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Pituitary Disease and Occupational Therapy

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Brief (Personal Perspective)

«I would like to introduce myself. My name is Sammy Harbut, I am a Pituitary patient and Occupational Therapist.

A little history

I was diagnosed with Cushing’s disease in 2010, and at that point I had been ill for several years, and my quality of life was considerably compromised. Cushing’s disease results from the over production of cortisol as a result of a pituitary adenoma [as opposed to Cushing’s syndrome which is caused by a direct problem with the adrenal gland(s)]. As it is the pituitary gland which produces adrenocorticotropic stimulating hormone (ACTH) which prompts the adrenal glands to produce the correct amount of cortisol, a tumor can cause ‘faulty’ messages to be sent to the adrenals, instructing them to produce excessive amounts of the hormone [1]. The physical effects of this are considerable, but as an illness Cushing’s remains relatively difficult to diagnose. Consequently whilst I displayed most of the physical and emotional symptoms, including weight gain, poor skin integrity, edema and severe bruising to my lower limbs, proximal weakness, poor sleep, classic ‘buffalo hump’ and moon face, mood swings excessive thirst, visual disturbances, loss of periods etc., my symptoms went undiagnosed for several years.

Upon diagnosis, I was fortunate enough to be given a leaflet about the Pituitary Foundation during my first hospital stay, but received no further advice or support about my recent diagnosis, how to manage the emotional impact of my illness, or how it would affect me and my family. I was desperate for more information, but my consultant concentrated purely on the medical aspect of my illness, the surgery I needed and medication I would have to take subsequently.

I contacted the Pituitary Foundation, and requested several booklets to help me make sense of what was happening. I felt so much more informed about the medical aspects of Cushing’s, what to expect from surgery, and the potential life I

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could lead subsequently, and was grateful for the support.

Fortunately the transphenoidal surgery to remove my rather large adenoma (14mm) at the Wessex Neurological Centre at Southampton Hospital in October 2010 was successful, and I began the slow road to recovery. During my time recovering after surgery, I had several setbacks, and became increasingly aware of experiencing tiredness I had never felt before. I also became aware of having days when I felt ‘unwell’, but found it difficult to explain and verbalize how I felt. Additionally, my moods and emotions were unpredictable, which I found difficult to manage at times. I was struggling to comprehend what had happened, felt I should have been constantly smiling because the tumor had gone, yet was concerned for the future. My endocrinologist initially hoped that I would not require hormone replacement therapy (hydrocortisone) indefinitely, but after two years it became clear that my body no longer produces natural cortisol, and I accepted the decision that I will be steroid dependent for life.

However, I did have days when I felt I could achieve anything, and it was during these times that I began to think about my professional career, which I had become increasingly disillusioned with. Using the bravery I had employed to endure the intrusive medical procedures, I believed that I if I could go through transphenoidal surgery, I can do anything! I returned to work as a Probation Officer, but could only manage 2 days a week, finding that I was emotional and exhausted most of the time. Furthermore, I endured considerable lack of tolerance from managers, together with their unwillingness to understand or appreciate how pituitary conditions change lives. During this time however I took the decision to become a Helpline volunteer for the Pituitary Foundation, as I felt they ‘understood’ my frustrations and difficulties, but also my desire to make the most of my life, participating in things which are important to me, and achieving things.

Pituitary conditions

Pituitary disorders are considered rare. It was last estimated that there are between 50,000 and 70,000 pituitary patients in the United Kingdom, which equates to 0.08% - 0.11% of the population.

The most common problem with the pituitary gland occurs when a benign tumor (used to describe a ‘growth’) also called an adenoma, develops. Pituitary adenomas are not 'brain tumors’. The term benign is used by doctors to describe a swelling which is not cancerous.

Some pituitary adenomas can exist for years without causing symptoms and some will never produce symptoms. Most occur in people with no family history of pituitary problems and the condition is not usually passed on from generation to generation. [Only very occasionally are tumors inherited - for example, in a condition known as multiple endocrine neoplasia (MEN1)] [2].

By far the most common type of adenoma (about half of all cases) is a ‘non-functioning’ one. This is a tumor which does not produce any hormones itself. However, it can cause headaches and visual problems or it can press on the pituitary gland, causing it to stop producing the required amount of one or more of the pituitary hormones. This effect can also happen by the treatment given for a tumour, such as surgery or radiotherapy. Alternatively, a pituitary adenoma may begin to generate too much of one or more hormones. Many patients with a pituitary disorder will require life-long drug treatment and monitoring and their condition will potentially impact on many aspects of their life. The most common pituitary disorders are: Acromegaly, Adult Growth Hormone Deficiency, Craniopharyngioma, Cushing's Disease, Diabetes Insipidus, Hypopituitarism, Non-functioning tumors and Prolactinoma [2].

Each of these conditions have many different symptoms, and are often difficult to diagnose. However, common difficulties experienced by pituitary patients include fatigue, depression, and reduced stamina, and forgetfulness, loss of confidence, memory problems, employment/work problems, pain/discomfort and reduced quality of life.

Many patients (like myself) require surgery and/or radiotherapy treatment, followed by a lifetime of living with a long-term health condition and often daily steroid and other medication. The life of a pituitary patient is not always an easy one, and each patient is completely unique. Even those with the same diagnosis will require different treatment regimes, and will experience different symptoms on their pituitary journey.

Pituitary patients and Occupational Therapy

Professionally, I decided to begin another degree, training as an Occupational Therapist (OT), graduating with a First Class BSci degree in 2015. I was attracted to this profession, as the idea that ‘occupations’ (or more commonly known as activities) which we all engage in and are important for maintaining health and wellbeing struck a chord with me, following my illness and treatment.

Occupational therapists work with adults and children of all ages with a wide range of conditions; most commonly those who have difficulties due to a mental health illness, physical or learning disabilities. They can work in a variety of settings including health organizations, social care services, housing, education, re-employment schemes, occupational health, prisons, and voluntary organizations or as independent practitioners [3].

As I progressed through my course, I was struck by how the medical profession approaches illness, sometimes with little consideration about how a person’s life is affected, physically and mentally, and how this impacts further on them and their families. I continued to work as a Helpline volunteer, and experience taking calls demonstrated how lives for pituitary patients are challenging and frustrating, and how our quality of life can be reduced by the restraints our conditions impose.

Occupational therapy aims to address such issues by taking a whole-person approach to both mental and physical health and wellbeing, enabling individuals to achieve their full potential [4]. Advice and guidance is given for Occupational Therapists working with individuals who have long-term health conditions, assisting people to achieve life satisfaction by improving their ability to undertake activities that are important to them. Helpline calls consistently demonstrate that pituitary patients are affected significantly by their conditions, (some more seriously than others), but there is currently no Occupational Therapy input from within Endocrinology departments, to advise and support people who struggle to engage in activities which are important to them.

We all need purpose and meaning in our lives, and if these are compromised due to long term health issues, quality of life, motivation to learn, achieve and engage in the world is lost. As fatigue is a problem for the majority of pituitary patients, they become more withdrawn from others, are prevented from undertaking activities once enjoyed and often have to stop work. Concentration and memory is often adversely affected, particularly following surgery and radiotherapy treatment. Patients who have professional careers can find themselves unable to recall information, make decisions due to what they describe as ‘brain fog’ and experience mental fatigue previously unknown to them. As a result they have little option but to leave jobs they once enjoyed, and determine a ‘new’ future as an individual with compromised functioning, and which may uncertain health wise. Anxiety, depression and a sense of hopelessness can result, but this may not be addressed, as currently emphasis is placed on stabilizing patients’ medical conditions and ensuring correct replacement of essential hormones.

Occupational Therapists play a critical role in helping people of all ages to overcome the effects of disability caused by illness, ageing or accident, and as skilled professionals find solutions to everyday problems by considering physical, psychological, social and environmental needs. By adopting a holistic view, and understanding the relationship between physical and mental health, Occupational Therapists are ideally placed to support individuals identify goals, maintain skills and learn new ones, all of which provide a sense of purpose and belonging in the world [5].

When working with individuals who have long term health conditions, Occupational Therapists can enable clients to function at an optimal level despite impairments, consider how clients feel about themselves and their ability to tackle problems, and how their physical and social environment can be altered so that restrictions are reduced [4]. Learning how to manage their new life, come to terms with a complicated drug regime and address fatigue are common difficulties faced by Pituitary patients, as well as coming to terms with the challenge of invasive medical procedures, all of which Occupational Therapists can support. This may involve educating about fatigue management, compromised concentration or memory problems, advising about sleep patterns, considering how medication regimes impact on daily functioning, or offering support to overcome mental health issues [6],[7].

Employed by the Pituitary Foundation, I now use my skills and experience to assist patients and their families who call our Helpline and on my visits to Local Support Groups, providing advice on how to restore a healthy balance to lives, fatigue management strategies, and how to help overcome anxiety about the future. I delivered a presentation about fatigue management skills at the Pituitary Foundation’s National Conference in April, 2016 which was well received, and I am currently writing the first Fatigue Management Booklet, which will be available to patients from July, 2016.

I am passionate about my work within the Pituitary Foundation, and equally as passionate about my role as an Occupational Therapist, appreciating the many areas of patients' lives that my profession can positively affect. Furthermore, as pituitary patient myself, I value Occupational Therapy, and know from personal experience that it is effective as a treatment option».

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