Patient Information Sheet 2

Meningioma UK Questions Guide

A pick & choose list of questions to ask your doctors, and things to think about.

1. What specific operation or procedure are you recommending for my meningioma brain tumour – and WHY?
   Are there different ways of treating this condition? Why do you advise this particular treatment instead of another? What are the advantages and benefits?
   a. What will my follow-up care be? (re-checks, medication, follow-up scans)
   b. If I don't do anything about this problem, what's likely to happen? When?
   c. If I have this treatment, what is the recurrence rate (chance of it coming back in the future)?
   d. What treatment options are available if my tumour is not suitable for neurosurgery and is too large for radiotherapy?

2. Why do you think I need this operation or procedure? How soon? To relieve pain? To reduce my symptoms? To make me function better? (One doctor may say you need surgery immediately, another one may say you have a weeks, months or even a year or more to consider treatment plans; you will have to choose what you are going to be comfortable with based on the information you have gathered and been given. NB: See Q9 below.)

3. What are the risks/side-effects associated with my condition and/or this treatment?
   a. How common are they?
   b. What is the current location, rate of growth and size of my tumour?
   c. What problems might I get from the tumour?
   d. What problems might I get from the treatment?

4. Should I continue to take all my regular medications, including hormone replacement therapy? Birth control? What if I am or get pregnant? (Note: Meningiomas are more common in women than in men, and have shown increased growth during pregnancy. Tumours have hormone receptors, and progesterone and oestrogen may play a role in their development, but that role is still unclear)

5. What effect will this surgery/procedure have on any other medical problems and medications? And how will it affect my family?

6. When will I be able to return to work, full-time, part-time, and handle everyday activities again?
   b. What about disability help and/or rehabilitation if I need it?
   c. Where can I get further support and information?
   d. Who is available to contact in the community?

7. What will my follow-up treatment be? How often do I have to come back? How often and for how long will I have follow-up MRI's (semi-annual or annual, for how many years)?
8. What other treatments might I have to consider in the future? Are there any medical chemotherapy treatments available that you know of? (You may want to see a neuro-oncologist to ask about this)

9. Seeking a second opinion? If you are unsure about what to do, you may wish to ask for a SECOND opinion. NB: You must often ask specifically! Your consultant can arrange it and will not be unfamiliar with such requests. It is common practice and perfectly acceptable for a patient with a serious condition to seek a second opinion from a consultant at another hospital.

Questions for your neurosurgeon:

10. **Is Watch and Wait** an alternative to having treatment for me? What are the risks for me if I choose to watch and wait for a period of time?

11. How long will the surgery or procedure take? What about my family – can they come and stay? Is there accommodation available at the hospital or nearby?

12. Hormone Receptor Tests: Will hormone receptor tests be included in the pathology report? (NB not very relevant)

13. Hospital Stay: How long do you think I will be hospitalised? In an Intensive Care Unit (ICU) or a High Dependency Unit (HDU)?

14. Additional costs or medication: What other medical costs or medications will there be after the surgery or this procedure? Will I still need more radiation or surgery? What for?

15. How long will I have to stay in the hospital?
   a. How much medical care might be needed when I return home?
   b. Can my family care for me? Can I get extra help? When can I drive again?

16. How long will I need medicine afterwards? MRI scans? How often will I be followed up? How many medicines, and for how long? What are their side effects?

17. What is your follow-up plan if there is residual meningioma or if the tumour regrows?

Questions for radiotherapy or radio surgery (Gamma Knife):

18. What is the difference between radiotherapy and Gamma Knife? What kind of equipment do you use? Can you explain what kind and how much radiation I will get? (There are several different types of Stereotactic Radiotherapy (Fractionated), and many brand names of brain radiation machines like Linac (Linear Accelerator), Gamma knife, X-Knife, etc.).

19. Radiation Effects. What are the short-term and the long-term effects of radiation?

20. What will my follow-up treatment be? Drugs, re-checks, MRI’s?

21. Might I need more treatment in the future?

*Think about taping your consultation, or take a friend along to make notes so you have a record to consult later. It is difficult to take in all the detail at first hearing. Note: It is a good idea to remind your friend or family member it is your consultation, not theirs!*