

## Preparing for Pituitary Surgery:

### Suggested questions for your outpatient appointment

Results from our Cushing's survey, coupled with feedback from those of you contacting us, show not all medical teams are managing to provide the information and support you may need to feel confident in your outcome following surgery and in the longer term afterwards. We've put together this factsheet to guide you to asking important questions to help you prepare for treatment.

In some centres you may see the endocrinologist and the neurosurgeon in a *joint* clinic, in others there may be *separate* clinics for the endocrine and surgical teams on different days.

We have put together a list of suggested questions you may want to ask your endocrine team/neurosurgical team as you attend your clinic visits and prepare for surgery. They may not all be relevant to you but should help you to consider a wide range of topics. They may also prompt you to ask further questions of your own.

#### Questions for the endocrine team

- How many **pituitary patients** do you treat each year?
- How many patients with **my specific condition** do you treat each year? (e.g. Cushing's, acromegaly, prolactinoma, NFA, apoplexy etc.)
- What **investigations/tests** should I expect?
- **When, where and how** will those investigations be performed and by **whom**?
- When and how will I get the **results** of those investigations? (e.g. phone or post)
- How quickly will I move on to **further investigations** if needed?
- How much **time** will I need to take away from work/responsibilities? Who do I ask for a **sick note** (GP or endocrine team)?
- Will I need to have **surgery**?
- How quickly will I be reviewed by the **surgical team**? (*if not being seen in joint clinic*)
- If I need **medication**, who will prescribe this and who will monitor it? (GP or endocrine team or mix)
- Can my GP **alter** any hormone replacements doses originally prescribed by the endocrine team?
- Could you outline **possible side effects** of the medication?
- If I need hydrocortisone, will I be given an **emergency injection kit**? Who will **train** me how to use this?
- Who should I **contact** if I have a problem? Is there an endocrine nurse?
- Will I be **copied in to letters** to my GP about my consultations/test results?

### Questions for the surgical team

- How **quickly** can I expect to have surgery?
- What are the **risks** of the surgery?
- How many patients with **my specific condition** do you operate on each year? (e.g. Cushing's, acromegaly, prolactinoma, NFA, apoplexy etc.)
- What is your **success rate** for performing Cushing's/prolactinoma/acromegaly/NFA/apoplexy surgery?
- When can I expect to feel **better** after my surgery? Am I likely to feel **worse** during recovery?
- **How** and **when** will I be followed up after my surgery? Will I need MRI scans? If so, who will organise these?
- When should I be **reviewed** after surgery? Will I need blood tests and who will arrange these?
- Will I need **hydrocortisone** after surgery? If yes, will I be given an **emergency injection kit** and **training**? Who will give me this training?
- How long will I need to take **time off** work/responsibilities?
- Can I **drive** following surgery?
- When can I **fly** after surgery?
- Do I need to inform the **DVLA** or my **car insurance** company?
- If I need **medication** after surgery, who will prescribe this?
- When will I be **discharged** from hospital?
- What happens if the **tumour regrows**?
- Who should I **contact** if I have a problem? Is there a time limit e.g. week/month post-op that I can contact the surgical ward?