

**References:** Cureous, Pub Med.

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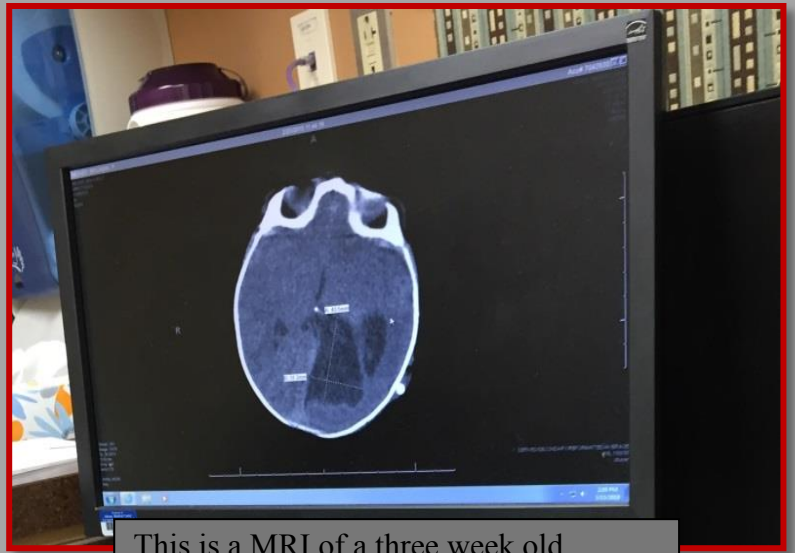
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## Arachnoid Cysts:

Not a lot of people have heard of Arachnoid Cysts.

It is considered a rare disorder because of this.



This is a MRI of a three week old baby which shows his Arachnoid Cyst measuring 6cm. He has had surgery with the insertion of a shunt to drain the cyst.

However many Arachnoid Cysts are found by coincidence while being investigated for another issue or due to ongoing symptoms. Imaging may reveal an Arachnoid Cyst or Cysts.

These may have been present at birth or are secondary cysts, due to an accident. Arachnoid Cysts can be found in the brain or on the spinal cord, applying pressure to these areas.

They can affect newborns, children and adults.

You may be reading this leaflet because you are a patient that has been recently diagnosed or you are a parent, family member or carer looking for information on Arachnoid Cysts. You are not alone!

There is information and support available!

It can be a very worrying time but there are places you can get advice and ongoing support from patients and carers going through the same thing.

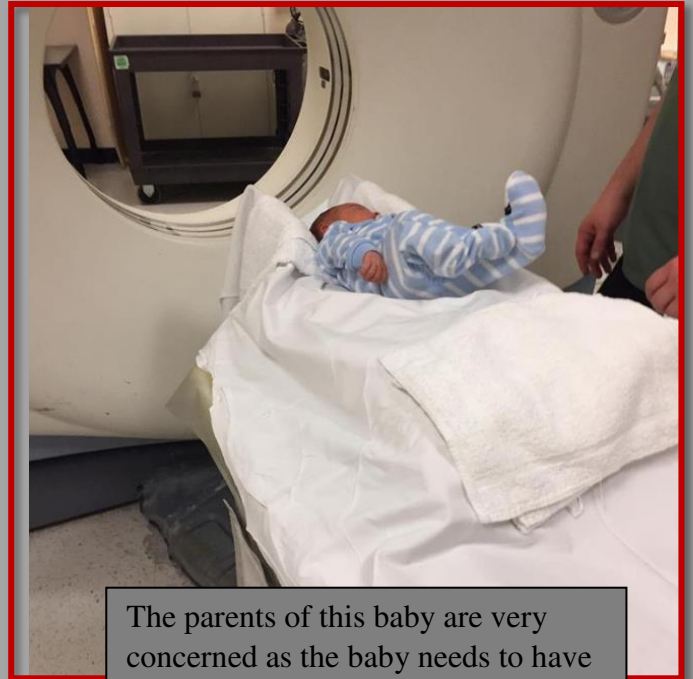
## So What Happens Next?

Most patients will be referred to a Neurosurgeon who will decide the best course of action in treating your Arachnoid Cyst.

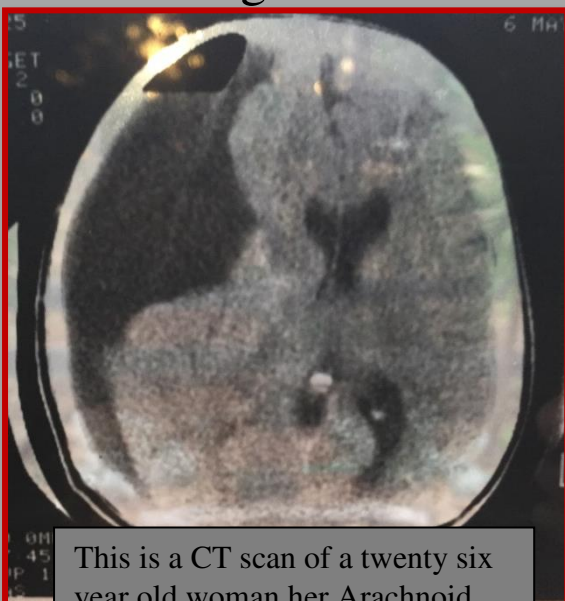
Due to where your Arachnoid Cyst is, will determine if it is to be monitored.

If you are a patient and the Neurosurgeon has decided to monitor you, you will most likely be referred to a Neurologist.

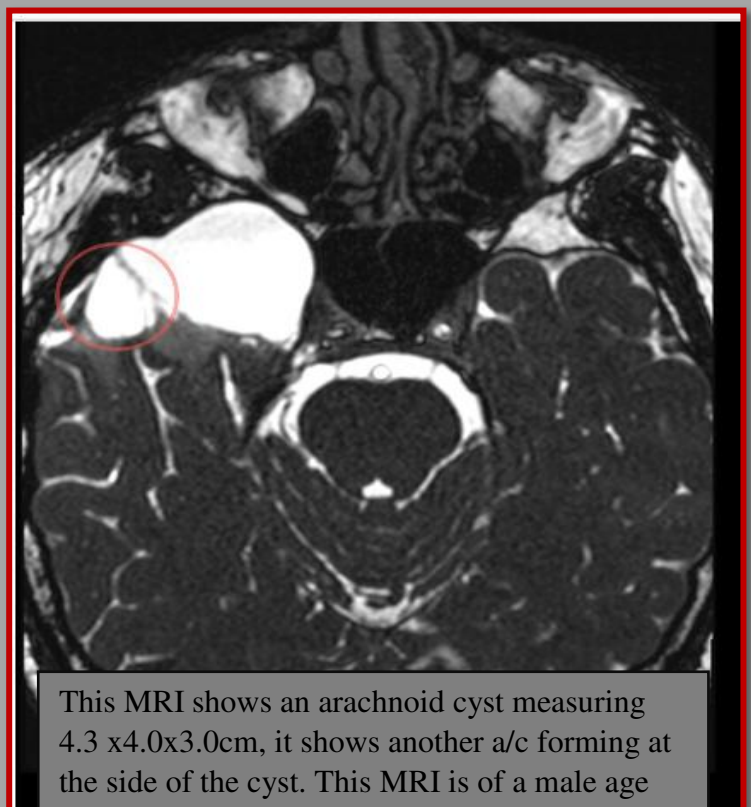
The Neurologist will decide what action is to be taken next. He may decide on a course of medication for your symptoms and have you undergo annual CT scans to monitor your cyst and liaise with your Neurosurgeon.



The parents of this baby are very concerned as the baby needs to have an MRI to determine which surgery will be appropriate for his A/C.



This is a CT scan of a twenty six year old woman her Arachnoid Cyst on the right measuring 4.5x11.5x16cm.



This MRI shows an arachnoid cyst measuring 4.3 x4.0x3.0cm, it shows another a/c forming at the side of the cyst. This MRI is of a male age 41.

This can be a very worrying time for you.

Your Neurosurgeon will discuss the best options for you.

## **Brain Surgery:**

You may either undergo a craniotomy to either remove the cyst or have the cyst pierced open to release the pressure of the cerebrospinal fluid (CSF) from your cyst to absorb naturally into your brain.

The Neurosurgeon will make an incision large enough to remove a piece of the skull and access the cyst. The piece of the skull is replaced and the wound site sutured.

It takes around ten days to heal and stitches/staples removed. Usually your staples will be removed as an outpatient at your hospital or your own general practitioner will remove them.

The other option is a shunt, this may be performed if the surgeon feels it is necessary.



This three week old baby is recovering from surgery to insert a shunt to drain csf fluid from his cyst into his abdomen.



A burr hole is made through the skull and a tube is inserted into the cyst allowing the pressure of the (cfs) cerebrospinal fluid from the cyst to be released into the tube which drains off into the abdomen.

You will have an incision made in your abdomen.

The tube will have a valve connected which will allow the correct flow of the cfs fluid, this will be a high, medium or low valve component and is set to allow the correct flow of fluid to drain away through another connected tube into the abdomen.

The tube is a small catheter and is fed along under the skin and is non-invasive to be able to be not noticed on the body. Once your surgery wounds heal you will be able to feel a small bump under the skin where the valve component sits on your head.



This picture shows a wound site for an incision made in the abdomen for a shunt.



The surgeon has brushed this lady's hair aside to shave her head and make her surgery incision. Her valve component is unnoticeable under the skin.

The surgeon will shave your head for both procedures, but in most cases he will pull your hair away from the area to be shaved, so if you have long hair you will be able to cover over your wound site once your stitches are removed and you are able to wash your hair.

This is usually in about ten days. If shaving your hair is a concern? You can discuss this with your neurosurgeon.

Most neurosurgeons are happy to oblige with your concerns and are pretty good with hair dressing.

### **Spinal Surgery:**

If you are to have spinal surgery and the neurosurgeon decides to insert a shunt, the catheter will be inserted into the cyst on your spine and will run under your skin from the area on your back to your abdomen. You will have a wound site on your spine and the other on your abdomen and both sites will heal in about ten to fourteen days.

With the spine, there is no need for a valve component. It is just a thin catheter and it will be unnoticeable to the ordinary eye.

The surgeon may decide that he is able to completely remove cyst from your spine, in this case, insertion of a shunt would not be needed.

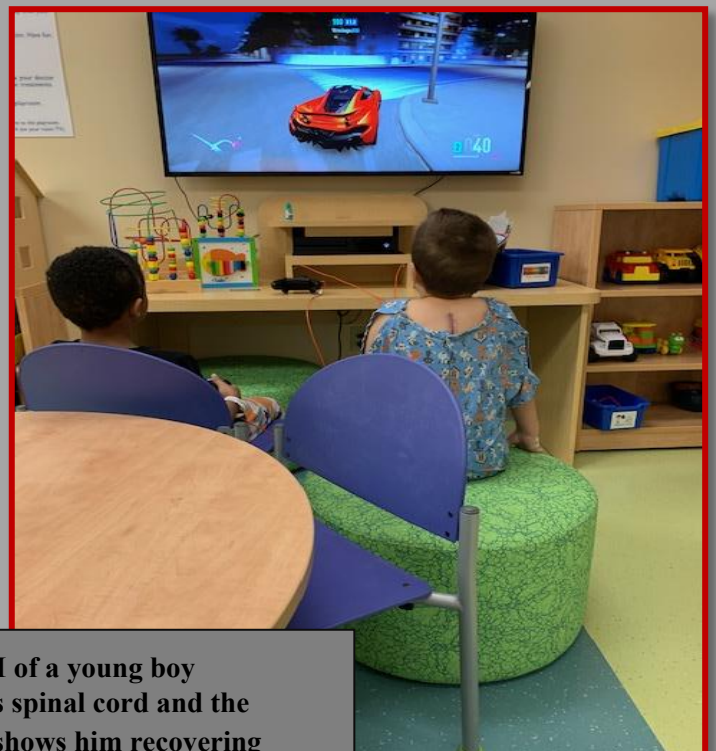
Your surgeon will discuss which approach will be best for you.

### **Endoscopic Cyst Fenestration:**

There is another recent procedure that neurosurgeons can also perform if it is suited to your situation and that is an Endoscopic Cyst Fenestration.

This is an advanced technique where the neurosurgeon uses an endoscope to make a small incision to insert a small tube with a camera attached to drain the cyst internally.

This is a less invasive procedure, taking around thirty minutes to an hour.



On the left is an MRI of a young boy showing a cyst on his spinal cord and the picture on the right shows him recovering after surgery.



The patient can usually return home within a day.

You may wish to discuss all of the procedures with your neurosurgeon to decide what is best for you.

All of these procedures are relatively safe and although as with any surgery, there are risks which will be clearly explained to you by your neurosurgeon, these procedures have been performed many times and you will be in safe expert hands.

If you are unsure of your options, or do not understand part of your procedure, ask questions. You can ask for a second opinion and you can obtain information through our Australian Support Group: Arachnoid Cyst Awareness Australia. The contact numbers or email will be listed at the end of this booklet. You are not alone, we are all patients, family members or carers who have been through or are going through this.

### **Your Stay in Hospital:**

Generally most operations performed will have you stay in hospital anywhere from two, or up to seven days depending on your recovery and the procedure performed.

After your surgery you will spend the first night in the high dependency ward where you will be monitored by nursing staff every couple of hours for observation.

You will have your blood pressure, temperature and have a set of questions asked to determine your awareness and surroundings.

You will also have your cognitive and coordination tested through squeezing the nurses hands and pushing down on your feet or being asked to move other limbs, such as raising your legs to detect any weakness. The nurse or Dr will also want to shine a torch in your eyes to detect pupil reaction.

Although this can be frustrating, because you may be aroused from sleep, it is a very important test to check you are coherent and test for any loss of limb sensation.

You may also have an oxygen mask on and leads from the monitor connected to you, as well as an intravenous drip. These will all be removed over time and going well, you will be moved to a normal ward the next day for the remainder of your recovery.

Sometimes after the operation you may experience some moving of fluid in your head, though being able to feel and hear these sounds. This may be



Following surgery, you can see this male patient's wound site on the left and the intravenous drip inserted in his arm during recovery.

quite unsettling but it is normal and it is air that enters through the operation into your brain.

It is not harmful and although the sensation is quite strange it will resolve over time.

### **Managing Your Pain:**

For the first twenty four hours you will be sore and you will be prescribed medication for your pain through your neurosurgeon.

If you are having problems with pain, speak with the nursing staff who will in turn liaise with your neurosurgical team. This will be made up of nurses, some interns and the neurosurgical registrar on the ward with your neurosurgeon visiting to check on you and liaise with the team each day.

If you are still, after speaking with your neurosurgical team, having problems with pain, discuss this with your neurosurgeon, as he may refer you to the neurosurgical pain management team who can review your situation.

You may also have problems with nausea, this may be a side effect of you having anesthetic, you can ask the nurse for something to settle your nausea.

### **Your Recovery:**

The next day the physiotherapist will visit you.

He/she will want to see how you are on your feet. One of the most important things is to get you up and mobile as this will stop any congestion on your lungs from lying in bed and will stop any blood clots from very little exercise or circulation of your limbs.

You will be given a pair of pressure stockings before surgery to help with circulation. It is important to leave these on until you are told you no longer need to wear them.

The physiotherapist will want to monitor how steady you are on your feet to plan how you will manage at home as you will be very tired for a while afterwards.



Your staples or stitches will most likely be removed in about ten to fourteen days by your own physician.

Gentle exercise like a small walk around the ward will help you get back on your feet and will help to reduce stiffness and further pain and get you back to feeling yourself again.

One other way you will be affected is your bowels if you are taking pain medication. You can discuss your options with

the nurses as some medications will upset your regularity, so it is really important that you take some medication to keep you regular.

Once you feel up to eating, include plenty of fruit and vegetables when ordering your meals, or if your family brings in meals for you this will help greatly.

Also drink plenty of fluids and take a short walk around the ward, this will help to keep things moving along. You can inquire with your nurse if you experience discomfort.

Most likely the nurse will ask you about this each day and this is the reason why. Do not be embarrassed, it is all part of the process and to avoid any further discomfort.

### **Support Networks:**

The other thing that will aid in your recovery is to have a good support network around you.

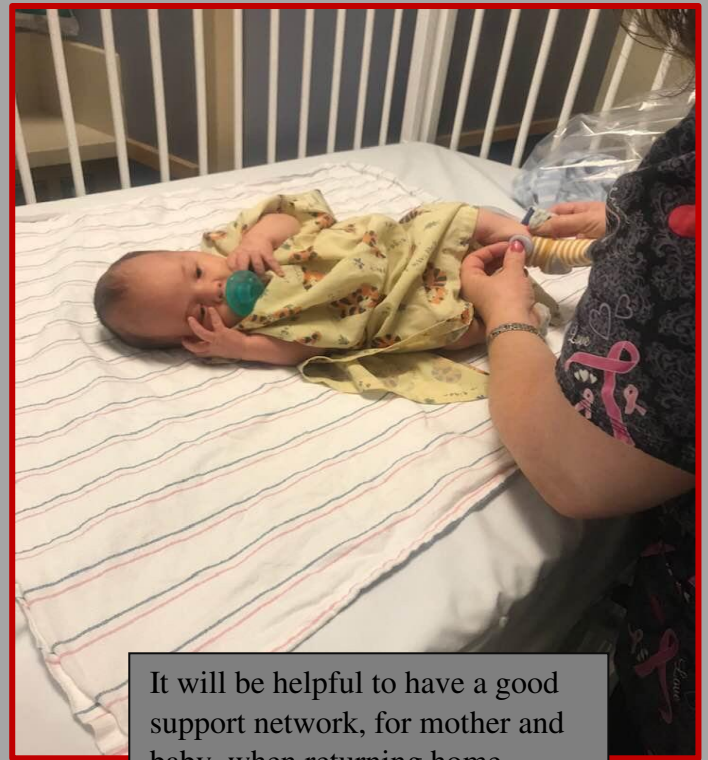
Throughout the whole journey, whether you are to be monitored for your cyst or have had surgery, you are going through an emotional as well as physically unwell time and it is really important to have people who understand your wellbeing.

Family can play a big part in helping out with meal preparation, house cleaning, running errands and



personal care for the first week you arrive home from hospital.

You will find you tire easily and will need to rest when you feel you are tiring. As the weeks go by you will start to feel more independent, but try not to overdo things, as your body will recover better if you are aware you need a break.



It will be helpful to have a good support network, for mother and baby, when returning home.

Pacing is a good practice. After completing a task, try to have a short suitable rest before going onto another task. Light exercise like a short walk and gradually increasing as you feel stronger each day, will help to get your strength back. You could consider doing Tai Chi or taking up a swimming class with other patients who are recovering from different surgeries. Both these activities are a gentle form of healthy exercise and are excellent for your breathing, relaxation and coordination while getting back to feeling healthier.

You can enquire through the hospital physiotherapist before you leave hospital, or your local council.

If you have young children and need assistance with their daily activities, a family member could perhaps help out?

Another thing you can put in place is to speak with the hospital's Occupational Therapist, to organize some home help, or speak with the welfare department. All hospitals have counsellors that are there to assist patients in need and can put these things in place for you.

This may be something to look at if family are unavailable for help due to unforeseen circumstances or other commitments.

### **Travel and Accommodation to and from the Hospital:**

If you live far away from the hospital doing your surgery, you may be a country patient or live some distance away, you can also enquire about motel accommodation.

Most hospitals have a list of accommodation close to the hospital that can provide cheaper rates or travel assistance for patients and a support person.

In each state of Australia, there is also a travel assistance scheme that can assist with subsidising accommodation and travel if you are over two hundred kilometres away and carry a health care card.

The hospital social work department can assist with organising this.

Do not be hesitant about asking questions if you are concerned about something, write it down so you can remember to ask your neurosurgical team or your Neurosurgeon.

As already mentioned there is an Australian Support Group of patients who are going through the same experiences as you. There is our Australian Website as well as Face Book support groups too.

These groups are very supportive and can provide extra information from patients diagnosed and who have experienced surgery. We have Australian patients as well as patients around the world who are there to support each other through this experience.

There are family members, parents and carers as well on these sites, so you are not alone!

Also we have available a post operative care support bag. In there you will find useful information on support and services, also some much needed items to make your hospital stay more comfortable. If you have not received one, you can contact our support group by phone or via our website.

## **Information for Family Members and Carers:**

For family members and carers, this can be a very worrying time and it is important that you understand your loved

or family member has just undergone a big adjustment in life as well as yourselves.

He or she may be worrying and unsure of how they will cope and recover from having had brain surgery when home.

The patient may feel a loss of independence and feel restricted with their daily activities, due to memory and cognitive skills adjusting. They may feel fatigued quite often and perhaps have some rising symptoms they have not experienced before, while the brain is adjusting from surgery.

The patient may become emotional and have bouts of personality changes along with irritability. This is not aimed at you, their brain will be going through adjustment of their surgery and things will take time to settle.

If a patient does have an emotional time or has an outburst because they are exhausted, they may feel depressed and ashamed afterwards. Younger patients such as children may be confused and frightened.

It is worthwhile before a child's surgery and after



The patient may tire easily and become emotional. Their brain will be adjusting after surgery.

surgery to be as honest and clearly explain to the child what is happening to them.

They will be frightened even more if they cannot understand what is happening. The more you tell them the more they will be prepared and willing to undergo a procedure or test.

You can reassure the patient, that they are recovering from a big surgery and their brain is healing and going through adjustments.

### **Visits from Relatives and Friends:**

Try to have a stress free environment at home whilst the patient is recovering. Ask your visitors to come in the mornings when they are fresh and not tired from the days activities.

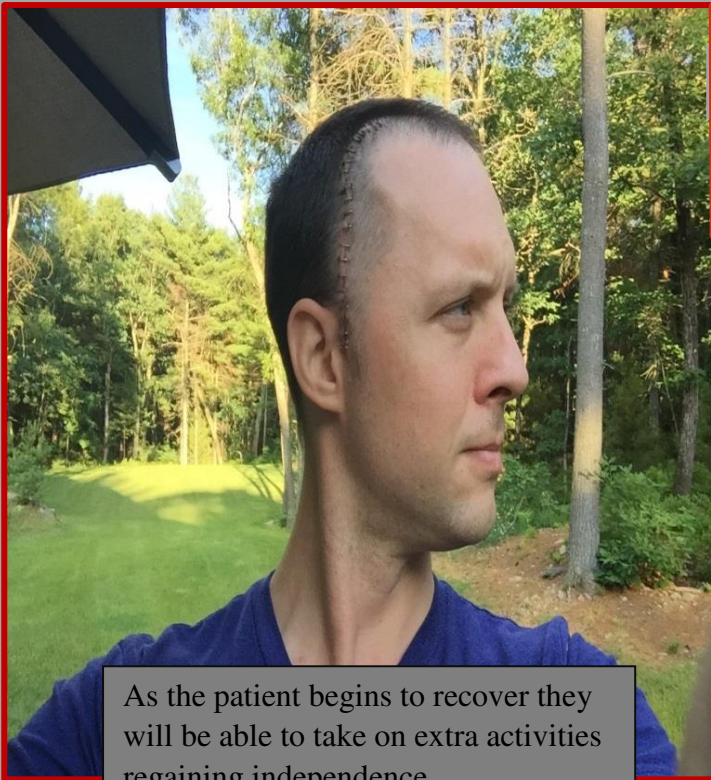
Explain to friends and family that the patient is needing a quiet, loving, stress free environment.

Although they may wish to visit, perhaps staggered visiting in hospital and at home will be helpful, so the patient or young child doesn't exhaust their concentration and daily



Let visitors know you are resting. Quiet stress free environments and rest will help with recovery.





As the patient begins to recover they will be able to take on extra activities regaining independence.

activity levels, with trying to keep up with conversation or children with their play activities. Thus causing exhaustion and frustration of patient.

As the patient begins to recover they will be able to take on extra activities, over time regaining independence.

Patience and love is needed from family and carers assisting in their recovery.

Surgery will help control the Arachnoid Cyst pressure on part of the brain or spine it is affecting, however, recovery will vary in each patient and it will be expected that the patient will feel better. Understanding that this is a condition, is vital to the patient.

Discuss any concerns you as a patient or caregiver may have with your neurosurgeon or general practitioner.

The help of a psychologist will help with retaining a cognitive and emotional balance, so the patient is less stressful over their recovery.

## **Caring for Yourself as the Carer:**

It is also helpful for the carer to take timeout to look after their needs and also if needed, seek counselling to help with your own emotional wellbeing. The help of close friends, family or home help for you to be able to attend to your own everyday activities, social outings and needs are very important so you don't burn out.

Sometimes asking for help and assistance may be difficult because by asking for help, may make you feel you cannot help the person you are caring for. You may feel you are failing to be there for your loved one, but it is ok to ask for assistance.

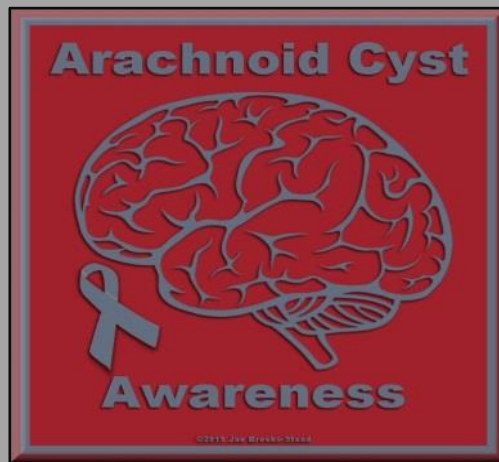
Being an advocate and finding out as much as you can about available services and this condition, will help both the patient, family and carers and your medical team to help you all throughout this journey.



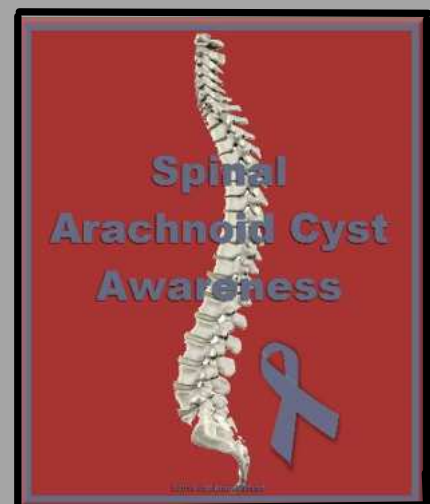
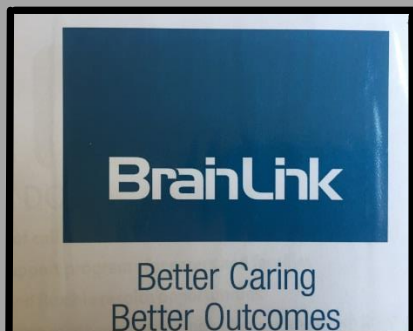
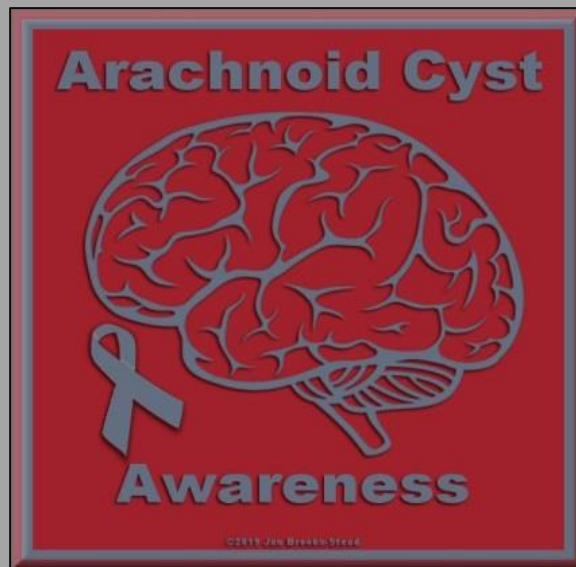
Our Patients after surgery in late 2018, early 2019. They are recovering well with the love and support of family and friends and carers.



**The Information in this brochure is intended as a guide only and has been written and produced by patients with Arachnoid Cysts and their experiences. It is not intended to replace correct medical treatment and information on Arachnoid Cysts. For accurate information, please consult your Neurosurgeon and your own Medical Professionals.**







**brainlink.org.au**  
For Family and Carers:  
email: [clientservices@brainlink.org.au](mailto:clientservices@brainlink.org.au)

**For Further Information and Support Contact:**

**The Australian Arachnoid Awareness Support Group-**

**[www.acystawareaust.com.au](http://www.acystawareaust.com.au) Ph:0419 993 462.**

**BrainLink: [clientservices@brainlink.org.au](mailto:clientservices@brainlink.org.au)**

**F/b:<http://www.facebook.com/> where you will find many supportive groups: type in Arachnoid Cyst Awareness. Arachnoid Cyst/Surgery/Removal/treatment. Spinal Arachnoid Cysts. Pediatric Arachnoid Cyst  
\_ Type in the headings of any of these four groups.**



