Committed to understanding and supporting people with Lupus, Sjögren’s, Schleroderma & Fibromyalgia or any autoimmune disease

Medications
What are you taking?
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We would like to acknowledge the Hon Mr. Michael Ferguson MHA for the printing of our Newsletter and his continued support.

The Lupus Association of Tasmania, Inc. does not recommend or endorse any drugs, treatments or procedures reported in this newsletter. The information is intended to keep you informed and we recommend that you discuss any information mentioned with your Doctor.

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*From the Editors Desk*

At the last Morning Tea I was given a copy of the Lupus UK News and Views, winter 2018, Number 116 and in it was an article about Hydroxychloriquine (Plaquenil is the name we know it by) and reading the article I had the idea that this quarter I would devote the newsletter to Medications which are manifest to Autoimmune Diseases. This proved to be an arduous task as I am a patient and have been prescribed several of the drugs which feature in the articles. These drugs Have kept my problem under control over some years. Therefore, I thought that maybe some of the information I have gathered might be interesting for our members.

There is quite a lot of information available, but one needs to talk it over with a doctor, only they can ascertain whether and what drugs are best for us. I hope that all our members and families have had a Happy Christmas and New Year.

Edna Brock
Editor

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*Wise Words*

To win you must risk losing,
To walk you must first stumble,
To enjoy the flowers the sun must be willing to accept the rain.

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**Presidents Report**

Welcome to 2019 and a special welcome to our new members. Our Library of Resources is about to have a makeover. Last year we cleared out all our out of date publications and conducted research into what new books would be beneficial. I have since received quotes for copies of about six (6) new books. I am aware that there is a grant scheme opening this month which might pay for these books and a few other resources that would be ideal to have. So I have not placed an order yet in hopes that we might be successful with grant pursuit. I believe it will only be a month or two before we have our new books. I would like to ask for some volunteers to read and give us a brief book review on the book that was read. This would include an outline of the book, its style, what you thought was good, any weaknesses and who you would recommend to read the book. I would post a book to you and we would include your review in the following newsletter.

Our AGM is not far away, please give thought to standing for one of the positions. If you are interested in the president’s position can you give me a call.

Best regards  
Lois Beckwith President

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**Regional Reports**

**Northern Group**

Our group meet on the fourth Thursday of the month at 10.30 am at the Joan Marshall Wing, Kings Meadows Health Centre. Occasionally we will consider having a meeting elsewhere and may be include morning tea or lunch. If anyone has any suggestions we will discuss them at our first meeting in February. See you February 28th. (This meeting will be in the Main Kings Meadows Building, as there is another meeting in the Joan Marshall wing, they apologised for the change at our January meeting.)

Northern Co-ordinator  
Lois Beckwith.

**West Coast**

The meeting at the West Coast was cancelled owing to holiday arrangements, we hope you International Visitors enjoyed our State. To get information about meeting times contact Barbara

West Coast Co-ordinator  
Barbara Gruner
Regional Reports Cont.

Southern report
The southern group have postponed their February Luncheon until the 18th March so we can, hopefully, see some photos of a cruise to New Zealand. We will meet at 12 midday, as usual, at Mathers House, in Bathurst St. Hobart, which is near the State Library and opposite Melville St. Car Park. It is really handy as we exit the car park on the Library side of the building. Walk a few steps to the pedestrian traffic Light crossing and Mathers house is immediately in front of us.

Mathers House has home cooked meals with a fixed rate 2 or 3 course meal, which is very good value or snacks like sandwiches. This is run by volunteers so there is not a wide selection on the menu but what is served, from the past experience, was delicious. We MUST reserve tables so please book in for the luncheon by 14th March. Invitations to regulars will be sent out in March.

As the next Centre activity usually starts about 1pm we end the luncheon by then. We are welcome to join in other activities at the centre. The 1pm conclusion means people who want to take part in the free parking option at the car park are able to do so.

New members and family are always made very welcome to our friendly gathering. We hope you can join us for our Autumn Luncheon.

Southern Co-ordinator
Heather Cowled
PH. 6272 3096

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North West Report.
The North west group did not meet in January as Robbie and I got married on December 15th at the chapel in the Launceston General Hospital. Robbie had had another stroke so our wedding was change to the LGH.

Robbie was discharged on the 28th December and we were on the plane to go on our honeymoon (13 day cruise around New Zealand) on the 10th January.

We were away for 17 days.

We are to meet next on the 19th February (a once off) then we revert back to the 1st Tuesday of every month.
We still meet at the Fuschia Farm, between Devonport and Ulverstone, at 12.15pm until 2.00 ish. Everyone is welcome, friends and families who support people living with Lupus/Autoimmune conditions are warmly welcomed.

We look forward to seeing you there.

North West Co-ordinator
Leanne Collins (New name)

Congratulations Leanne and Robbie. We hope that Robbie is keeping well now and that you both had a good cruise around New Zealand.
New Drug Target For Immune Diseases Discovered

Researchers from Mount Sinai School of Medicine have found a new mechanism that explains how certain immune cells are activated to create protective antibodies against infections or pathological antibodies such as those present in autoimmune diseases like lupus and rheumatoid arthritis. The research is published online in the September issue of *Nature Immunology*. Autoimmune diseases like lupus and rheumatoid arthritis are characterized by exaggerated production of molecules that activate the adaptive immune system and abnormal antibodies, which attack normal cells causing inflammation and tissue damage. This exaggerated production may occur partly as a result of abnormally strong signalling from TACI via MyD88. By analyzing cells and tissues from immunodeficient patients and genetically engineered mice, Dr. Cerutti's team found a previously unknown interaction between TACI and MyD88 that is important for the production of antibodies against infectious agents. Yet, the same interaction may cause the exaggerated immune response in people with autoimmune diseases.

"Our discovery provides a novel specific target, the signaling pathway between TACI and MyD88, to block the overreaction of the immune system and tissue damage in individuals with autoimmune disorders," said Dr. Cerutti. "We look forward to studying this discovery further and developing therapeutic targets that will inhibit the interaction between TACI and MyD88, preventing autoimmune diseases from progressing with fewer side effects than currently prescribed treatments."

Dr. Cerutti's team collaborated with other researchers at Mount Sinai School of Medicine, including Charlotte Cunningham-Rundles, MD, Professor of Medicine and Pediatrics, and Huabao Xiong, PhD, Assistant Professor of Medicine. According to the National Women's Health Information Center, autoimmune diseases impact 23.5 million Americans. Common examples include lupus, in which the immune system attacks the skin and/or several organs within the body; rheumatoid arthritis, in which the immune system attacks joints; multiple sclerosis, in which the immune system attacks the nervous system; and Type 1 diabetes, in which the immune system attacks insulin-producing cells in the pancreas.

Source: The Mount Sinai Medical Center

Article URL: http://www.medicalnewstoday.com/articles/196711.php

Main News Category: Arthritis / Rheumatology

Also Appears In: Immune System / Vaccines, Lupus,

*Article taken from Science News from research Organizations, August 4 2010.*
This information sheet has been produced by the Australian Rheumatology Association to help you understand the medicine that has been prescribed for you. It includes important information about:

- How you should take your medicine;
- What are the possible side effects;
- What tests you must have to monitor your condition and to detect unwanted effects; and
- Other precautions you should take.

Please read it carefully and discuss with your doctor.

What is methotrexate?

Methotrexate (brand name Methoblastin) is a medicine used to treat rheumatoid arthritis as well as other rheumatic conditions such as juvenile arthritis, lupus, (also known as SLE), psoriatic arthritis and polymyositis (muscle inflammation).

Methotrexate is an immunosuppressive medicine. It works by reducing the activity of several enzymes involved in the immune system. By blocking an enzyme called dihydrofolate reductase, it reduces production of a form of folic acid. It is not entirely clear how methotrexate decreases the severity of arthritis but it reduces inflammation in the joints and associated pain and swelling.

Because methotrexate reduces the damage to the joints, rather than just relieving the pain, it belongs to the group of medicines called disease modifying antirheumatic drugs (DMARDS). Methotrexate has been used to treat rheumatoid arthritis for more than twenty years.

It is also used at very high doses (1000mg-5000mg a day) to treat some cancers.


What benefit can you expect from your treatment?

Methotrexate is one of the most effective treatments for rheumatoid arthritis. Most, but not all, patients will benefit from this medicine. Some achieve remission, where the arthritis virtually disappears.
Methotrexate cont.

Methotrexate does not work straight away. Reduced pain, stiffness and swelling may be noticed after 4 weeks. The effects to delay or prevent joint damage will take several months.

Other medicines may be given to improve your symptoms while waiting for methotrexate to work.

How is methotrexate taken?

Methotrexate may be taken by mouth as a tablet or given by injection either into the muscle or under the skin.

Injections may be used instead of tablets if the medicine is not being absorbed well, or if you feel sick (nausea) or vomit when you take the tablets, or your condition is not improving with tablets.

Methotrexate is taken just once a week, on the same day each week. If you are taking the tablets, it is a good idea to specify and diarise the day of the week that you will take your tablets to avoid making mistakes.

If you take the tablets at night on an empty stomach you will absorb them best. Taking the medicine in the evening or at meal time may also help to reduce nausea.

What is the dosage?

Tablets come in 2.5mg or 10mg strengths. Treatment usually starts with a very low dose, which is increased and adjusted depending on the response, up to about 25mg once a week.

The dose is usually taken all at once on a single day. It may be divided into separate doses taken during that day if necessary.

Are other medicines taken with Methotrexate?

Folic Acid or folinic acid are recommended while you are taking methotrexate as they reduce the risk of side effects. Your doctor will explain how much of the folic/folinic acid to take and when to take it.

Methotrexate is often taken in combination with other arthritis medicines, including:

- Other DMARDs;
- Biological DMARDs (a newer type of DMARD, which act on natural substances in the body that contribute to inflammation and joint damage);
- Steroid medicines such as prednisolone or cortisone injections into joints;
- Anti-inflammatory medicines (NSAIDs) such as naproxen (Naprosyn) or ibuprofen (Brufen/Nurofen); and/or
- Simple pain medicines such as paracetamol.
Methotrexate Cont.

How long is the treatment continued?
The treatment is continued indefinitely as long as no serious side effects occur.
If Methotrexate treatment is stopped for more than a few weeks there is a risk that your condition may worsen. Continue with your treatment unless advised by your doctor or unless side effects develop.
If you have an illness, which makes you unwell enough to change plans for the day, e.g. gastroenteritis or fever, it is reasonable to miss the weekly dose until you have recovered.

Are there any possible side effects?
Below are side effects that you might experience with your treatment. Tell your doctor if you experience any side effects.
If you do experience side effects, a reduction in dose may minimize these so that you can continue to take the medicine. Your doctor will advise on any dose changes that are necessary.

Most common possible side effects:
• The most common side effects are nausea, vomiting and diarrhea. These can be reduced if methotrexate is taken with food or in the evening. Antinausea tablets can be used if needed.
• Mouth ulcers can occur, but the use of folic acid or folinic acid supplements makes this less likely.
• Skin dryness, a variety of skin rashes and increased sensitivity to the sun may also occur. You should wear sunscreen and a hat when out in the sun.
• Some people report mild tiredness, headache and mental clouding. Some also experience a temporary increase in muscle and joint pain after taking the weekly dose.

Less common or rare possible side effects:
There are some rare but potentially serious side effects with methotrexate.
• Blood counts: Methotrexate can rarely cause a drop in the number of white blood cells, which are needed to fight infection. It can also cause a drop in the number of platelets, which help stop bleeding.
• Regular blood tests aim to pick these problems up early if they occur. However, if you develop a sore mouth, mouth ulcers, easy bruising, nosebleeds, bleeding gums, breathlessness, infection or fever tell your doctor straight away.
• Liver: Methotrexate can inflame the liver causing a type of hepatitis. Regular blood tests aim to pick this up early if it occurs. The dose of methotrexate may need to be reduced or stopped if problems occur. Liver problems may be increased when methotrexate is combined with the medicines azathioprine (Azahexal, Imuran,) or leflunomide (Arava) or with heavy alcohol use. (see Alcohol over leaf).
• Lungs: Methotrexate can cause inflammation of the lungs. This may be more likely if leflunomide also is being taken. This may develop quickly. If you have a sudden onset of breathing difficulties seek medical attention as soon as possible. The problem may also develop slowly with symptoms such as a dry cough.
Methotrexate cont.

- **Hair thinning:** This may occur rarely. It is not permanent and hair will grow back when the medicine is stopped.
- **Cancer:** see below

**Long term possible side effects:**
Methotrexate may be taken for long periods e.g. more than twenty years, to manage rheumatoid arthritis. In addition to possible effects mentioned above, the following are rare but possible long term side effects, or long term issues that may concern patients:

- **Liver:** very rare cases of increased fibrous tissue in the liver have been reported after long term treatment. Regular monitoring can minimize the risk of this occurring.
- **Cancer:** People who have rheumatoid arthritis have an increased risk of lymphoma (a lymph node cancer). It is not clear whether methotrexate increases this risk further, but any additional risk is likely to be very small. Methotrexate may reduce the risk of these cancers by controlling the rheumatoid arthritis, but this is unproven. For general cancer prevention, stopping smoking is recommended. An annual skin check to detect any early skin cancer is also recommended.
- **Fertility:** Methotrexate does not affect a person's ability to have children in the long term. See also **precautions** over leaf.

**More information about possible side effects**
Information that comes with your methotrexate medicine will also outline in detail potential serious side effects that may occur with methotrexate. Many of those side effects relate to a high dose methotrexate for the treatment of cancer. These may not be applicable to the much lower doses that are prescribed for the treatment of rheumatoid arthritis. Talk to your doctor if you have concerns about any possible side effects.

**What precautions are necessary?**

**Blood tests:**

- As methotrexate may affect the liver and blood cells, you must have regular blood tests during your treatment. This is very important, as you may not get symptoms with some of these problems.
- Blood tests are particularly important during the first few months of treatment and when methotrexate is taken with leflunomide.
- As well as monitoring for side effects, blood tests help monitor your condition to determine if the treatment is effective.
- You will need to have full blood counts and liver function tests every 2 to 4 weeks for the first few months of treatment and then every 1 to 3 months after that.
- If there are no problems seen after 3 months of treatment at a specific dose of methotrexate, the blood tests may be done less frequently.
- Your general practitioner will be informed about the monitoring schedule. It is important to see them if you have been asked to do so as they play and important role too in monitoring your condition.

**Avoid infections:**

- Because your immune system may be depressed, there is an increased risk of developing some infections, especially herpes zoster (chicken pox and shingles). You should try to avoid contact with people who have these infections. If you have an infection or persistent fever, tell your doctor straight away.
**Methotrexate Cont.**

**Other Medicines:**
- Methotrexate can interact with other medicines. You should tell your doctor (including your general practitioner, rheumatologist and others) about all medicines you are taking or plan to take. This includes over the counter or herbal/naturopathic medicines. You should also mention your treatment when you see other health professionals.
- Antibiotics containing trimethoprim (e.g. Bactrim, Septrim and Triprim) can cause problems when taken with methotrexate and should be avoided.
- Aspirin can also be used safely in low doses taken for prevention of heart attack and stroke.
- Methotrexate can be safely taken with anti-inflammatory drugs (NSAIDs), as long as your kidney function is normal.
- The simple pain reliever paracetamol and combined medicines such as Panadeine and Panadeine Forte, can be used while taking Methotrexate provided you take them as directed.
- Most vaccines can be given safely. Pneumovax and yearly flu vaccinations are safe and recommended to reduce your risk of those infections. Talk with your rheumatologist before receiving any vaccines.

**Alcohol:**
- Alcohol increases the risk of liver damage while taking Methotrexate. Methotrexate usage in heavy drinkers has been associated with cirrhosis of the liver.
- It is not known precisely what level of drinking is safe when on Methotrexate, however, there is general agreement that 1-2 standard drinks taken once or twice a week is unlikely to cause a problem.
- Drinking more than 4 standard drinks on one occasion, even if infrequently, is discouraged.

**Surgery:**
If low dose once weekly methotrexate is continued during surgery, there seems to be no change in wound healing or increased infection.

**Pregnancy and breast feeding:**
- Methotrexate should not be taken during pregnancy as it can cause miscarriage or foetal deformity. It should also not be taken during breast feeding.
- Women of child bearing age should use effective contraception while taking methotrexate.
- Women planning to become pregnant should stop methotrexate 3 months before attempting to conceive.
- The optimal time for a male partner to stop methotrexate before trying to conceive is not known.
- Methotrexate does not affect a person’s ability to have children in the long term.

*The information in this article has been obtained from various sources and has been reviewed by the Australian Rheumatology Association. It is intended as an educational aid and does not cover all possible uses, actions, precautions, or interactions of the medicines mentioned. This information is not intended as medical advice for individual problems nor for making an individual assessment of the risks and benefits of taking a particular medicine. It can be reproduced in its entirety but cannot be altered without permission from the ARA.*
Changes in screening guidelines for hydroxychloroquine retinopathy
Dr Natasha Jordan, Consultant Rheumatologist, Addenbrooke’s Hospital, Cambridge

Hydroxychloroquine is an immunomodulatory medicine that is effective in treating various inflammatory and autoimmune disorders such as lupus, Sjögren’s syndrome, rheumatoid arthritis and the Antiphospholipid Syndrome. If you are one of the patients with lupus who regularly takes hydroxychloroquine (trade names Plaquinil and Quinoric), please be aware that updated guidelines regarding screening for hydroxychloroquine retinopathy were introduced by the Royal College of Ophthalmologists in February 2018.

Hydroxychloroquine has long been the cornerstone of treatment for patients with lupus. It is particularly useful in the management of musculoskeletal and skin manifestations of lupus. As well as being disease modifying, hydroxychloroquine has benefits in terms of reducing the risk of disease flares, increased long-term survival, and protection against thrombosis and loss of bone mass. In addition, hydroxychloroquine reduces damage accrual over time and has a protective effect on kidney damage in patients with lupus nephritis. Hydroxychloroquine has also been shown to be compatible with conception, pregnancy and breastfeeding. Patients with lupus who remain on hydroxychloroquine during pregnancy have less disease activity and require lower doses of steroids at the end of pregnancy than those who stopped hydroxychloroquine for conception or those who were never taking it.

The new guideline was written by the Royal College of Ophthalmologists in response to evidence from the United States that shows that hydroxychloroquine retinopathy is more common than previously recognised. The guideline makes recommendations regarding the techniques and timing of baseline and follow-up screening eye tests for hydroxychloroquine retinopathy. In general, hydroxychloroquine is a safe and cost-effective medication; however, some patients taking hydroxychloroquine can suffer permanent loss of vision due to the harmful long-term effect of hydroxychloroquine on the retina. The condition where hydroxychloroquine can affect the retina and vision when taken for a long period of time is called “hydroxychloroquine retinopathy”.

Hydroxychloroquine retinopathy becomes more likely the longer a patient is taking the medication. The disorder is rarely seen within the first five years of treatment, but becomes more common with a longer duration of use. If advanced, hydroxychloroquine retinopathy can cause symptoms of loss of peripheral vision, and then in later stages, central vision can become affected too. It is possible to detect early signs of hydroxychloroquine retinopathy using specialized techniques that can look at layers of the retina with photographs of the eye, and by visual field testing. These tests, when taken together, can detect early signs of the condition.

The risk of hydroxychloroquine retinopathy is increased for patients taking more than 5mg/kg/day and for those also taking the medication tamoxifen, and those with impairment of their kidney function.
Hydroxychloroquine Retinopathy Cont.  
The Royal College of Ophthalmologists guidelines state that screening for hydroxychloroquine retinopathy should include having a baseline test at the eye service where the screening will take place. This will mean having a photograph taken of the retina within a year of starting hydroxychloroquine. The reason for these baseline tests is to determine whether an individual can undergo screening, and whether any conditions of the retina or the eye already exist which may make screening difficult or impossible. Thereafter, most patients will be screened after five years of taking the medication, and will be screened annually thereafter, with a combination of retinal photographs and visual field tests. The Royal College of Ophthalmologists have suggested that a useful aide memoir for the guideline for hydroxychloroquine retinopathy screening is the 5 x 5 rule; ideally keeping the dosage < 5mg/kg/day and screen after five years of drug use. As a consequence of this guideline, many patients with lupus on visiting their Rheumatology department in recent months have been asked to reduce their dose of hydroxychloroquine. The likelihood of a subsequent increase in disease activity and flares of lupus following this has yet to be ascertained. Another concern is how Ophthalmology departments nationwide will be able to cope with the influx of patients taking hydroxychloroquine who will need monitoring. Should patients notice an increase in her lupus symptoms following a reduction in their hydroxychloroquine dose, they should discuss this with their Rheumatologist. More information on hydroxychloroquine and screening for hydroxychloroquine retinopathy is available from:  


Our thanks to Dr Natasha Jordan for providing this article, following much discussion on this topic on HealthUnlocked. Printed with permission from Lupus UK News and Views, Winter, 2018, Vol. 116.

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An Amusing Story
While I sat in the reception area of my doctor’s office a woman rolled an elderly man in a wheelchair into the room. As she went to the receptionist’s desk, the man sat there alone and silent. Just as I was thinking I should make small talk with him, a little boy slipped off his mother’s knee and walked over to the man. Placing his hand on the man’s, he said “I know how you feel. My mum makes me ride in the stroller too”.  

Story of Two Men

A great note for all to read it will take just 37 seconds to read this and change your thinking.

Two men, both seriously ill, occupied the same hospital ward. One man was allowed to sit up in his bed for an hour each afternoon to help drain the fluid from his lungs. His bed was next to the only window in the room. The other man had to spend all his time flat on his back. The men talked for hours on end. They spoke of their wives and families, their homes, their jobs, their involvement in the military service, and where they had been on vacation.

Every afternoon when the man in the bed by the window could sit up, he would pass the time describing to his roommate all the things he could see outside the window.

The man in the other bed began to live for those one hour periods where his world would be broadened and enlivened by all the activity and colour of the world outside.

The window overlooked a park with a lovely lake. Ducks and swans played on the water while children sailed their model boats on the lake. Young lovers walked arm in arm amidst flowers of every colour and a fine view of the city skyline could be seen in the distance.

As the man by the window described all this exquisite detail, the man on the other side of the room would close his eyes and imagine the picturesque scene.

One warm afternoon the man by the window described a parade passing by. Although the other man could not hear the band—he could see it. In his mind’s eye as the gentleman by the window portrayed it with such descriptive words.

Days and weeks passed by. One morning, the day nurse arrived to bring water for their baths only to find the lifeless body of the man by the window, who had died peacefully in his sleep. She was saddened and called the hospital attendants to take the body away.

As soon as it seemed appropriate, the other man asked if he could be moved next to the window. The nurse was happy to make the switch, and after making sure he was comfortable, she left him alone.

Slowly, painfully, he propped himself up on one elbow to take his first look at the world outside. He strained to slowly turn to look out the window beside the bed. It faced a blank wall. The man asked the nurse what could have compelled his deceased roommate who described such wonderful things out side this window.

The nurse responded that the man was blind and could not even see the wall. “Perhaps he just wanted to encourage you”, she added.

Epilogue: There is tremendous happiness in making others happy, despite our own situations. Shared grief is half the sorrow, but happiness when shared, is doubled. If you want to feel rich, just count all the things you have that money cannot buy. Today is a gift, that’s why it is called the present.

The origin of this story is unknown, but it brings good luck to every one who reads it.
Warning Signs of a Lupus Flare

- Becoming **overtired** or feeling as though your **stress** level is building up.
- Having more frequent or higher **fevers** than usual.
- **Aching** in your **muscles**, or more painful and **swollen joints**.
- The development of a **rash**.
- **Hair loss**
- The development of any **symptoms** you have **not had before**.
- **Headache**
- **Dizziness**
- **Abdominal discomfort**

Remember that lupus can affect almost **any area of your body**. It is important to report any new symptoms to your lupus doctor so you can get treated for your lupus flare quickly.

Agora the platform
Northern Morning Teas: Every fourth Thursday, 10.30 am at Joan Marshall Wing, Kings Meadows Health Centre. Bring a plate and join us for a chin-wag. Finish around 12 noon.

North West: 19th February (a once off) and then every 1st Tuesday of the month at Fuschia Farm, between Devonport and Ulverstone, 12.15 pm—2.00. Everyone is welcome, friends, family and support people are warmly welcomed.


West Coast: Please ring Barbara Gruner for Details

AGM March 17th 2019, Joan Marshall Wing, Kings Meadows Health Centre. 10.30 am Please bring a plate with finger food to share. All positions available. Please consider helping our Association. We are only a small group of helpers and need your help to run our association.