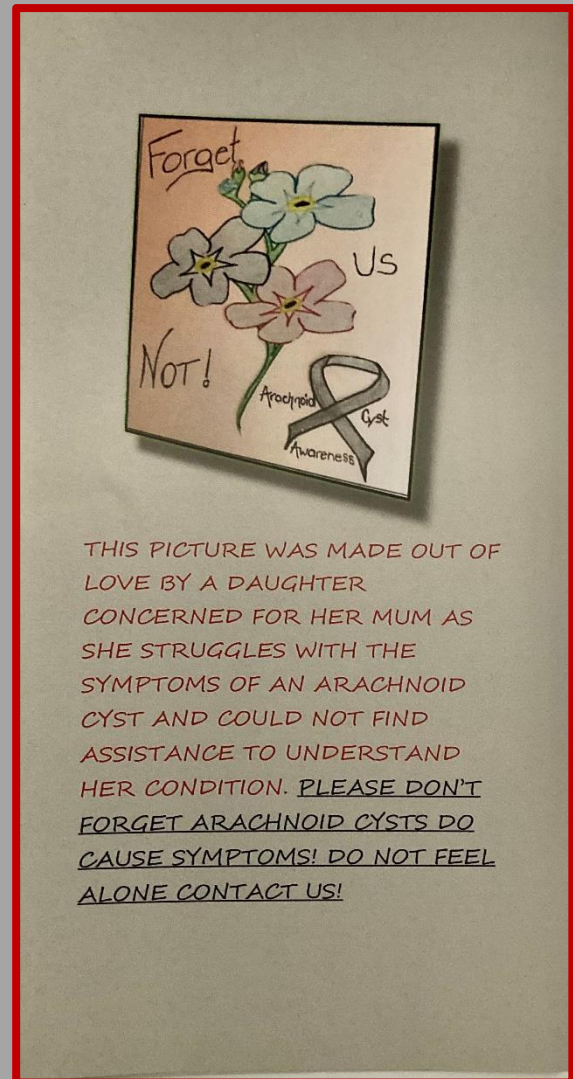
: Distributing brochures to neurosurgery and Neurology and Drs Rooms.

: 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/acystawareaustsupportgroup/

Applying for the NDIS **Cont.**

Having to put in a review.

Throughout our newsletters I have been putting information in for our members on how to apply for the ndis.

Appying for the ndis can be very confusing and with all the wording and terms used it can become quite overwhelming trying to navigate the application and then there are those members who have applied and been knocked back. So I decided to try to explain navigating the ndis in simpler terms.

Some of our members may be managing quite well in their lives, but then there are those

families with children or teenagers that require assistance to manage their daily lives and we also have members such as myself and others who also are needing support.

I have covered the different categories and what it all means with the ndis.

I explained the different support categories which you would use your funding for- if your application has been accepted.

I then explained how to apply for the ndis and what reports would be good to get together to help your application.

I explained how if you are needing help completing your

application there are agencies who can help you to apply. If you phone the ndis they can help you to find an agency.

Finding support to help you apply and manage your plan.

You may have already been put in touch with a support agency and local area coordinator to help you with your application.

If you have not, you will need to find an agency with a local area co-ordinator once you have your plan approved.

A local area coordinator (this is called a **LAC**) will help you to understand your plan. He/she will also provide

support during your plan, should you have any problems.

Your LAC will also show you how to organise your funding and manage it between your needed supports. They can also put you in touch with services and support people.

A LAC is payed by the NDIA. In the last newsletter I explained that the NDIA manages the NDIS.

Support Coordinators are also there to help find a mix of supports and services. Support co-ordinators are payed from your funding and funding needs to be provided in your plan for a support coordinator.

So what happens if things go wrong or you didn't receive your funding for your needs to support you effectively to in your plan?

You will either need to apply for a Internal review or put in a complaint.

This is if you have been denied your application to the ndis or perhaps something that has been in previous funding has not been accepted in your latest plan.

This sort of review is called an internal review of a decision made through the ndis. This is not to be confused with a review you would have if your ndis plan has

finished. Ndis plans are ususally set up for 12 months on your first application. Then when that plan finishes you would apply for a review of your plan.

The next plan you receive will usually last two years.

But if you are requiring a new decision on an application or plan you have already submitted, then you need to go to the ndis web site –

<https://www.ndis.gov.au>
go to the menu and look for - for participants then go to that menu and look for request internal review of a decision **find the request for a Review of a Decision form.**

It is important to submit any further evidence you

may have that supports your application.

An example of what happened to me was I submitted a plan variation which is a continuation of my plan because it had run out. In this new plan of mine I had to explain my recent paralysis of my legs and ask for the further supports that I would need to help me function in my daily life.

This included more hours for an OT to work with me to regain strength in my waist, legs and upper core, to be able to transfer from wheelchair into cars or onto a bathboard or into bed from my chair. I also needed to be able pull myself up onto support rails to climb three steps

to my kitchen. Also I could not propel outdoors on my manual wheelchair. As I live in regional Victoria this was a problem as we do not have any sealed roads or footpaths.

My Occupational therapist recommended a power electric wheelchair to be able to access outdoors. Without this I could only propel my manual wheelchair indoors and not be able to get into family or support workers cars to go shopping and to appointments. I could not even access my garden past my back door.

I was confined to three rooms and so there was a definite need for these supports.

I was given extra hours for my OT but the power electric wheelchair was knocked back.

During the process, I had a accessor phone me to say that he felt because his father has MS and rides a scooter, I did not need an power electric wheelchair. There where futher comments in the conversation but in the end it was apparent I was not going to get funding for a power electric chair.

I asked for an email to outline the conversation.

If a ndis operator cannot send an email outlining your conversation. Then you can request a reciept number and I would document points from your conversation, the time and date so you have this as proof of any

converstion that can be followed up in any inquireries if you are putting in a review or internal review.

I was knocked back on my wheelchair, so I did have to apply for a internal review.

After filling in the reassessment of an internal review form, I also wrote my own statement of why I was needing this electric chair and how my mental health was suffering because I could not access the out doors.

I resubmitted my OT report and also the email from the conversation I had with the fellow from internal reviews that phoned me.

I also wrote a complaint to the complaints department on how I felt this fellow had compered me to his father and that my condition was totally different to his father's and that not all degenerative neurological conditions are the same and I felt my decision was impacted from his own personal judgement.

I asked that my review be made urgent for my own health and mental health.

I got a phone call to say my situation was escalated.

Within four weeks, I had a better outcome from submitting my internal review.

My funding for my electric wheelchair was approved.

You can review how the internal review process works under how do I return this form to the NDIA? On the NDIS website. Under this if you scroll down it will tell you how the internal review process works.

Once you have submitted your form and paperwork, you will be notified in writing that it has been received.

If your internal review has not been escalated due to urgency then the process usually takes 60 days. You will be contacted if more information is needed and you will be told what further information you will need to submit.

Sometimes its something you have already submitted, this is why it is good to have photocopies of everything.

Forms can get lost or computers go down.

You will be notified in writing of their outcome.

If like me you are unhappy with any of the ndis services you can lodge a complaint. You can either email feedback@ndis.gov.au

or you can phone

1800 800 110

In our next newsletter I will explain what happens if you still are not happy with an NDIS outcome and how to lodge an external review with the Administrative Appeals Tribunal.

I hope this helps with making the NDIS process clearer for you all.

