

Australian Addison's Disease News

Issue 119

July 2017



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The problem with “adrenal fatigue”

Oscar-award winning actress Gwyneth Paltrow has proudly announced to the world that she is suffering from a condition known as “adrenal fatigue”.

This declaration also came with another announcement—that her doctor had developed a vitamin supplement line, which includes a pill to help prevent or treat adrenal fatigue called “Why Am I So Effing Tired”.

These pills join a range of other purported “adrenal fatigue treatments”, from special yoga routines to diets. A quick Google search of “adrenal fatigue” provides more than 2.68 million results.

The problem? According to doctors “adrenal fatigue” doesn't exist.

In their article “Adrenal fatigue does not exist: a systematic review”, Flavio A. Cadegiani and Claudio E. Kater noted that “the term ‘adrenal fatigue’ (AF) has been used by some doctors, healthcare providers, and the general media to describe an alleged condition caused by chronic exposure to stressful situations”.

The term “adrenal fatigue” is believed to have been first coined in 1998 by naturopath and alternative medicine practitioner James Wilson. Wilson described it as a “group of related signs and symptoms (a syndrome) that results when the adrenal glands function below the necessary level”.



To date, “adrenal fatigue” has not been recognised by medical bodies, which maintain there is no evidence for the existence of this syndrome.

Furthermore, there is no approved test to diagnose “adrenal fatigue”.

The Endocrine Society, the world's largest organisation of endocrinologists flatly says that adrenal fatigue is not a real disease. It says the symptoms of adrenal fatigue are so general that they can apply to many diseases or conditions (depression, sleep apnea, fibromyalgia) or stem from everyday life.

(Continued on page 12)

President's Report

Where has half the year gone?

From the AADAI's perspective, it's been a very busy few months.

As you know, the calendar is full of special months, weeks and days, but did you know that May was Addison's Disease Awareness Month? That's why we had a number of important events across the country to connect with members and raise awareness of Addison's disease and adrenal insufficiency.

I for one really enjoyed attending some of the recent events. The attendance was fantastic, especially when you consider how uncommon adrenal insufficiency is.

The highlight was attending the annual Sydney seminar for the first time. Apart from the wonderful and informative speakers, it was great to talk to so many

members and see them share their stories with one another.

For me, what stood out the most was the look in people's faces when they realised that for the first time they were meeting another person with their condition.

They could tell they were speaking with like-minded friends who understood what they were going through. It was also clear that everyone is on their own journey—some are doing really well, some are in the middle of the road, and some are struggling. Meeting members reaffirmed the importance of our Association in not only driving awareness of Addison's disease and adrenal insufficiency, but also providing support to members.

Michelle Dalton



Our Valued Patrons

Helen Reddy

Australian singer, actress & activist

Geoff Starling

Australian former professional rugby league footballer

Welcome from the editor

I recently told a friend that I was diagnosed with Addison's disease last year. After explaining the disease to her, to my great surprise she said she had heard of it.

But not too long into the conversation, I came to appreciate that she was talking about "adrenal fatigue" she had read about on the internet and in social media posts.

It struck me my how dangerous this confusion was—not just for those with Addison's disease and adrenal insufficiency, but also for those who have been labelled with "adrenal fatigue" in lieu of addressing the real underlying issues.

Many of us are acutely aware how unknown Addison's

disease and adrenal insufficiency is in the wider community. What hope do we have when it's being confused with something that the medical community says doesn't exist?

While some remain adamant they have "adrenal fatigue", in this era of "alternative facts" and "fake news" it's important we remain vigilant.

The medical community may not always be right, but we need to support their quest for substantiated, peer-review research about matters that have the potential to impact our health.

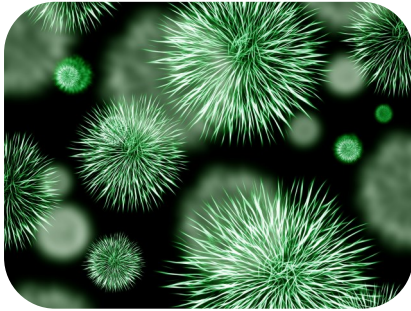
Matthew Hart



Disclaimer: The material in this newsletter offers information as unbiased "information only" and is not intended to be complete. The authors of most information in this newsletter do not practice medicine; they are members of a support group. The intention is only to give information to patients and others about these disorders and the support that is available. We urge you to contact your medical practitioner(s) before making any changes to your treatment.

Making headlines: Addison's in the news

Greater awareness needed on risks Addison's disease poses to patients



May 2017: Two new studies presented at the recent European Congress of Endocrinology showed the possible dangers facing patients with Addison's disease were higher than previously thought.

Dr Stefanie Hahner, working at University of Würzburg, looked at the incidence of adrenal crisis in 472 German patients with Addison's disease. She found infectious disease provoked 39% of the crises, with psychological stress also causing problems. She also noted that while 95% of the patients were aware of the dangers of an adrenal crisis, only 28% had an emergency injection kit.

In another study from the University of Utrecht, Dr Lisanne Smans showed that patients with Addison's disease had a 1.5 times higher risk of infectious disease compared to the rest of the population, and were significantly more likely to be hospitalised for infectious diseases.

<https://www.sciencedaily.com/releases/2011/05/110502092326.htm>

Prednisolone may raise cholesterol

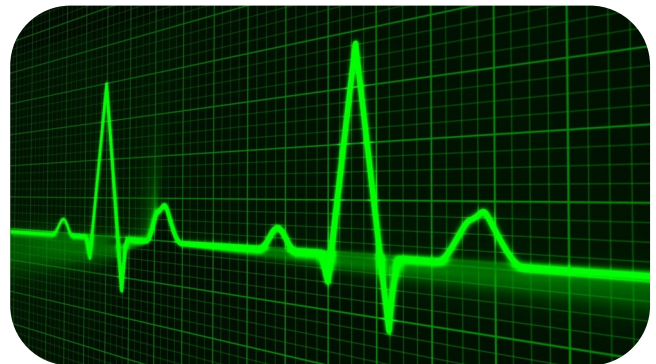
April 2017: Prednisolone treatment of people with adrenal insufficiency is associated with significantly elevated total and low-density-lipoprotein (LDL) cholesterol levels compared with use of hydrocortisone, new data suggests.

The new findings support recent recommendations from the Endocrine Society to use hydrocortisone as first-line glucocorticoid replacement therapy for primary adrenal insufficiency.

In April 2017, data from the European Adrenal Insufficiency Registry was presented at The Endocrine Society Annual Meeting by UK endocrinologist Dr Robert D Murray.

"In addition to previous data showing that prednisolone can cause lower bone mass, we've now shown that it may raise cholesterol to a higher degree than hydrocortisone," he said.

<https://www.sciencedaily.com/releases/2011/05/110502092326.htm>



JFK's Addison's disease in spotlight

May 2017: With the new US President in the Oval Office, there has been a surge of media articles highlighting the medical conditions of previous Presidents.

Until a few decades ago, the physical fitness of presidents was kept private and not much of an issue to voters. US President Grover Cleveland had a cancerous tumour in his mouth. President Woodrow Wilson had an incapacitating stroke.

President John F. Kennedy, who would have turned 100 this year and at 43 was the youngest president ever elected, was portrayed as healthy and vibrant. In reality, he had Addison's disease and other problems controlled by a regimen of steroids and drugs.

Arsenic not Addison's for Austen?

March 2017: The British Library claims several pairs of glasses found in Jane Austen's writing desk may reveal what caused the early death of the one of the world's most-loved authors.

On 18 July 1817, novelist Jane Austen died at the age of 41, but how she died remains an enduring mystery.

In her later letters, she complained of bilious attacks, facial aches and fever. Austen experts fingered several possible killers, including Addison's disease.

But the British Library has suggested spectacles found in Austen's writing desk show a rapid deterioration of eyesight, potentially from cataracts caused by arsenic poisoning. However, other experts have disputed the claims so the mystery remains.

Member news

Using education and advocacy to promote positive change for members

Our Association supports and cares for people living with Addison's disease and other forms of adrenal insufficiency. As a part of this, the AADAI is increasing its advocacy role on behalf of our members. To do this we have a number of 'advocacy campaigns' in development. In summary, these are:

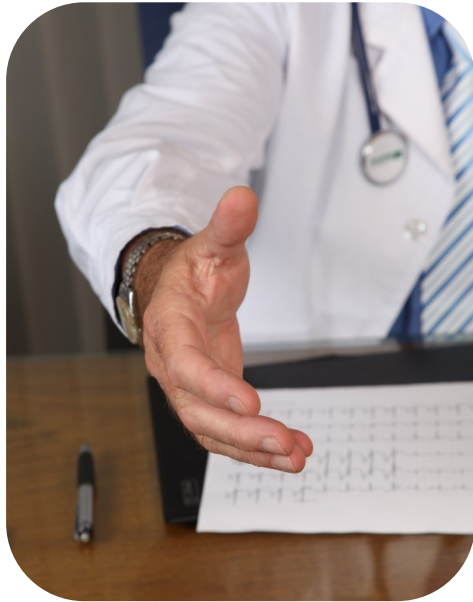
Ambulance Service protocols in each State and Territory

This aims to obtain up-to-date information for members about the protocols that exist in each state and territory for managing a person with Addison's disease and other forms of adrenal insufficiency (AI) in crisis. In the process of gathering information, some pressure is applied to those jurisdictions where ambulances don't carry Solu Cortef etc. For information about this campaign, watch the website or contact Des Rolph at vicepresident@addisons.org.au.



The following four campaigns are at an early stage of development.

Contact Grahame Collier at grahame@addisons.org.au for further information or if you can help out.



1. Endocrinologists

This campaign will target practicing endocrinologists to raise their understanding and awareness of Addison's/AI issues, diagnosis and journeys from the perspective of people with the disease. It will also raise awareness of AADAI and request them to promote the Association if appropriate.

2. A&E departments in hospitals

This campaign is similar to the one currently in progress for Ambulance Services and identifies any protocols in A&E departments that exist to facilitate treatment and care of people with Addison's/AI. This campaign would need to identify relevant policies at the Ministry of Health/Department of Health level that all public hospitals must adhere to.

3. Illness/misadventure policies for school students with Addison's/AI

This campaign is directed at obtaining and providing information to parents and guardians of young people who are still at school and are diagnosed with

Addison's or AI. Policy advice will be sought from government education departments and Catholic Education offices in each state and territory. Non-systemic independent schools will not be included.

4. Member journeys survey

This campaign involves the development of an online survey of people living with Addison's or another form of adrenal insufficiency. Its intention is to draw together a snapshot of the experiences, treatment options and challenges of respondents. The resulting information could be used in other campaigns and as an education product generally.

Grahame Collier

Happy birthday Jean!

Long-time Perth member Jean Armanesco recently turned 95, which we believe makes her our oldest current member! We wish her many more happy and healthy birthdays to come!

Keep your doctors in the loop

Ask your health professionals if they'd like to receive our newsletter for free, along with some updated brochures for their office. If you let us know, we can easily organise.

Member news

Website committee: Planning new improvements to benefit members

Since the last report, the Website Committee has met on a regular basis to progress plans on several fronts for improvements to the Association's website. The group has started to gain real momentum and I am confident that what will be produced will benefit both members and the general public.

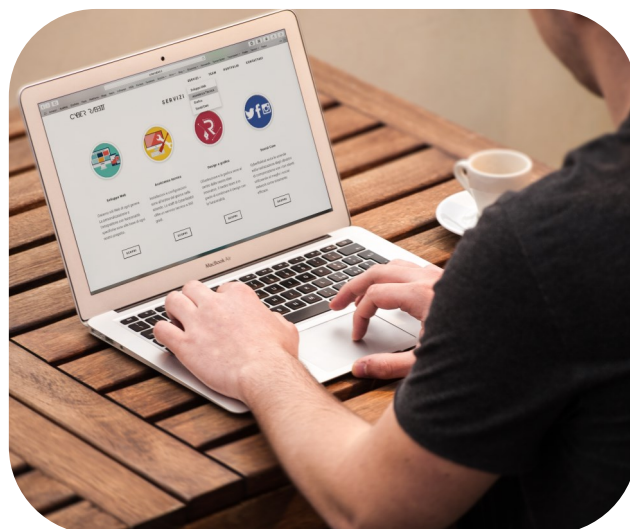
The work will be tackled in stages with the most critical "public facing" areas being initially the focus of the review. Another critical aspect of the initial review will be the "under the hood" work to ensure not only that the website is secure but that it has adequate system storage for our ongoing needs. Another critical component recently actioned was the continuing registration of our domain name (www.addisons.org.au). The issue with the "Contact Us" page, where the information on the completed form was not being received, has also been successfully resolved.

In terms of actual content updates, there will be several improvements that will be visible during this year. These include:

- A major update of the key document "What is Addison's" being coordinated by Dr Gisela Spallek
- Ambulance protocols for all Australian states and territories sourced and published
- The Medical and Pharmacy FAQ's will be updated and more clearly identified with the source of the information.

Feedback and suggestions are always welcome and they can be sent to: g.mullins@addisons.org.au.

Geoff Mullins



Treasurer's Report: Membership growth boosted by valued activities

Member events in New South Wales, Queensland and South Australia, along with positive feedback for the April newsletter, have played an important role in boosting Australia-wide membership during this final quarter of the financial year. On the other hand, donations, a welcome source of funds we are grateful to receive at any time and which we receipt as well, are well below prior years.

A reminder for those renewing their annual membership between 1 July to 31 December this year, the membership fee increases to \$30 per annum. For those renewing from 1 January 2018 onwards, it increases to \$35 per annum. While pleased to keep the fee at an affordable level after more than 20 years at \$25 per annum, it is prudent to progressively introduce reasonable fee increases that will help to sustain the financial health of the Association.

Peter McDonald

Vale Ron Hession

The Association was sad to hear the news that member Ron Hession passed away on 9 March, aged 91.

Ron and Fay regularly attended seminars, meetings and picnics with other Sydney members and Ron is fondly remembered.

Our sympathies are extended to Fay and his family.



Feeling generous? Donate!

If you'd like to further support the Association and its activities, donations can be made at any time. No matter how small or large, all are greatly appreciated. Contributions over \$2 are tax deductible.

Sydney seminar snapshot

Seminar: Looking after your adrenals and eating your way to wellness

The “Early Birds” were chattering away from 8am. This pre-seminar session was a great innovation with more than 50 people taking advantage of the chance for a chat and cuppa with someone who is sharing their life journey.

There was real excitement as some people met their very first “other person” living with Addison’s disease / adrenal insufficiency.

We are a “rare” bunch of people, you know! The 50 “Early Bird” attendees alone outnumbered the previous seminar attendance record from three years ago.

When formal proceedings opened, 101 cheerful participants gathered in the auditorium. Dr Paul Lee, Staff Endocrinologist from Sydney’s St Vincent’s Hospital, was engaging and on the ball.



Attendees Emma, left, and Ashley, right, with their baby

He gave a wonderfully clear rundown on the nature of latest treatments.

Dr Lee suggested that it is good for the endocrinologist to “listen to the patient” as well as hand out advice.

His slides and case study were stunning, and he fielded some remarkable questions (*see page 13*).

Morning tea gave attendees the chance to digest the contents of Dr Lee’s presentation and to share their insights with other participants.



Left to Right: President Michelle Dalton, endocrinologist Dr Paul Lee, Organising Committee member Bronwyn Monro, and Vice-President Desley Rolph

Then we were very pleased to be able meet our President, Michelle Dalton, in person. Michelle, along with Vice-President Desley Rolph, had come down from Queensland especially for the seminar.

Perryn Carroll had a thoroughly prepared talk on the nutritional needs for people dependent on steroids.

Perryn is an Accredited Nutritionist at Concord Hospital. Again her explanations were very clear; although what really captured everyone’s attention was the fact that you need 10½ cups of broccoli to meet the daily requirement for calcium. She wisely advised that if it was calcium you needed another source might work better!

(Continued on page 7)



Committee member Trevor Berthold, right, with the Bessant family.

Sydney seminar snapshot

27 May 2017: Kerry Packer Auditorium, Royal Prince Alfred Hospital

Finally (well apart from the rather beautiful lunch that Perryn approved of), a special team of Clinical Nurse Consultants (Endocrinology) took us all through the practical aspects of managing Addison's disease / adrenal insufficiency. It is largely possible to stay well most of the time, but when an "Addy Sick Day" occurs, some wise increases in medication may avoid the need for a trip to hospital.



Julie Hetherington and Klaus Sommer showed us that if the onset of illness is too fast or difficult to manage (eg severe vomiting) the emergency injection kit has become simpler to use with a special needle adapter to load the syringe.

Their demonstrations of the techniques to small groups lasted throughout the lunch period. We are very grateful for their dedication to this and in supporting the seminar over many years.

A huge vote of thanks to the Association's Executive Committee for help with catering on the day with enthusiastic help from many members.

Dietician Perryn Carroll, middle, with organising committee members Jim Monro, left, and Kerry Wheeler, right.

Bronwyn Monro



Clinical Nurse Consultant Klaus Sommer, left, and Julie Hetherington, right, demonstrate an improved emergency injection kit



Thank you!

The Association would like to thank the seminar organisers, speakers and all those who attended for making the event a great success. We look forward to seeing everyone again next year!

Event Wrap-up

SA Event: Addison's Lunch at Hackney Hotel on 22 April 2017



Members and friends in South Australia enjoyed an Addison's Lunch in April at the Hackney Hotel.

The get together went well, with 11 people attending—six of whom were Addisonians. Seven people came to the city from country areas especially for the lunch.

Everyone agreed that it was important to have a letter from your doctor ready to give to hospital staff in the event of

a crisis. Attendees also spoke about the importance of wearing their medic alert emblems. Most attendees were newly diagnosed with Addison's disease, while two were diagnosed with another condition that contributed to them developing Addison's.

The next gathering, a picnic lunch in Mitcham Reserve, will be held on Saturday 7 October. For more information or to RSVP contact kaye.e@internode.on.net.

Qld Event: Morning Tea at Toowong Bowls Club on 6 May 2017

Almost 30 Queensland members and friends gathered for a special morning tea in May to learn more about their disease.

President Michelle Dalton spoke about circadian dosing, while state representative Desley Rolph followed up with an overview of pump therapy and how it worked. The guest speaker was clinical psychologist Tamara Callaghan, who talked about coping with chronic illness. There was also a demonstration of how to draw up an emergency injection after a request from the group.

The feedback after the event was very encouraging, with many people eager to attend future events.



Education and awareness

"They got it wrong!": How patients and health professionals can collaborate to achieve a positive outcome

Maureen Williams is a patient advocate with more than 40 years' experience within the health system. She delivered this address at the recent 1st Australasian Diagnostic Error in Medicine Conference in Melbourne.

She has lived with Addison's disease and Hashimoto's and has been admitted to emergency departments more than 100 times.

During that time, Maureen has been involved in many aspects of healthcare, including Australian Addison's Disease Support Group, Australian Institute for Patient and Family Centred Care, Community Advisory Committee for NSW Health and the Australasian College for Emergency Medicine as a committee member for Quality Standards and Procedures and a Patient Safety Working Group.

One of the characteristics of our modern world is the greater awareness of risk and it's many implications.

In the field of medicine, it is the risk of diagnostic error that is prominent in terms of legal and professional vulnerabilities.

The Medical Journal of Australia calls diagnostic error, the most common, most costly and most dangerous of medical errors. An error impacts on the health professional in many different ways – but let's be clear – the real consequences are borne by the patient – sometimes fatally.

I stand before you today – a walking diagnostic error, one who has survived to tell the tale and I am thrilled to be invited to represent the patient voice.

Almost 40 years ago I was in London studying singing with Geoffrey Parsons, an internationally famous accompanist and teacher.

He told me that I had a world-class voice and a promising career in Opera. This was the realisation of a dream. I had overcome many obstacles up to that point, not least of which was being born into a typical "Ocker Aussie" family, with a father who simply couldn't understand why I wanted to sing in a "bloody foreign language!"

It was at that time that I began to feel ill. I lost a lot of weight, had no strength, couldn't sing the high notes (and you can't be The Queen of the Night from The Magic Flute without high notes!).

I had nausea and vomiting, psycho motor retardation and my skin darkened. I felt extremely unwell. I had

returned home and I subsequently went through 18 months of hell!

No one could give me a diagnosis. I went from doctor to doctor, possibly seeing up to 10 different doctors without success.

I was prescribed Valium and anti-depressants, neither of which I took. At one point, when feeling gravely ill, I became suicidal. I felt that these doctors can't all be wrong and I must be going insane. Yet, intuitively, I knew there was something really wrong with me and if I was going to survive, I needed to find a solution.



On my own initiative, I made an appointment with a Diagnostician. He looked at me, asked if I was always suntanned, then rubbed his hands together and said "You will make my day – you have Addison's Disease!!!" and I did. I was told that I was close to death by this time and in hospital, was found to have hypothyroidism as well. The consequences were that I lost my voice, I lost my career and I lost my marriage.

(Continued on page 10)

Education and awareness

"They got it wrong!" How patients and health professionals

So, instead of gracing the halls of Opera Houses, I have graced the corridors of Emergency Departments.

In the 40 odd years that I have lived with Addison's, I have had well over 100 admissions. I have been in many different hospitals during this time and have received life saving and very caring treatment.

However, I have also been misdiagnosed, mistreated and patronised. I have been called an attention seeker, a malingerer and accused of being a Munchausen.

There were times when I was afraid I would die before getting my intravenous steroid. I like to think I present with a modicum of intelligence – I made it my mission to find out as much as I could about my illness and was frankly mystified as to why no-one wanted to hear what I had to say.

Since my diagnosis, as well as my personal journey – I have been involved in many aspects of healthcare. These include establishing support groups and as a patient advocate for several organisations and health services.

So, from my own experience and research, I believe that there are three areas where patients and health professionals can work together to minimise diagnostic error.

The first and most important is communication.

I was speaking with a woman whose husband died recently of heart failure after being in hospital for three months.

His wife told me that the biggest problem was communication and especially that of being heard. The patient was a 59 year old man who had a cardiac arrest at his workplace. He was introduced to the Cardiologist by the Nurse as a 78 year old who had collapsed at a shopping centre!

When the wife intervened and said "You have the wrong patient" she was told "This is what's on the chart!!" The wife almost had a fight on her hands to convince them. She also said that in the entire time her husband spent in hospital, where he had many

tests—he was not given one test result.

Good communication is a recurring subject with all the patients that I have spoken with. They either don't feel that they have been given enough information or more importantly, they don't feel that they have been listened to. We just need someone to say "I see you and I hear you". I believe that this is vitally important in the healthcare system, where patients are already anxious and vulnerable.

In the New Quality Standards publication for the Australian College for Emergency Medicine it states "the team demonstrates a questioning attitude in routine and non-routine situations, to enable high quality patient care" and yet in studies mentioned by the Clinical Excellence Commission, it states that most patients responding to questions by the doctor, are interrupted within 18 seconds and at most 30 seconds.

Patients are anxious and unwell and most are not comfortable in the presence of a health professional. Once they have been interrupted, they are unlikely to offer any more meaningful information. Why is it so hard to listen??

As patients, we are in awe of the vast amount of knowledge that you require to do your job. The sheer volume of information that you have learned earns our deepest respect. This knowledge is used by you to determine what is happening in our bodies, and this is where we are the experts. We have lived in our bodies for 24/7 for as many years as we have been on the planet and we know what is happening inside our bodies. We may not have the insight to identify it or be able to easily verbalise it, but we do know it's there and if we are truly listened to, we can provide useful clues.

Bear in mind that a patient in hospital can see upwards of eight different practitioners in one admission. The triage nurse — admitting nurse, different doctors – pathologists, radiologists etc. This is confusing and frightening, especially when there is no adequate and accurate exchange of information. Communication and acknowledgment are necessary for a patient to feel safe.

(Maureen's address continues in the next edition)

Member profile

The long and tiring road to diagnosis: Michelle's journey

After years of suffering symptoms and being dismissed by doctors, Michelle Dalton was eventually diagnosed with secondary adrenal insufficiency.

Here she shares her personal journey and why, as Association President, she is keen to educate the wider community and advocate for others with Addison's disease and adrenal insufficiency.

For many years, I had suffered from migraines and what I was told was sinusitis. I also had bouts of severe fatigue and crippling diarrhoea.

I had episodes starting in my teens of times when I would get abdominal pain and be unable to eat. I had my appendix removed and an exploratory done when I was seventeen after I collapsed in my final exams at TAFE. I survived the surgery, but took a very long time to recover – much longer than I was told by the doctors. I was even accused of trying to lengthen my recuperation time so I didn't have to get a job!

I did eventually recover and was working happily at my jobs when I decided I would return to school to finish my High School Certificate. But by exam time, again I was crippled with diarrhoea, unable to eat, extremely weak and fatigued. I had to quit school as I missed so much and I took time off work, but doctors once again could not find anything wrong with me. I finally completed my High School Certificate the following year, taking time off work during exams and only suffering mild symptoms this time.

I entered university but was once again experiencing fatigue, exhaustion, and terrible headaches.

My doctor just told me I was depressed and prescribed antidepressants. I never filled the prescription.

I ended up with the same abdominal pain. I told doctors that it was the same pain as when I had my appendix out, however I was barked at. They said I had already had my appendix out so it wasn't that and that I was clearly making up the pain for attention as there wasn't anything wrong with me. I was discharged from hospital again, barely able to walk and doubling over with abdominal pain, branded a hypochondriac and a liar. I spent a few months quietly recovering, then returned to work as a chef again.

Every time I had one of these episodes, I would seem

to take longer to recover. One morning, when my friend had come in to talk to me before her shift started, I was standing at the grill when I passed out. My friend caught me and prevented me from face-planting the grill and permanently wearing grill marks on my face for the rest of my life. I ended up in hospital and when they did a CT scan they discovered a shadow on my pituitary. An MRI and consequent blood tests confirmed it to be a prolactinoma. Well, at least the headaches and sinusitis were explained! The tumour was removed, but I recovered slowly from the surgery.

I was told I would be as good as new and resume my old life in a couple of months. However, I did not improve.

I had new symptoms, balance issues, light headedness, diarrhoea returned, the fatigue was overwhelming, and I was rapidly losing weight. I was craving salt, when I had never really been much of a salt eater. I saw endocrinologists, neurologists and ear, nose and throat specialists. I returned to my GP and complained again about the fatigue, but once again I was told I was depressed and needed a psychologist.

I refused as I knew I wasn't depressed, just exhausted. I returned to work, but after just two shifts I collapsed again. This time when I went to hospital, they finally tested my cortisol level. It was virtually undetectable.

More tests revealed that with a low baseline ACTH, I didn't have autoimmune or Addison's disease, but secondary adrenal insufficiency hypopituitary. I am now on steroid dependent and I take four doses every day. It took many years to find the right dosing schedule and mix of medication, and while it is still a work in progress, the four times a day dosing gives me a far better quality of life.

(continued on page 12)

The problem with “adrenal fatigue” (*continued*)

(Continued from page 1)

The Endocrine Society adds that while some of the treatments, such as improving your diet and exercise, could make you feel better no matter what ailment you have, other suggested treatments could be dangerous. For example, taking supplements to help your body produce extra cortisol if you don't need it may cause your adrenal glands to stop working.

Rather than focus on labelling patients as having “adrenal fatigue”, The Endocrine Society instead urged medical practitioners to focus on the underlying symptoms the patient is displaying.

While debate continues over the existence of “adrenal fatigue”, there are additional concerns for those with Addison’s disease / adrenal insufficiency.

Endocrinologists worry that “adrenal fatigue” has the potential to create further confusion in the medical community. Doctors might dismiss people showing symptoms of Addison’s disease if they front up to the doctor’s surgery declaring, after extensive research on Dr Google, that they have “adrenal fatigue”. Likewise, the real impacts of those with Addison’s disease / adrenal insufficiency may be dismissed by those confusing it with “adrenal fatigue”.

While adrenal fatigue is not accepted by most doctors, Addison’s disease/ adrenal insufficiency is a real medical condition that occurs when adrenal glands cannot produce enough hormones. These conditions are diagnosed through blood tests, and can be treated with medications that replace the hormones the adrenals would normally make.

However, there is no test that can detect adrenal fatigue. Many times, a person will be told he or she has adrenal fatigue based on symptoms alone. Sometimes, a blood or saliva test may be offered, but tests for adrenal fatigue are not based on scientific facts or supported by good scientific studies, so the results and analysis of these tests may not be correct.

Doctors urge patients not to waste precious time accepting an unproven diagnosis such as “adrenal fatigue” if they feel tired, weak, or depressed. If patients have these symptoms, they may have Addison’s disease, adrenal insufficiency, depression, obstructive sleep apnea, or other health problems. Getting a real diagnosis is very important to help patients feel better and overcome their real health problem.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4997656/>

<http://www.hormone.org/diseases-and-conditions/adrenal/adrenal-fatigue>

(Continued from page 11)

I have had several adrenal crises during the past ten years, including almost losing my life to chicken pox, infection from a tooth abscess, tearing the meniscus in my knee , and when my 13 year old dog died.

I do carry an injection kit of injectable hydrocortisone with me that I have had to learn how to give myself. I also hope that if I am unable to give it to myself, someone around me can and will.

Heading to an emergency department is always a gamble and many times we are faced with staff that have either not heard of adrenal insufficiency, and don’t know that we should not be triaged but seen immediately. Sometimes doctors vaguely remember that one lecture back in medical school about the disease they were told that they would probably never come across because it is so rare.

So all in all I do fairly well. I have become an educated patient and a strong self advocate—these two things have saved my life more than once.

I live with this disease, sometimes it wins, some days I do. It is my constant companion and arch nemesis. A foe that I dare not turn my back on or put out of my mind even for a little while.

Disclaimer:

These stories reflect the author’s personal experience, and as individuals we experience our disease uniquely. Always discuss any thoughts you may feel useful as a result of these articles with your physician.

The Help Desk

Your questions answered by Dr Paul Lee

- Q. At what point would a Cortisol Day Curve Test be considered for a patient who is struggling with low cortisol symptoms, and should this be considered a worthwhile investigation?
- A. Cortisol day curve may be useful when there is uncertainty surrounding the relationships between symptoms and hydrocortisone dosage. It may help patients and doctors to evaluate the cause of some symptoms.
- Q. If a patient is found to be a fast metaboliser, and was able to afford the pump, would it be something that should be considered?
- A. Research into continuous subcutaneous hydrocortisone infusion is beginning. At this stage there is insufficient data to make definitive conclusions. Hopefully future research will shed further insight on this issue.



This edition, your questions have been answered by endocrinologist Dr Paul Lee, who addressed the Association's May Sydney Seminar.

Association welcomes new Western Australia (Albany) representative

The AADAI is excited to announce Felicity Tadj as the new Western Australian (Albany) representative. Members in the region are encouraged to reach out to Felicity on 0417 181 004 or felicity@dftadj.com

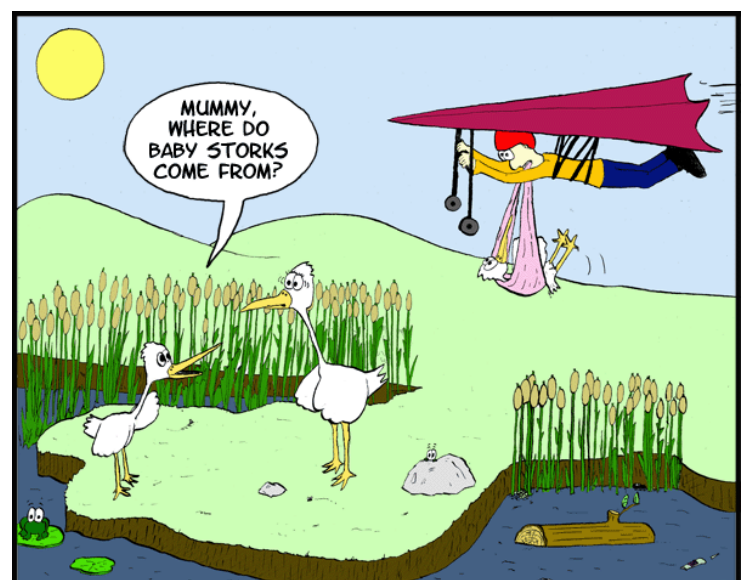
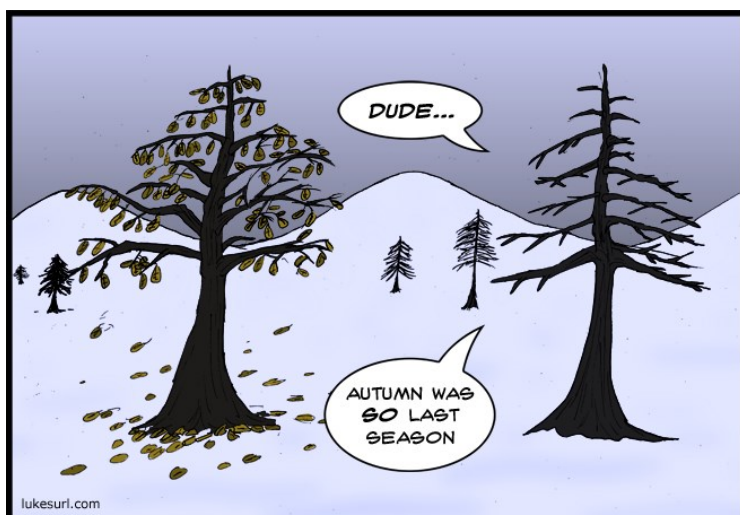
Our network of state and regional representatives play an important role connecting members with each other in their own communities. If you'd like to be an Association representative in your area, please don't hesitate to let us know.

Steroid emergency card for overseas travel

The Endocrinology Society offers a range of mobile-friendly and printable emergency cards in different languages that are available for free download.

www.endocrinology.org/clinical-practice/clinical-guidelines/adrenal-crisis/

On the lighter side... by www.lukesurl.com



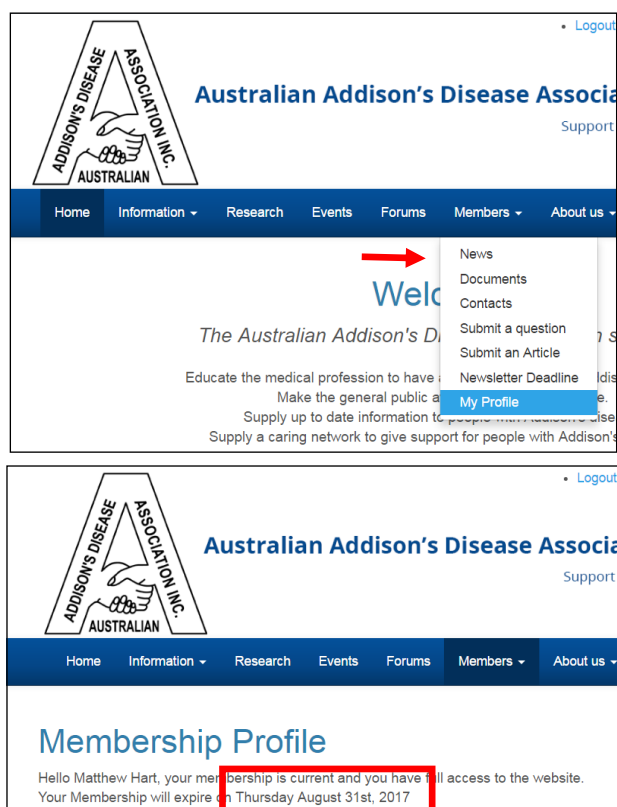
Housekeeping

How to check your membership expiry

We're calling on members to keep an eye on their membership and remember to renew it before it expires. Your membership expiry date is shown under "My Profile" once you've logged onto the Association website (*see below*).

Your membership runs for 12 months from the date that you joined the Association.

Individual reminders are also sent out via email or post. Contact the Treasurer for any assistance (*see next page*).



Do you have a burning question?

Did you know that you can email or text us a general Addison's disease-related question to be answered by our medical advisor, Professor Torpy?

Of course, questions of a personal, case-specific nature are best directed to your personal health care providers.

Send your questions via email or text message:

- editor@addisons.org.au
- 0455 534 472

Keep in touch: we don't want to lose you!

Please let us know if you change your address, phone number or email. There are a few ways you can do this:

- Email: secretary@addisons.org.au
- Text or call: 0455 534 472
- Website: Find 'update member details' under the 'Members' menu on the home page.

Tip for making EFT payments

If you are paying for your membership via electronic funds transfer (EFT), please be aware that you must include your FULL NAME in the description. Otherwise we may have no idea who the payment came from.

Bank: Westpac
BSB: 032 576
Account: 269471
Account name:
Australian Addison's Disease Association Inc.

If you are not renewing online, we ask that members complete the renewal form found on the website.

Would you like to help us?

Perhaps you have a good idea for fundraising?

Can you spare the time to be a State or Regional Representative?

Would you like to share your Addison's story?

Have you discovered a product that could benefit all Addisonians?

How ever you might be able to help, please contact the committee to discuss your idea.

We'd love to hear from you!

Get in touch

Phone: 0455 534 472

Please call between 8am and 9 pm

If your call is unanswered, send a text so we can call you back as soon as possible or try again at a later time.

Post: Australian Addison's Disease Association Inc.
48 Glassop Street
Balmain NSW 2041

Website: addisons.org.au



Association Committee

President

Michelle Dalton

president@addisons.org.au

Vice President

Desley Rolph

vicepresident@addisons.org.au

Committee Members

Trevor Berthold

Geoff Mullins

Grahame Collier

Secretary

(all general enquiries)

Bronwyn Monro

secretary@addisons.org.au

Treasurer

Peter McDonald

treasurer@addisons.org.au

We're currently looking for people to be representatives in other parts of Australia. Let us know if you might be keen to help out.

State & Regional Representatives

NSW (Acting)

Bronwyn Monro

P: 0427 601 795

E: nsw@addisons.org.au

Queensland

Desley Rolph

P: 0413 082 346

E: vicepresident@addisons.org.au

South Australia

Kaye Toshach

P: 08 8547 9155, 0408 976 165

E: kaye.e@internode.on.net

Tasmania

Lisa Terry

P: 0428 218 268

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Western Australia (Albany)

Felicity Tadj

P: 0417 181 004

E: felicity@dftadj.com

With assistance from:

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Matthew Hart

editor@addisons.org.au

Medical Advisor

Professor David Torpy

Adelaide, South Australia

Webmaster

Matthew Dyball

webmaster@addisons.org.au

Join our Association

MEMBERSHIP FORM 2017

Please FULLY complete the following in **BLOCK LETTERS** and forward to:

The Treasurer, Australian Addison's Disease Association Inc., 48 Glassop Street, Balmain, NSW 2041 Australia

I have paid via: Cheque/Money Order ☐

EFT* ☐

PayPal ☐

\$30 for membership within Australia

\$40 for membership outside Australia

and an optional donation of \$ _____

**EFT - please make sure you put your name / member's name in the reference*

Bank: Westpac

BSB: 032 576

Account: 269471

Acc. Name: Australian Addison's Disease Association Inc.

OFFICE USE ONLY

Date Rec:

Rec No:

Mem \$

Donation \$

Title:		
Surname:		
Given name(s):		
Date of birth:		
Postal address:		
Town/City:		
Postcode:	State:	Country:
Phone:	()	
Mobile:		
Email:		
GP:		Ph No.
Endocrinologist:		Ph No.
Only to be completed by new members or members whose details have changed		
Next of Kin contact details	Name:	Ph:
When were you diagnosed with Addison's disease?	Year:	
I have (tick one)	Primary Addison's <input type="checkbox"/> Secondary Addison's <input type="checkbox"/> Other <input type="checkbox"/>	
Details of Other		
I wish/don't wish to make contact with other members in my area:	By phone <input type="checkbox"/> by email <input type="checkbox"/>	
How would you like to receive your newsletter?	Email <input type="checkbox"/> Post <input type="checkbox"/>	

Australian Addison's Disease Association Inc. 48 Glassop Street, Balmain NSW 2041, ABN: 60 466 289 835
P: 0455 534 472 E: info@addisons.org.au W: www.addisons.org.au

The Australian Addison's Disease Association Inc. conforms to the requirements of the Privacy Act in the way it collects, stores & uses the information provided by its members and applicants.