Pituitary tumours: recommendations for service provision and guidelines for management of patients

Consensus statement of a working party from the Committee on Endocrinology of the Royal College of Physicians and the Society for Endocrinology, in conjunction with the Research Unit of the Royal College of Physicians

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Although patients with pituitary tumours are uncommon (incidence about 20–30/million per year), they require specialist investigation and treatment and life-long follow-up with considerable life-time use of National Health Service resources. These resources must be defined and used in the most cost-effective manner. The initial presentation may be to one of several clinical disciplines. In many instances there is evidence of repetition of expensive investigations and repeated visits to several specialist clinics, leading to inefficient use of resources. Consequently one group, normally clinical endocrinologists, should assume responsibility for *co-ordination* of investigations, treatment decision-making, follow-up and outcome assessment. To this end there is a need for more data on long-term outcomes of treatment, particularly factors which affect mortality, and for future treatment plans to be modified in the light of these data. Registers and accurate documentation of morbidity/mortality in such patients, held at regional or national level, are considered central to this objective.

In view of the above, a working party of clinical endocrinologists, pituitary surgeons, neuroradiologists, radiotherapists, a general practitioner (RCGP rep) and patients under the auspices of the Endocrinology and Diabetes Committee of the Royal College of Physicians and the Society for Endocrinology has considered these issues and compiled this report, which is intended to inform health care purchasers and providers of acceptable standards of care for this patient group. These guidelines should be interpreted in the context of individual patients' specific circumstances, which may be variable.

This summary document provides guidance on an acceptable standard of service provision only for this patient group. Management guidelines for the different subtypes of pituitary tumours is available in the full Consensus Statement document.

Methods

Recognised United Kingdom authorities with an international reputation for clinical research as pituitary specialists were invited to produce background papers on specific aspects of the topic that summarised the relevant available published evidence from peer-reviewed journals (see contributors of background papers available in full document). Because of the potential for bias in consensus development by small groups the background papers were circulated to members of a larger working group before a workshop held at the Royal College of Physicians of London. The working group consisted of specialists in endocrinology, general physicians, pituitary surgeons, ophthalmologists, radiotherapists, gynaecologists, general practitioners, and representatives of the Pituitary Foundation on behalf of patients (members of the workshop listed in full document).

The workshop consisted of a brief (10 minute) introduction to each background paper followed by rigorous debate (30 minutes per section) and the recording and agreement of the consensus view on management of each specific pituitary tumour (or craniopharyngioma) subtype. When more than one acceptable approach to management existed these strategies were incorporated as options of acceptable standards. The configuration of service provision for this patient group was also considered and an acceptable 'flow-through' scheme agreed. After the workshop a summary of the discussion was circulated to all contributors of the background papers so that these could be amended. A small group abbreviated the salient points in order to produce a concise statement for good practice, which was evidence-based wherever possible. This was circulated to all members of the workshop, inviting comments and approval. After three iterations the final document was agreed. This consensus statement of good practice is also intended to provide the basis for

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Copies of the full Consensus Statement document can be obtained from the Publication Department, Royal College of Physicians, 1 St Andrew's Place, London NW1 4LE, UK. Price £10.

future audit of both the immediate process of management and, in the longer-term, the clinical outcomes of treatment.

Recommendations for service provision for patients with pituitary tumours

Once the diagnosis is suspected, patients should be referred to a specialist centre for further assessment and treatment. Pituitary disease is rare and professionals in primary and secondary care are unlikely to see sufficient numbers of these patients to provide the full range of expertise required to take sole responsibility for management.

In view of the complex nature of pituitary tumours and the possibility of other endocrine and general medical complications, it is usual that a clinical endocrinologist will assume responsibility for co-ordinating treatment and long-term follow-up.

At the specialist centre, which may be located across several sites, it is highly desirable that management plans are agreed jointly by endocrinologists, pituitary surgeons and radiotherapists. Options include joint clinics or case discussion sessions. Neuroscience units should have formal links with an endocrinologist. Joint surgical/endocrinological review is desirable at least within the first 12 months after diagnosis and treatment.

Adequate visual field and acuity testing facilities must be available. These can be managed by an endocrinologist with experience in pituitary-related problems. However, supervision and quality control should be by an ophthalmologist, who should also be available for interpretation of tests and advice in complicated cases.

Pituitary imaging and interpretation should be performed in an experienced centre where this is done regularly. MRI is preferable to CT as it provides better anatomical definition prior to surgery and is more likely to identify non-tumorous lesions in the pituitary region. In urgent cases, or in patients in whom MRI is contraindicated, a CT scan is acceptable.

Pituitary function testing should be performed in an investigation unit with appropriate facilities for sample collection, handling, analysis and interpretation of results. All centres should have access to an accredited hormone assay service that participates in the National Quality Control Scheme.

Histological anlaysis, including routine immunohistochemistry, should be performed by an experienced histopathologist, usually a neuropathologist.

Surgery should be performed by surgeons specialising in pituitary surgery, able to choose the most appropriate method of operation for a patient with a 'non-functioning' tumour. Additional superspecialisation, expertise and operative experience, optimise outcome for a patient with hormone-secreting adenomas. Outcome data are required to determine the minimum number of operations that should be performed per year by a single surgeon in order to achieve best results.

All patients should have access to and receive detailed explanation and counselling by professionals conversant with all aspects of their condition, including likely immediate and long-term outcomes. Counselling may be provided jointly by an endocrinologist and pituitary surgeon. Patients should be informed about self-help groups such as The Pituitary Foundation and Child Growth Foundation. Printed literature should be provided where available.

Specialist fertility advice should be available for those patients intending to conceive.

Access to psychiatric services is essential.

Paediatric patients will require support from a psychologist/educational psychologist.

Registers of all patients should be held at the Endocrine Unit and should include all information necessary to conduct audit and provide both short- and long-term outcome data.

Protocols agreed between specialist centre and other local professionals should be available to enable some aspects of long-term follow-up to be provided in referring units.

Prescribing for patients with pituitary disease

General practitioners may be asked to prescribe appropriate drugs for these patients in the community, provided adequate shared care treatment plans have been agreed locally with both clinicians and purchasing authorities. Experimental treatments should usually remain under specialist prescription. Provision of routine medication may be expected through the general practitioner, once the patient's condition and therapeutic regimen have been optimised.

Objectives of treatment

Objectives of treatment are broadly defined as:

Restoration of feeling of well-being

Relief of pressure symptoms

Treatment of hormone excess symptoms

Restoration of or substitution of specific system deficits

Prevention of tumour regrowth

Reversal of increased long-term mortality.

Standards of management for each pituitary tumou subtype

The standards of management for each pituitary tumou subtype were debated in detail and consensus achievec The following subsections form the basis of the full document, which is fully referenced: investigation and management of non-functional (hormone-inactive) tumours; investigation and management of craniopharyngiomas and peripituitary tumours; functional hormone testing and replacement therapy; investigation and management of Cushing's syndrome; investigation and management of acromegaly; investigation and management of hyperprolactinaemia.