

Change NHS: Help build a health service fit for the future

Organisational response - The Pituitary Foundation

2 December 2024

About You

We are the UK's leading patient support organisation for people affected by a pituitary condition. Approximately 70,000 people live with rare pituitary conditions which have a significant life-long impact often requiring surgery, and ongoing life-sustaining treatment. The Pituitary Foundation was established 30 years ago as a result of the partnership between clinicians and patients. We exist to provide support, information, and advocacy for the pituitary community across the UK.

We welcome the opportunity to submit an organisation response to the national engagement for a new 10 year plan for the NHS. In preparing this response we have drawn on our knowledge of people's experience of living with a pituitary condition and of NHS services. This has included feedback from our Lived Experience Committee and Medical Committee. We've also drawn on the evidence from our 2022 patient survey 'Awareness and Communication', our Patient's Charter, and the report, Get it right first time: Endocrinology, GIRFT Programme National Specialty Report, by Professor John Wass and Mark Lansdown (February 2021).

Q1: What does your organisation want to see included in the 10 year health plan and why?

We want to see a 10 year health plan that delivers:

1. Earlier diagnosis of pituitary conditions
2. Specialist, co-ordinated, multi-disciplinary treatment and care for people living with a pituitary condition
3. Recognition of the mental health impacts of pituitary conditions and provision of appropriate mental health services
4. Signposting to information and support provided by patient support charities

In more detail:

1. All pituitary patients receive care in appropriate specialist centres

Pituitary conditions are rare and require specialist care which can only be provided through centres which have concentrated the necessary expertise, equipment, and resources to effectively treat and manage pituitary conditions. We want all pituitary patients to have the option to be referred to a specialist centre.

2. All pituitary patients have access to a specialist endocrine nurse

The patient care benefits of a specialist endocrine nurse service, within an endocrine centre, are well known. This service provides efficiencies as well as quality of life improvements for patients. We recommend that all pituitary patients have access to an endocrine nurse who they can contact with questions or concerns. We want to see all endocrine centres have the appropriate number of specialist endocrine nurses for their patient numbers, as well as workforce development and investment to attract endocrinology as a career pathway.

3. A multi-disciplinary approach for all pituitary patients

We recommend that all pituitary patients receive care through a multi-disciplinary team (MDT) made up of endocrinologists, endocrine nurses, pituitary neurosurgeons, radiotherapists, ophthalmologists, psychologists, and other specialists as needed. MDTs should meet regularly in specialist centres to review care and ensure patients are included as active participants in their care planning. Outcomes from MDT discussions should be documented and shared with the patient and primary care providers within 7 days.

4. All transitions from paediatric to adult NHS services for pituitary patients are well managed

A well-supported and stable transition is needed as paediatric services can differ to adult services for the individual concerned. We suggest a standardised protocol for transitions across the NHS to ensure quality and consistency. This should include standardised transfer of medical records to the adult NHS service 6 months before transition, at least two transition meetings where the patient meets with both the paediatric and adult care teams, and patients provided with a named transition coordinator to facilitate communication and address concerns during this period.

5. Care for people living with multiple health conditions must be properly co-ordinated

Living with a pituitary condition can be extremely challenging and life changing. Combining this with other conditions increases the complexity and patients can end up feeling overwhelmed and unable to navigate the system to get their health needs met. This calls for the need for care to be co-ordinated. Approaches to this could include 'care co-ordinators'.

Q2: What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

- 1. The rarity and complexity of pituitary conditions necessitates a specialist service which must be provided through a specialist endocrine (tertiary) centre.***

Primary health care providers must have sufficient awareness of symptoms which could be explained by a secretory pituitary problem. Once this is suspected, a referral must be made to a specialist endocrine centre with a wait time of no more than 18 weeks. Whilst ongoing routine management might shift to community care, the initial diagnosis, treatment, and care must be provided by specialists in specialist centres.

- 2. Care and treatment for pituitary patients must be co-ordinated with clarity about roles and responsibilities***

It is vital that the ongoing management of care is agreed between the specialist endocrine centre and providers of care in the community, to enable some aspects of long-term care to be provided more locally. This requires a joined up and coordinated approach with clear delineation between the roles of primary and secondary care. Each patient should have a named clinician and endocrine nurse responsible for their endocrine management, with these roles clearly documented in patient records.

A written care plan, including medication details, emergency management and protocols, and follow up schedules should be developed and shared with primary care providers. Primary care teams should receive specific guidance on when to refer patients back to specialist services ensuring timely intervention when symptoms change or worsen.

- 3. All clinicians must be made aware of and understand the importance of life-sustaining medication***

The safe management and instruction of a pituitary condition when accessing non-endocrine care or emergency care is vital. All clinicians including paramedics must have a level of awareness and training on the importance of life sustaining medication such as hydrocortisone in an adrenal crisis (in line with the National Patient Safety Alert (NPSA)), and desmopressin for managing AVP-D (Arginine Vasopressin Deficiency) plus appropriate sodium margins.

We suggest a specific mechanism for training such as mandatory e-learning modules on these topics. All NHS Trusts should include training on life-sustaining medications as part of their mandatory induction for emergency care staff.

Patient records should clearly state where a patient requires life-sustaining medication so that clinicians can identify when medication is required in emergencies. These records should be available to emergency care staff.

4. *The diagnosis and treatment of mental health impacts can be a challenge*

There can be a significant mental health impact of living with a pituitary condition and this requires support and treatment. This is often not available and must be considered as part of effective long term management. We suggest that patients are offered easy access to psychological support from the outset following diagnosis so that they are aware that these services exist. The inclusion of a psychologist in the multi-disciplinary care team may also provide for mental health care planning.

Q3: What does your organisation see as the challenges and enablers to making better use of technology in health and care?

1. *Medical records must be made available to relevant clinicians.*

Digitalised records will ensure easier and faster access for health care professionals. Paper based records are still the norm in many centres and we know that these are not always appropriately shared between centres. Reliance on paper records can also pose other risks for example delays in emergencies due to inaccessible records. We are aware that current disconnected systems can pose problems for transferring the care of patients between NHS Trusts and the updating of test results between primary and secondary care.

Patients should have access to their own digital records if desired. Digital systems however must be secure and safe to protect patient information. Clearly there are considerable gains to be made from the increased use of digital technology, but this shouldn't be at the expense of those groups who lack the means or skills to access services digitally.

2. *Specialist equipment must be available and used by experienced professionals*

Pituitary imaging (e.g. MRI scans) utilising the appropriate equipment must be performed in a centre where pituitary scans are carried out regularly by experienced professionals. Regular imaging by experienced professionals will reduce the risk of misdiagnosis or the need for repeat imaging. Accessibility can be improved by creating a clear pathway for prioritising pituitary patients needing specialist equipment for diagnosis and treatment (e.g. gamma knife surgery, proton beam).

3. The appropriate use of data could build knowledge of pituitary conditions and could drive improvements in care and treatment

Building collective specialist knowledge of pituitary conditions would be supported by the collection and analysis of patient data. The creation of a national database for pituitary conditions would be beneficial for research. It could also support steps to address health inequalities by enabling the identification of people who are medically under-served, and the development of services. Additionally, the appropriate sharing of anonymised data with patient support organisations can help us to develop our services for our community. Clearly this must be done in ways that are compliant with data protection.

Assessing the effectiveness of surgery and treatment relies on the collection of relevant data for audit and improvement purposes. This should also include patient reported outcome measures.

4. Diagnosis, clinical care, and patient self-management could be supported by use of technologies

Technologies including AI (artificial intelligence) has potential to support diagnosis and treatment. Providing patients with the tech to track and record symptoms could assist diagnosis and provide clinicians with useful information for decision making on care (for example, fatigue, mental health). Technologies could also offer potential for supporting patients with the management of symptoms if they were signposted to appropriate and approved online support tools and apps. There are existing examples that have been utilised to good effects in other specialities, for example diabetes, and blood pressure monitoring.

Q4: What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

1. Speeding up diagnosis will improve outcomes for patients and for 'the system'

It can take many years to be diagnosed with a pituitary condition with symptoms having both a short- and long-term impact on an individuals' health including the increasing risk of other comorbidities. This will also impact on NHS resource with multiple health issues, arising from the delay in diagnosis, requiring treatment and care.

Awareness of pituitary conditions in primary care with a timely endocrine referral for diagnosis and treatment is vital. Regular mandatory training on recognising symptoms of pituitary conditions would increase awareness. GP face-to-face appointments (rather than telephone or online) can be necessary to assist with diagnosis of a pituitary condition especially for identifying nuanced physical symptoms. Incorporating some initial screening tests in primary care could

support referrals to specialist tertiary care (i.e., overnight dexamethasone tests and 24hr urine cortisol as a screening for Cushing's). The development of a national symptom checklist for pituitary conditions to support GPs during consultations could be integrated into electronic health systems for consistency.

All pituitary patients must receive a referral to an endocrinologist within 18 weeks, in line with current NHS standards.

2. Pituitary conditions require proactive long term management so that patients can live as well as possible

Providing education to patients and carers on condition management should occur as part of an annual clinical review. We would like to see patients and carers routinely signposted to patient support organisations so that they can access our information and support services. A holistic approach to the patient which considers mental health, impact of hormones on weight, and appropriate exercise, will support effective long term management.

Regular medical review must be provided given that pituitary conditions can reappear with worsening symptoms. Regular medical review will help to spot change and/or deterioration at an early stage so that action can be taken. We recommend that patients are reviewed at least annually to monitor for recurrence or progression of pituitary disorders.

Safe care provided through non-endocrine care or emergency care, for treatment for other conditions, illnesses, or injury, relies on an understanding of the importance of life-sustaining medication in order to prevent any harm. Awareness training should be made available and provided as a mandatory requirement. Also, prompt and reliable accessibility to updated medical records is vital.

3. Medicines supply and prescribing are important for management of care

It is vital that there is an adequate supply of medications i.e., desmopressin and hydrocortisone tablets and injections. There is significant risk to patients when supply shortages occur. We would like to see proactive monitoring of medication supplies and action when there are issues. This should include collaboration with pharmaceutical companies and supply chain stakeholders to develop contingency plans for ensuring availability of critical medicines.

Repeat prescribing for life long endocrine medication should be on a minimum of 56 day prescriptions. For adrenal insufficiency prescribing, there should be an extra 1-2 month's supply given, as routine. The standardisation of emergency injection kits and the routine issuing of these to patients is vital. This must happen immediately following diagnosis with training provided to patient and carers.

In addition, listening to patient feedback as to which medication or device works best for them, enabling compliance to treatment, is important. There should be a holistic approach in dealing with change in treatment options.

End.