

LIVING WITH CHRONIC HYPOPARATHYROIDISM

HYPOPARATHYROIDISM



Initiated and funded by Shire.

Shire paid for the writing services of MHP Communications with full editorial control resting with Shire for the development of this report. Shire is grateful to Hypopara UK for its role in developing and disseminating the survey and for providing valuable insights and case studies from patients it works with for inclusion within this report. Hypopara UK received no payment from Shire.

Date of preparation: November 2017 | Job number: C-ANPROM/UK//0397

CONTENTS

Executive summary	3
Methodology	5
Introduction to chronic hypoparathyroidism	6
The impact of hypoparathyroidism	7
How hypoparathyroidism is managed in the UK	9
Analysis: living with severe hypoparathyroidism	11
Focus on hypoparathyroidism in England	13
The full picture of hypoparathyroidism	14
About Shire	16
About Hypopara UK	16

EXECUTIVE SUMMARY

Chronic hypoparathyroidism (hypopara) is a rare and debilitating condition in some patients, which has no cure. Hypopara leads to low blood calcium levels, which can cause a wide array of symptoms ranging from muscle spasms to memory loss.

In early 2017, Shire conducted a survey of 230 chronic hypopara patients in the UK. This survey was carried out in collaboration with Hypopara UK, a patient support charity dedicated to supporting and providing a voice for patients in the UK.

This report sets out the survey findings: from the impact the condition has on their ability to lead a normal life — to work, drive and socialise — to the frequency with which their condition causes them to make an unplanned stay in hospital, or a trip to Accident and Emergency (A&E).

11%

For a rare condition which is often caused by accidental damage during neck surgery, specialist care and support is vital. Just 11% of patients are regularly seeing an endocrinologist who specialises in hypopara or calcium deficiency.¹

2/3

Nearly two thirds of patients feel that the care they currently receive could be improved, and 40% feel that their chronic condition is worsening.¹

71%

71% of patients find that their chronic hypopara has an impact on their ability to maintain full or part-time employment, and 76% of patients find that their condition has an impact on their ability to interact with their friends and family.¹

22%

22% of patients had to make an unplanned hospital visit at least once a year. For those whose hypopara caused them to stay in hospital, 50% of patients reported a typical stay of three days or more.¹

2X

Patients with severe chronic hypopara are twice as likely to make unplanned visits to A&E than those whose condition is mild or moderate.¹

This report offers a rare insight into the common challenges which this relatively small group of patients face, identifying significant gaps in the services and support currently available to them.

SARAH

Sarah, a 24-year old student, first realised something was wrong when her face felt numb, her vision began to blur, and she began to lack focus and memory.

Although she had made visits to A&E for years due to these symptoms, which also included mood swings and anxiety, Sarah had never had her calcium levels tested before. It was only after 10 years of hospital visits that Sarah received the full round of blood tests that revealed very low calcium levels (hypocalcaemia). This led to immediate hospital admission and eventual diagnosis on the advice of a specialist.

“This disorder has had a drastic impact on my ability to finish my final year, as the memory, concentration and lethargy problems are affecting my ability to study and the anxiety problems are making it hard to complete the stressful practicals.”

Along with the impact on her studies, Sarah has also experienced heart palpitations as part of her hypopara, meaning she is sometimes prevented from every day activities such as driving.

“I think calcium levels should be one of the standard blood tests for GPs, as it would make it easier in detecting this disease. I would have found my condition years ago if this was the case.”

Within weeks of being diagnosed, Sarah has been able to manage her condition so that some of her symptoms have improved, although memory and concentration issues still remain.



CASE STUDY



**TOTAL NUMBER OF
PATIENT RESPONDENTS**

METHODOLOGY

This report is based on the findings of an online survey conducted between March and April 2017. The survey was shared with respondents by Hypopara UK, a patient organisation for adults and children living with a parathyroid condition in the UK and Ireland. Two hundred and thirty patients responded to the survey. Respondents had the option to skip any question as they took the survey, and therefore not all questions were answered by all respondents.

Respondents who took part in the survey did so with the understanding that they were taking part in market research conducted by a pharmaceutical company to understand the experiences of those living with chronic hypopara. Respondents agreed for their responses to be anonymously presented in this report. Respondents did not receive payment for their involvement with the survey.

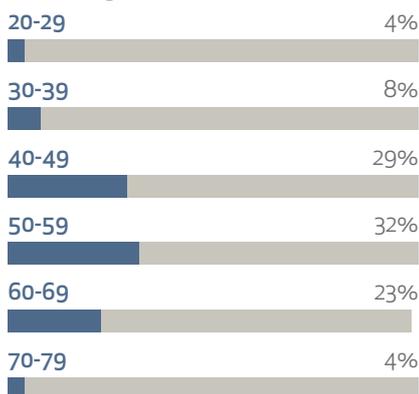
Patients were asked to describe the severity of their condition and symptoms based on their subjective perception, and this classification was not based on biochemical parameters such as an assessment of blood calcium levels.

OVERVIEW OF FINDINGS¹

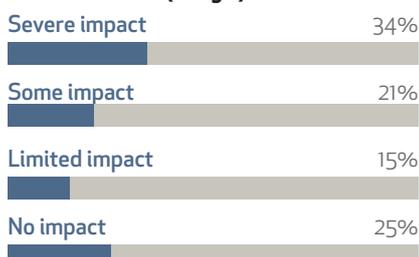
GENDER (N=230)



AGE (N=230)

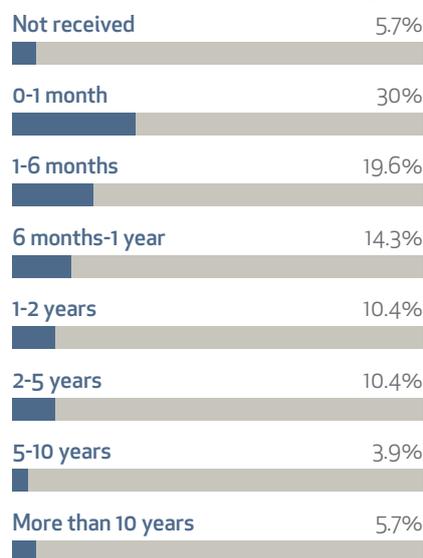


ABILITY TO MAINTAIN FULL-TIME EMPLOYMENT (N=196)[†]

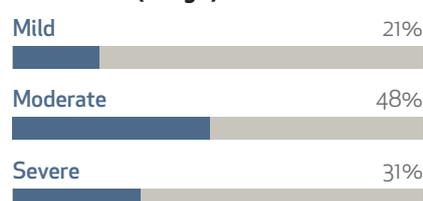


[†]5% of respondents answered "Don't know"

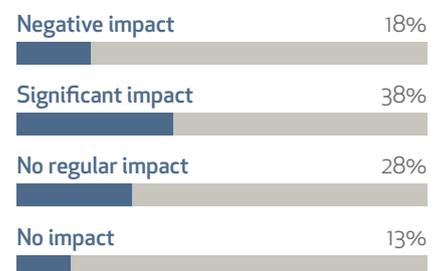
TIME TO FORMAL DIAGNOSIS (N=230)



PERCEPTION ON SEVERITY OF THE CONDITION (N=230)



IMPACT ON MENTAL HEALTH (N=211)*



*3% of respondents answered "Don't know"

NUMBER OF SYMPTOMS REPORTED

20 symptoms ranging from tingling to dental problems and anxiety. The most common symptoms reported by the 225 patients who answered the question were:



**in the hands or feet

INTRODUCTION TO CHRONIC HYPOPARATHYROIDISM

ABOUT HYPOPARATHYROIDISM^{1,2}

The parathyroid glands (located in the neck) produce parathyroid hormone (PTH), which helps to regulate the levels of calcium, phosphorus and vitamin D in the bones and blood

Hypoparathyroidism (HypoPT or hypopara) is a rare condition which is caused when the parathyroid glands produce too little PTH

When the parathyroid glands produce too little PTH, blood calcium levels drop (hypocalcaemia) and blood phosphorus levels rise (hyperphosphataemia)

Unstable calcium levels caused by hypopara can result in a range of symptoms, ranging from tiredness and anxiety, to memory loss

More than eight in ten cases of hypopara are caused by accidental damage to the parathyroid glands during surgery to the neck

There is no known cure for hypopara, but oral calcium and active Vitamin D supplements are available to help patients manage their calcium levels

Due to its rarity, there is a serious lack of awareness of hypopara and its symptoms. Hypopara is generally detected upon symptoms of having low blood calcium levels, which can range from physical symptoms such as muscle spasms and numbness, to emotional symptoms such as anxiety and tiredness.

Hypopara most commonly occurs as the temporary or permanent result of surgery to the neck due to the removal of, or damage to, the parathyroid glands. Hypopara is typically diagnosed as chronic if a patient's calcium level does not return to normal within six months of their surgery.

However, hypopara may also be due to a congenital, genetic or idiopathic disorder which affects the function of the parathyroid glands, or due to radiation treatment for cancer.

87% of hypopara patients who responded to our survey were female.¹ These results are supported by previous research undertaken by Underbjerg et al. which found that 88% of patients affected by hypopara were female.³

30% of patients are diagnosed with hypopara within a month of first experiencing symptoms¹, and nearly two thirds of patients are diagnosed with

having seen just one or two healthcare professionals.¹

Nevertheless, 45% of patients wait longer than six months to receive a formal diagnosis, 20% of patients wait longer than two years and nearly one in ten patients see more than five healthcare professionals before they are diagnosed.¹ The NHS Clinical Guidelines for specialised endocrinology services states that all endocrine referrals should be managed within 18 weeks. Furthermore, it specifies that if a service chooses to query a referral, it must do so within 48 hours in conjunction with the senior clinician in the service.⁴

The management of hypopara is mostly carried out in secondary care in the UK, with patients referred to specialised endocrinology services, as stated by NHS Clinical Guidelines.⁴ For 37% of patients, a general endocrinologist is their most frequent point of contact in the NHS.¹ 36% of patients see a GP most frequently.¹ Severe patients, whose symptoms may be difficult to manage, are more likely to have a GP as their most frequent point of contact.¹ This is often due to the need to manage the various conditions associated with hypopara and the need for ongoing urgent testing.

WHAT IS THE CAUSE OF YOUR CONDITION?*

67.7%

Surgery to the neck
(such as laryngeal, parathyroid or thyroid surgery)

9.6%

Idiopathic
(the cause of the condition is unknown)

6.1%

Autoimmune
(relating to the immune system)

3.9%

Genetic
(due to a faulty gene, inherited)

3.1%

Pseudo and pseudopseudo
(a condition associated with insensitivity to the biologic activity of parathyroid hormone)

0.4%

Congenital
(developed in the womb in the absence of a genetic or chromosomal cause)

0.4%

APS-I
(Autoimmune polyglandular failure syndrome type 1)

* 3.5% of respondents answered "Don't know"

5.3% of respondents answered "Other"

THE IMPACT OF HYPOPARATHYROIDISM

Hypopara can have a huge impact on a patient's life due to the symptoms that they experience, and nearly a third of patients describe their condition as severe.¹ For all patients, managing the symptoms and conditions associated with hypopara can affect their ability to lead a normal life.

SYMPTOMS OF HYPOPARA

People living with hypopara can experience a range of symptoms as a result of their condition. Out of the 225 patients who reported that they experience specific severe symptoms, the top four symptoms were:¹

- 1 **Tiredness**
215 patients
- 2 **Tingling or numbness in the hands or feet**
207 patients
- 3 **Brain fog**
198 patients
- 4 **Irritability**
196 patients

In addition to the symptoms experienced by those living with hypopara, many of these patients can also live with additional related conditions. Living with multiple long-term health conditions can be difficult for patients and their healthcare professionals to manage.¹

“ I had to give up work, and struggled with the thought of being stuck with a whole raft of symptoms for years ”

Survey respondent

OVERVIEW OF FINDINGS¹

BONE PAIN



Of the 138 patients (70%) who identified bone pain as an additional result of their condition, 29% of these described this as severe

MIGRAINE-LIKE HEADACHES



Of the 102 patients (51%) who identified migraine-like headaches as an additional result of their condition, 25% of these described them as severe

DEPRESSION



Of the 133 patients (67%) who associated depression with their condition, 17% classed this as severe

DIZZINESS



Of the 121 patients (61%) who identified dizziness as an additional result of their condition, 17% classed this as severe

“ I can't work, can't wash, can't shop, can't see my friends ”

Survey respondent

QUALITY OF LIFE

The symptoms associated with the low calcium levels often caused by hypopara can have a significant impact on a patient's ability to lead a normal life and to do the things that matter to them, such as going to work or socialising with their friends and family. We asked people living with hypopara how their condition affected their ability to perform everyday activities:¹



44% of patients find that their hypopara has an impact on their ability to make a cup of tea
Including 8% of patients who find that their ability is severely impacted



53% of patients find that their hypopara has an impact on their ability to drive a car
Including 18% of patients who find that their ability is severely impacted



59% of patients find that their hypopara has an impact on their ability to prepare a meal
Including 16% of patients who find that their ability is severely impacted



67% of patients find that their hypopara has an impact on their ability to go to the supermarket
Including 24% of patients who find that their ability is severely impacted



71% of patients find that their hypopara has an impact on their ability to maintain full or part-time employment
Including 34% of patients who find that their ability is severely impacted



76% of patients find that their hypopara has an impact on their ability to interact with their friends and family
Including 23% of patients who find that their ability is severely impacted

The survey's results regarding the impact on quality of life are reinforced by similar conclusions drawn from Hadker et al. (2014) PARADOX Study, which found that 45% of patients with hypopara reported a significant interference with their lives, 85% an inability to perform household activities, and 20% experienced a disease-associated change of employment status.⁵

People living with hypopara can also find that their emotional and mental wellbeing is affected by their condition. Two thirds of patients living with severe hypopara reported that their condition has an impact on their mental health.¹ Patients who say that their hypopara is severe are nearly three times more likely to find that their condition affects their mental health and emotional wellbeing every day than those with mild or moderate hypopara.¹

Hypopara can also have a significant physical impact: one in ten hypopara patients find that their condition causes them to temporarily lose their mobility at least once a day.¹ For people trying to maintain full- or part-time employment or to socialise with family and friends, losing their mobility, even temporarily, can have a real impact. Furthermore, patients affected by severe hypopara are almost three times more likely than those with a mild or moderate condition to lose their mobility in this way at least once a month.¹

“ Hypopara is a very isolating disease... I want my old life back ”

Survey respondent

MANAGING CALCIUM LEVELS THROUGH TREATMENT

Though there is no cure for hypopara, patients can seek to manage their blood calcium levels by taking oral calcium and active Vitamin D supplements. In practical terms, this often means that patients have a high number of pills to take every day:¹



17% of hypopara patients take six or more calcium pills each day



27% take three to five pills each day



More than a quarter of patients find the number of pills that they are required to take to be challenging



7% of patients take six or more active vitamin D capsules each day



11% of patients find the number of active vitamin D capsules they are required to take each day to be challenging

HOW HYPOPARATHYROIDISM IS MANAGED IN THE UK

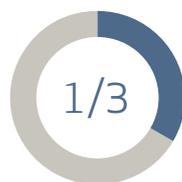
To ensure that those living with hypopara have the best care possible, they require access to specialist endocrinology services. As hypopara is so rare, being treated by a specialist endocrinologist is vital in ensuring that patients' care and support are tailored to their needs and based on a good understanding of their condition. In England, specialised services for patients with hypopara are commissioned by NHS England.⁶

Despite the importance to those living with hypopara of seeing a specialist regularly, 69% of patients report that they never see an endocrinologist who specialises in parathyroid/calcium, 10% of patients report seeing an endocrine nurse at least once a year, and 70% of patients report seeing a general endocrinologist at least once a year.¹ This is in line with patient experience as it has been reported that patients don't get priority treatment despite the potential for emergency situations to rapidly develop.

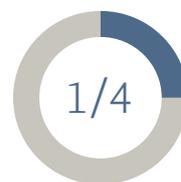
For patients whose hypopara is considered severe, newly diagnosed patients and those in crisis, this lack of contact with specialist services can be very challenging. Our survey found that just 11% of patients are regularly seeing an endocrinologist who specialises in hypopara or calcium deficiency.¹ Some endocrinologists including specialists do see their patients more frequently, if necessary or are in contact via phone or email, but most don't. This can lead to the need for emergency treatment in A&E or admittance into hospital to resolve a crisis that could have been avoided with better understanding and management of the condition, or better shared care between the GP and consultant. Unsurprisingly, more than a third (36%) of hypopara patients see a GP more often than any other kind of healthcare professional and GPs are a vital partner in the ongoing care for hypopara patients.¹

Managing hypopara and blood calcium levels effectively can require patients to change the number of calcium pills and active vitamin D capsules that they take on a daily basis. 21% of patients find the regular changes to the number of calcium pills they are required to take to be challenging, and this figure is 16% for changes to the number of active vitamin D capsules.

A diagnosis of hypopara can be a frightening and isolating experience, partly because the condition is so rare. We asked patients about the information that was made available to them at the time of diagnosis, uncovering the picture of what support and information is available to patients at this time:



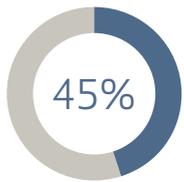
More than a third of patients found the information given to them about their condition to be highly unsatisfactory¹



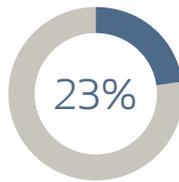
More than a quarter of patients found the information given to them about their treatment to be highly unsatisfactory¹

Hypopara patients' symptoms can be exacerbated if their calcium levels are not well managed. In some instances, this can lead to patients being admitted to A&E, or to hospital, often without prior warning. Other times, however, exacerbated symptoms may mean that a patient with hypopara has to change their plans for the day, which can be frustrating and upsetting.

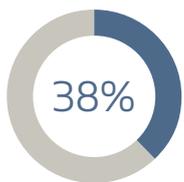
Unexpectedly having to visit a healthcare setting such as an A&E department, or making an unplanned inpatient stay in hospital, can be severely disruptive to a patient's life. We found that:¹



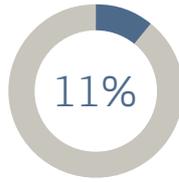
45% of patients have had to make an unplanned visit to an A&E department as a result of their hypopara



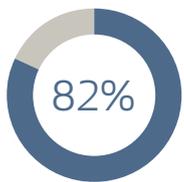
23% of patients have had to make an unplanned hospital visit as a result of their hypopara



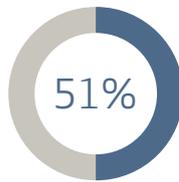
38% of patients have need an unplanned intravenous (IV) calcium infusion as a result of their hypopara



11% of patients have had to make an unplanned hospital visit more than four times in a year



82% of patients have had to change their plans for the day as a result of their hypopara



51% of patients have had to have a telephone call with an endocrinologist as a result of their hypopara

The survey findings are corroborated by results from Hadker et al. (2014) PARADOX Study, which highlights that of 374 patients with hypopara, 79% required hospital stays or visits to A&E.⁵

Of those patients who have had to make an unplanned stay in hospital as a result of their symptoms, 37% did not then have a follow-up appointment arranged by their medical team.¹ A follow-up appointment could seek to address the issue that may have led to the admission in the first place, and could avoid future unplanned admissions.

Key to the effective management and treatment of hypopara and the support for those living with it is awareness amongst healthcare professionals. As a rare condition, a healthcare professional such as a GP may encounter just a handful of cases in their whole career. For those living with hypopara, there is no prospect of a cure. It is therefore vital that non-specialists, including GPs, are trained to be able to support people with hypopara.

“ Hypopara patients all too often fall into the yawning gap between vital need for access to specialist care and actual provision. This situation needs to be urgently addressed to improve patient experience and safety. ”

Liz Glenister, Chief Executive, Hypopara UK

“ There is a severe lack of understanding from the professionals I see ”

Survey respondent

ANALYSIS: LIVING WITH SEVERE HYPOPARATHYROIDISM

31% of patients identify their condition as being severe based on their perception.¹ As this report demonstrates, the impact of severe symptoms caused by low calcium levels is significant — affecting a patient's ability to work, drive and even socialise.

Compared to those patients whose condition is mild and moderate, patients with severe hypopara typically report a worse experience of their care.¹

For these patients, whose hypopara has such a significant impact on their lives, it is vital that they have the specialist support and advice that they need. As this survey shows, patients whose condition is severe are far more likely to require unplanned care and treatment from the health service than those with mild and moderate hypopara.

Severe patients are much more likely than those with mild and moderate conditions to have their lives disrupted by their condition:¹

5X

5 times more likely to make an unplanned visit to A&E at least 4 times a year

(15% of severe patients, 3% of mild and moderate patients)

2X

Nearly twice as likely to make an unplanned hospital visit

(82% of severe patients, 44% of mild and moderate patients)

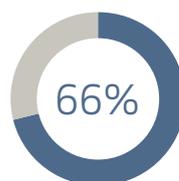
2X

More than twice as likely to have an inpatient stay in hospital

(60% of severe patients, 27.5% of mild and moderate patients)

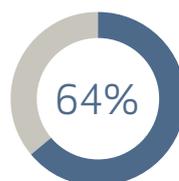
Severe patients are less likely to feel that they are able to make joint decisions with their healthcare team about managing their condition than those with more moderate symptoms

(29% of mild or moderate patients and 45% for severe, disagreed or strongly disagreed that they were able to make joint decisions)



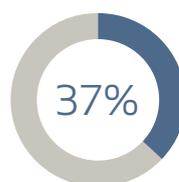
66% of severe patients found that the information offered to them, at the time of diagnosis, about their condition to be unsatisfactory or highly unsatisfactory

This proportion is 66.5% among patients with mild or moderate hypopara



64% of severe patients found that the information offered to them, at the time of diagnosis, about their treatment options to be unsatisfactory or highly unsatisfactory

This proportion is 56.5% among patients with mild or moderate hypopara



37% of severe patients would rate the care that they received at specialist level as being poor or very poor

JANE

Jane first became aware that she was “not feeling right” aged 50. She was tired all the time, irritable and forgetful. After visiting several doctors, Jane was told she would need surgery on one of her parathyroid glands. As a complication of the surgery, Jane was left with permanent hypopara.

After being diagnosed, Jane found it difficult to manage her calcium levels, which would often swing violently up and down, damaging her quality of life and leaving her in hospital more and more. As time went on, Jane found herself increasingly unsociable due to her condition. With her health continuing to deteriorate, she felt she couldn't go on living like this.

“It was not like me at all. Previously, I had always been energetic and kept very busy with my four children and busy job as a nurse.”

More recently, Jane has found her condition better to manage now that her calcium levels have become more stable, and can do more of what she has planned with her family and professionally. Sadly, however, she still lives with the symptoms of hypopara, including aches, fatigue and issues with her memory.

“I feel much better in myself without my calcium swinging around and try to manage these problems by pacing myself.”



CASE STUDY

FOCUS ON HYPOPARATHYROIDISM IN ENGLAND

Hypopara is a rare condition, and patients are affected across the UK. Our survey found some variations in care across the UK's nations, with patients in Scotland and Northern Ireland, in particular, reporting lower levels of access to specialist endocrinology services.

81% of survey respondents (N=183) indicated that they live in England¹, where specialised services for patients with hypopara are provided by NHS England.

This survey has provided a picture of hypopara in England:¹

89% of patients are female



11% of patients are male



Just 28% of patients received a diagnosis within a month of first expressing symptoms of hypopara, and nearly a third had to wait more than a year to receive a formal diagnosis



Just under a third (32%) of patients indicated that their condition is severe



Two thirds (67%) of patients identified the cause of their condition as accidental damage to the parathyroid glands during surgery to the neck



4% of patients reported that the cause of their hypopara is unknown



HOSPITAL ADMISSIONS IN ENGLAND

25% of patients reported making at least one unplanned hospital visit each year as a result of their hypopara. Of these, 11% made an unplanned hospital visit at least once a quarter.¹

In addition, 35% of patients reported that they had to have an inpatient stay at least once a year as a result of their hypopara. For those whose hypopara caused them to stay in hospital, 50% of patients reported a typical stay of three days or more.¹

More than a third of patients who have stayed in hospital as a result of their hypopara did not have a follow-up appointment arranged by their medical team, potentially missing the opportunity to prevent another future unexpected admission. The NHS standard contract for specialised endocrinology services (adults) states that continuity of care in long-term follow up with access to specialist services should be maintained for patients with a chronic endocrine condition.⁴

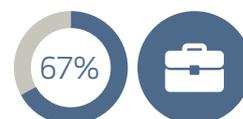
This sample of hypopara patients living in England also paints a picture of the impact their condition has on their ability to lead a normal life¹:



45% of patients find that their hypopara has an impact on their ability to make a cup of tea or coffee



51% of patients find that their hypopara has an impact on their ability to drive a car



68% of patients find that their hypopara has an impact on their ability to maintain full or part-time employment



75% of patients find that their hypopara has an impact on their ability to interact with their friends and family

THE FULL PICTURE OF HYPOPARATHYROIDISM

This report sets out for the first time a comprehensive assessment of the experience of hypopara patients in the UK.

As with many rare conditions, patients report limited access to specialised endocrinology services, and express frustration with often having to interact with healthcare professionals whose understanding of their condition is limited.

It is also clear that hypopara has a significant impact on the ability of patients to lead normal lives, not least in terms of their quality of life and not feeling able to work, drive or socialise.

These factors are compounded by further challenges such as unplanned stays in hospital or trips to a GP or hospital as a result of low calcium levels. These admissions are disruptive for patients while, at the same time, putting further pressure on an already-stretched health service across the UK.

It is also clear that each of these challenges is even greater for patients living with severe hypopara. Patients with severe hypopara are between five and nine times more likely than those with mild or moderate hypopara to require an unplanned visit to hospital or their GP as a result of their condition.¹ For these patients, managing their blood calcium levels and maintaining a good quality of life is all the more difficult.

Improved awareness among healthcare professionals of hypopara and the impact of the symptoms of hypopara, coupled with improvements in access to specialist services, could begin to address the challenge faced by hypopara patients across the UK.

“ The worst part of living with this condition is that because it’s unseen people expect you to live normally ”

Survey respondent

“ Many doctors I have seen know about the condition but have little understanding of the impact it has on life in general ”

Survey respondent



ISABEL

Since childhood, Isabel had been in and out of hospital. However, matters worsened when, at the age of fifteen, Isabel was diagnosed with thyroid cancer. As a result of the ensuing surgery, she was left with permanent hypopara due to her parathyroids not being saved during the operation. Despite her symptoms worsening as she grew older, past GPs consistently misdiagnosed them, referring her to clinical psychologists and throat clinics, or telling her there was nothing wrong or prescribing painkillers. For the first 25 years of living with her condition, not one doctor requested a calcium blood test, with the exception of her endocrinologist.

“When I experienced a serious hypocalcaemic crash, I didn’t know that that was what it was. I was home alone and felt my body drop, a sensation like dropping from a height such as a roller coaster. I was trembling and I heard deafening noises as if there was a helicopter inside my brain. I was overcome with fear and panic. I didn’t take any extra calcium because I didn’t know that’s what I was supposed to do.”

As Isabel’s hypopara continued to worsen, she found that her GPs were not knowledgeable enough about the condition to help her, and at one point they reduced her medication without consulting her endocrinologist.

“Although I’m sure he meant well, my then-GP, who was not informed about hypopara, didn’t refer me for emergency IV calcium, but instead, erroneously made the decision to reduce my medication without a blood test and without consulting my endocrinologist. I became very withdrawn and quiet. I couldn’t talk properly because my tongue wasn’t working properly. It was during my routine hospital appointment that my endocrinologist learned that my medication dose was incorrect.”

Over time, Isabel also came to learn that taking calcium and vitamin D to help her hypopara had led to her kidney function suffering. However, it took nearly 20 years before she was referred to a nephrologist, despite high creatine levels recorded on her regular blood tests. After eventually being referred to a nephrologist by her endocrinologist, Isabel was shocked to receive a diagnosis of stage 3 chronic kidney disease. After this diagnosis, Isabel was closely monitored by her nephrologist before being discharged once her kidney function was considered more stable.

After 25 years of living with hypopara, Isabel discovered Hypopara UK, which she describes as a “lifeline”, and which finally connected her with other people living with the condition. Isabel has since become an active member of the group and learned about how to manage her hypopara, as well as her associated hypocalcaemia, for the first time.

“We, the patients are writing history as we continue to campaign and raise awareness of this condition. As I look to the near future, I hope that hypopara becomes a well-known and well-recognised condition, so that when dealing with the medical profession at all levels, our needs are met and we are understood.”

ABOUT SHIRE

Shire is a leading global biotechnology company focused on serving people with rare diseases and other highly specialised conditions.



ABOUT HYOPARA UK

Hypopara UK is a patient organisation for adults and children living with a parathyroid condition in the UK and Ireland. Hypopara UK aims to improve quality of life for those affected and raises awareness about parathyroid conditions. It also supports new research, fundraises, and offers friendly support and reliable information to everyone affected by these conditions.

hypopara.org.uk

lizglenister@hypopara.org.uk

01342 316 315

REFERENCES

1. Shire Market Research 2017.
2. NHS Choices, Hypoparathyroidism and hyperparathyroidism. Available via: <http://www.nhs.uk/conditions/hypopara-hyperparathyroidism/Pages/Introduction.aspx> [Last accessed October 2017].
3. Underbjerg L, et al. "Cardiovascular and Renal Complications to Postsurgical Hypoparathyroidism: A Danish Nationwide Controlled Historic Follow-Up Study", *Journal of Bone and Mineral Research*, 2013, 28 (11), pp: 2277-2285.
4. NHS England, NHS standard contract for specialised endocrinology services (adult), 2013/2014. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/06/a03-spec-endo-adult.pdf> [Last accessed October 2017].
5. Hadker N, et al. "Understanding the burden of illness associated with hypoparathyroidism reported among patients in the PARADOX study", *Endocrine Practice*, 2014, 20 (7), pp: 671-679.
6. NHS England, Specialised endocrinology, May 2017. Available via: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a03/> [Last accessed October 2017].