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Members experiences of the Pituitary Foundation.

Underwood, A

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pituitary Life

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CONNECTED, SUPPORTED, INFORMED: EXPERIENCES & BENEFITS OF MEMBERSHIP OF THE PITUITARY FOUNDATION

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A while ago we asked members of the Pituitary Foundation to talk to one of the students from the University of Plymouth (Anneliese Underwood) about their experiences of being a member of the Foundation. We were particularly interested in gaining some insight into how the various services offered by the Foundation help individuals with a pituitary condition to manage their condition. Ten people (four male and six female, aged from 37 to 72 years) talked to Anneliese about their experiences. The interviews were recorded and then transcribed before being analysed using a qualitative method known as inductive thematic analysis (Braun & Clarke, 2006). Transcripts were scrutinized to identify themes associated with having a pituitary condition and having contact with the Pituitary Foundation.

We found four main themes, all of which had specific issues associated with them which we have labelled as sub-themes. The themes and their associated sub-themes are shown in Table 1. In both the report we have made to the Foundation and our summary of results here, we describe the themes in the order shown in the table. Our starting point in theme 1 is the importance of the support as it is experienced by these members of the Pituitary Foundation. We then go on to consider how they found out about the Foundation (theme 2), before moving on to exploring their experiences of the local support groups (theme 3). In our report to the Foundation we finish by reporting on the issues that this group of people wanted support with (theme 4), but in this article we want to focus on themes 1 to 3, i.e. our participants' experiences of being members of the Foundation. This is a very descriptive analysis, and to that end we have used the voices of our participants in the form of anonymised quotes to illustrate the themes and issues we have identified in the data.

Table 1: Table of Themes

Theme	Sub-theme
1. The Foundation as a source of support	a) Condition management b) Reducing isolation
2. Access to the Foundation	Publicity
3. Attendance at support groups	Geographical location
4. Life changing diagnosis	a) Mental health impact of diagnosis b) Difficulties with condition management

Theme One: The Foundation as a source of support

Our study participants found the Foundation to be very beneficial for them especially in helping them to live with their pituitary condition. There were two aspects to this: a) support with various aspects of condition management, and b) reducing isolation, i.e. reducing the sense of being the only person struggling to live with the condition.

Sub-theme a) Condition management:

All participants found the help provided by the Foundation to be invaluable, particularly in the provision of information, support and professionals who understand the pituitary conditions patients have:

“I don’t think I would be alive without the Pituitary Foundation”

“I certainly came away feeling very impressed with the organisation... the leaflets about my condition and the endocrine support nurse and the support groups, those are probably the three things that have helped me”

All the participants described how the Foundation has been a great source of information about their diagnosis and condition, as well as lifestyle management:

“...the Pituitary Foundation have really opened my eyes on how to look after myself... I was wandering around without extra pills and I was going without a cortisone injection...so if I had of collapsed that would have been it”

“Oh it helps me understand the condition, understand what to do about it, understand the effects of the medication...it helps me to find the specialist medics that I should see...It helps me feel not alone and having the nurse at the end of the support it just so reassuring...”

Sub-theme b) Reducing isolation:

Participants felt that support groups not only helped them gain reassurance, they created a space which helped them achieve a shared understanding as individuals disclosed their mutual experiences of living with a pituitary condition.

“You’re talking to somebody who knows what you mean,... You do not have to start from scratch... can pick up handy tips...”

“So I think...giving me the confidence that I could actually get involved...there are other benefits as I have actually quite a few friends through it as well...”

Theme two: Access to the Foundation

Many participants described how they initially found finding information about the Foundation quite challenging:

“The Pituitary Foundation I didn’t know about initially, the endocrine team didn’t tell me about it ...I think that they have got their act together and I am pretty sure that the Pituitary Foundation have got their act together and its far more professional”

So the general experience was one of more accidental discovery of the existence of the Foundation, and an important element of this was associated with publicity.

Sub-theme: Publicity

Individuals need to be given information regarding the Foundation as soon as possible after their diagnosis, but the general experiences related by our study participants tend to suggest that this is not happening. It seems so straightforward; medical professionals just need to

signpost newly diagnosed individuals to the Foundation, and it definitely happens in some areas:

“people now get referred to a support group but they’re also given the information about the Pituitary Foundation...the endocrine nurse and the consultants can hand out a piece of paper which says that this is the Pituitary Foundation, this is the local support group”

The participants were aware that the Foundation has been working hard to ensure a better referral pathway from hospitals, but there was recognition that it is an uphill struggle to get medical professionals and medical services on board:

“I know that they have tried to contact more of the local hospitals so it would be about spreading the word by having different information points in hospital”

“The key issues I think is persuading endocrinology and neurology departments to actually publicise their existence...I think there is an education problem there with the people that have direct interface with those with pituitary conditions, seemingly not being terribly aware or not being terribly interested...”

Theme three: Attendance at support groups

Local groups are one way in which the Foundation provides support to patients with pituitary conditions. It was clear from the conversations with our study participants that there are key features that make local groups a success such as having a regular membership attending the sessions. Leadership was similarly key for success both in terms of attracting members to the group, but also in terms of managing group cohesion part of which was sharing similar values and interests.

“I think the only negative thing is getting folk to come to meetings um but that’s not so much a problem now with a group leader”

Sub-theme: Geographical location

It was clear that the local support groups are highly valued, and travelling for some participants is a sacrifice worth making:

“I have travelled from Cheltenham to Bristol to the meeting so that will give you some idea of how important it is...”

However, not being able to attend a local support group can be ameliorated by members using other aspects of support provided by the Foundation, such as the information provided on the website. This highlights how the online resources of the Foundation also help to keep members connected:

“I do get copies of their newsletter emailed and it does help to know that some of the problems that I have...that other people with similar conditions are feeling the same way. So just knowing that is helpful...”

In conclusion, the participants who took part in this study clearly value the Pituitary Foundation as a vital source of support and information when trying to make sense of their pituitary condition. That the organisation provides long-term support, not just immediately

after diagnosis, but through the patient journey, matters to patients. However, it is clear that there are difficulties with patients learning about the Foundation and the services it offers. This may, in part, explain why so many people with pituitary conditions throughout the UK are still not members of the Foundation. It is clear that greater publicity is required, along with enhanced referral pathways with health professionals working in the field.

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