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# Connected, Supported, Informed: Experiences & Benefits Of Membership Of The Pituitary Foundation



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## Abstract

**Background:** Pituitary conditions have been found to have a wider impact on quality of life (Osbourne et al, 2006). As such it is important that patients receive access to support services to ensure their ongoing physical and psychological needs are met. The aim of the study was to explore the experiences of patients with pituitary conditions who are members of the Pituitary Foundation to better understand how the Foundation supports their needs.

**Methods:** A series of qualitative interviews were conducted with 10 (four male and six female, aged from 37 to 72 years) self-selecting members of the Pituitary Foundation about their conditions, their needs and their experiences with the Pituitary Foundation. Data were analysed using thematic analysis. Secondary thematic analysis was conducted on a wider sample of 935 members of the Pituitary Foundation.

**Results:** The main theme addressed the life changing nature of a pituitary diagnosis. Subsequent themes relating to the Pituitary Foundation identified the Foundation as a source of support, highlighted issues in accessing the Foundation and problems associated with attending support groups.

**Conclusions:** Participants clearly valued the Pituitary Foundation as a vital source of support and information when trying to make sense of their pituitary condition. Better training is required for health professionals about pituitary conditions and their long term consequences, and the need to signpost patients to wider services at the point of diagnosis.

## Objectives

Many pituitary conditions require life-long monitoring and management as it impacts on many areas of day-to-day functioning.<sup>1</sup> This management is notoriously difficult and patients often experience high levels of distress which are rarely addressed by health professionals.<sup>2</sup> As a result, pituitary conditions have been found to have a large negative impact on quality of life.<sup>2</sup>

Part of the difficulty in understanding the effect pituitary conditions can have on patients is the lack of research looking at the needs of patients with pituitary conditions and how they manage their care.<sup>3</sup> Further research is needed to understand the psychosocial needs of patients with pituitary conditions, including how support groups like the Pituitary Foundation function in supporting them with their condition.

## Aim:

The aim of the study was to explore the experiences of patients with pituitary conditions who are members of the Pituitary Foundation to better understand how the Foundation supports their needs.

## Results

*"There were dark days when I first was diagnosed with Cushing's really dark days; in fact I didn't think I was going to make it".*

### Theme 1: Life changing diagnosis

### Theme 3: Access to the Pituitary Foundation

*"The PF 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"*

### Theme 2: Pituitary Foundation as a source of support

*"I don't think I would be alive without the Pituitary Foundation"*

*"You're talking to somebody who knows what you mean,... You do not have to start from scratch... can pick up handy tips..."*

### Theme 4: Attendance at support groups

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

## Methods

**Participants:** The first part of the study was conducted with 10 participants (4 male, 6 female) who were all members of the Pituitary Foundation. Participants were aged 37 to 72 years of age.

The second part of the study consisted of a sample of 935 members of the Pituitary Foundation (634 females and 301 males) with an age range of under 18 years to over 65 years of age.

**Design & Procedure:** The interviewer in the first part of the study conducted semi-structured qualitative interviews with the participants over the phone. Questions were designed to elucidate information about how participants viewed their condition and the role the Pituitary Foundation had in supporting them.

The second part of the study employed a questionnaire that participants completed online via survey monkey or using pen and paper.

**Analysis:** Data from the interviews were analysed using thematic analysis. A further confirmatory thematic analysis was then conducted on the free-text sections of the questionnaire responses.

Analysis of the interviews highlighted a main theme of the life changing nature of a pituitary condition. This was associated with 2 sub-themes; a) difficulties with condition management and b) mental health difficulties following diagnosis. This theme was also highlighted in the questionnaire data with over 40 participants specifically identifying the difficulties with condition management and a further 116 discussing mental health difficulties following diagnosis.

The remaining themes related to the Pituitary Foundation as a source of support (Theme 2), highlighted issues in accessing the Foundation (Theme 3), and problems associated with attending support groups such as geographical location (Theme 4). These were also identified in the questionnaire data.

## Conclusions

Participants clearly valued the Pituitary Foundation as a vital source of support and information when trying to make sense of their pituitary condition.

Better training is required for health professionals about pituitary conditions and their long term consequences, and the need to signpost patients to wider services at the point of diagnosis.

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