MISSION STATEMENT
The APF’s mission is to support and educate people impacted by pituitary conditions. We convey awareness and provide relevant information to the general and medical communities and act as a collective voice for pituitary patients and their families.

FEATURE ARTICLE:
Psychological Impact of Pituitary Conditions

Clinicians report two common experiences that make pituitary disease particularly difficult to manage.

The first is that treatment may not be followed by a ‘feeling of cure’, even if it is effective in regulating hormonal levels to what is regarded as normal.

Secondly, even when patients who have pituitary insufficiency are receiving adequate hormone replacement therapy, they may still feel that they have diminished overall capacity.

Disentangling the physiological, social and psychological aspects of any illness is a difficult task; nevertheless, all these factors need to be considered when providing care for the patient. A study of cancer patients’ perceptions of their own needs found that only 30% of their concerns were associated with the management of the disease, while 60% were concerned with psychological needs: self image and self control (30%) and the need to receive and share information (30%).

Pituitary disease is often associated with a number of psychological problems, and patients will need sympathetic help in dealing with them. Psychological issues that may be encountered include the following.

- The emotional impact of neurosurgery
- The need to adapt to altered body image
- Depression
- Social interactions and the effects of chronic illness on family

EMOTIONAL IMPACT OF NEUROSURGERY
Surgical treatment for pituitary disease may be perceived as threatening and often produces a slower-than-hoped-for improvement in the condition. After treatment, some patients may experience severe symptoms similar to post-traumatic stress disorder. Patients will be concerned that some of the tumour remains in situ and may regrow. A full recovery undoubtedly takes a considerable time and building up unrealistic expectations before treatment impedes rather than helps recovery.

THE NEED TO ADAPT TO ALTERED BODY IMAGE
Acromegaly can have a profound effect on physical appearance, causing body dysmorphic disorder. People with acromegaly experience facial changes and enlargement of the hands and feet that are largely irreversible. Some patients regard themselves as ‘very unusual looking’, and learning to cope with this may take years rather than months. Support is available from international networks such as Changing Faces, and from the Australian Pituitary Foundation.

Cushing’s syndrome patients usually suffer from truncal obesity. Increased glucocorticoids in Cushing’s syndrome affect weight and body fat distribution. They are also associated with muscle weakness, reduced capacity for physical activity and decreased glucose tolerance. GH therapy may help some patients.

Altered body image is particularly stressful for women, and can be a major cause of depression when it affects relationships.

DEPRESSION
Depression is common in pituitary disease and may be due to psychological factors that precede the disease, the direct effect of high levels of cortisol, the patient’s perception of loss of control, or environmental triggers such as relationship changes.
High levels of cortisol have been shown to be directly associated with depression and this is a common and important complication of Cushing’s syndrome. However, it is clear that personal, psychological and social factors also play a significant role. Quality of life is negatively affected as much as those with other diseases such as cancer or multiple sclerosis.

The psychological state of many Cushing’s patients will improve after cortisol levels have normalised, but for some, symptoms may persist or even worsen, despite their physical recovery. In these patients, treatment with antidepressants may be needed. Even in those in remission from Cushing’s disease, impaired quality of life, physical and emotional dysfunction is pronounced more than those without disease.

Patients need to rebuild themselves as normal people, feeling in control of their own lives. Feeling normal is about being able to carry out normal tasks, coping with daily events, being adequately informed and able to share worries with others. These are major concerns for patients and override concern about the nature of the treatment received.

SOCIAL INTERACTIONS AND THE EFFECTS OF CHRONIC ILLNESS ON FAMILY

The physical, emotional and behavioural problems that pituitary patients experience both before and immediately after treatment may have a profound effect on the functioning of the family unit. This can affect the recovery of the patient. Patients with pituitary disease may have depression, impaired communication, and reduced affective responsiveness. This may cause intense strain and, in some circumstances, complete breakdown of relationships. Difficulties with relationships will, in turn, profoundly affect the physical and psychological recovery of the patient.

Sexual function will be affected in many pituitary patients, with obvious effects on relationships. Patients may not volunteer this information, so your doctor should ask the question so that reassurance and treatment can be given if required. This is very important – the blame of impotence can be lifted from a man; the zero libido blame (caused by low oestrogen and vaginal dryness), can be lifted from a woman.

The problem of snoring, common in people with acromegaly, can split up marriages. It can be helped by treatment to lower GH, and also by continuous positive airways pressure devices (CPAP).

This factsheet has been adapted for an Australian audience from the original produced by The Pituitary Foundation (UK), with their kind permission. Our grateful thanks go to the original authors, reviewers and editors, including (but not limited to): Andy Levy, Peter Bayliss, Claire Blessing, Peter Clayton, Trevor Howlett, Jurgen Honnegar, Stafford Lightman, John Monson and Peter Trainer.

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Adapted by Jennifer Gan (Accuwrite Medical®)

Reviewed by Dr Carmela Caputo, Endocrinologist Oct 2017 (St Vincent’s Hospital, Melbourne).

The following articles were written by Lynne Gibbs, Psychologist.

COPING WITH FEELINGS AND MANAGING DEPRESSION

After receiving a diagnosis of a pituitary condition, there are many feelings that you will be feeling. There are also helpful and unhelpful ways of coping with these feelings. Depression is different from feeling sad. Depression lasts longer, ranging from weeks to months and longer.

People who are depressed will notice changes in their behaviour, thoughts, feelings and physically. They often lose interest in things that were previously interesting, have disturbances to their normal sleeping and eating routine, can feel irritable and have changes to their memory and concentration.

You may notice changes in your thoughts, such as:

“I cannot seem to do anything right”
“There is no hope for the future”
“Everything is wrong in my life”
“I’m pathetic”

You may notice that your feelings are dominated by some of the following feelings:

<table>
<thead>
<tr>
<th>Sad</th>
<th>Anger</th>
<th>Unhappy</th>
<th>Uncertain</th>
<th>Upset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of confidence</td>
<td>Feeling</td>
<td>Overwhelmed</td>
<td>Disillusioned</td>
<td>Blameworthy</td>
</tr>
</tbody>
</table>

You may notice changes in your body, including:

<table>
<thead>
<tr>
<th>Frequent Headaches</th>
<th>Insomnia or sleeping too much</th>
<th>Changes in your appetite</th>
<th>Lack of energy</th>
<th>Stomach problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes to your productivity</td>
<td>Isolating yourself from close friends and family</td>
<td>Problems with concentration</td>
<td>Not wanting to go out</td>
<td>Not engaging in your usual activities</td>
</tr>
</tbody>
</table>

If you believe that you are experiencing depression, speak to your GP or a mental health care professional to access what help you may need. You can also check out Beyond Blue’s website for more information at www.beyondblue.org.au

Your GP or mental health care professional will be able to give you information on how to manage depression.

Some things that help are:

Talking to others often helps. This might be a friend or family member or a professional like a GP or psychologist. It is important to find someone to talk to who will really listen to what you are saying and not judge you. It does
not help when you talk to someone about your inner most feelings and they say things like you are ‘crazy’ or you do not have the right to feel that way.

Eating a healthy diet and exercising. Research has shown that exercise has a beneficial effect on someone who is depressed. Exercising can sometimes be hard for some people with pituitary conditions due to the effects of the condition on their body. However, you should try to do what exercise you can. You might want to talk to your health care professional about what type of exercises they would advise.

Keeping up contact with others. You may not feel like being social and may not be able to participate in activities that you once did. Keeping in contact with others helps with the sense of isolation, and helps with depressive feelings. You may not be able to participate as you once did, however you may find ways to still be involved. For example, if you are no longer able to play a sport, you may be able to still cheer your team from the side.

Do activities that relax you and give you pleasure each day. Each of us find different things relaxing and pleasurable. Some examples are:

- Going for a drive
- Watching a movie
- Listening to your favourite music
- Doing craft activities
- Playing with your pet(s)
- Reading a book

Sometimes we might have to get creative in order to engage in our relaxing activity. For example, if you live far from the beach however you find sitting on the beach relaxing, maybe get a tray of sand to put your feet in and play an ocean sounds CD. Take some time to think about what are the activities that you find relaxing and pleasurable. It often helps to write down this list, and put it in a spot where you will notice it, as it will act as a reminder to do these activities each day.

Thoughts of suicide are not uncommon when a person has received a diagnosis of a pituitary condition. If you have thoughts of suicide, please speak to your GP, a mental health care professional or call Lifeline on 13 11 14.

If you do have depression, it is important to remember that depression does not mean that you are a ‘bad’ or ‘weak’ person. There is help available if you do have depression and it is something that can be treated.

MARRIAGE AND RELATIONSHIP ISSUES

Being diagnosed with a pituitary condition might cause marriage and relationship issues. If you are single, then having a pituitary condition might impact on your ability to find a partner. If you are married, then having a pituitary condition might impact on your marriage.

Being single

If you are single when you develop a pituitary condition, then it might affect your ability to find a partner. Your self-esteem might be affected by changes in your physical appearance and this might lead to thinking that you are not physically attractive. You might think negative thoughts about yourself and project these thoughts onto what other people must be thinking. Remember that you do not know what anyone else is thinking. Also that despite changes in your physical appearance, you are still the same person and you have many positive attributes.

You also might be uncertain about when to tell someone about your condition when you are dating. For example, should you tell them on the first date or wait a while. There are no guidelines regarding the time to tell the person you are dating about your condition. It will depend on many individual factors, such as how well you knew each other before dating, how comfortable you are about discussing your diagnosis and how long you have been diagnosed for.

Depending on the pituitary condition that you have, you might experience a loss of libido. Again it is up to you how soon you tell someone you are dating about this issue. If the loss of libido is a concern for you, you may wish to consult with your doctor about possible treatments.

Due to physical changes in your body, you may feel negatively towards your body and may not like to be intimately touched or seen in certain ways. For example you may not like your partner to touch your stomach or you do not want to have sex with the lights on. If you do establish a sexual relationship with someone, it is important to discuss your preferences and the reasons for them. If you do not tell your partner, you can become resentful towards them when they do not follow your preferences, even though you know that they do not know them.

Being married (includes people who are in a long term relationship)

If you are married when you are diagnosed with a pituitary condition, the condition might cause some issues in the marriage. If you are unable to work due to your condition, it might put financial strain on the marriage.

Due to the physical limitations and fatigue of your condition, you may not be able to contribute to the running of the household as you once did. For example, running errands, housework and maintenance of property. If this is the case, it is advisable to sit down with your partner and work out what you can still do and what you are no longer able to do. Maybe you can do some tasks that your partner has done previously and your partner is able to do your tasks. In some cases you might be able to call on services to help complete the necessary tasks, such as gardener to mow the lawn. Friends and family might also be able to assist if needed.

Your partner is likely to be affected by your condition. They might have to take time off work to attend appointments and treatments with you. They may need to be present to help you recover after surgery. They also are likely to be
affected by seeing their loved one in pain, upset or any other emotion that you feel. They are likely to have their own emotional reaction to your condition. It is important that neither partner hides their feelings from the other, because they do not want to “burden” their partner. Talking about each other’s feelings can help. Also seeing a psychologist, either separately or as a couple, might also help to cope with the feelings.

Your sexual relationship with your partner might be affected if you have a loss of libido. It is important to tell your partner about the loss of libido, as it will avoid any misunderstanding about the reasons for the changes in the sexual relationship. You may wish to speak to your doctor about potential treatment options. Your sexual relationship may also be affected if you feel negatively about your body and would prefer not to be touched intimately in certain areas. It is important that you tell your partner about how uncomfortable you feel when touched in certain places and the reasons for it. As the partner, it is important to respect your partner with the pituitary condition wishes. Your partner’s condition might not have affected your sexual attraction to them, however their feeling of sexual attractiveness may have changed. Try to have good communication and tell your partner with the pituitary condition that you are still attracted to them, however being dismissive of their feelings about themselves is unhelpful to the relationship.

This factsheet has outlined some of the main possible relationship issues. There are likely to be others that are not addressed in detail. With all issues, it is important to have good communication between partners, so they can try to work out the issue together. When one partner has a pituitary condition, it is essential that both partners support each other. Remember to seek professional support when needed.

SELF IMAGE

Our self-image is how we see ourselves as a person, our physical appearance, our likes and dislikes, and our strengths and weaknesses. It is also, to a lesser extent, how we think other people see ourselves. When you have a pituitary condition, your self-image can be affected.

The ways your self-image can be affected is dependent on what parts of yourself you see as important. For example if your self-image was focused around your physical appearance and your pituitary condition changes your appearance, your self-esteem may decrease and your self-image may become negative. Another example is that if your self-image was focused around that you are a healthy person, having a pituitary condition can change your belief about being a healthy person and may lead you to question how you view yourself.

It is essential to remember that there are many aspects that make up who you are. Having a pituitary condition does not need to define who you are. You are more to you than your medical condition. To remind yourself of this, you may find it helpful to write down all the different aspects that make up you. For example you are a son/daughter, friend, partner, animal lover, taxi driver for your children. You may find it helpful to reread the list when you are feeling down.

Your self-esteem might also be affected. Your self-esteem is the judgement you have about your overall worth. When you have a pituitary condition, you may believe that you are not worth much as a person. There are many things that you can do to improve your self-esteem. Including –

- Try not to think negative thoughts about yourself, or try to change negative thoughts for more positive ones. For example instead of “I am worth nothing”, think “I may not be able to do some things but there are many things I can still do”.
- Do not try to be perfect, no one is.
- Do not be hard on yourself when you make a mistake or something goes wrong.
- Do not compare yourself to other people, everyone’s situation is unique and you do not always know everything about someone else’s life.
- Exercise as much as you can, as it is a natural mood lifter.
- Pay more attention to the things you can do, rather than the things you cannot do.
- Make sure that the people around you are supportive.
- Celebrate small achievements, every little bit counts.
- Be nice and helpful to others, as this can make you feel better about yourself.

You may wish to research other ideas that can help you to improve your self-esteem. You might like to ask friends and family members for tips as well.

Your self-image might be improved by accepting yourself. Acceptance does not mean that you have to like a situation, it means accepting that is how it is at the moment. You can accept yourself while still trying to do things to improve yourself.

Remember that having a pituitary condition means that there is a problem with your physical self, NOT that there is a problem with you as a person.
WHAT WE’RE DOING – NATIONAL & STATE REPORTS

A Message from the Chairperson

I hope you all kept as well as you could through the winter months. The various viruses and flu’s were in epidemic proportions.

We hope you enjoy this issue which amongst other things covers the very important subject of mental health which impacts many in our pituitary patient community. We have endeavoured to provide some useful information and strategies on the ways to cope. Thank you to Lynne Gibbs who provided these articles.

The Board has been discussing new strategies for support for patients and their families. We feel it is critical to provide local support and as a result we are looking for expressions of interest for State Co-ordinators, initially for the eastern states. We are seeking motivated and passionate people keen to make a difference and support those impacted by pituitary conditions. We encourage you to apply or forward to anyone who may be interested.

A new website will be launched later this year. In the interim if you would like to make changes to your membership or become a new member – please contact Sue on 1300 331 807.

Malini

QLD

Social News:

Be prepared for a fun day out. If it’s hot, we have air-conditioning and the pool!

Please come to a social BBQ in Mount Ommaney. It has been so long since we have seen each other.

Bring your togs for the pool and any “bring a plate” will be helpful to me.

Saturday 25th November 10.00am. (let’s swim first, eat later)

RSVP to Sue on numbers coming real soon!

qld@pituitary.asn.au or phone 1300 331 807

Seminar News:

We had a packed room of interested patients, family members and health care providers at our education day at Princess Alexandra Hospital on Saturday 29th July.

The team of experts certainly put on an informative morning that suited everyone in the room. Growth Hormone, Sex Hormones, Cortisol, GammaKnife and Sick day and medication management.

Thanks must go to Professor Ken Ho, Assoc. Prof. Warrick Inder, Dr. Viral Chikani, Assoc. Professor Matthew Foote, and Endocrine Nurse Specialist Jane Sorbello. Endocrine nurses Lizzie and Juanita from the hospital who helped us promote the day and of course our APF volunteers, Tania, Beth and Eric who filmed the presentations in readiness for the members’ area of our website.

As a lead up to Pituitary Awareness Week we had an information stall in the foyer of the Hospital. Thanks to volunteer Noel who manned the stall for us. We managed to get a short session on ABC morning radio to talk about the pituitary and gamma Knife. Thanks to Assoc. Prof. Matthew Foote and Assoc. Prof. Warrick Inder for attending at such short notice.
APF MATTERS - NOTICES AND NEWS

ESA Symposium

On the 26-28th May 2017, APF Chair Malini Raj, accompanied by Steve Lewis, VIC social coordinator, attended the Annual Endocrine Society of Australia Seminar 2017 in Melbourne, representing APF.

APF is keen to focus on fostering and developing the relationship with the Endocrine Society as these clinicians are the primary and critical player in the care of patients of pituitary disease. The Endocrine Society of Australia has also recently expressed a similar desire to increase and deepen our interactions.

The President of the Endocrine Society of Australia Assoc. Prof. Warrick Inder, long-time supporter of APF, and Seminar Convenor Prof. Bu Yeap were particularly supportive and generously hosted APF as a sponsor and allowed us to have a stand at the Seminar to showcase and distribute resources, increase awareness of the APF and provided an opportunity to expand our database and engagement amongst the Endocrinology community. The presence of APF at the seminar as a sponsor was called out in the opening and also at the Conference dinner and the interest and recognition by the ESA of the importance of the APF in the pituitary patient journey.

This ESA seminar was particularly relevant as it focused on the management of pituitary disease, with a second theme of bone disease. The APF would like to thank the ESA for the opportunity to attend.

ENSA

The Endocrine Nurses Society of Australasia held their annual symposium in Perth this year with a well-attended, interesting mix of presentations, workshops and speeches. The APF’s in-depth contribution to the successful submission to the PBS for the treatment of Acromegaly was recognised several times and especially mentioned by the sponsors Pfizer.

The annual ENSA dinner was held during the conference on the evening of the 28th August in the Parmelia Hilton Hotel, Perth and the APF was represented by Rob Wilton (Board member). During the presentations at the dinner Rob had the opportunity to present the APF Travel Certificate to the winner, Ann Robinson (past President of ENSA) and discuss the role the APF plays in advocacy, support and education for individuals across Australia suffering from pituitary disorders.

Rob and the APF greatly appreciated the opportunity to attend, for the warm welcome by Daniela Sabolo (event manager) Soteria Simos & Kirsten Preston (Pfizer) and for being graciously hosted by Bin Moore and Yuk Fun Chan (ENSA President).
**Somavert (chemical name Pegvisomant)**  
Prof. Ken Ho.

The PBS listing of this new treatment for acromegaly from the 1st of September is welcomed news for patients with acromegaly.

**What is Somavert?** Somavert works by blocking the action of growth hormone produced by the pituitary tumour. Somavert is a genetically engineered form of modified growth hormone that binds to the growth hormone receptor but not activating it. This occupancy prevents natural growth hormone from accessing and activating its receptor.

**How is it different from other drugs?** Octreotide, lanreotide and pasireotide, called somatostatin analogues are the major drugs used to treat acromegaly. They work by inhibiting the secretion of growth hormone from the tumour. Somavert has no action on the pituitary tumour. Its action as a blocker therefore works very differently from somatostatin analogues.

**Who are eligible?** Patients who are not adequately or cannot tolerate octreotide, lanreotide or pasireotide are eligible for Somavert treatment. An application by the treating doctor requires the completion of a PBS authority application form to the Department of Human Services. The PBS listing for Somavert will not apply if the patient is already receiving a PBS listed somatostatin analogue for acromegaly.

Somavert is administered as a single daily injection. The medication is available in three dosage strengths of 10, 15 and 20mg. The treatment dose is determined by monitoring the level of IGF-1 in blood. IGF-1 is a hormone produced by the body in response to the action of growth hormone. Growth hormone itself is not measured during treatment. This is because Somavert is chemically similar to growth hormone such that standard laboratory methods cannot distinguish between the two.

**What are the Side Effects?** Somavert has been used in Europe and in the United States for over 15 years. It has a good safety profile. The side effects are mainly from injection site reactions. The drug may affect the function of the liver in a small proportion of patients. This easily detected from routine blood tests and return to normal on stopping the medication. There is no evidence that Somavert effects the size or growth of the pituitary tumour.

**NOTE FROM APF:** Thanks so much to all the wonderful people who were part of our consumer submission.

We’ve been told it was a very powerful pitch from the consumer point of view. Pete, Claire and Toni from APF, all the supportive members who did the survey and of course the patient organizations from overseas facilitated by World Alliance of Pituitary Organizations.

**Celebrations all round.**

Sue Kozij, was awarded Life Membership to the Australian Pituitary Foundation in recognition of her 20 year-long efforts to advance the Foundation, support families and advocate for change. Sue initially found out about the Foundation through a newsletter dropped off at her treatment center, and formed the QLD branch in 1997. In 2005 she then became a Board member.

Although Sue retired from the Board late 2016, she will continue to work with the Foundation and remain active in advocating for and assisting the pituitary community.

Her family attended the presentation with her friends, and the doctors she is very fond of said some really nice words.

Sue commented that she has been privileged to meet so many wonderful people through her pituitary connections, and has thoroughly enjoyed her role within the Foundation.

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**VOLUNTEER POSITIONS AVAILABLE**

Like many support organisations, the APF needs volunteers to keep its wheels turning smoothly.

The Australian Pituitary Foundation is looking for a volunteer for the position of State Coordinator who will be the initial contact in the region for people with pituitary conditions enquiring or needing support and services. The State Coordinator will also work with Health Care Providers and become the “face” of the APF in their State.

You will become a key member of a friendly dedicated operational team of volunteers and as such, will also be required to provide assistance to any volunteering team by mentoring and coordinating the tasks performed by the volunteers in your region.

**SELECTION CRITERIA**

- Has a tertiary qualification in health or a community service discipline
- Personal connection with pituitary conditions/disease will be favourably considered but is not essential
- Lives in Brisbane QLD, Sydney NSW and Melbourne VIC
- Able to work from a home office
- No remuneration apart from reimbursement of expenses incurred in fulfilling role
- Volunteer requires flexibility in availability – during business hours, some after hours, weekend events, evening conference calls/meetings – would suit a part time worker, a person with independent children or a part-time retiree
- Some inter/intra state travel may be required

If you are interested in the above position please email registrations@pituitary.asn.au requesting further information, along with your resume. It is anticipated the position will commence early next year.

**Interested in graphic design or writing? Can you help us?**

We have a number of fact sheets to be designed. This would be a great opportunity to put your artistic talents to work!

Our new website will be launched towards the end of the year. To keep in line with “Health on the Net” a few of the fact sheets need to be adapted to a lay audience. If you have experience in this, please, please, make contact to Sue.
If you wish to receive the newsletter by email, which will help us considerably with mailing costs, send an email to support@pituitary.asn.au.

If you would like to contribute, please send your submission by email (membership@pituitary.asn.au) or fax it to 07 3376 2896. Photos and graphics are always very welcome. The next edition is planned for December 2017. Deadline: 1 December 2017

The information in this Newsletter, whether provided by APF or any third party, is not intended to be used as a substitute for professional health or other advice. The content of patients stories are the opinion of individuals and not the Australia Pituitary Foundation or its office bearers. You should not rely on this information to make decisions about your health or lifestyle without consulting a health professional. APF does not accept liability for any injury, loss or damage incurred by use of or reliance on information in this Newsletter. PRIVACY POLICY: to see our Privacy Policy go to www.pituitary.asn.au.

Thank you for your tax deductible donation to the Foundation. Your contribution is sincerely appreciated and will assist the Foundation to meet its mission to support and educate people impacted by pituitary conditions. We convey awareness and provide relevant information to the general and medical communities and act as a collective voice for pituitary patients and their families. You can securely pay online using the donate button at www.pituitary.asn.au.

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