Australian Addison's Disease Association Inc.

Our Journey...
Living with Adrenal Insufficiency

The story of Australians living with adrenal insufficiency (including those with Addison's disease)

Results based on a survey conducted by the AADAI in October 2017

'The difference your organisation and the Australian Pituitary Foundation have made to my life has been immense.'

Our journey – living with adrenal insufficiency – an introduction

Welcome to our journey. This is the story of how 231 Australians are living with and managing the rare health condition, adrenal insufficiency. It provides a snapshot of what living with a significant health issue is like.

This story is especially produced for the people who contributed to the Australian Addison's Disease Association Inc (AADAI) survey in late 2017. One hundred and eighty-six of the 231 who completed the survey were members of AADAI, which gives us an overall member response rate of 57%. Forty-five people from the wider community also completed the survey. The majority of respondents completed the survey online; with only 13% completing a printed copy of the survey[1].

The survey has provided us with detailed information about people's individual journeys with adrenal insufficiency. Some of the comments were nothing short of inspiring: *I do not 'suffer' from adrenal insufficiency. I am a happy, strong, intelligent woman who has adrenal insufficiency and, as such, manage my condition and get on with living my life the best I can.*[2]

At the outset, the information obtained was designed to help us gain a valuable understanding of the different experiences of people living with Addison's disease or other forms of adrenal insufficiency in Australia. We want to use this information in a number of ways including gaining and sharing knowledge and experiences with our members; as well as informing doctors, nurses, other health professionals, parents, carers and interested people in the community, about what it is like to live with an adrenal system that is not functioning as intended. The level and depth of your responses and the time you invested in completing this survey is greatly appreciated.

Welcome to our report. We have been challenged and enlightened in bringing it to you.

Tammy McLandsborough and Grahame Collier
for the AADAI Executive Committee

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[1] All percentages in this report are rounded to the nearest whole number. When the letter 'n' is used in graphs it refers to the number of responses to each question.

[2] Note - all quotes in this report are in italics.

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About our journey with adrenal insufficiency - the important messages

By way of summary, the following messages are taken from the survey:

- **Everyone’s journey with the treatment of adrenal insufficiency is different.**
    - *The doctors need to realise that we are not all the same, that we are affected differently and that we don’t ever get back to normal. My life is very different to what it was before I had AI. It is important to let people know that there will be a new normal and that’s ok.*[3]

- **For many of us the period before diagnosis was a very difficult journey.**
    - *GP could not find the cause of my symptoms and I kept going back for months until I insisted I see an Endo and he picked it up immediately.*

- **People living with adrenal insufficiency generally have a positive attitude to living with their condition.**
    - *I am active, healthy and happy. Still have blah days where I struggle for energy, but it can usually be managed by lifestyle adjustments or about 10% HC bump dose. I’m not as active as I once was, but by knowing my body’s limits I exercise daily and still work part time.*

- **We still have our concerns**.
    - *I am always worried that I may get really sick and have a crisis and that the hospital and GP won’t be able to treat me as they don’t understand.*

- **Talking with others helps but it is a personal choice.**
    - *I talk openly with my family and a couple of close friends. I don't feel everyone needs to hear about my health issues on a regular basis.*

- **Most of us experience good health most of the time.**
    - **Forty-four percent of respondents** said they experience good health most of the time and that their adrenal insufficiency is reasonably well controlled.
    - **Even better**, **34%** said their adrenal insufficiency is very well controlled and they believe they function normally.

- **Our medical professionals are important to us.**
  The majority of respondents (52%) report that their endocrinologist ‘works with them for optimal health and quality of life’. A further 38% say that their endocrinologist is receptive to expanding their knowledge.
    - *It's very hard to find an Endo with a true understanding - very hard. I still feel they need a lot more education.*

- **AADAI has a very important role to play.**
    - *I've enjoyed hearing from others via the Association. I'm particularly interested in tips and positive stories as I don't want to be defined by Addison's and for my health to be the only thing*

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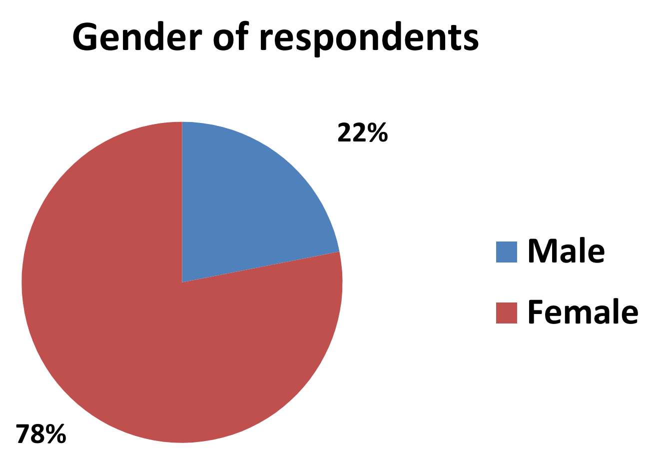
[3] In this summary all quotes are identified in italics.

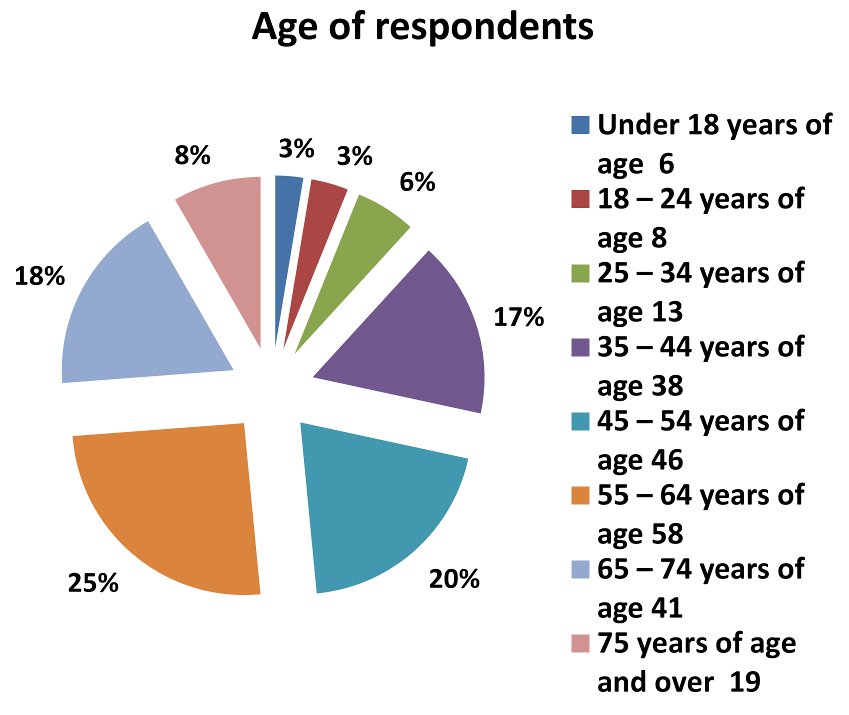
1. About us

To give you an idea about who told us about their 'journeys' with adrenal insufficiency, the following seeks to provide an overview of those who responded to the survey.

Gender (n =228)
Many more women than men completed our survey.



Age (n =229)
Most of the people who told us about their journey with adrenal insufficiency were between 35 and 74 years of age. Only 19 people (8%) were over 75 and 14 people 6% were under 25. Interestingly, over 65s was represented at a higher proportional level (26%) than the entire Australian population, where 15% of Australians are over 65.[4]
Note in the graph at right, the number of people in each age category is shown in the key.



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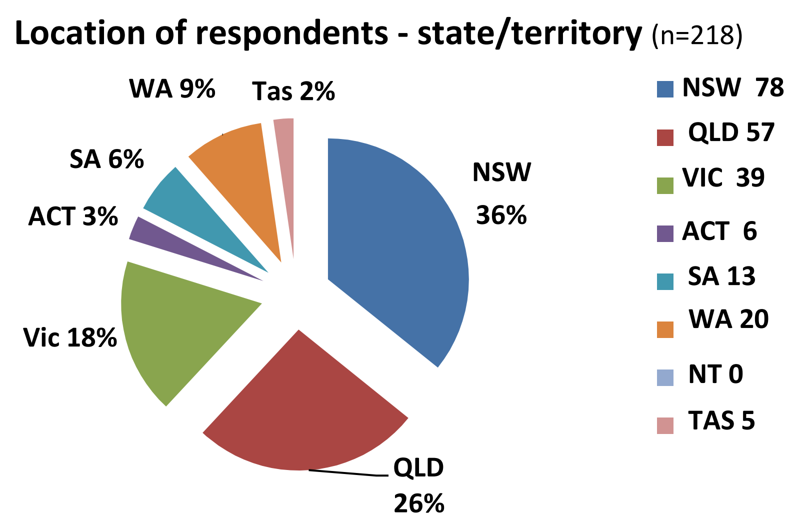
[4] For population data see: https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile

<table>
<tr>
<td>Location (1) n=218
Note: numbers in each state included in key. 36% of people live in NSW and 26% in QLD. This is more likely to be reflective of the fact that AADAI has more members in these two states rather than anything about the prevalence of adrenal insufficiency overall. Note there were no respondents from NT.</td>
<td>
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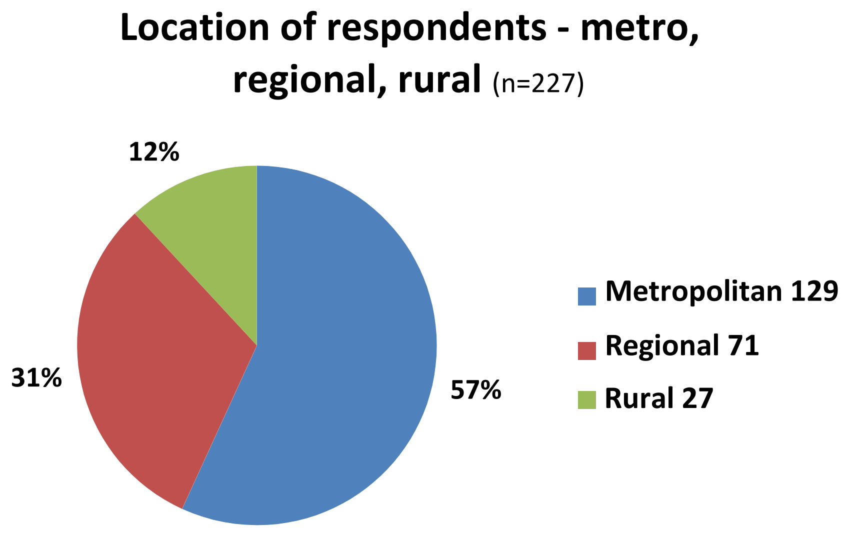
<tr>
<td>Location (2) n=227
57% of people live in metropolitan areas. The 2016 census shows that over 66% of Australians live in capital cities.[5]

Note in the graph at right the number of people in each location is included in the key.</td>
<td>
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Work

As shown in the graph below (n = 216), overall 41% of us are working and 28% are retired; 10% are unable to work due to adrenal insufficiency and 5% are students. Note in this graph the numbers in each category are included in the key.

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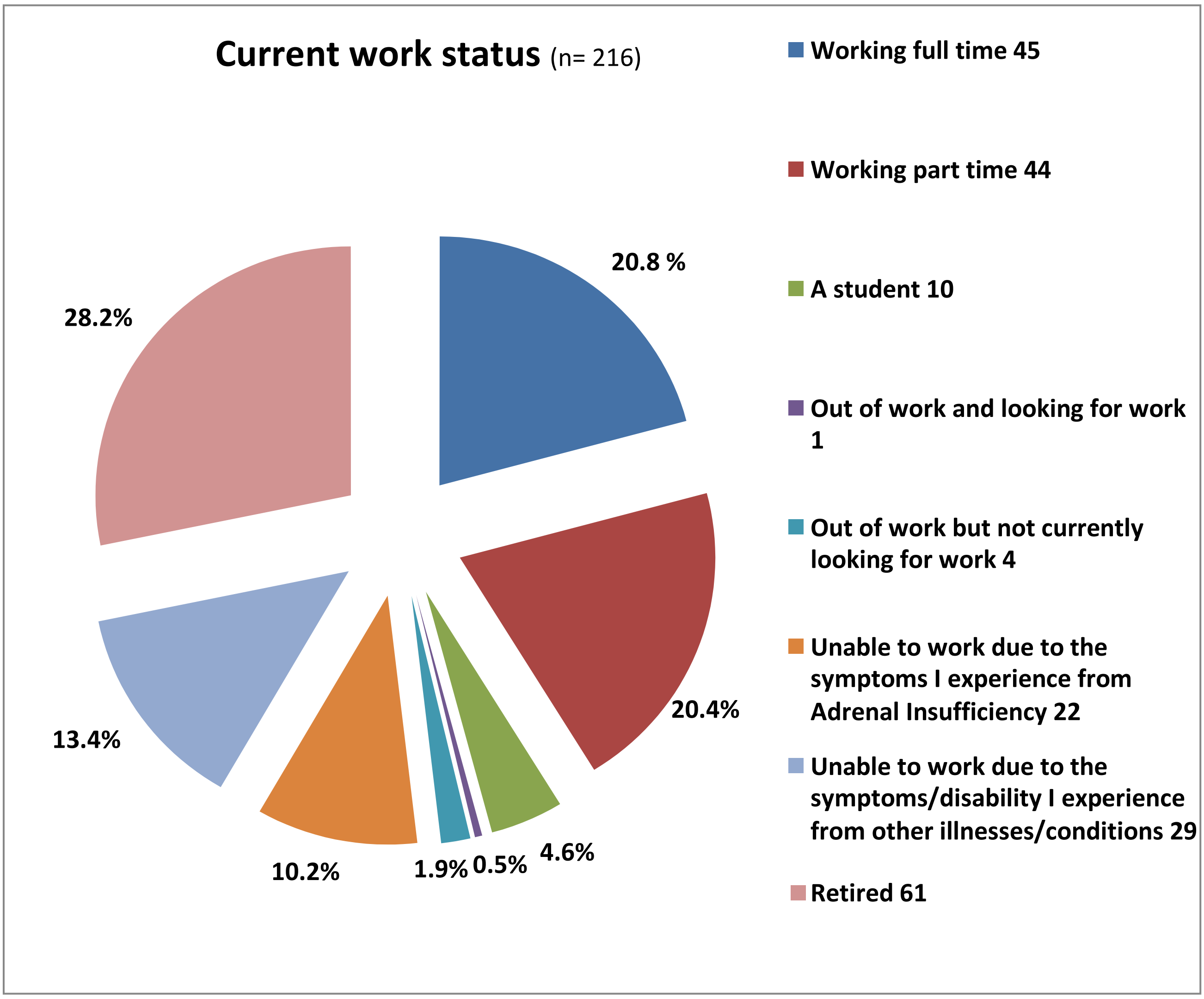
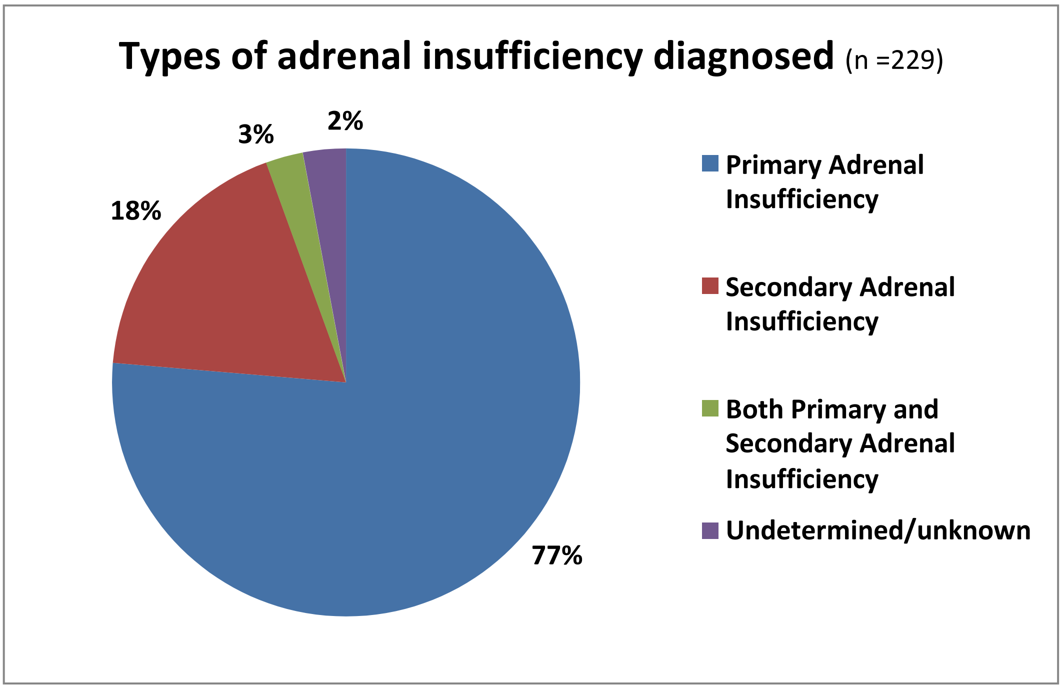
[5] *Australians living in rural and remote areas generally experience poorer health and welfare outcomes than people living in metropolitan areas. They have higher rates of chronic disease and mortality, have poorer access to health services, are more likely to engage in behaviours associated with poorer health*. Australian Institute of Health and Welfare https://www.aihw.gov.au/reports-statistics/population-groups/rural-remote-australians/overview


Current work status (n= 216)
Working full time 45
Working part time 44
A student 10
Out of work and looking for work 1
Out of work but not currently looking for work 4
Unable to work due to the symptoms I experience from Adrenal Insufficiency 22
Unable to work due to the symptoms/disability I experience from other illnesses/conditions 29
Retired 61
20.8 %
20.4%
4.6%
0.5%
1.9%
10.2%
13.4%
28.2%

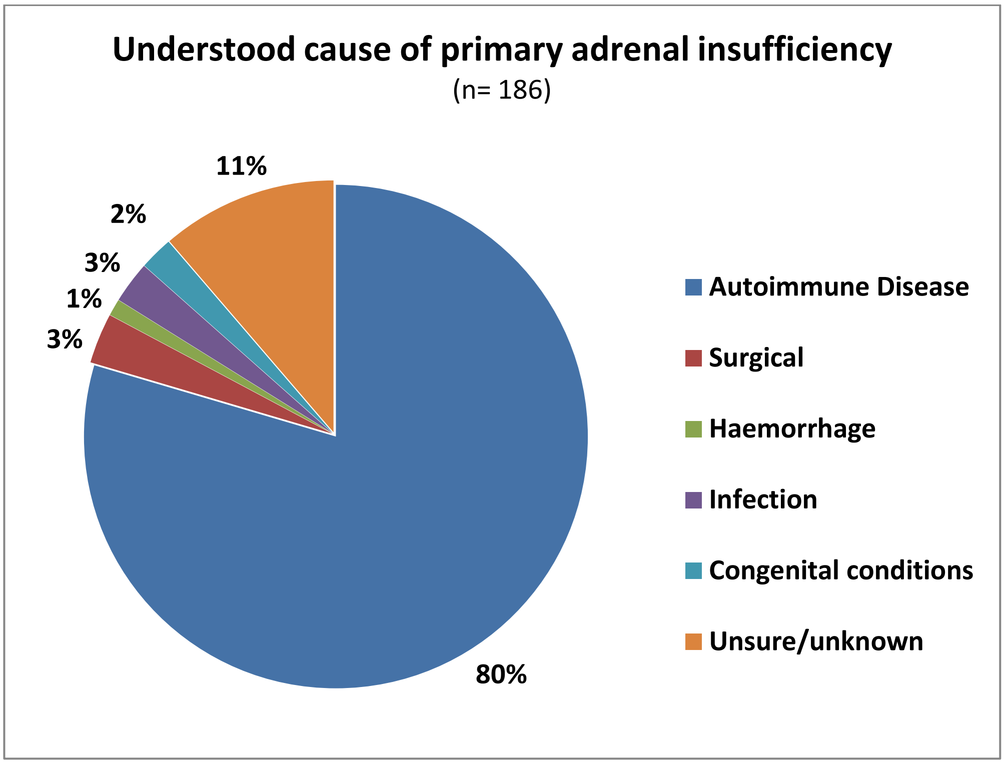
2. Types and causes of adrenal insufficiency

The majority of survey responses received were from people living with primary adrenal insufficiency/Addison's disease (77%). This is not surprising because the AADAI has existed and been involved in supporting those of us with Addison's for over 20 years; therefore predominantly attracting members with primary adrenal insufficiency. It's hoped in the future that AADAI may become just as valuable a resource and community for those who have secondary adrenal insufficiency.

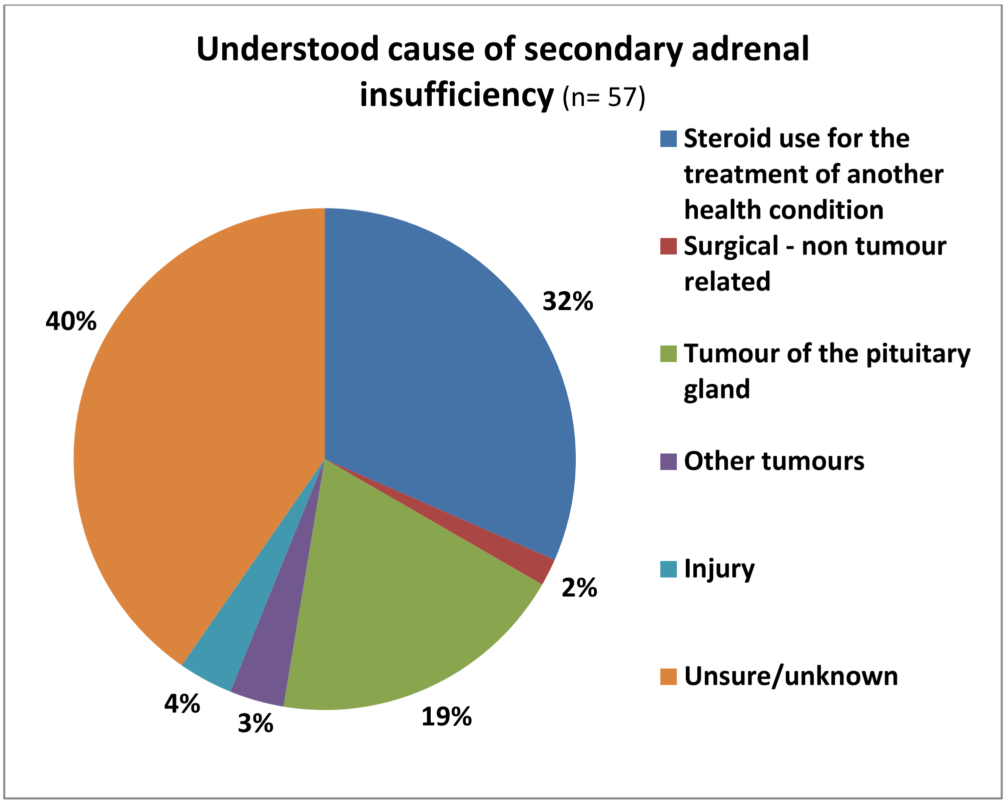


People living with primary and secondary adrenal insufficiency demonstrated a good level of understanding of what caused their medical condition.

Most people (80%) with primary adrenal insufficiency (Addison's disease) were able to identify the cause as an autoimmune[6] disease. Also, for a number of people (11%) the cause of their primary adrenal insufficiency was surgical, for example: *bilateral adrenal haemorrhaging following bowel cancer surgery*.
Note: this data is only relevant to those with primary adrenal insufficiency, hence the lower number of responses.



For the almost 18% of people who indicated that they had secondary adrenal insufficiency, (note: total n only 57) steroid use and tumour of the pituitary gland were listed as the major causes. It is noted however, that a significant number of these people did not know the cause. The following quote from one person illustrates this problem: *'They are not sure if it's primary, secondary from pituitary or from steroids. But I don't care as treatment is all the same. Adrenals are shrunk and not coming back.'*



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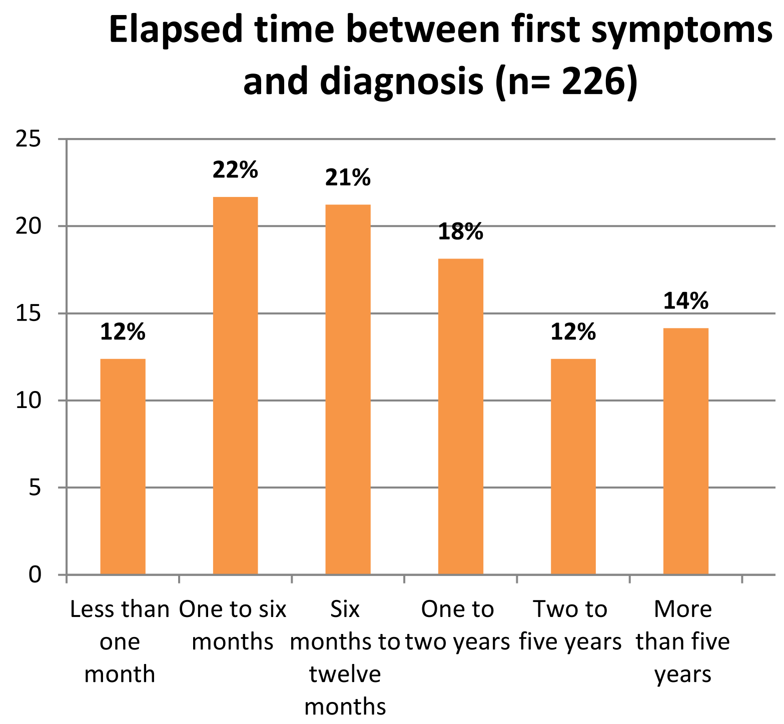
[6] *Autoimmune diseases* are a broad range of related diseases in which a person's immune system produces an inappropriate response against its own cells, tissues and/or organs. This results in inflammation and damage.

3. Prior to Diagnosis

Many people living with adrenal insufficiency reported a difficult journey before being diagnosed. In general we experienced a vast range of symptoms in the significant time that elapsed between first symptoms and diagnosis. In total 44% of us were not diagnosed for at least a year (or longer) after first symptoms. Only 12% were diagnosed in the first month.



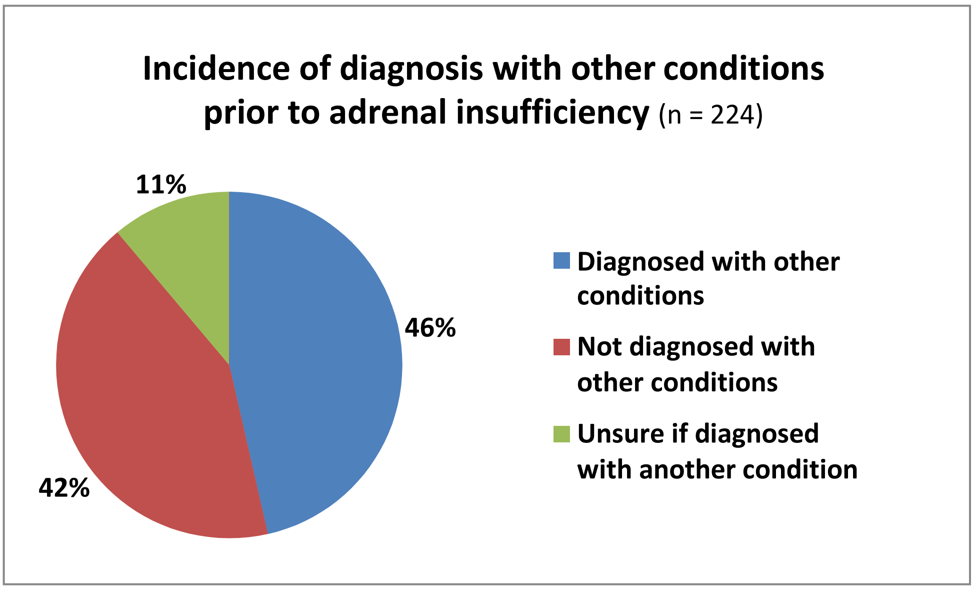
The sorts of symptoms experienced prior to diagnosis are fairly consistent for all of us, despite whether we are living with primary or secondary adrenal insufficiency. The table below indicates that most of us felt fatigue (87%) weakness (83%) and low blood pressure (71%). Other symptoms were felt by a fewer number of people, but still a substantial number of people overall.

People with adrenal insufficiency exhibited a range of symptoms prior to diagnosis. The table below indicates the percentage of respondents who demonstrated each identified symptom. Note that many people told us they had more than one symptom.

Number of Respondents Exhibiting Symptoms	Number and % /n =231	
Severe fatigue	201	87%
Weakness	192	83%
Weight loss	156	68%
Change in skin pigmentation	152	66%
Salt craving	146	63%
Dizziness on standing	73	32%
Loss of appetite	137	59%
Nausea	144	63%
Vomiting	108	47%
Diarrhoea	73	32%
Stomach pains	91	39%
Muscle/joint pains	123	53%
Low blood pressure	163	71%
Headache	94	41%
Difficulty concentrating	126	55%

Anxiety	**71**	**31%**
Depression	**66**	**29%**
Premature ovarian failure	**19**	**N/A over whole sample. 11% of female respondents**
Irregular menstrual periods	**45**	**N/A over whole sample. 25 % of female respondents**

Often, we were diagnosed with other conditions prior to being diagnosed with Addison's disease or another form of adrenal insufficiency. Forty-six percent of us indicated that this was the case.



Some interesting comments from respondents shed some light on these experiences.

- *There were a lot of guesses as to what was wrong but none of them were right. My daughter who is a nurse came home and told them to have me tested for Addison's disease and the results were right.*
- *I was sent to a psychologist - my mum had just died so they thought I had grief/ psychological problems.*
- *I was diagnosed to have chronic fatigue the last 5-9 years. My existing hypothyroidism and early menopause, weight loss, depression were not connected to chronic fatigue.*
- *Was constantly misdiagnosed with vertigo, inner ear infections (due to being dizzy all the time) and depression.*
- *Being bullied at school, psychological, perhaps diabetes.*
- *GP was unsure but anorexia and chronic fatigue syndrome were mentioned.*

4. At diagnosis

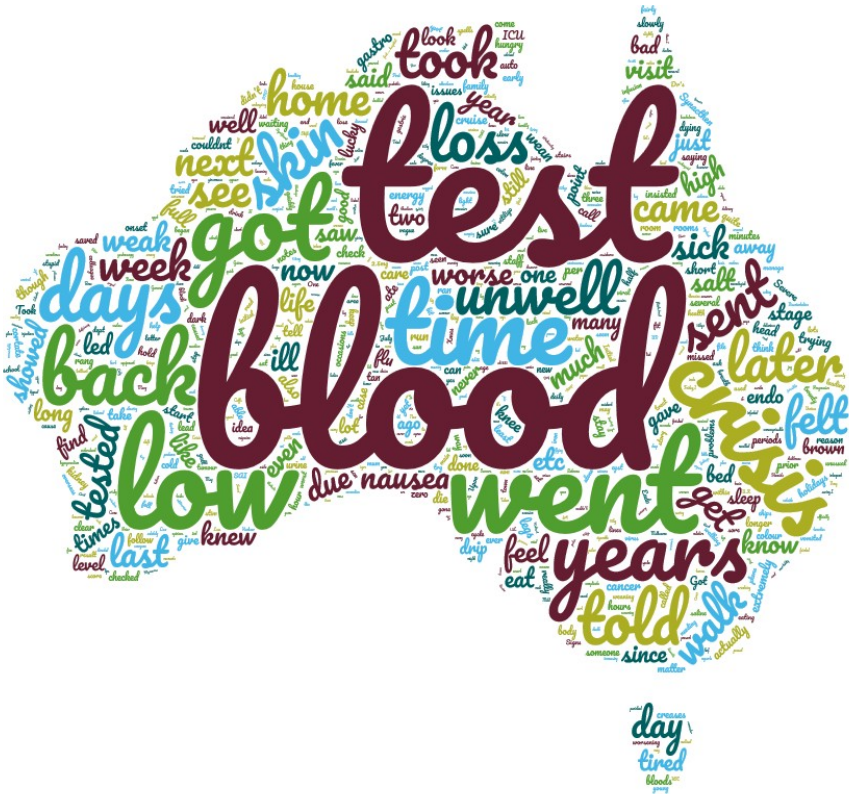
For many of us being diagnosed was a real relief:

- *The day I was diagnosed I was so grateful to finally have some solutions.*

Many of us had very challenging journeys around diagnosis, for example:

- *I knew there was something wrong with my adrenals. I even asked my doctor to check my cortisol levels. Another holistic doctor checked many of my hormone levels but did not do the one diagnostic test for Addison's.*
- *I had had dental procedures and ended up with painful face. Dentist said to go see a doctor. Dr I saw asked me if I was suffering fatigue and if my skin had got darker. I went home and researched those symptoms and came up with Addison's disease. I returned to my own doctor the next day. He had spoken to the previous doctor who had suggested Addison's, but they dismissed it because I was pregnant at the time. My husband said "something is wrong with my wife and I want to know what it is". I was sent to endocrinologist who diagnosed Addison's.*
- *I got Cushing's Syndrome due to steroid use for an auto immune disease, when they cut back the steroids, my body started to shut down. My endocrinologist tested my adrenal function and it was practically zero and my ACTH was completely knocked out.*
- *I was travelling in Central America and presented at a clinic with stomach pains, fatigue, dizziness, extremely low blood pressure and was told I had gallstones and would have to undergo immediate surgery as there was a blockage. One month post-surgery I was still in Central America and still very unwell - vomiting, unable to walk more than a few steps unaided, plus an infected surgical wound. I eventually returned to Australia about a month and a half after my surgery. About a week later I was diagnosed with Addison's disease.*
- *GP could not find the cause of my symptoms and I kept going back for months until I insisted I see an Endo and he picked it up immediately.*
- *Unable to walk without assistance and very dizzy, not eating much and having trouble breathing on standing. Feeling sick all the time and terribly weak.*
- *4yrs with tiredness, skin pigmentation unaware of underlying problem, Cytomagella virus (*sic: cytomegalovirus*) brought things to crisis point but managed alone with fluids/rest (we were camping). Diagnosed 9 months later when symptoms listed above didn't resolve.*
- *Last ditch attempt to prevent mortality by a brilliant diagnostician who decided cortisone tablets would be worth trying!*

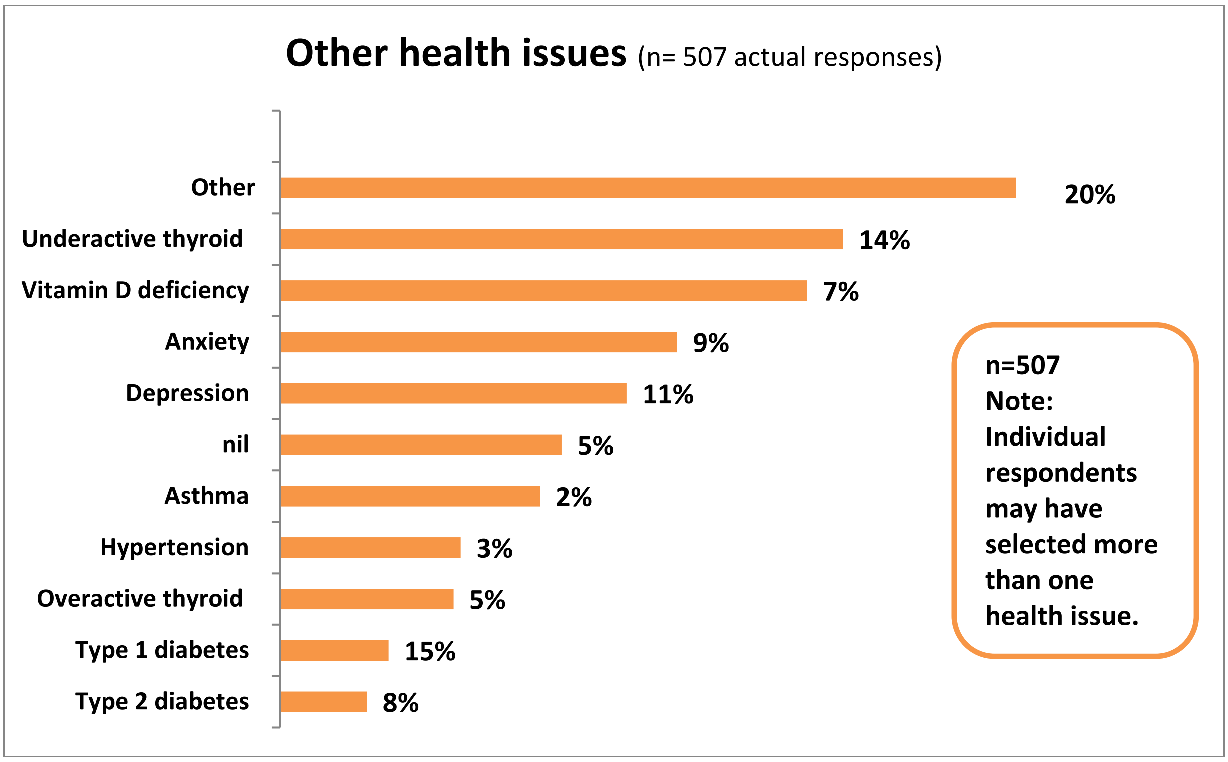
The following word cloud charts some of the key words expressed by our people at diagnosis. Word clouds collect and represent the most popular words within a group of text. Words in larger print were said by more people.



Key concepts drawn out from the word cloud are:

- ‘Test’ and ‘blood’ indicate the memories many people have in relation to having a blood test taken.
- ‘Low’ relates to low cortisol level and we would all expect that.
- There are lots of words relating to time taken ‘year’, ‘years’, ‘time’, ‘later’, ‘week’, ‘days’. For many of us the time taken to be diagnosed was a major issue.
- Words like ‘crisis’, ‘unwell’, ‘sick’, ‘nausea’, ‘weak’ and ‘worse’ indicate that our health was a real concern at that time. In general, we were health compromised and that is what caused us to get tested in the first place.
- Often people reported going ‘home’ after unsuccessful testing.

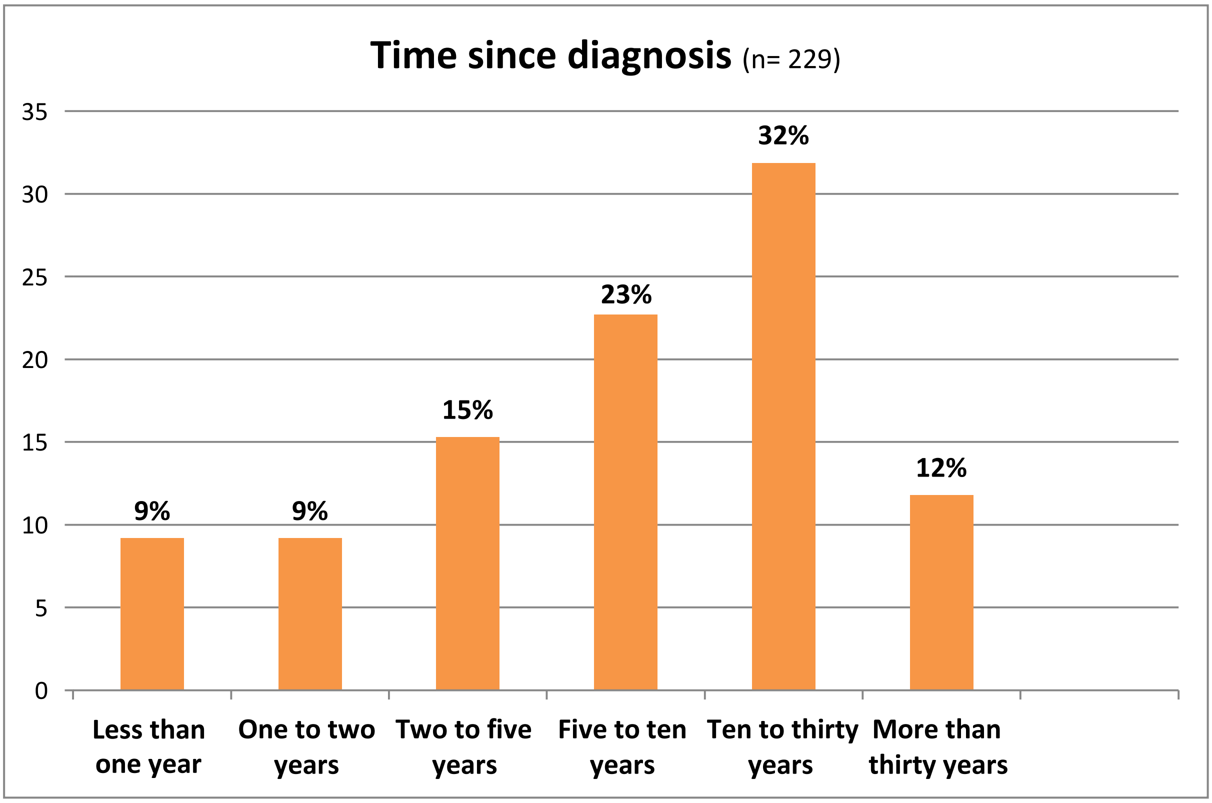
Also, for many of us, the diagnosis with adrenal insufficiency was only a part of the story with many of us also having other health issues.



5. How long have we had adrenal insufficiency?

In general, we represent an experienced group of people living with adrenal insufficiency. In all 67% of us have been living with adrenal insufficiency for more than five years; 12% for more than 30 years.

It is encouraging for AADAI to note that 18% of respondents are newly diagnosed (less than two years), and yet they have found our Association and are engaged enough to take part in this survey. In the graph below n = 229.



Overall, it could perhaps be argued that the 'adrenal insufficiency experience' of those who completed the survey skewed the results, because they are generally on top of their condition. They are most often well informed and managing their lives and their condition well. It is impossible to know the extent to which their journeys represent that of others who have not completed the survey.

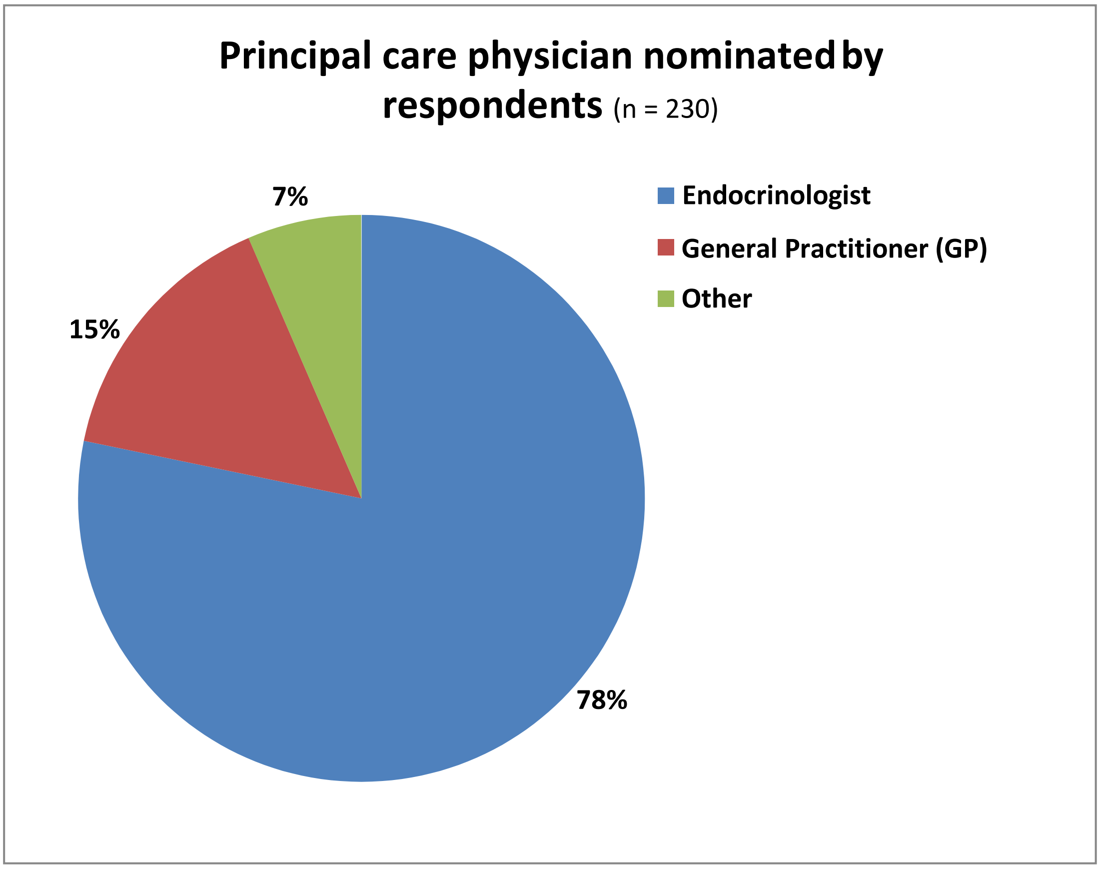
6. Our Endocrinologists

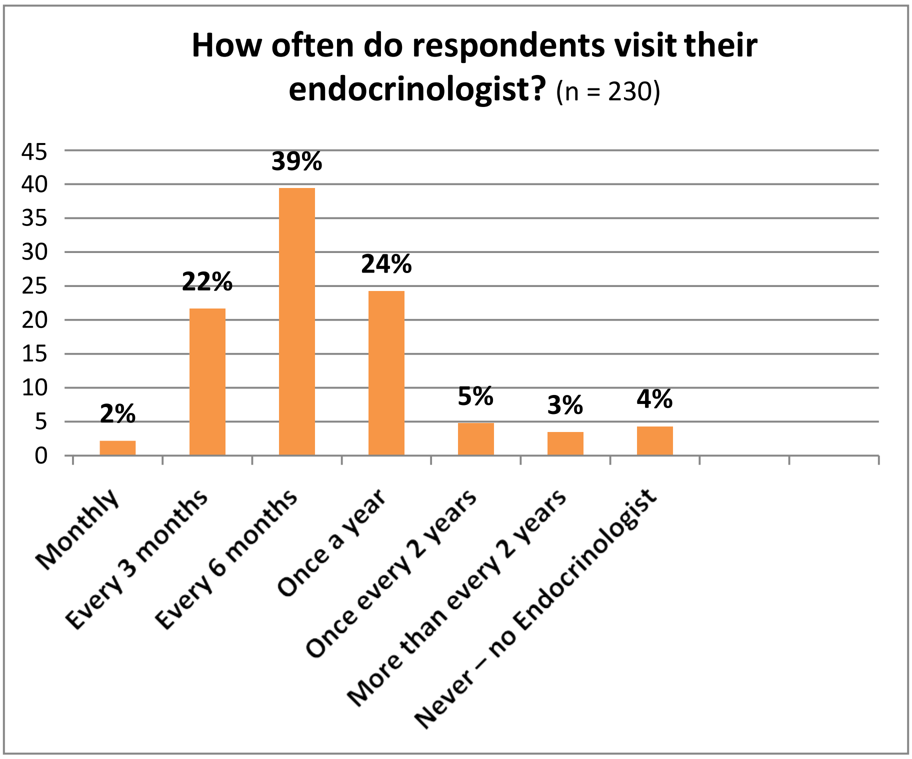
The majority of those living with adrenal insufficiency reported that their main (or principal) care physician for adrenal insufficiency is an endocrinologist; they consult them often and generally report that their endocrinologist has a good understanding of adrenal insufficiency.

It is interesting to note that despite the spread of people across metropolitan, regional and rural areas, (see section 2 above); the majority of us (78%) see an endocrinologist for primary care of adrenal insufficiency. Fifteen percent said they see a GP and it is unknown whether they cannot access an endocrinologist regularly or they are happy to have their condition managed by their GP. Note that 7% saw someone else as their principal carer and so selected the 'other' option.
Other carers included the following:

i. Another specialist doctor - for example:
  - *Physician in country. Was under endocrinologist when I lived closer to city.*
  - *Heart specialist.*
  - *Specialist Physician.*

ii. Reportedly, self-managed - for example:
  - *I now live in Italy and manage my own health care, with a visit to my endocrinologist every couple of years when in Australia.*
  - *Myself, we are very sick of the attitude we get from the medical profession.*
  - *Me, I have to work out what needs doing with meds and tests.*



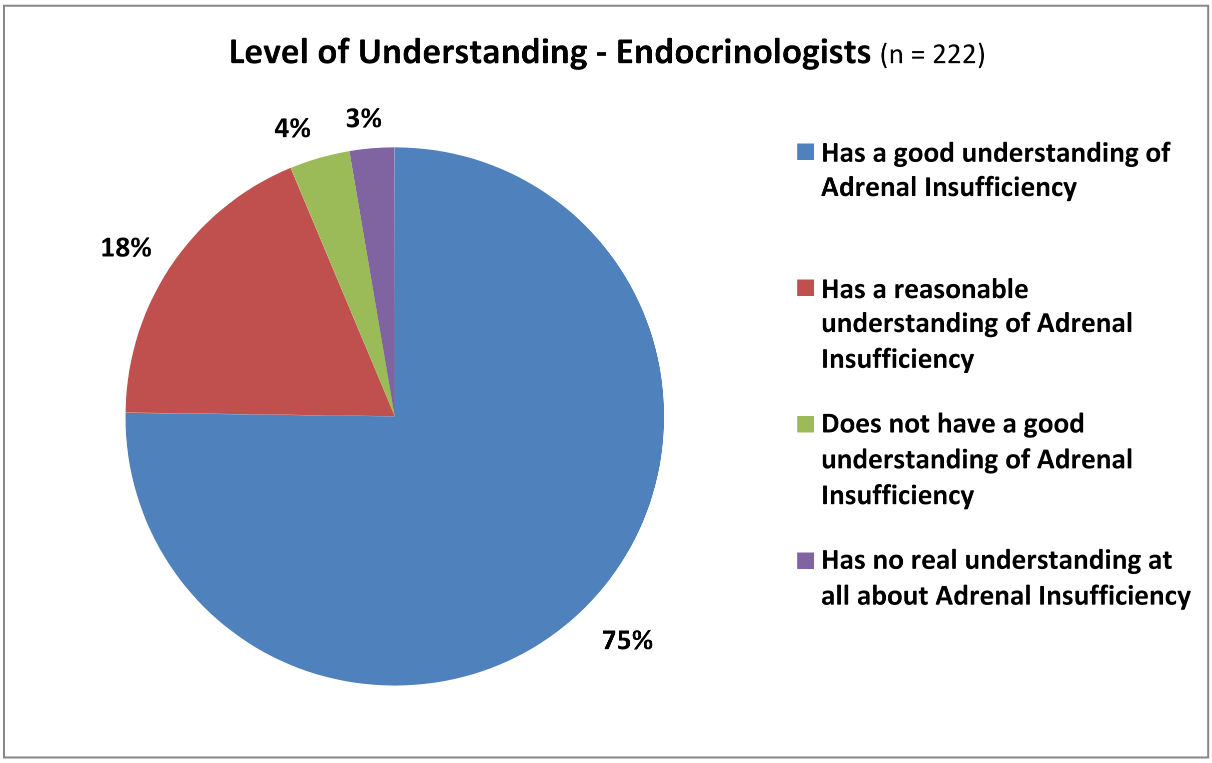


For those who do see an endocrinologist, they generally have regular appointments and see their endocrinologist often. Two percent have monthly consultations; 23% have check-ups every 3 months; 39% every 6 months and 24% yearly. Only 8% saw their endocrinologist less often than annually; 5% every two years and 3% even less frequently. Note some respondents did not consider their endocrinologist as their main physician (above).

While there are some exceptions, those who see endocrinologists as their principal physician for adrenal insufficiency are satisfied with their level of understanding of adrenal insufficiency. The following example quotes and the table below, provide evidence of this:

- *Our first endocrinologist didn't have a clue, so we searched for one that did, she has a couple of other patients with Addison's and is extremely interested, most times we go we meet a lot of student doctors because she believes doctors need to be aware of Addison's.*
- *He's right on the ball! I have his private mobile number for emergencies.*
- *I feel confident in her care.*
- *Knowledgeable and prepared to listen to my requests to adapt dosages etc. Doesn't look for unproven side effects of Addy. Could be more holistic however and look at the entire body system and stressors, hence also seeing a naturopath.*
- *My Endocrinologist is very knowledgeable about Adrenal Insufficiency and understands what impacts the patient. She always makes herself available when I need her and instructs my other physicians what I need if I am unwell with one of my other conditions.*
- *My endocrinologist has empowered me to self-manage and communicates well with me. She travels overseas and updates me on the latest information.*
- *I searched to find a good one! Several did not have a good understanding at all.*

It is important to note that 75% see their endocrinologist as having a 'good understanding' of adrenal insufficiency and another 18% 'have a reasonable understanding.' So, while some negative experiences are reported, these represent the views of only very few people who have seen endocrinologists who have 'no real understanding at all' (3%) or a 'limited level of understanding' (4%) of adrenal insufficiency.



Some respondents reported having negative experiences:

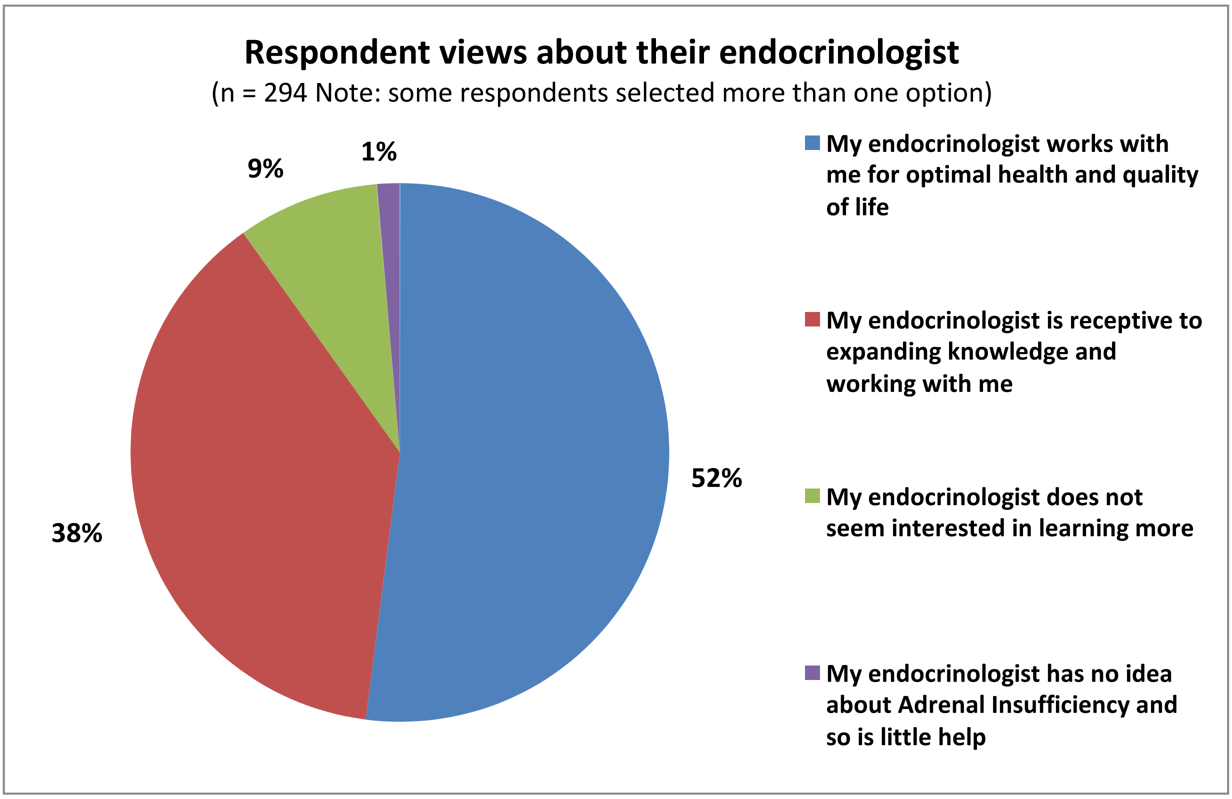
- *15 endocrinologists tried, none have any idea about complexities of multiple endocrine issues. Specifically on adrenal insufficiency, most (I want to say all) have no idea about hydrocortisone dosages, trying to approximate a circadian cycle, the delay from dosage to cellular levels rising, absorption variations, believe that less is better while ignoring the long term effects of low cortisol on the body, there is a middle ground that is optimal!*
- *My original endo was with a hospital clinic and was hopeless. I would see a new registrar each time and he'd just pop in at the end.*
- *Would prefer endocrinologist monitors adrenal insufficiency more closely and ask questions about my health relevant to AD rather than primarily diabetes. Too often, I feel that medical symptoms are attributed to diabetes or general fatigue when they may be related specifically to Addison's Disease.*
- *He doesn't always listen to me but has now retired so I am looking for another Endocrinologist.*

The majority of people (52%) report that their endocrinologist 'works with them for optimal health and quality of life.' A further 38% say that their endocrinologist is receptive to expanding their knowledge. It is disturbing to hear that (9%) report that their endocrinologist 'does not seem interested...' and 1% indicate that their endocrinologist 'has no idea' and is 'of little help.'

One telling comment below highlights what a person living with adrenal insufficiency can go through and the importance of receiving knowledgeable medical assistance:

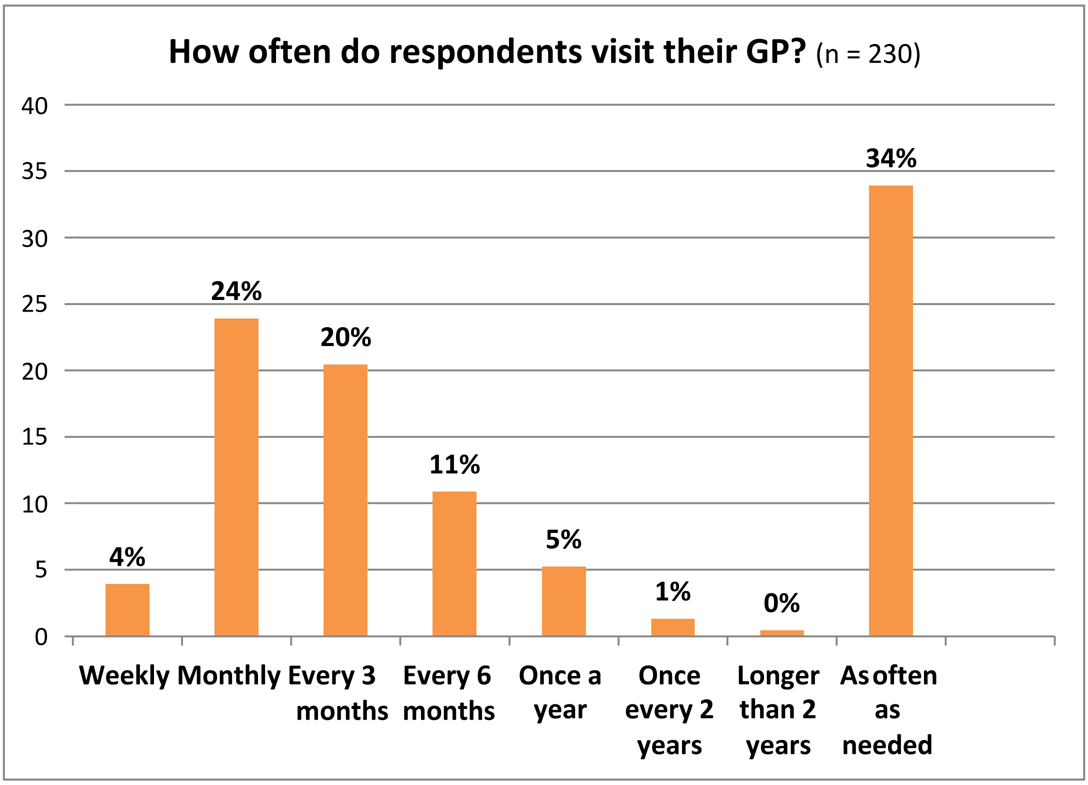
> *I was recently referred by a gastroenterologist to a different endocrinologist for a second opinion as I had been having daily diarrhoea, with periods of nausea and vomiting (I was referred to the gastroenterologist by my GP who has little understanding of Addison's and so didn't recommend I see my endocrinologist). The second opinion was that I should change and reduce my*

medication. I decided to see my original endocrinologist who advised I was actually under medicated and bordering on Addisonian Crisis. No one else picked this. I increased my medication to the levels prescribed by him, and the symptoms resolved within days.

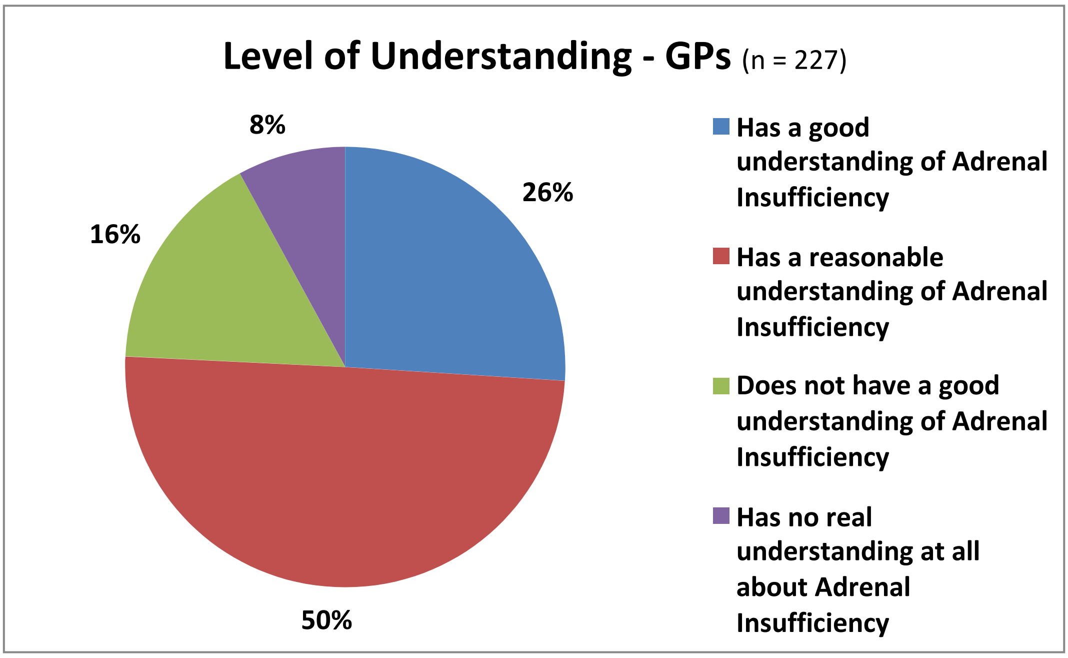


7. Our General Practitioners (GPs)

A relatively small but significant number of people living with adrenal insufficiency (15%) identified their GP as their principal care physician for adrenal insufficiency. However, almost everyone with adrenal insufficiency visits their GP often, even if they do not consider them to be their main physician.



GPs have a variable level of knowledge of adrenal insufficiency.



Twenty-six percent said that their GP has a good understanding of adrenal insufficiency. For example:

- *Given I am a GP, we tend to discuss things more as colleagues, although she makes any decisions when it comes to management, but with my input. It works well.*
- *My GP understands how the Addison's reacts with other conditions that I have and takes it into consideration when prescribing or arranging tests etc. She understood my request to stay overnight in hospital before a colonoscopy (and has included this in her referral).*
- *This is not my 'GP' but the specialist 'GP' who referred me to the endocrinologist. He knew enough to suspect Addison's but knew enough to recognise I had had 2 incidents of Addisonian crisis and was bordering on a more severe episode. He carries out regular blood tests and, after the experience of the last 12mths, I will go back to my endocrinologist if there are any concerns with the results as he fully understands my situation.*

Fifty percent said that their GP has a reasonable understanding of adrenal insufficiency. For example:

- *My GP doesn't know a lot about Addison's, but she will ring my endocrinologist if needed.*
- *Has a reasonable understanding of Adrenal Insufficiency now. My GP had never heard of Addison's until I was diagnosed.*
- *She explained her basic knowledge and willingly rang my endo to ask for further knowledge, which I really appreciated.*
- *My GP says that I know more about Addison's than she does. I have, however, trained my GP to ring my endo if she thinks my symptoms are Addison's related.*
- *I live rurally, and I am his 1st and only Addison client. So he will be on a learning curve from me and my endocrinologist.*

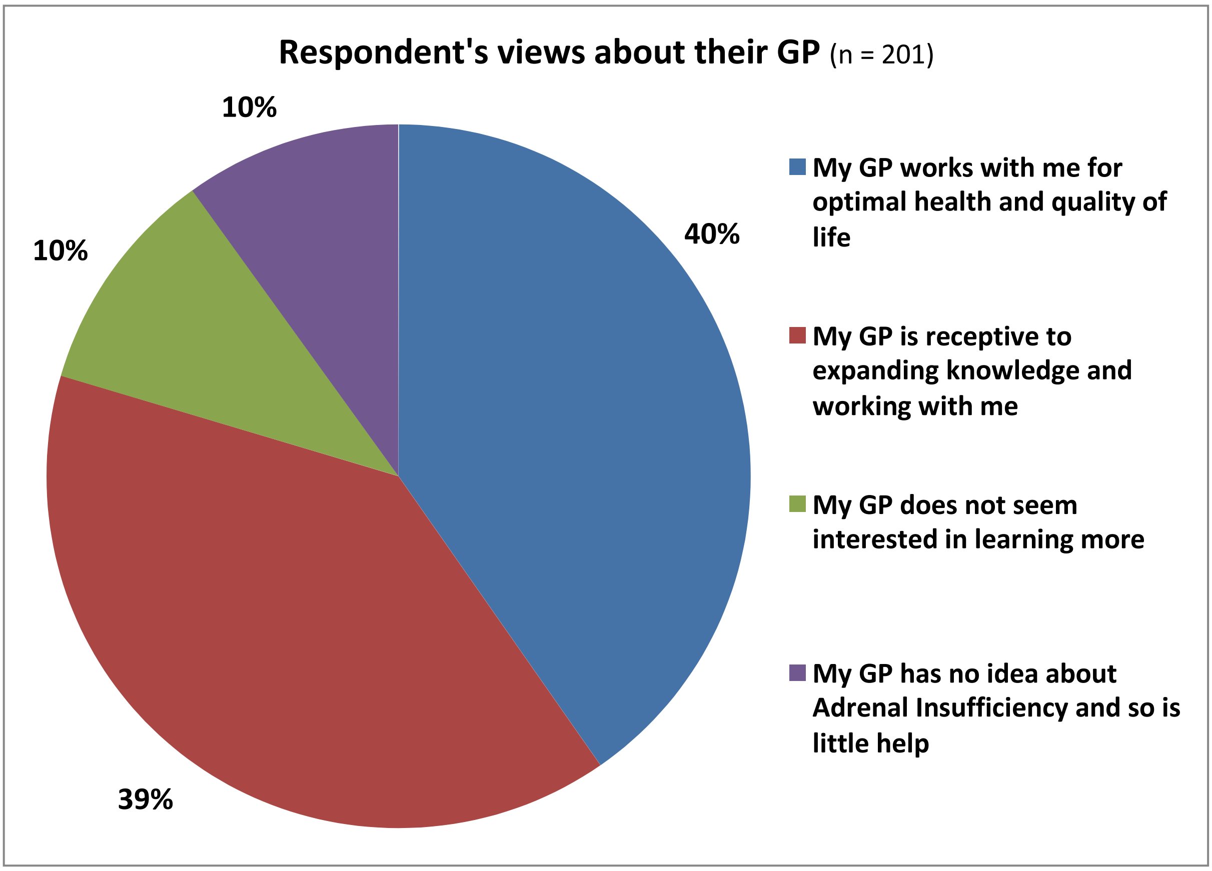
Sixteen percent said that their GP has a limited ('not good') understanding of adrenal insufficiency. For example:

- *My GP does not discuss my illness with me she just provides my prescriptions.*
- *I feel my GP only has a basic knowledge and doesn't understand the impact of other conditions on the AI and also how I am more susceptible to low cortisol issues because of pain and infection.*
- *My main GP seems hesitant to give advice regarding AI. Some GP's at the same practice have been more confident; however most don't have a deep understanding of AI.*
- *I just have to visit for prescription. I end up guiding the GP. She is a great GP. No GP I have met has a clue.*

Disappointingly 8% of our people say that their GP has a poor understanding of adrenal insufficiency. For example:

- *He is always referring me to another doctor rather than answering me.*
- *I had a wonderful GP who was very knowledgeable and interested but since he moved away I have struggled to find anyone who seems to engage.*
- *Didn't know what Addison's was. I was the first patient to be diagnosed at GP clinic. No help in a crisis. Doesn't know symptoms. Doesn't know what to do when I am seen to.*
- *My GP has a really poor understanding of the clinical significance of Adrenal Insufficiency.*

- *My GP has a really poor understanding of Adrenal Insufficiency I have tried to educate her with resources from the Addison's Association, but I feel this is to no avail really.*



There was a consistency between people's views about their GPs level of understanding of adrenal insufficiency and their views about the extent to which the GP is working with them to achieve optimal health and lifestyle. It is evident that when the GP and the endocrinologist (if there is one) work together and communicate well, then the person living with adrenal insufficiency benefits greatly.

- *My GP is fantastic and helps manage my health in conjunction with my AI. She has a pretty good understanding of AI in general and if there's something that she is unsure about she is happy to defer to my endocrinologist for support.*
- *In consultation with my GP and other related medicos dealing with me my endocrinologist has communicated well with me to ensure good results.*

8. Treatment

Regardless of whether people have primary or secondary adrenal insufficiency, similar treatment options are involved, and all treatments replace the cortisol that is not being sufficiently produced.

We all have our own individual medication regimens[7], they are all different and getting them right often requires significant trial and error. Our stories around medication reflect this and are diverse and individual. Here are just a few of them:

- *I have my dose of dexamethasone compounded by a pharmacist specially for me.*
- *I was on dex and had a much better quality of life, now on hydro, I live to survive.*
- *If you don't simulate the circadian pattern of cortisol release, the patient will never feel the best they can be.*
- *Recently had to swap to Hysone because Australia ran out of cortisone acetate!!! This abrupt shortage caused me a lot of trouble when meds literally ran out.*
- *At one stage when there was a shortage of Hydrocortisone I was prescribed Cortate...unfortunately my body did not respond well to it, so I had to access the UK HC promptly to return to good health.*
- *I used to take prednisone and was found to have osteopenia. Hydrocortisone is thought to be a more natural product and I am on a slightly reduced dose.*
- *Over 36 years I've been through Dexamethosone (serious bone damage), Prednisone as well Hydrocortisone seems best, at this stage, but I've fiddled with dosage and timing through the day forever.*

Of the 231 people that were surveyed, it is not possible to determine consistency or even similarity with what medication is taken and how regularly it is taken. As we are all aware, it is always a real challenge for those with adrenal insufficiency and their treating physicians to determine the optimal dose that a person should receive, as it is such an individual thing. A challenge made even more complicated for those of us who live with other conditions as well.

The first of the graphs below indicates the medications that are most frequently used. No data was collected about the quantity of each dose, but anecdotal comments below confirm that this varies greatly.

Hydrocortisone is taken by 56% of surveyed people as their primary form of replacement therapy. Cortisone acetate remains a popular form of primary treatment with 20% of respondents taking this medication. Prednisone (15%) and Dexamethasone (5%) are also used. It is noted that 4% of respondents did not complete this question for reasons that are unknown. It is noted that, increasingly, medication is prescribed and dosed in a way that best reflects the circadian rhythm.[8]

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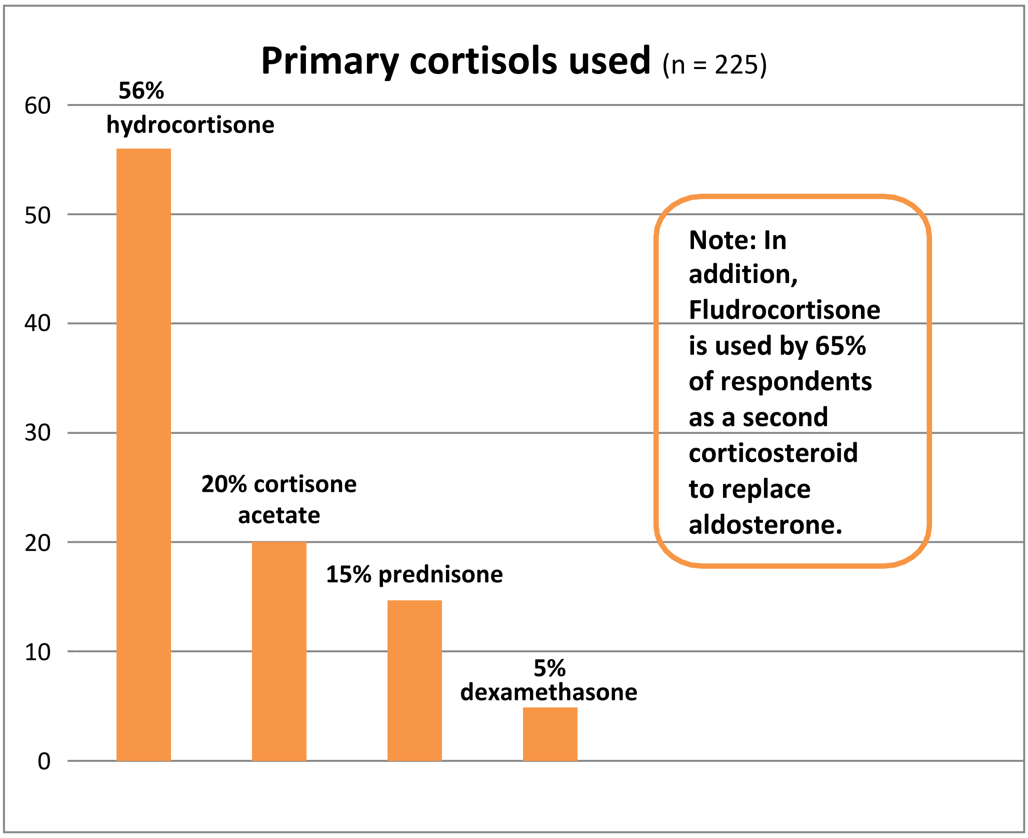
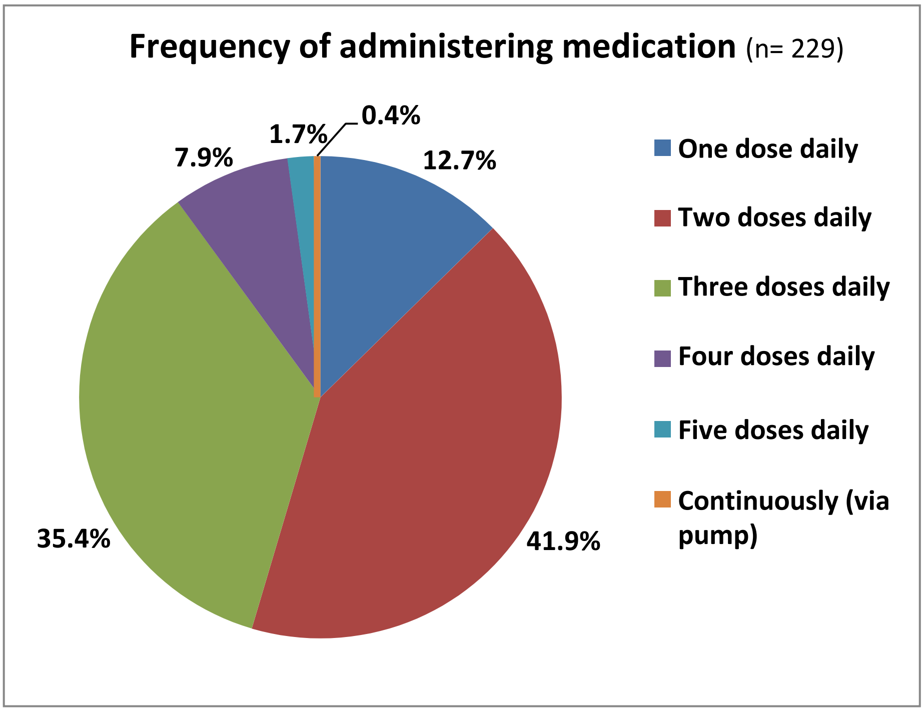
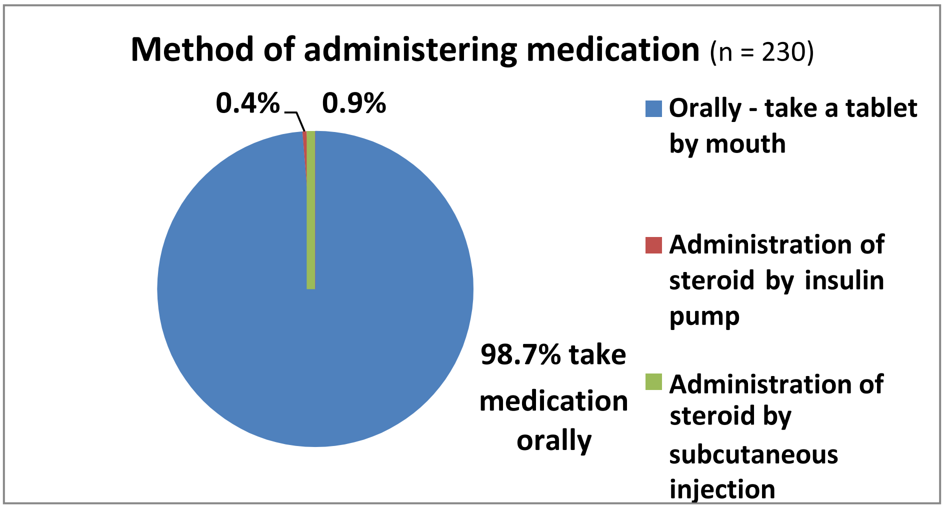
[7] Regimens: a prescribed course of medical treatment, diet, or exercise for the promotion or restoration of health

[8] A circadian rhythm is a roughly 24-hour cycle in the physiological processes of living beings,





The number of doses per day of the primary cortisol taken vary greatly. 12.7% (including one of the authors of this report) take one dose per day. Almost 42% take two doses a day and over 35% take three doses. Attempting to simulate the circadian rhythm of cortisol release as a treatment option is used much more often in recent years.



There is much more consistency in the way in which cortisol is taken - over 98.7% of us take it orally and 0.4% [one person] uses a pump. The other 0.9% use a subcutaneous injection.

9. Increasing your dose

People living with adrenal insufficiency need to take extra cortisol in addition to their daily doses when they are sick, injured, under significant stress and before any kind of surgery. This is called stress dosing or sick day dosing. All but 5% of our 231 people have sick/stress day dosed. However, 57% have done it rarely. The graphs below show that those who do sick/stress day dose more often than rarely are actually doing it quite often. Ninety percent of people feel confident about taking an additional dose.

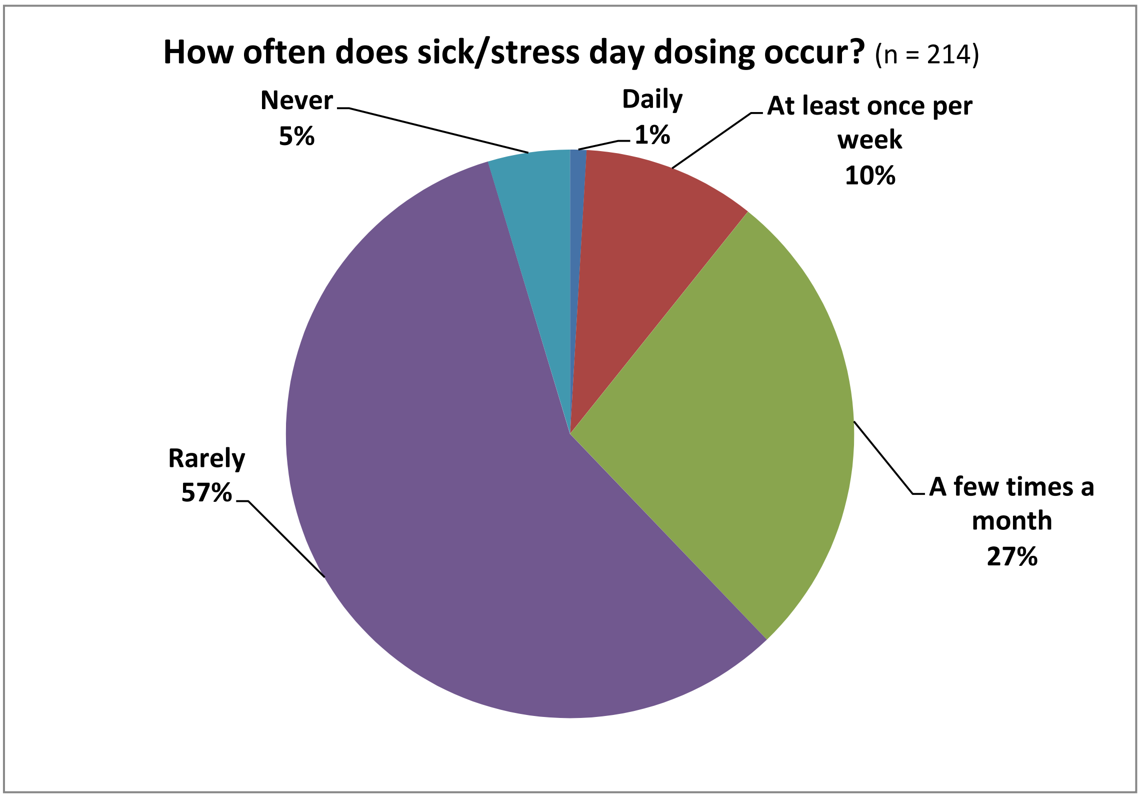
Many comments were made in the survey about sick/stress day dosing. Some of these have been grouped and listed into two key areas below:

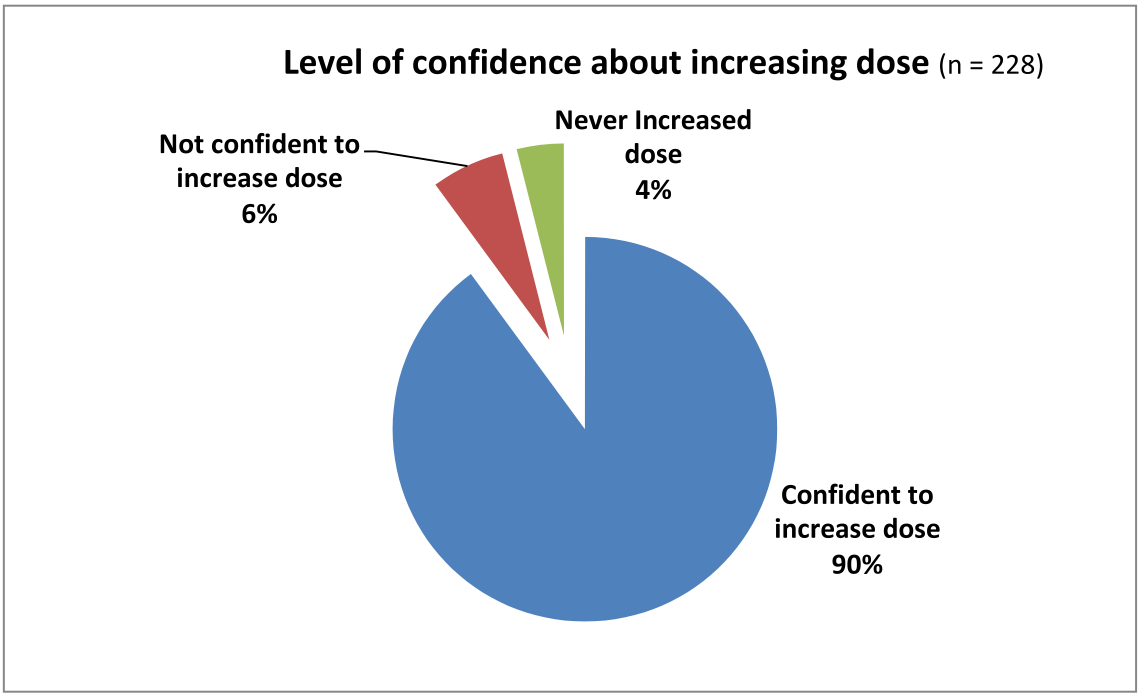
Taking an increased dose

- *At the moment I am sick with a chest infection. Hysone has been doubled. I am still on that dose. I have also been sick in the last few weeks.*
- *I try not to increase unless I really need to. I may go two to three months without needing to, then need to a few times within a month depending on what's happening in my life.*
- *It depends on a lot of things: heat, stress, sickness, cold etc. Just depends how I feel when I wake up and what I do or what happens on the day. Stress dosing is a very individual thing, there is no one size fits all.*
- *For many years I never took a "stress dose" orally for anything, even when sick and vomiting. I do now listen to my body more and have identified when I am low on cortisol and will updose as necessary.*

What do your doctors think?

- *My Endocrinologist supports this and has given me written instructions. So far I have not done this and I remain nervous of doing so.*
- *Addison's patients usually have a pretty good idea how they feel when a 'crash' is starting, but if you tell the doctors that, most only go on numbers and let you actually crash before they treat you. Very scary.' Prevention is better than cure', should be the gold standard of care.*
- *I believe my endocrinologist's view of when to use increased dosage is too limited to only very severe illness or injury - e.g. fractured leg, serious viral illness - when in my opinion increased dosages could be used more frequently to help deal with stress and mild illness. Having said this, I also have osteoporosis, so increased steroids are contra-indicated for this condition.*
- *Stress dosing is a very individual thing, there is no one size fits all. But try telling the doctors that... they just go by numbers, not by feelings. I was running too fast so dropped my dose & I'm still only 2 months from diagnosis so I'm trying to figure out what's 'normal'... my Endocrinologist was very much against increasing on stress days.*


How often does sick/stress day dosing occur? (n = 214)
Never 5%
Daily 1%
At least once per week 10%
A few times a month 27%
Rarely 57%

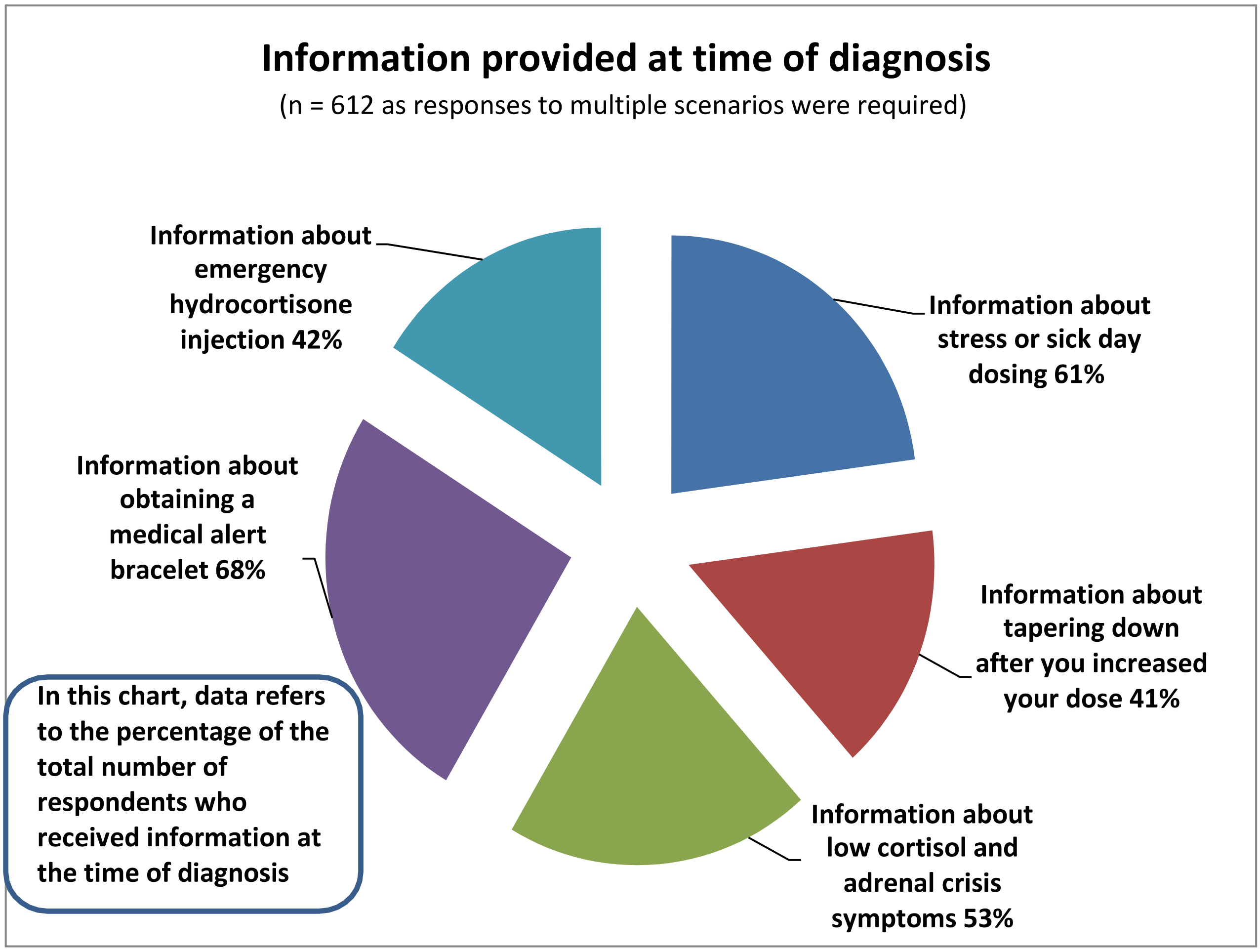

Level of confidence about increasing dose (n = 228)
Not confident to increase dose 6%
Never Increased dose 4%
Confident to increase dose 90%

10. What we do in emergencies

Many of us were well informed about what to do in emergencies at the time of diagnosis. This seems to be a more regular occurrence for those people who have been more recently diagnosed. For example: '*My diagnosis was a long time ago. Information about stress/sick day dosing and solu-cortef was not available.'*

My endocrinologist '*is available for questions regarding up-dosing when needed and was the one who informed me that I required an emergency injection kit and that both my husband and I should be trained to do this. She organised the lesson for us with the endocrine nurse at the hospital.'*

'I learnt this information over the first few years. Doctor did prescribe injectable hydrocortisone but I could not get anyone to teach me how to administer it. So I don't use it.'



Some respondents indicated that this Association (the AADAI) is a valuable source of information for them:

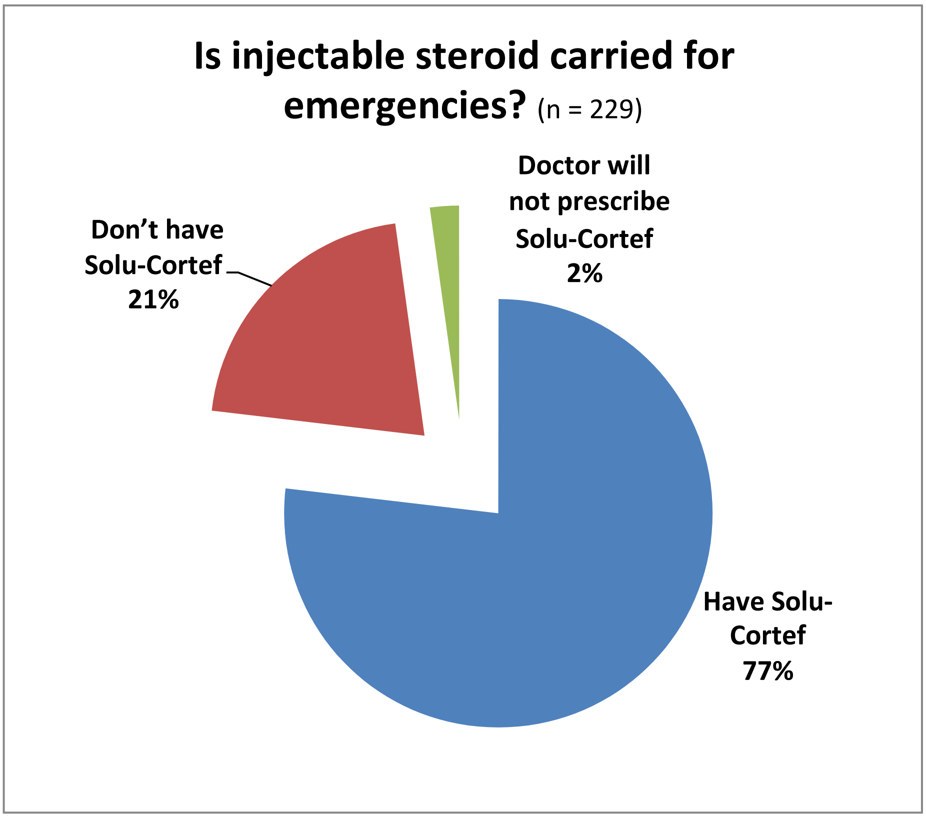
- *'I found out about Solu-Cortef and medical alert bracelet through AADAI.'*
- '*As I was diagnosed 30 years ago, I did not get a lot of information at that time. I have worked at my self-education over the years and have picked up tips from others and from the newsletter. I now feel I have a lot of information and feel confident overall about how to manage my Addison's condition.'*

Some of us seek out information from a variety of sources. For example: My *'Endocrinologist provided the sick day info. I got medical alert on own, and requested the Solu-Cortef, and needle through the GP.'*

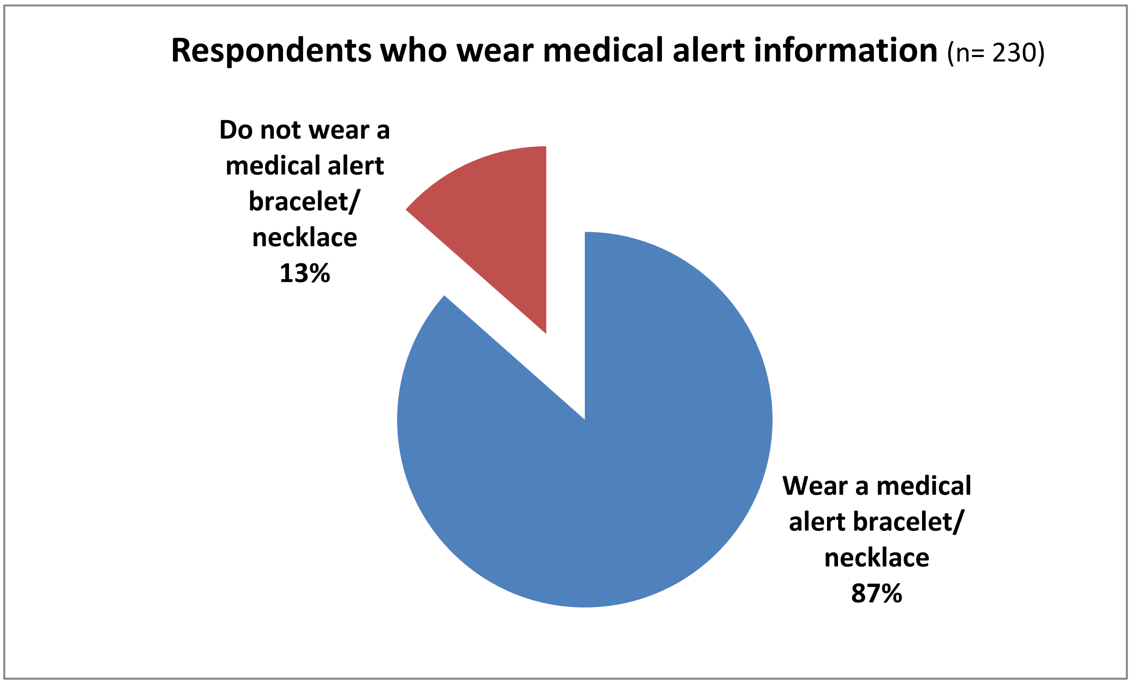
11. Guarding against emergencies

Survey results show that as a group we are generally well informed and that we try to be prepared for emergencies:

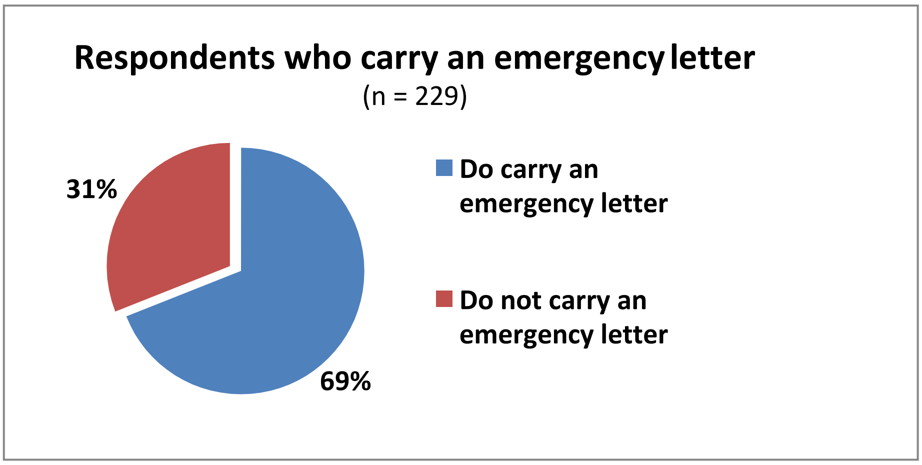
- Seventy-seven percent of us carry an injectable steroid for emergencies.
- There are lots of varied stories about carrying injectable steroids:
  - *'My GP refused to prescribe Solu-Cortef initially, but I was going overseas so she reluctantly gave me a script. I attended my 1st Addison's meeting in Brisbane this year and a presenter showed us how to draw up and inject the Solu-Cortef. I have not had to inject myself but I have presented at a doctor's surgery and they have done so.'*
  - *'My endo says injection Solu-Cortef is just for camping.'*
  - *'Uncontrollable vomiting and diarrhoea, major fluid loss, low blood pressure, inability to maintain cortisone levels. I was in NZ for work, called the ambulance and was taken to hospital I gave them my letter with the treatment protocol and injectable cortisone. They seemed to think I had some type of infectious disease, isolated me and did not treat me with an antiemetic and cortisone for almost 2 hrs. I yelled the place down and they gave in but kept me in isolation!'*



Most of us (87%) wear medical alert jewellery. It is unknown if we wear it all the time.

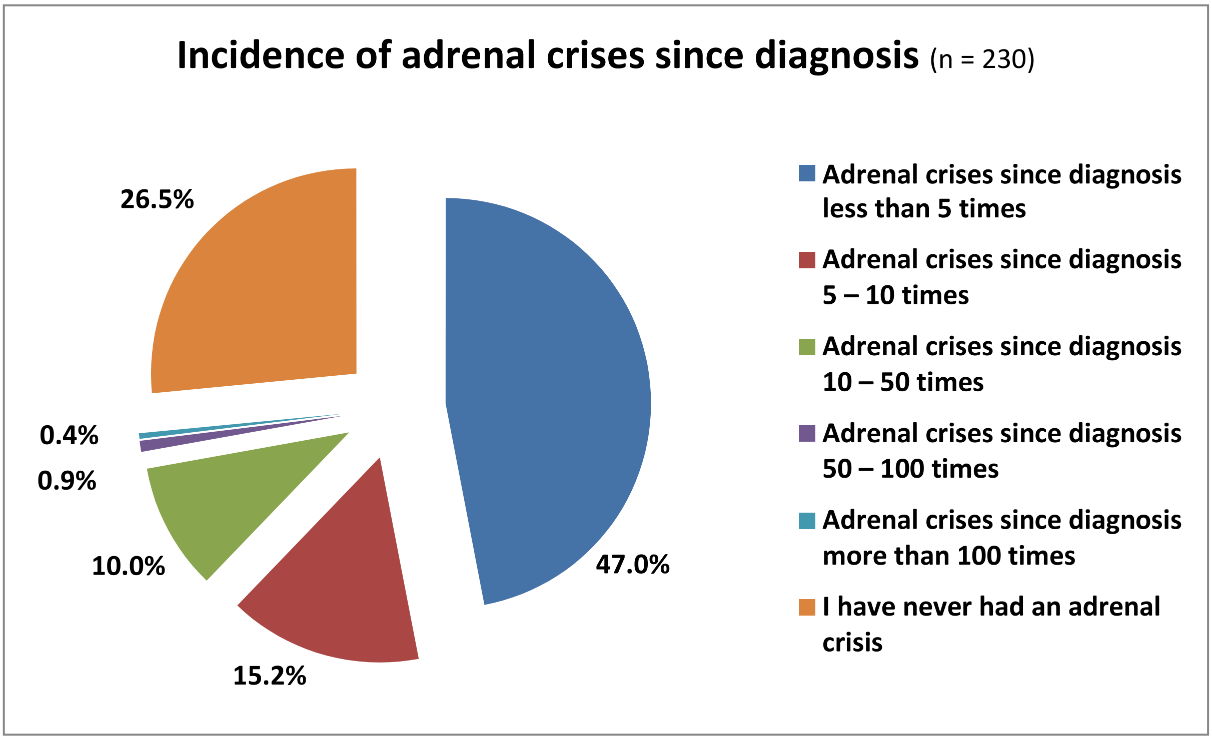


- It is interesting to compare this result with the number of our people who carry a doctor's letter. Notably, people seem more comfortable wearing the jewellery.
  - *I wear medical alert bracelet and necklace.*
  - *I am becoming better at talking about AI. Many people know that I have Coeliac Disease and have had colon cancer and you can almost see them rolling their eyes when I start talking about AI, so I try not to push the issue. But I do mention it in my various recreational/voluntary roles so that people know to check my medical bracelet in an emergency.*
- Thirty-one percent of us do not carry an emergency letter. If you are one of these, you should consider requesting one from your doctor or the AADAI.
  - *I was given a MedicAlert brochure and an Up-to-date page about Addison's but no letter.*
  - I *got a letter from my endocrinologist.... We had to wait (for the first time in 5 years). But now we have a letter and the staff were great once we got in.*

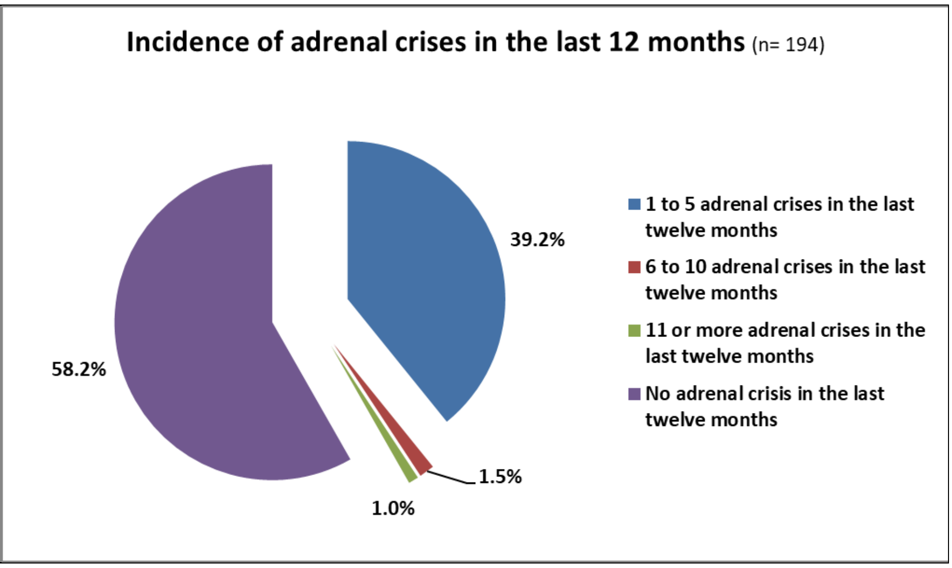


12. About adrenal crises

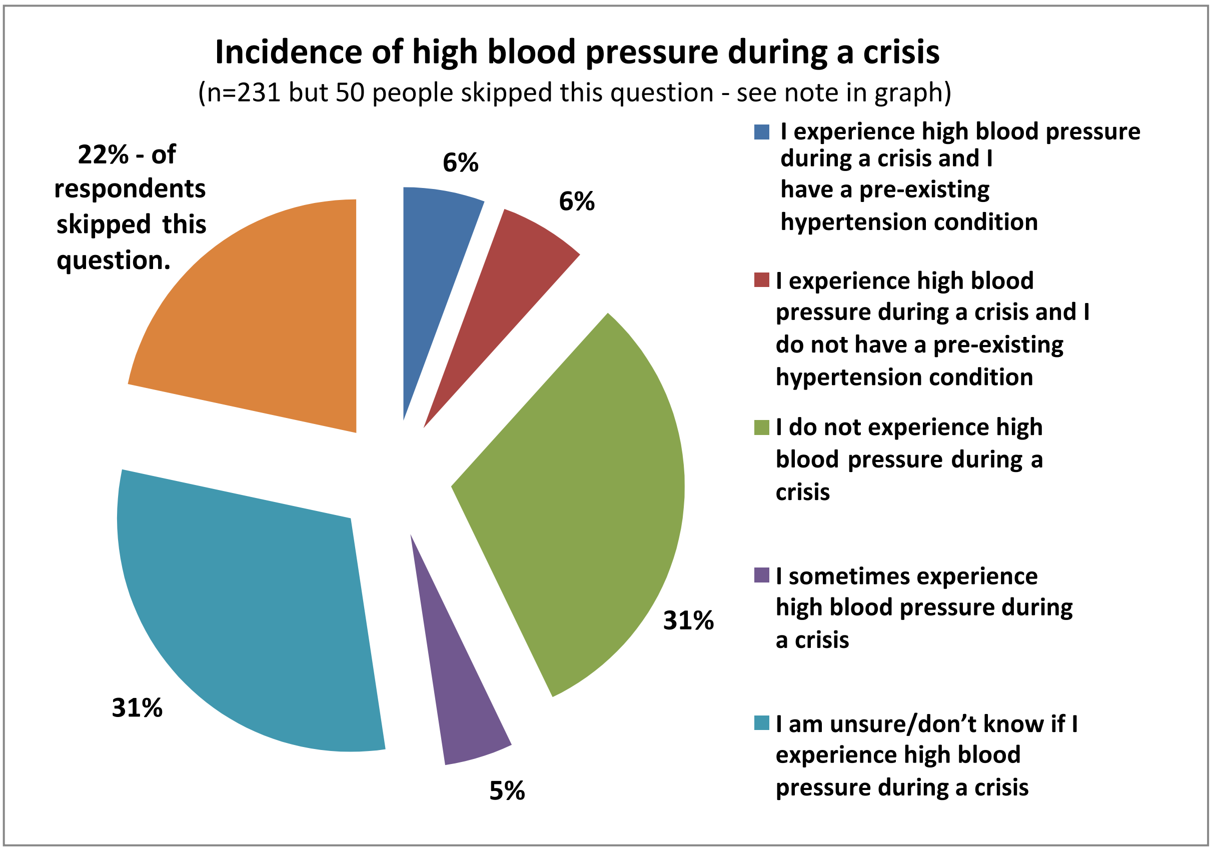
The responses given about adrenal crisis again indicates how diverse our experiences are. Twenty-six percent had never experienced a crisis and 47% had experienced an adrenal crisis less than five times since diagnosis. At the other end of the spectrum 10% of people indicated they had experienced a crisis between ten and fifty times. Only 1.3% (3 people) had experienced a crisis more than fifty times since diagnosis.



In the last 12 months 58% of people told us they had not experienced a crisis and 39% had between one and five crises over the past 12 months. Only five people (1.5%) had more than six adrenal crises in the previous 12 month period. It should be noted that for unexplained reasons only 194 people responded to this question.



The issue of high blood pressure at the time of adrenal crisis was questioned. The data provided is included below. The 22% of people who skipped the question (not included in the key) probably represents people who had not experienced a crisis, or perhaps they may have been confused by the question.



How people described their views of what caused their crises is indicated in the following word cloud.

Key feedback that can be extracted from the word cloud is:

Illness. Words like: *infection, vomiting, diarrhoea, stress* indicate that for many people, the crisis could be linked to a physical cause:

- *Influenza hospitalized for 16 days.*
- *Severe diarrhoea and dehydration.*
- *Treated with IV saline and a shot of steroids from ER department. Cause was due to a stomach bacterial infection.*
- *Uncontrollable vomiting and diarrhoea, major fluid loss, low blood pressure, inability to maintain cortisone levels.*

Emergency - Human error or unavoidable circumstances

- *Realized something was wrong and went thru what cause might be ... checked Webster pack! Ooops - instead of 16 (10 + 4 + 2) mg at brekkie, was taking packaged dose of 8 (2 +4 + 2) for 6 mornings.... Error: halved a 4mg instead of a 20mg. Alerted pharmacy and it was corrected with minimal apologies. I keep them on their toes now!*
- *I failed to take my tablets for a week and surprise surprise...*
- *Was travelling overseas - flying between cities and the plane couldn't land because of bad weather. Was diverted to another city and the need to reorganise flights and perhaps accommodation stressed me out. The flight crew were fantastic and took me to first aid where I could inject and infuse fluids.*

- *Change in medication as my regular medication (Hysone) was temporarily unavailable and was substituted with Cortef. For an unknown reason this wasn't effective and ultimately led to a crisis. I was admitted to hospital and provided with intravenous hydrocortisone.*
- *Had a reaction to glucosamine/Chronidrite – tablets. Severe vomiting, diarrhoea, dehydration. Admitted to hospital 3 days treated with saline drip - increased hydrocortisone.*

Other complications

- *I cut my leg, it turned septic and I nearly lost my leg due in no small part to adrenal crisis. Last time I was found unconscious in hospital.*
- *Had food poisoning couldn't keep medication down.*
- *Septicaemia after an operation.*

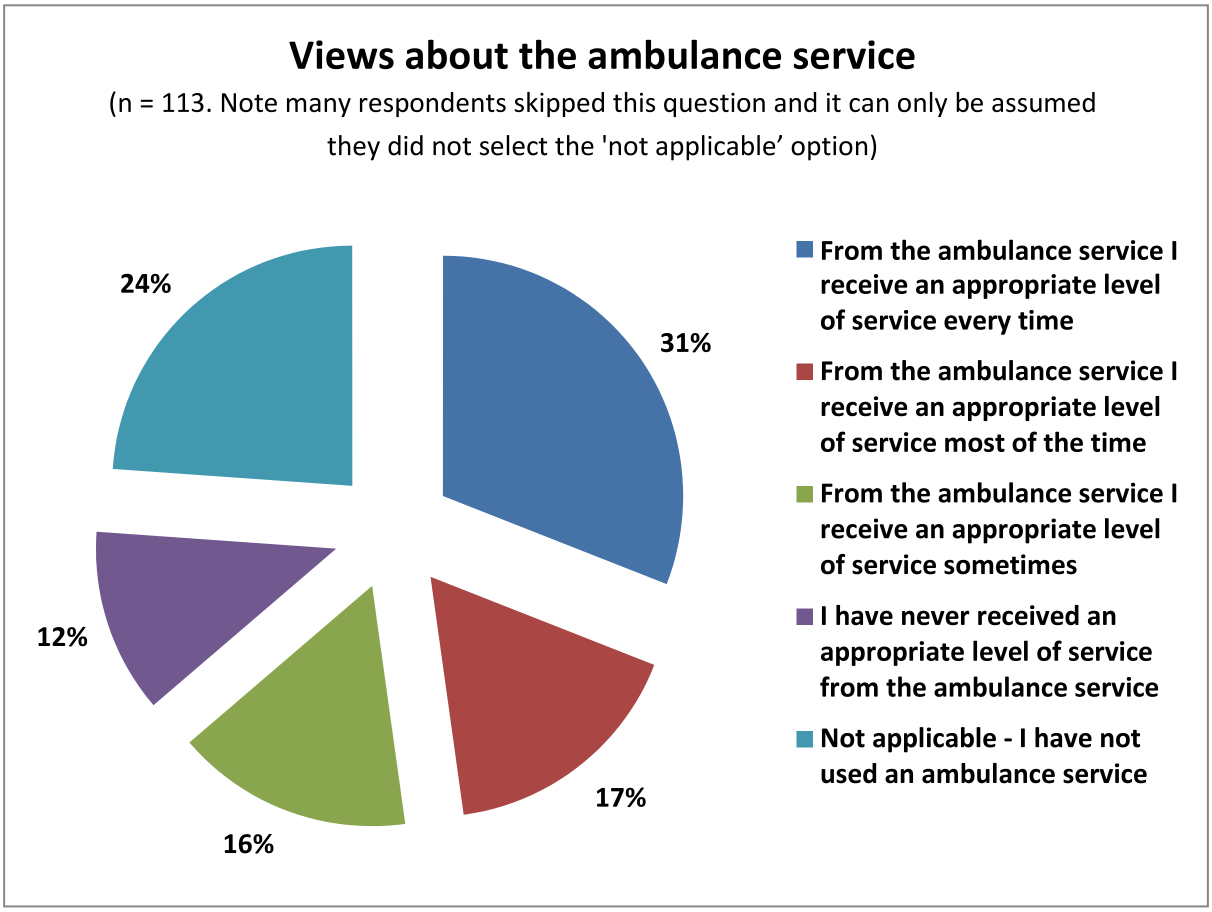
The word cloud above highlights how important spouses/partners and those who are close to you can be in times of crisis, for example: *My husband picked up the symptoms quickly and got me to the local hospital.*

13. Our views about the Ambulance Service and Hospital Accident and Emergency

Some questions in the survey focused on gaining some feedback about the services people have received from both the ambulance services and from the accident and emergency (A&E) services in hospitals.

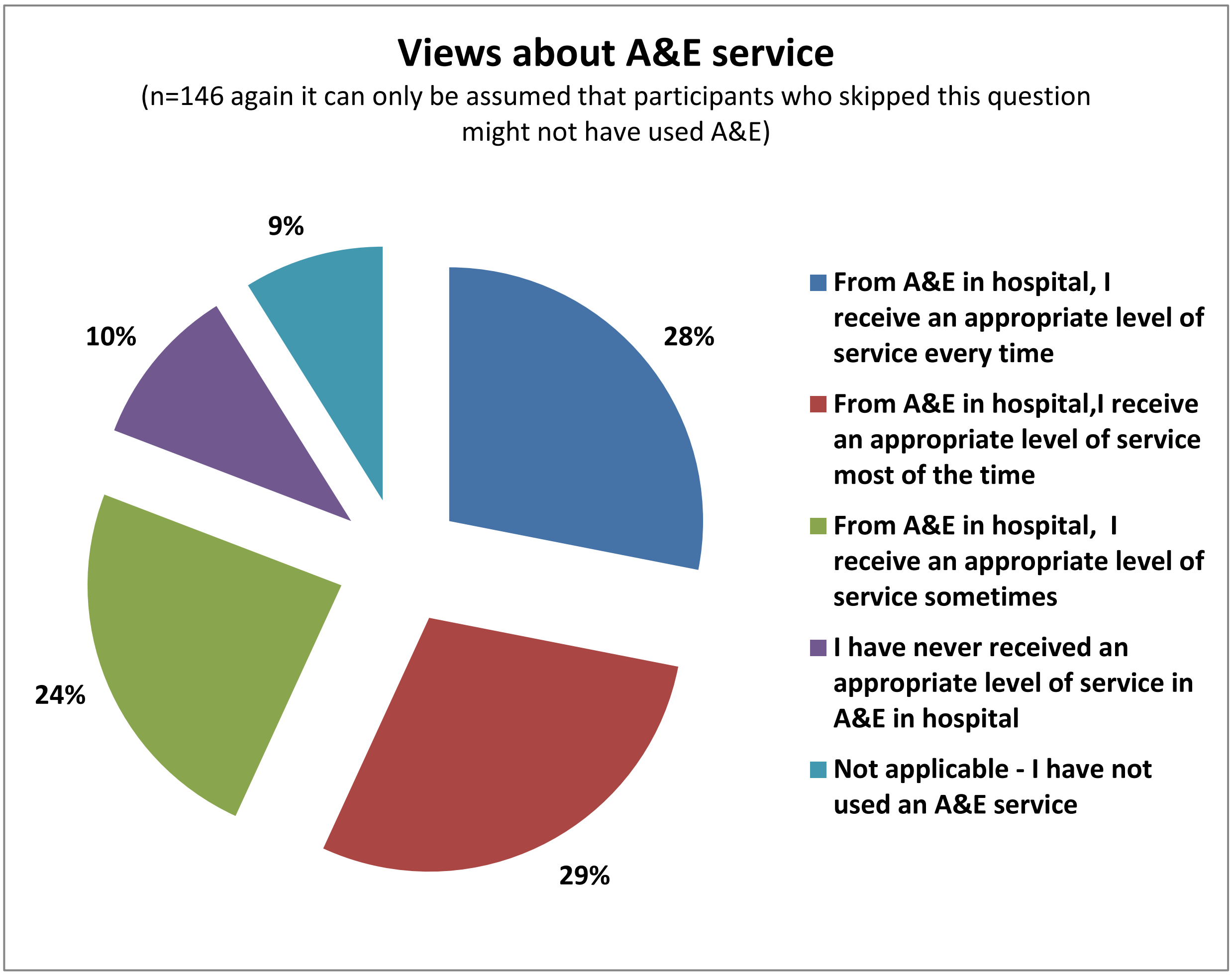
In summary, 24% indicated that they had never used an ambulance service. Twelve percent felt they had never received an appropriate level of service on any occasion, which is concerning; 31% received an appropriate level of service every time, 17% said most of the time and the remaining 12% said they received an appropriate level of service only some of the time.

Many people reported that they had used the ambulance service at times of crisis, but only one comment was made: *I wish Ambulance Tasmania would get a protocol for patients with adrenal insufficiency.*



For more information about the protocols on emergency injections in each jurisdiction see the AADAI website at www.addisons.org.au

Many more views were expressed about services in hospitals and not all of them were positive. Specifically, and with respect to A&E services: 28% found their level of service appropriate every time, and 29% said most of the time. Only 9% had never used an A&E service; 10% had never found them appropriate and 24% said that they had only found them appropriate sometimes.



A number of very telling comments were made both in support of and against the services received in hospitals. These reflect the lack of confidence that a number of people have in hospital services and conversely the very positive experiences of others:

Some of our people are fearful of going to hospital:

- *I will never go to hospital with this. There is not enough education and I do not feel safe with the lack of knowledge in the medical profession with this. I would do anything to not go to hospital with my AI.*
- *It's frightening when the 1st page of your hospital notes is Wikipedia!!! I've had nurses tell me to go home you don't look sick.*

Some have had challenging experiences:

- *I am house-bound dependent on others to help me care for my family and have been turned away from hospital half a dozen times in the past year.*
- *I also was very close to a crisis whilst in hospital where I had gone to emergency and nobody would take note of my request to increase my Hydrocortisone - and was almost 2 days on regular dose - just in time surgery provided the increased dosage - after this, I got a letter from my endocrinologist.*

- *The prior crisis I went to hospital, after my husband administered injection, but they were clue-less, so after resting for 2 hours and still not been seen by a Dr, I walked out and went home.*
- *Family stress over Christmas time. I was taken by ambulance to my nearest hospital who were told of my Addison's but despite repeated requests to see an endocrinologist, my requests were ignored. I ended up a few days later taking myself to hospital where they successfully rehydrated me and gave me adequate Hydrocortisone.*

Some have had wonderful experiences:

- *The 3 times I have had a crisis has been because of a gastric infection. Each time I have had to go to hospital and each time I received excellent treatment.*
- *I experienced nausea and diarrhoea and stomach pain. I took a taxi to the hospital, explained that I suffered from adrenal insufficiency. They immediately put me on a cortisone drip to increase my levels.*

Some have been misdiagnosed:

- *Then I went to hospital for a very bad occurrence of heart palpitations and chest pain. In the hospital apparently they found there was nothing wrong with me, not even asthma.*

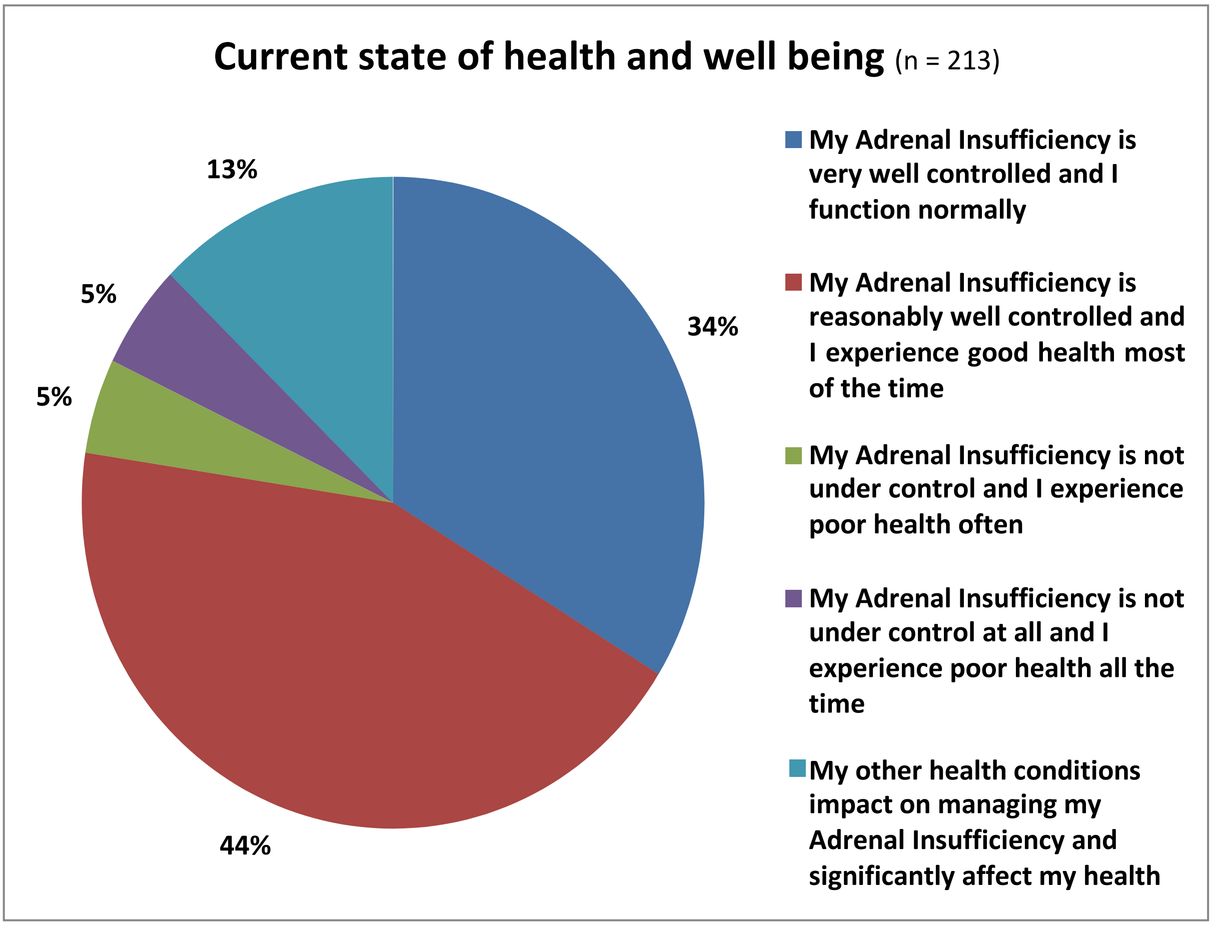
Some have been diagnosed:

- *My husband came home to find me collapsed on the couch. He took me straight to hospital and had to carry me. The doctor first thought I had a suntan but a physician soon diagnosed me with having typical Addison's symptoms.*

14. Our current state of well being

When reflecting on their current state of health people generally indicated that they were doing very well. Thirty-four percent said their adrenal insufficiency is well controlled and they are functioning well; a further 44% said it is reasonably well controlled and that they experience good health most of the time.

For many of us, the fact that we have other conditions has a real impact on our overall health - 13% said that these conditions, along with their adrenal insufficiency were having a significant effect on their health. In addition, 5% experience poor health often and report that their adrenal insufficiency is not well controlled and a further 5% experience poor health all of the time and believe they have out of control adrenal function. This would indicate that at least 23% of our people are dealing with major health issues.



Some of the following comments reflect different experiences about our challenging journeys:

Other Health Conditions

- *I have no immune system so need monthly antibody infusions to try and reduce my number of infections. I have chemotherapy every 6 months to control the RA and Felty's. My body goes into crisis and toward sepsis very quickly. It has required that a permanent* *infusa port be surgically implanted in my arm so that quick access can be done that will not rely on blood pressure to get the steroids into my system fast.*

- *I think I am doing reasonably well with Addison's. I've had it for 4 months only. During that time, I've been back to hospital to have an ileostomy reversal and now I can concentrate on Addison's. Apparently, I am still in state of shock and grief from the cancer diagnosis and Addison's diagnosis. I have concentrated on recovering from the 4 surgeries and at this point I feel well. Occasionally I have days of extreme tiredness (2 days in bed sleeping all day and night). I seem to run out of energy by dinner time but perhaps I am still in the recovery stage from surgery and the cancer. I was quite fit when all this happened, and my Endocrinologist is attributing my excellent recovery to this state. This week I am scheduled for another test to establish if I have started producing any cortisol again. At onset I produced 0% cortisol with no prospect of doing so I was steroid dependent.*
- *Bowel problems including lactose intolerance can trick me I cannot get through the day as well or achieve what I used to be able to as well on the lower dose.*
- *Used to be very stable but High BP and low potassium has de-stabilised it in the past year.*

Not doing OK

- *I am currently depressed, severely fatigued and stress is a major factor of my health.*
- *Just spent 3 weeks in hospital; I do not function on a daily basis. I exist from bed to chair.*
- *Difficult to exercise, can't lose weight, I get tired. Other than that, I work full time & run a business.*

Doing OK

- *I get headaches often due to heat/dehydration. Hard for me to manage in QLD Other than that I have a part time job, a child with special needs and manage family with a bit of exercise. Get tired easily. Not fantastic quality of life but pretty good.*
- *I have good days and not so good days, but the small fibre neuropathy contributes to that I think as it is worsening.*
- *If I pace myself and listen to my body I am able to function normally most of the time, but I must be vigilant in keeping hydrated and resting regularly.*

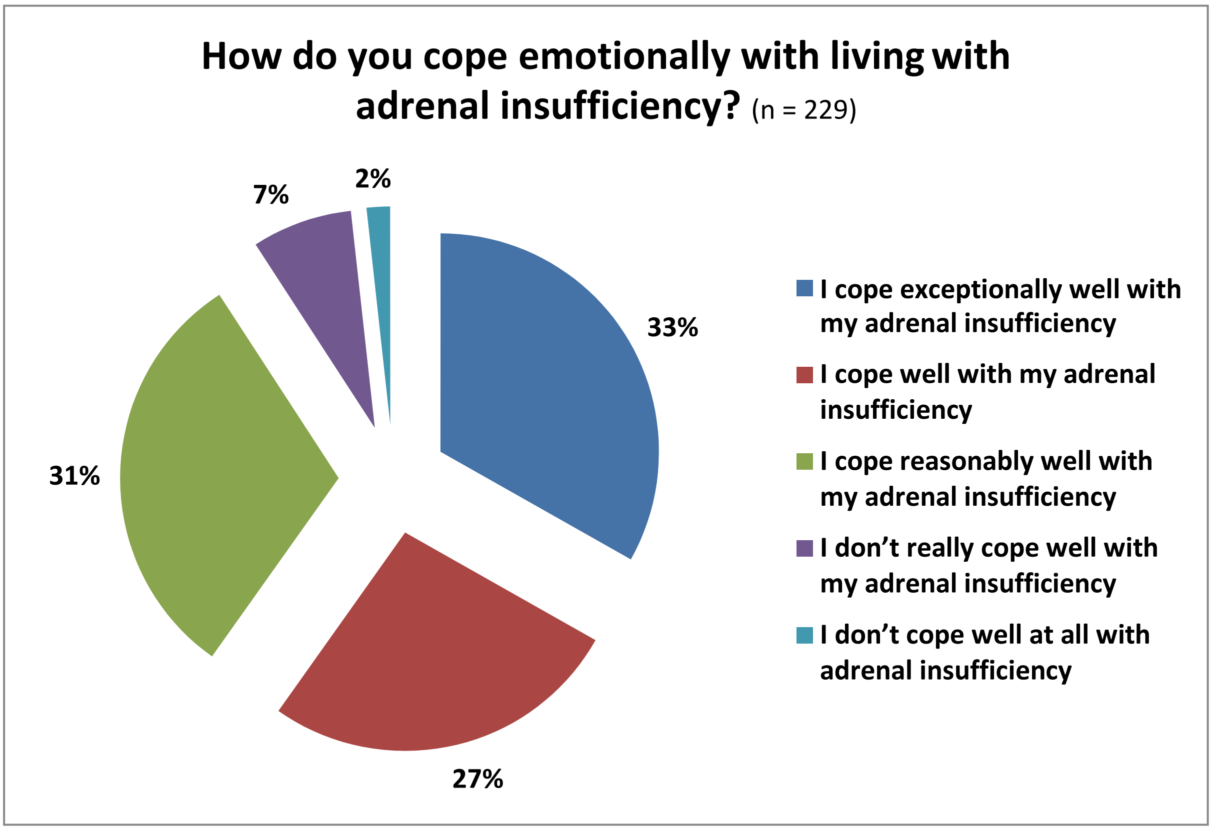
A positive attitude

- *I try to be as 'normal' as possible and there are a lot of my friends who can't believe I have any health problems. My philosophy is get on with it even though some days I could curl up in a corner and stay there all day. Being active and involved in lots of different things helps.*

If you were to just glance at the word cloud below, in some ways it would give you a slightly misrepresented view of the feedback that was given. As mentioned previously, word clouds collect and represent the most popular words within a group of text. In this instance because 77% of our people were reporting positive views about their health and many of the remaining 23% were trying very hard to be positive in their attitudes toward their health, the word cloud does not pick up the challenges that some people living with adrenal insufficiency experience. You have to look hard to find words like ‘sick,’ ‘issues,’ ‘pain,’ ‘crisis’ and ‘bed.’ This does not mean that the word cloud is not valuable analytically: rather it must be seen in context with the question and the intention of the survey.

On the whole though, it is wonderful that 77% of us are well and living quality lives. The frequency of words including: ‘well,’ ‘still,’ life’ and ‘normal’ is a testament to the way in which people are living their lives.

15. How are we coping emotionally?



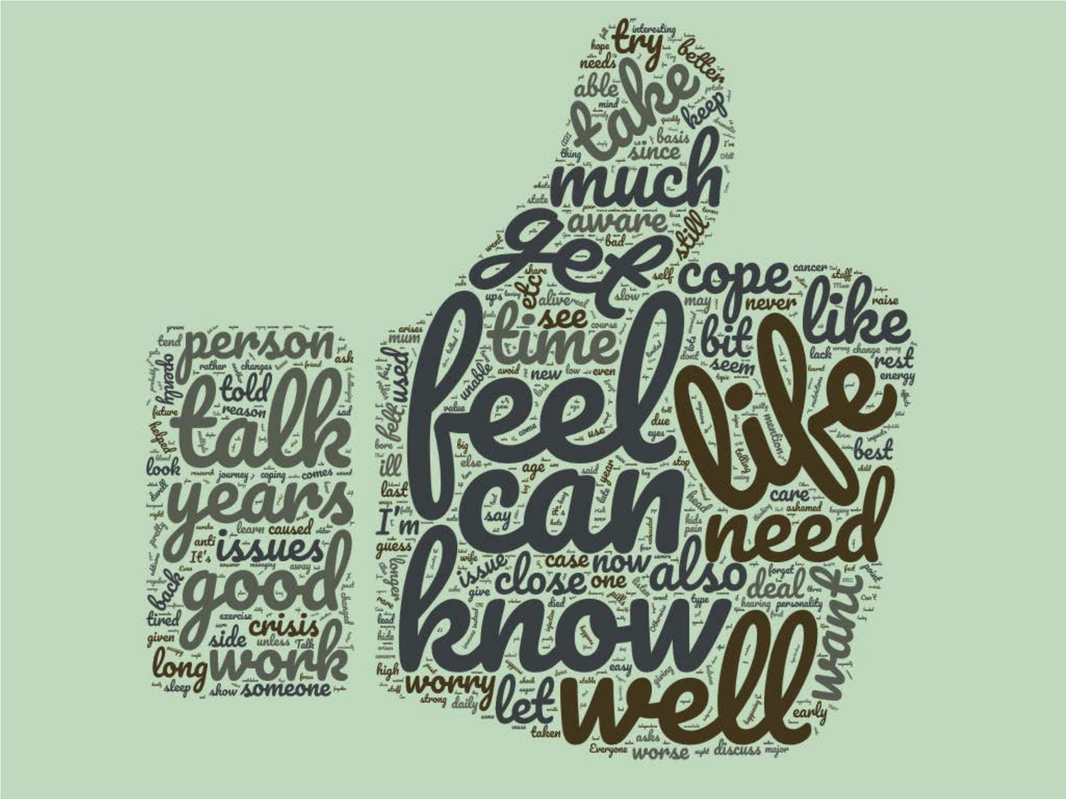
The most rewarding outcome of this survey is learning how well most people feel they are coping with the condition. There can be no doubt that it is a challenging journey. However, this survey shows that over 90% feel they are coping either 'reasonably well' or better. Thirty-three percent are coping 'exceptionally well', 27% are coping 'well' and 31% 'reasonably well'.

Unfortunately, 9% of people indicated they are struggling and a further 2% are not coping at all. For these people we hope that the AADAI can offer a level of support and the opportunity to connect with others and assist them with their journey.

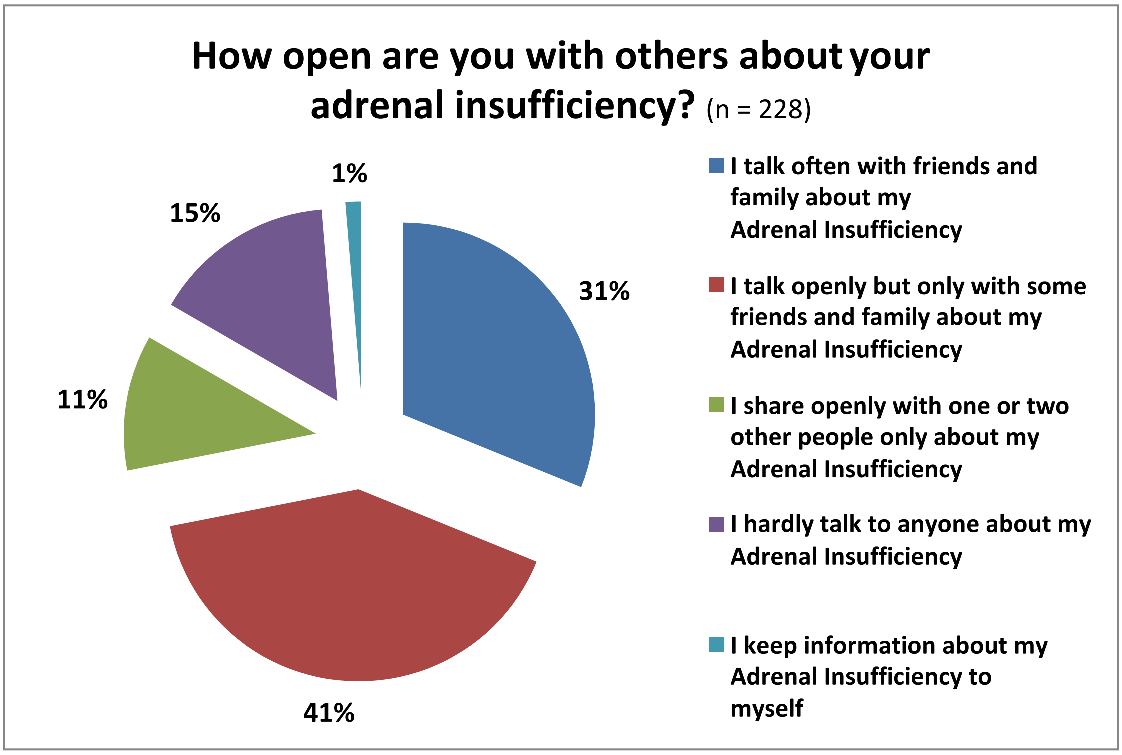
The following extracts seek to illustrate these findings. The responses vary widely and reflect the need for a strong and supportive group of people acting together to increase the knowledge and understanding for all of us.

- *It is not easy to live with Adrenal Insufficiency. People don't understand or support me. They don't want to listen or learn about what I am going through or how I am feeling. People are very judging and disrespectful to how my health is and what I can do on a daily basis. Life is very hard as a young person with adrenal insufficiency because I need full-time care. I am single and won't be able to have children because I am unable to look after myself. People just don't support me, care about me or understand my adrenal Insufficiency.*

- *I have had a year of frightening encounters with doctors. They are unaccountable to their negligence and I feel alone. Scared.*
- *I don't back-down anymore, after a crisis where I had no blood pressure detectable, I take life by the horns and I'm no longer afraid to kick back.*
- *Apart from being a Type A personality, I cope well with being an Addisonian. I do take care of my health generally and I can tell if I need stress day dosing. And so can my wife - the whites of my eyes show all the way around my pupils. I have needed replacement cortisone for so long I can almost read the signs too well. Diabetes 2 is much harder to manage. I get no physical symptoms of a high sugar reading and taking my sugar readings daily feels like a maths exam. I remain happy healthy, working and productive at 69. For someone who might have died at 30 it has been a remarkable journey.*
- *I have had Addison's disease for 60 years and I have been very fortunate to have family that support me and I hope that my experience with the condition for the past 60 years might give encouragement to others that you can live a good life if you look after yourself. I certainly am looking forward to many more years.*
- *The difference your organisation and the Australian Pituitary Foundation has made to my life has been immense. If I hadn't had an epiphany where I went "I need outside help" and then actually sought it out I would be going through this alone because no health care provider ever made that recommendation.*
- *I've enjoyed hearing from others via the Association.*



You need only glance at the word cloud above that has been extracted from our people's comments to see how positively people feel about their health. The 'thumbs up' shape was chosen to reflect this positive attitude. Sure, some of us do it tough, but most want to get on and live life as well as possible.



A range of views were expressed when talking about their condition. While only 1% of people kept information about their condition to themselves, 15% hardly talked with anyone and 11% shared only with one or two people. Conversely 31% talked often with family and friends and a further 41% spoke openly about their condition but only with some friends and family.

Some people might argue that speaking more openly about this condition is important to managing it better. There is evidence within these survey results that demonstrates having someone close to you who knows what is happening is very helpful, for example: *My family understands Addison's, therefore I am not prone to feeling guilty when I need to rest or sit out. It has taken awhile for them to understand. I pace myself and say no when I have to. Not being emotionally available for my grown up family can be distressing, but I have to pick and choose my battles...... Having family backup is very important.* See also Section 12.

Anecdotally, respondents expressed the following reasons for talking/not talking with friends and family about their condition. For ease, these have been grouped into four categories.

I don't feel the need…

- *To me, having Addison's disease is just part of me. It occasionally gets talked about, but I don't feel the need to start conversations about it. I'm more than happy to educate people on it if it's brought up, but honestly, I don't even think about having it.*
- *I don't like to sound too dramatic, (I) just get on and make the best of things.*

I just don’t talk much…

- *It's difficult for people to understand.*
- *Tried in the past, most people think it is all in my mind.*
- *Don’t want to bore people with all my stuff.*
- *I don't see a need to converse about it regularly only if I am feeling not so great. I will let people know.*
- *There is no point. People will not understand what you are going through.*

I only talk with selected people…

- *I really only talk to other Addies.*
- *I talk openly with my family and a couple of close friends. I don't feel everyone needs to hear about my health issues on a regular basis.*

I talk with others very openly

- *I try to raise awareness of this rare disease wherever I can.*
- *I have wonderfully supportive and interested friends*
- *I don't believe that it helps to hide what I am going through.*
- *To help others understand the Disease. I also help at the Medical teaching school in Endocrine as a patient, where the students have to diagnose my condition.*
- *I think sharing experiences helps us see other perspectives and learn more ways of dealing with what life deals us.*
- *I have always been very open with my family. It is only in the last 10 years that I have been more open with friends and work colleagues. It has been good for my emotional well being to be more open. I think in early times I did not share information about my health for fear of being labelled as 'sick'.*
- *I strongly feel that my judgement is compromised when I am not feeling well, meaning that usually my family recognises and addresses the symptoms before me and reminds or asks me if I have to stress-dose. I have educated my husband and kids (now 16 and 19) about AI and we use expired solu-cortef to practice giving injections (into a potato or apple) together. We also travel a lot, sometimes into regions / countries with limited healthcare options, so it is important that as many people as possible (e.g. expedition leaders) know about my condition and what to do should I become sick or get injured.*
- *It is better if friends and family understand and they appreciate knowing how I feel and how I manage my life. My main problem is the juggling with Diabetes and Addison's and keeping them both in balance at the same time.*
- *I have no "hang ups" about having Addison's if it comes up during a conversation. I find people are interested and ask lots of questions.*

Appendix – the survey

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Introduction

Our Association, the Australian Addison's Disease Association Inc (AADAI) is seeking to collect information and stories from people with Addison's disease and other forms of adrenal insufficiency. Your response and those of other members will help us to gain an invaluable understanding of the different experiences of people living with Addison's disease or other forms of adrenal insufficiency. We can use this information in a number of ways including gaining and sharing knowledge and experiences with our members; and, informing doctors, nurses, other health professionals, parents, carers and other interested people about what it is like to live with an adrenal system that is not functioning.

Please be assured that your responses to the survey are completely anonymous. We are not requesting your name or contact details. If you choose not to share your information with us, we fully understand that decision. If you decide to participate, you will find that most questions are multiple choice; just put an X against your selected answer/s. However, there are some questions that require you to insert a few words or a short paragraph or two. If you choose **not** to answer these questions, just write N/A in the box and move on. By completing the survey, you are giving AADAI permission to use all of the information you provide, but you will not be identified.

The survey will take approximately 15 minutes of your time. Please complete the survey and return it to us in the reply-paid envelope by the deadline, November 30 2017.

If you have any questions about the survey, please email us at grahame@addisons.com.au or call Grahame on 0419 148 551. As a member of AADAI who is living with Adrenal Insufficiency, we would love to hear from you!

From all of us on the Executive Committee at AADAI, we wish you well.
Michelle Dalton President.

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1. Please indicate what you feel best describes the type of Adrenal Insufficiency you have been diagnosed with.
    - **a.** Primary Adrenal Insufficiency (Addison's Disease) **Go to Q2 if you selected this**
    - **b.** Secondary Adrenal Insufficiency **Go to Q3 if you selected this**
    - **c.** Both Primary and Secondary Adrenal Insufficiency **Go to Q2 if you selected this**
    - d. Undetermined/unknown
    - **e.** I have not been diagnosed with any type of Adrenal Insufficiency **If you selected this, thank you for your time. Please do not complete the remainder of the Survey and do not return it.**
    - f. Other … please specify – then **go to Q4**.

2. Can you identify the main cause of your Primary Adrenal Insufficiency?
    - a. Auto immune disease
    - b. Surgical

c. Haemorrhage
d. Infection
e. Infarction
f. Tuberculosis
g. Tumour
h. congenital condition/s
i. Unsure/unknown

j. Other … please specify

3. Can you identify the main cause of your Secondary Adrenal Insufficiency? *Skip this question if you have primary adrenal insufficiency (Addison's Disease)*
    a. Steroid use for the treatment of another health condition e.g. asthma
    b. Surgical - non tumour related
    c. Tumour of the pituitary gland
    d. Other tumours
    e. Injury
    f. Unsure/unknown

g. Other … please specify

4. From the initial onset of symptoms, how long did it take for you to receive a diagnosis of Adrenal Insufficiency?
    a. Less than one month
    b. One to six months
    c. Six months to 12 months
    d. One to two years
    e. Two to five years
    f. More than five years

5. How long has it been since your initial diagnosis? Hence how long have you have been receiving treatment for your Adrenal Insufficiency?
    a. Less than one year
    b. One to two years
    c. Two to five years
    d. Five to 10 years
    e. 10 to 30 years
    f. More than 30 years

6. Please indicate which symptom/s were present at the time of your diagnosis? (Select as many answers that apply to you)
    a. Severe fatigue
    b. Weakness
    c. Weight loss
    d. Change in skin pigmentation
    e. Salt craving
    f. Dizziness on standing
    g. Loss of appetite
    h. Nausea

i. Vomiting
j. Diarrhoea
k. Stomach pains
l. Muscle/joint pains
m. Low blood pressure
n. Headache
o. Difficulty concentrating
p. Premature ovarian failure (women)
q. Irregular menstrual periods (in women)
r. Anxiety
s. Depression

t. Other … please specify

7. Were you misdiagnosed with other conditions prior to your diagnosis of Adrenal Insufficiency?
   a. Yes … please specify what these were in the text box below
   b. No
   c. Unsure

If you answered yes, what were they?

8. Briefly describe the circumstances leading to your diagnosis

9. Do you have any other health issues that are related to or have an impact on your Adrenal Insufficiency? (allow for multiple response)
   a. Nil
   b. Underactive thyroid (hypothyroidism or Hashimoto’s thyroiditis)
   c. Overactive thyroid (hyperthyroidism - Graves disease)
   d. Type 1 diabetes
   e. Type 2 diabetes
   f. Hypertension
   g. Anxiety
   h. Depression
   i. Asthma
   j. Vitamin D deficiency

J. Other … please specify

10. My Adrenal Insufficiency is primarily managed by my:
   a. Endocrinologist
   b. GP
   c. Endocrine nurse

d. Other … please specify

11. How often do you visit your Endocrinologist?
    a. Weekly
    b. Monthly
    c. Every 3 months
    d. Every 6 months
    e. Once a year
    f. Once every 2 years
    g. More than every 2 years
    h. Never – I do not have an Endocrinologist (**Go to Question 13)**

12. I feel my Endocrinologist:
    a. Has a good understanding of Adrenal Insufficiency
    b. Has a reasonable understanding of Adrenal Insufficiency
    c. Does not have a good understanding of Adrenal Insufficiency
    d. Has no real understanding at all about Adrenal Insufficiency

e. Other … Can you explain your answer in a few words, please?

13. How often do you visit your GP?
    a. Weekly
    b. Monthly
    c. Every 3 months
    d. Every 6 months
    e. Once a year
    f. Once every 2 years
    g. Longer than 2 years
    h. As often as needed
    i. Never – I do not have a GP. (**Go to Question 15 if you don't have a GP)**

14. I feel my GP:
    a. Has a good understanding of Adrenal Insufficiency
    b. Has a reasonable understanding of Adrenal Insufficiency
    c. Does not have a good understanding of Adrenal Insufficiency
    d. Has no real understanding at all about Adrenal Insufficiency

e. Other … please provide a few lines to explain your answer.

15. With regard to your primary care physician for your Adrenal Insufficiency as identified in Q10, please indicate the level of support you feel they provide you? (Please rate only the primary carer identified in Q10 by placing a cross in each box that applies for that carer only)

Primary Care Physician/ Level of Support	Your Endocrinologist	Your GP	Or Another Provider
Works with me for optimal health and quality of life			
Is receptive to expanding knowledge and working with me			
Does not seem interested in learning more			

Has no idea about Adrenal Insufficiency and so is of little help			
Other please record brief comment at right if appropriate			

16. Briefly describe a positive experience you've had in relation to your condition with one of the medical practitioners that has cared for you.

17. Which medication/s do you use to treat your Adrenal Insufficiency? Please circle all that apply to you.
    a. Hydrocortisone (Hysone, Solu-Cortef)
    b. Cortisone Acetate (Cortate)
    c. Prednisone/Prednisolone (Predsone, Panafcort, Sone, Redipred, Predmix, Predsol, Panafcortelone, Predsolone, Solone)
    d. Dexamethasone (Ozurdex, Maxidex)
    e. Betamethasone (Celestone Chronodose)
    f. Fludrocortisone (Florinef)
    g. Unsure/unknown

h. Other … please specify

18. How do you take your medication?
    a. Orally (take a tablet by mouth)
    b. Administration of liquid steroid delivered by an insulin pump
    c. Administration of liquid steroid via subcutaneous injection

d. Other … please specify

19. How do you split your normal daily steroid replacement dose over the day?
    a. One dose daily
    b. Two doses daily
    c. Three doses daily
    d. Four doses daily
    e. Five doses daily
    f. Six or more doses daily
    g. Continuously (via pump)

20. Do you feel confident to increase your dose when you need to? This question refers to stress or sick day dosing. This means taking extra medication when you are under stress and/or you are ill)
    a. Yes
    b. No
    c. I've never increased my dose on a sick or stress day

21. Can you please indicate how often you increase your dosage above and beyond your normal steroid replacement dose?

   a. Daily
   b. At least once per week
   c. A few times a month
   d. Rarely
   e. Never

If you selected ‘never’ tell us why For example: ‘I do not know when or by how much I should increase my dose.’ Any other reasons?

22. Do you have injectable Solu-Cortef or Dexamethasone for emergencies (liquid steroid plus needles)?
   a. Yes
   b. No
   c. I have requested one but my doctor will not prescribe it

23. When you were diagnosed, did your doctor supply you with information regarding your condition? Circle each option that occurred for you.
   a. stress or sick day dosing
   b. tapering down after you increased your dose
   c. low cortisol and adrenal crisis symptoms
   d. obtaining a medical alert bracelet
   e. emergency hydrocortisone injection, e.g. Solu Cortef (prescribed)

Please provide any relevant comments

24. Do you wear an emergency medical alert bracelet or necklace?
   a. Yes
   b. No
   c. I do not know what a medical alert bracelet or necklace is

25. Do you have an emergency letter that explains your condition from your physician or AADAI?
   a. Yes
   b. No

26. How many times have you experienced an adrenal crisis since your initial diagnosis and commencement of treatment for Adrenal Insufficiency? (Note: Adrenal crisis for this question is a severe low cortisol event that required the use of an emergency injection kit and/or emergency medical assistance)
   a. Less than 5
   b. 5 – 10
   c. 10 – 50
   d. 50 – 100
   e. More than 100
   f. I have never had an adrenal crisis **Go to Q31**

27. How many times have you experienced an adrenal crisis in the last 12 months?
   a. 1 – 5
   b. 6 – 10
   c. 11 or more

d. I have not experienced an adrenal crisis in the last 12 months

28. Do you know what caused a crisis? Describe the most recent time you experienced an adrenal crisis and how that was treated.

29. Do you experience raised blood pressure when you are in early crisis?
    a. Yes and I have a pre-existing hypertension condition
    b. Yes and I do not have a pre-existing hypertension condition
    c. No
    d. Sometimes
    e. Unsure/don't know

30. Reflecting on your past experiences, when you presented with symptoms of an adrenal crisis, did you feel you received treatment by medical staff (ambulance staff, hospital accident & emergency - A&E staff) that was appropriate? Complete tables below:

Ambulance staff	Check one answer here	**A&E Staff**	Check one answer here
Every time		Every time	
Most of the time		Most of the time	
Sometimes		Sometimes	
Never		Never	
Not applicable		Not applicable	

Please tell us more about your answer here

31. Please indicate how you would describe your current state of health and wellbeing in relation to your Adrenal Insufficiency?

    a. My Adrenal Insufficiency is very well controlled, and I function normally
    b. My Adrenal Insufficiency is reasonably well controlled, and I experience good health most of the time
    c. My Adrenal Insufficiency is not under control and I experience poor health often
    d. My Adrenal Insufficiency is not under control at all and I experience poor health all the time
    e. My other health conditions impact on managing my Adrenal Insufficiency and significantly affect my health

Can you tell us why you scored your current state of health in the way you did?

32. On the scale of 1 to 5 below, please indicate how you feel that you cope emotionally as a person living with Adrenal Insufficiency and why? Select one answer only and then tell us more.
    a. Exceptionally well

b. Well
c. Reasonably well
d. Not really well
e. Not well

In the box below write a paragraph or two about your emotional wellbeing

33. On the scale of 1 to 5 below, please indicate how open you are in talking with your friends and family about your condition and why? Select one answer only and then tell us more.

a. Talk often with friends and family
b. Talk openly but only with selected friends and family
c. Share openly but only with one or two other people
d. Hardly talk to anyone about my Adrenal Insufficiency
e. I keep it to myself

Can you tell us why you answered this question that way?

34. Is there anything more that you would like to tell us about your journey with Adrenal Insufficiency? You might tell us positive and/or negative stories.

35. What is your gender?

a. Male
b. Female

36. What is your age?

a. Under 18 years of age
b. 18 – 24 years
c. 25 – 34 years
d. 35 – 44 years
e. 45 – 54 years
f. 55 – 64 years
g. 65 – 74 years
h. 75 years and over

37. Which state do you live in?

a. NSW
b. QLD
c. VIC
d. ACT
e. SA
f. WA
g. NT
h. TAS

38. Do you live in a metropolitan or regional/rural area?

  a. Metropolitan
  b. Regional
  c. Rural

39. Are you currently?
  a. Working full time
  b. Working part time
  c. A student
  d. Out of work and looking for work
  e. Out of work but not currently looking for work
  f. Unable to work due to the symptoms I experience from Adrenal Insufficiency
  g. Unable to work due to the symptoms/disability I experience from other illnesses/conditions
  h. Retired
  i. Other

Thank you for your time. Please mail your survey back in the replied paid envelope provided.

Michelle Dalton, President