

MENTAL, EMOTIONAL, AND
RELATIONSHIP HEALTH
RESULTS OF PITUITARY WORLD NEWS SURVEY
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The Survey

The survey was conducted through the Pituitary World News website by asking for voluntary responses through an online survey platform linked to the PWN news magazine website. All identifying information about respondents is kept confidential. Each respondent was given as much time as they needed to complete the survey. This survey consisted of a single open-ended questions posed to the website visitors as follows:

Many of you have shared your experiences with the emotional and mental health factors affecting pituitary disease. Comments describe anxiety, mood fluctuations, depression, cognitive difficulties, tensions with relationships, short temper, anger, etc. Do you think your pituitary disease has affected you emotionally and/or mentally? How did it affect you? Please write your answer in the space provided below. You may write as much as you like.

Who responded?

A total of 142 responses were received with a 34.3% completion rate. A total of 414 people started the survey with 272 dropping-out before completing the questions. Responses were received from those identified from 8 countries and “unknown”. The largest responses were received from the US, Canada, and the UK totaling 81.4%. Other countries represented included Australia with 6.76%, Ireland with 2.42%, New Zealand with 2.93%, South Africa with .97%, and 1.21% described as unknown.

Mental, Emotional, and Relationship Health

So, what did responders say about their mental health? Many responded with single word descriptors and others wrote paragraphs to describe not only mental health issues but how their lives had been affected negatively and positively by pituitary disease. In analyzing and coding all of the responses a total of 29 categories of mental health symptoms were identified based upon specific descriptive words used by respondents to the questions posed. We coded the exact language as stated by the respondents in an effort to preserve the very personal, subjective experiences of those who chose to respond to the survey. Many people reported specifically that the mental health issues or symptoms they described had begun only after the discovery of their tumor, however, many also said they had medical treatment(s) and their symptoms either began following this or even got worse.

The largest number of “symptoms” described anxiety and mood concerns that included various forms of anxiety, depression, and mood fluctuations. Various descriptions were used to describe anxiety which topped the list for all those mentioned. Several people wrote about thinking mildly to seriously about suicide. Respondents described severe trouble with sleep and not ever being able to feel relaxed. A few stated that medications prescribed by their endocrinologist did seem to help these symptoms.

Several people described not feeling “normal”, and not even sure what this was anymore. They talked about how difficult it was for them to think clearly as it was before the tumor. Others described a “foggy” brain with difficulty finding the right words sometimes or even “like I’m trapped in my own head”. Some stated that they were in the process of trying to find a new normal state for

themselves. Forgetfulness was described as something quite irritating and more than an occasional lapse of memory.

An overwhelming sense of how difficult it is to obtain a proper diagnosis and then to get treatment was written about by several in this survey. “The availability of helpful, understanding, relevant therapies for this particular kind of stressor is really difficult to find”, describes the frustration in getting not only medical but mental health support. One person put it this way, “The years it took to be diagnosed made me think I was imagining or exaggerating my symptoms, the initial dismissal of my pain from doctors was confusing and belittling...”.

Anger, irritation, shortness of temper was described by several respondents. This also appears to have influenced many personal relationships including marriages as well as in their employment settings. Sometimes underlying reasons for anger were extensively described as due to delayed, poor, and/or improper medical treatment or the side-effects from medical interventions that apparently were not helpful. One woman described her anger as, “more decisive and brusque. It's hard to know how much of it is chemical, attitudinal, or situational.” Sometimes anger was expressed toward insurance limitations and lack of coverage for treatment. One person described the frustration of early-on going to emergency rooms only to have the mental/emotional symptoms dismissed as related at all to a potential physical illness.

The direct and indirect effects in their relationships was frequently described. One man wrote about his wife finally leaving him and his child, “watching his loving dad turn into a scary stranger.” A woman wrote, “I feel stupid in the

eyes of my young children.” Another woman stated that she realized the “profound impact” her illness has on her husband. “I get so tired of people asking me how I am doing and why I say I am 'fine' “, described the difficulty in connecting with people who may try but just do not understand. Several expressed fears that they have let their family down since becoming ill. Others said they have just isolated themselves since this seems easier, but feel lonely as a result.

The survey did not specifically ask for commentary pertaining to patients’ physical symptoms but some did offer comments about this as well. Probably the number one complaint was feeling tired, exhausted etc. In reading respondents’ descriptions, the fatigue seemed as physical as mental/emotional in nature. This points to an example that the mind and the body just can’t be separated since they both influence the other positively and negatively. Weight gain was another issue frequently mentioned. A woman wrote, “My weight gain and inability to lose weight even after my second surgery has caused much pain in my mental well-being.”

A few people offered that psychotropic medications have been helpful for the depression and/or anxiety they’ve experienced. Others report that the hormone replacements they’ve been prescribed have helped the mental/emotional symptoms.

In addition to the multitude of negatives they felt respondents did offer positives. Several commented on the helpfulness from their physicians. Others mentioned the positive support from social media. One woman expressed gratitude to internet connections she’s made, “Sometimes it's great to know

you're not the only going through this and others understand without you having to or trying to explain. My suggestion is do your research and get connected with a great support community.” Some wrote about their gratitude for family, friends, and yes some even said their pituitary disease was something to be grateful about! Sometimes specific people in their lives were acknowledged, such as, “Thankfully my husband is really supportive...if it wasn't for him I don't know where I'd be.” One person even thanked Pituitary World News, “Thank you for asking about this side of the disease. I feel like it is not addressed as much as needed.” And someone else said, “Finally a survey to capture the reality of anxious, depressed, confused patients!” Another wrote, “Mostly I feel normal, free, strong, and like I've been given a second chance.” And finally, “I have learned that this is just a condition that can be controlled with medication and not something that controls me.”

The following tables show responses to the survey

Table 1 - Response distribution

C O U N T R I E S	R E S P O N S E S
US	60.63%
United Kingdom	11.35%
Canada	9.42%
Australia	6.76%
Ireland	2.42%
New Zealand	1.93%
South Africa	0.97%
Unknown/other	1.93%

Table 2 - Mental Health SX

MENTAL HEALTH SX	N = 189	% OF TOTAL
Anxiety/panic	23	12%
Depression	18	10%
Relationship difficulties	16	8%
Mood fluctuation	15	8%
Anger/rage/'short temper'	14	7%
Memory impairment	11	6%
Isolation/agoraphobia	10	5%
Low or no sex drive	9	5%
"I'm not the same person"	9	5%
Cognitive changes	7	4%
Poor concentration/focus	6	3%
Low self-esteem	6	3%
How to explain to others	6	3%
Suicidality	5	3%
Lack of enthusiasm/apathy	5	3%
Poor body image	4	2%
Neg effect on job	4	2%
Daily struggle	4	2%
Poor quality of life	3	2%
Loneliness	3	2%
Agitation	3	2%
Not know where to get help	2	1%
Personality change	1	1%

MENTAL HEALTH SX	N = 189	% OF TOTAL
Paranoia	1	1%
Mania	1	1%
Confusion	1	1%
Cannot cope with stress	1	1%
Brain fog	1	1%

Table 3 - Positive comments regarding medical care received

POSITIVES	N = 18
Loving life again	3
No mental emotional sx	2
Faith	2
I'm taking back my life	2
Resolution of most symptoms	1
Feeling good again. Grateful for ...(person in life	1
Understanding husband. Learned therapy to cope	1
How far I've come in 5 years	1
Grateful for doctors	1

Table 4 - Physical symptoms reported

PHYSICAL SX	N = 38
Fatigue	13
Headache	6
Weakness	3

PHYSICAL S X	N = 38
Insomnia	3
Chronic pain	2
Joint pain	2
Vertigo	1
Weight gain	1
Infertility	1
Physical changes	1
Poor balance	1
Amenorrhea	1
Stretch marks	1
Hair loss	1
Muscle loss	1

Table 5 - Negatives

NEGATIVE EXPERIENCE WITH PHYSICIANS	N = 18
Not willing to listen	7
No referral help	2
Frustrated with doctor	2
Little or no communication	2
Hard to explain to doctor	1
Doctor is confused (with me)	1
Not treat the emotional sickness	1
Told not to seek support group help	1
Feel betrayed by doctors	1

So, what does this all mean?

The primary theme resulting from this survey is that disorders of the pituitary gland are, indeed, often accompanied by a multitude and variety of mental health issues which cause significant distress and lowered quality of life. In addition, the mental health aspects of pituitary illness often are overlooked or untreated even in today's world. The question then becomes how does this inform patients as well as professionals charged with trying to help them?

Therapeutic treatment of hormone disorders is unique, in that it necessitates treatment that involves physical, psychological, and ultimately a systemic perspective (Banker, Valeras, & Rio, 2014). A system's viewpoint takes into consideration the entirety of a person's life including their physical and mental health, socioeconomic factors, relationships and more. What the results of this survey mean to us at Pituitary World News is that information such as this needs to be shared with patients and family members but also physicians, nurses, psychologists, marriage and family therapists, social workers and others who may spot behavioral or psychological changes that could lead to earlier diagnosis and treatment. It is also important for patients and family members as well as professionals to understand the important interplay the pituitary has with a person's mental health and to obtain specialized treatment for all aspects that are affected by a tumor on the pituitary gland.

It is impossible to report on the enormity and extent and impact in reading all the responses that were given. The tables submitted here do not do justice to

the extremely personal and emotional descriptors that were provided. When we initially decided to pose this survey, we were not sure what to expect. The responses have been overwhelming in number, but more importantly highly emotional to read. Once we saw how freely patients were willing to describe their symptoms, their lives it seemed like such a compelling project to attempt to succinctly summarize such pain, desperation...and sometimes hope. Our intention is to use the information gathered in this survey to spurn enthusiasm for continued study and research into the mental and medical aspects of pituitary illnesses. We need to know more and more need to know about this. This paper has in no way done justice to all of that those who responded gave to us but because of the words sent through this survey we will continue to try to educate and inform as best as we can. We are most grateful to all those who submitted to this survey.

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