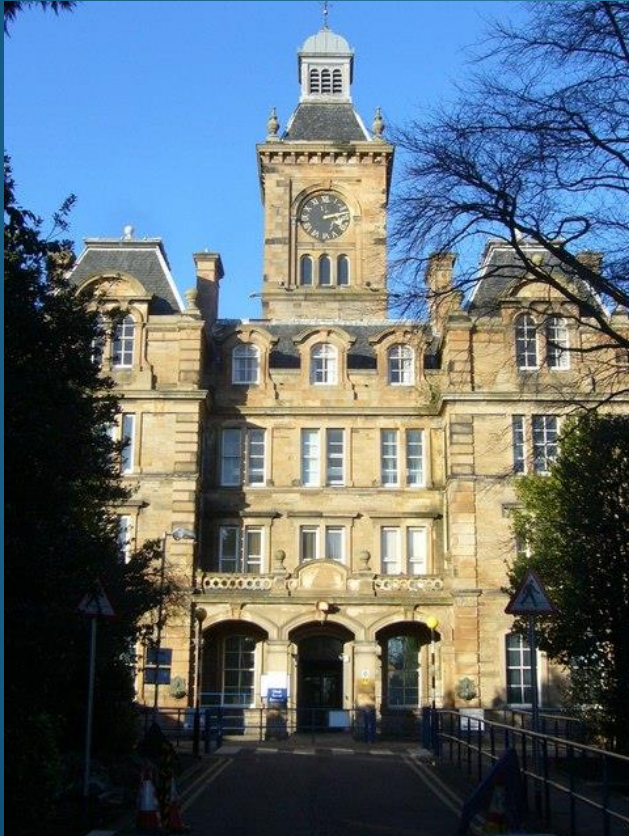




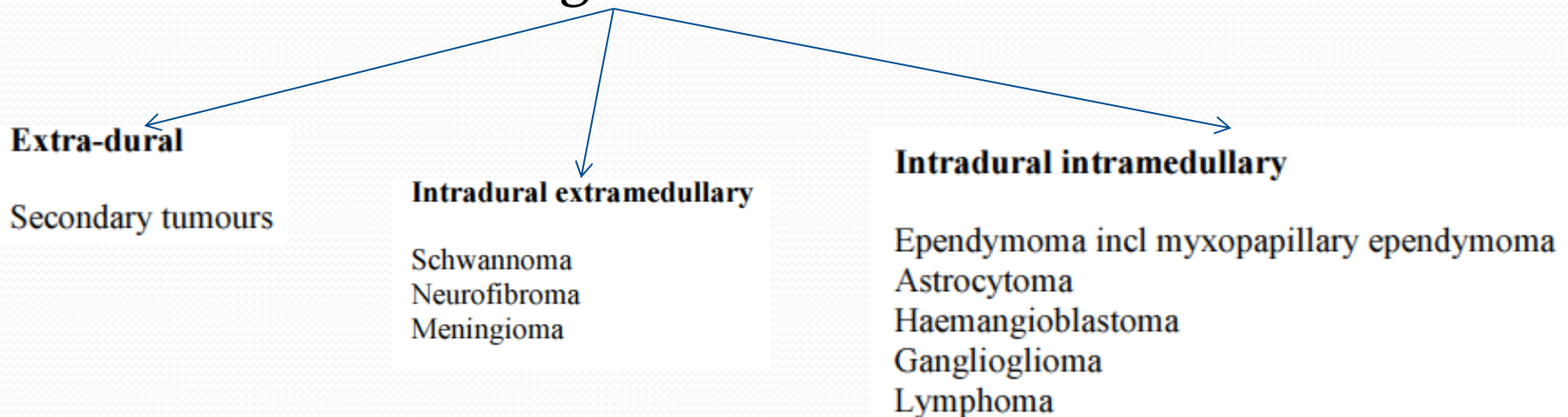
THE DIAGNOSIS OF AN INTRAMEDULLARY SPINAL CORD TUMOUR: A QUALITATIVE EXPLORATION OF PATIENTS' CLINICAL JOURNEY

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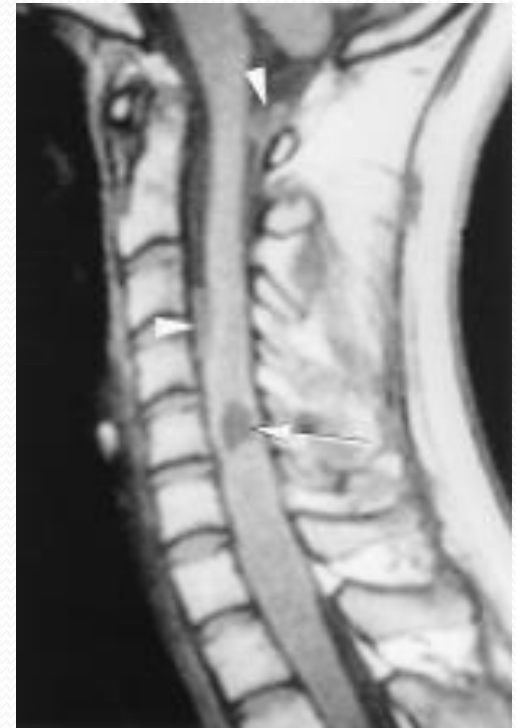
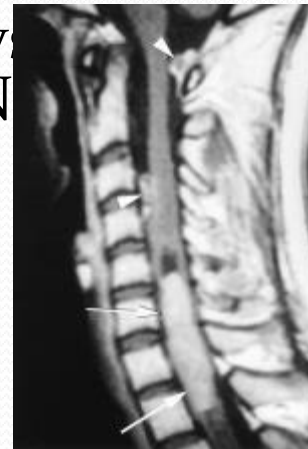
Basic facts in brief:

- Primary spinal cord tumours are 15 times less common than primary brain tumours:
 - In the UK in 2009, approximately 450 patients (spinal cord) vs. 8835 patients (intracranial).
- Classified according to their anatomic location:



Intramedullary spinal cord tumours (IMSCTs):

- Least common of the 3 types:
 - 10% of all cases in adults and 35% in children.
- Commonest types:
 - Ependymomas 60% (incl. myxopapillary ependymomas)
 - Astrocytomas 30%
- Review article:
- Spinal cord tumours: New views, future directions. Mechtler & N 2013



The present study: The Rationale

1. to describe in detail patients' clinical presentation prior to the diagnosis of IMST and to correlate this with radiological imaging and pathology results;
2. To describe in detail patients' information needs and preferences across the cancer care continuum;
3. To describe patients' general experience of using National Health Service (NHS) for their management of IMST (from primary care to secondary care and following discharge).

Methods:

- Study setting:
 - Edinburgh Centre for Neuro-Oncology, Western General Hospital, Edinburgh;
 - The Centre covers the population of 1.25 million people.
- Sample:
 - Sub-specialty patient database from 2000.
 - **Inclusion** criteria: (1) living; (2) ≥ 16 years of age; (3) a MRI Dx of IMSCT
 - **Exclusion** criteria: MRI images suggestive of IMSCT but alternative diagnoses are made, i.e. demyelination, vascular lesions, myelitis, GBS.

Intramedullary Spinal Cord Tumour Patient Questionnaire: Version 2

Rehabilitation:

15. Did you receive any rehabilitation during treatment or post operatively? Y / N

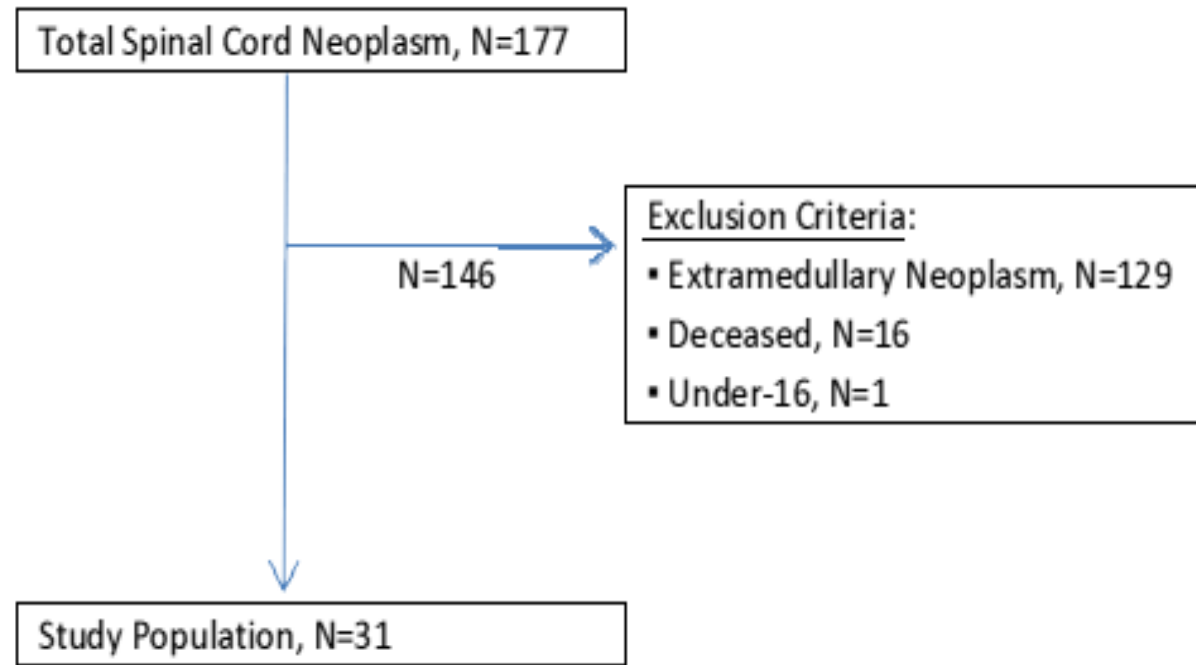
If yes – where and who by?

Any other comments?

We thank you for your time completing this questionnaire.

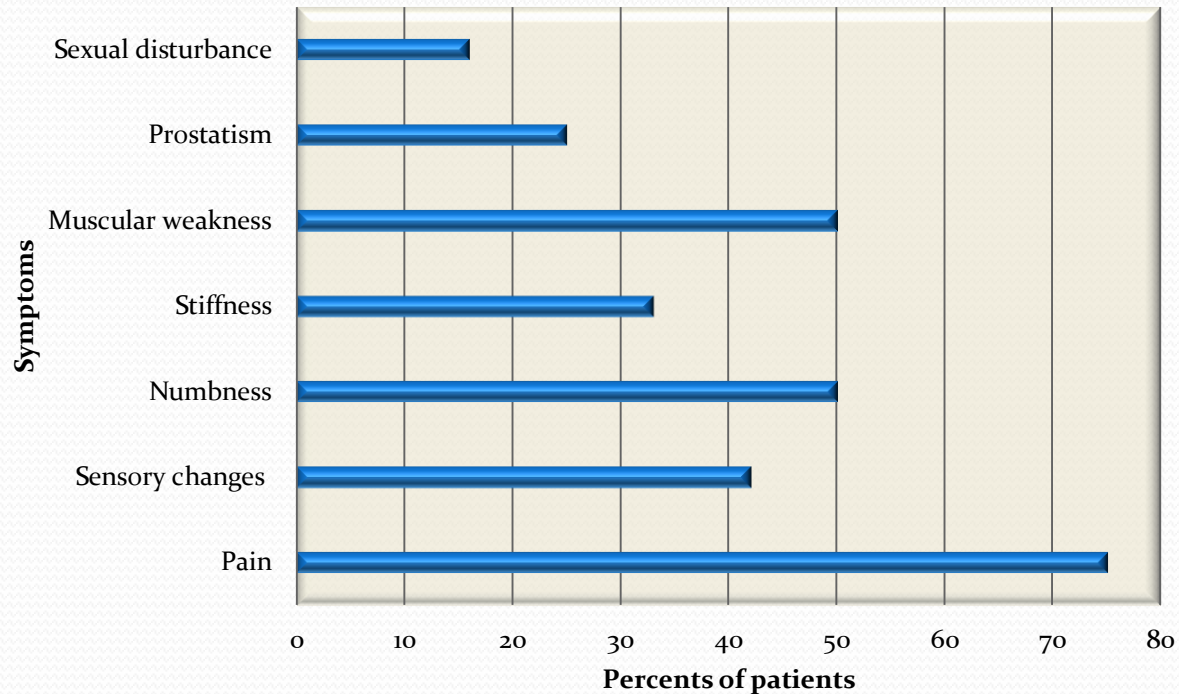
Y/N

Results:



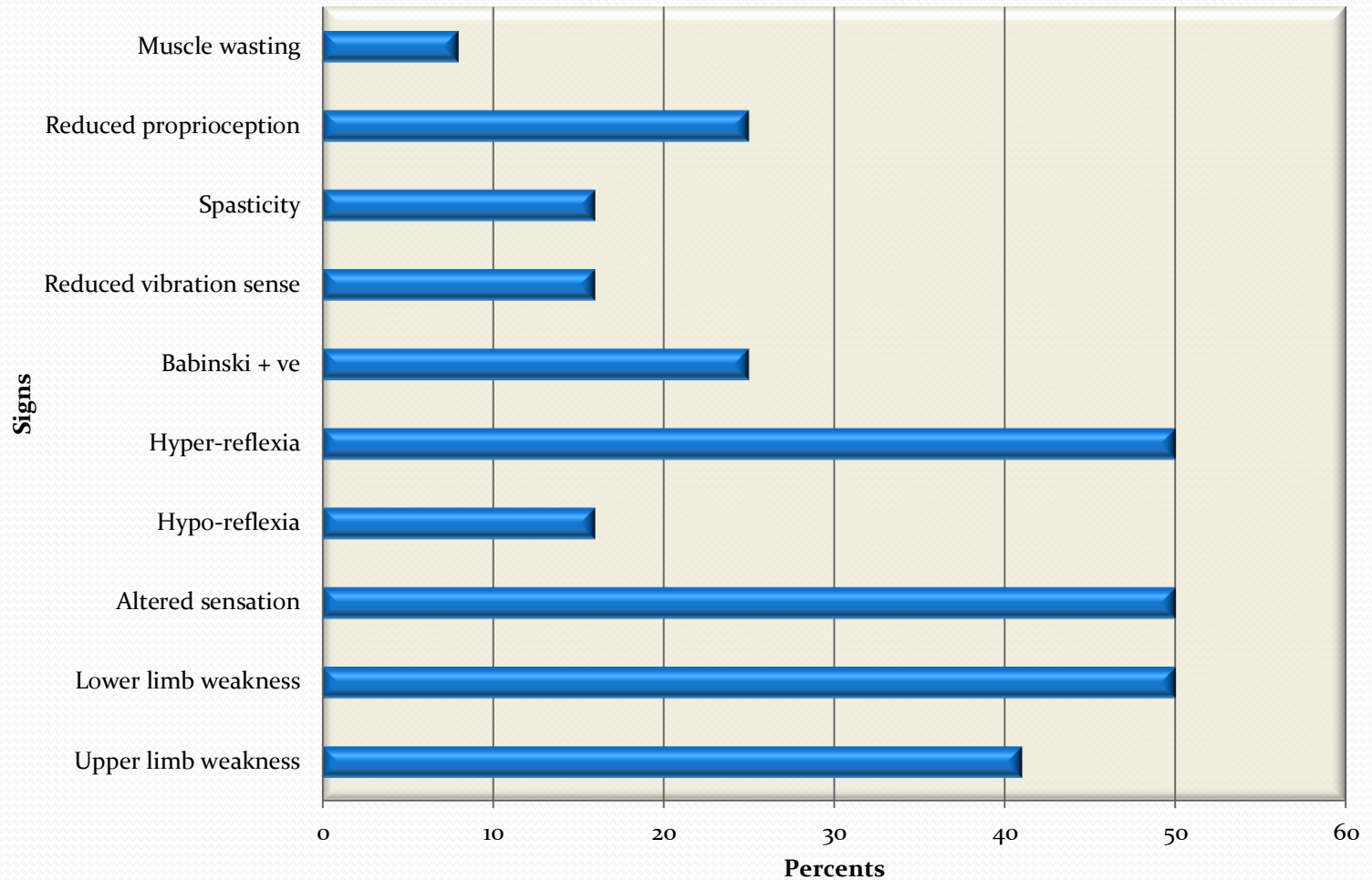
- 12 patients returned the questionnaire.
- 7 males and 5 females.
- age at receiving the diagnosis ranged from 36 to 59, with a mean of 46.1 years
- 6 ependymomas, 3 myxopapillary ependymomas, 1 astrocytoma, 1 haemangioblastoma and 1 probable inflammatory demyelination were histological diagnoses

Symptoms prior to Dx:

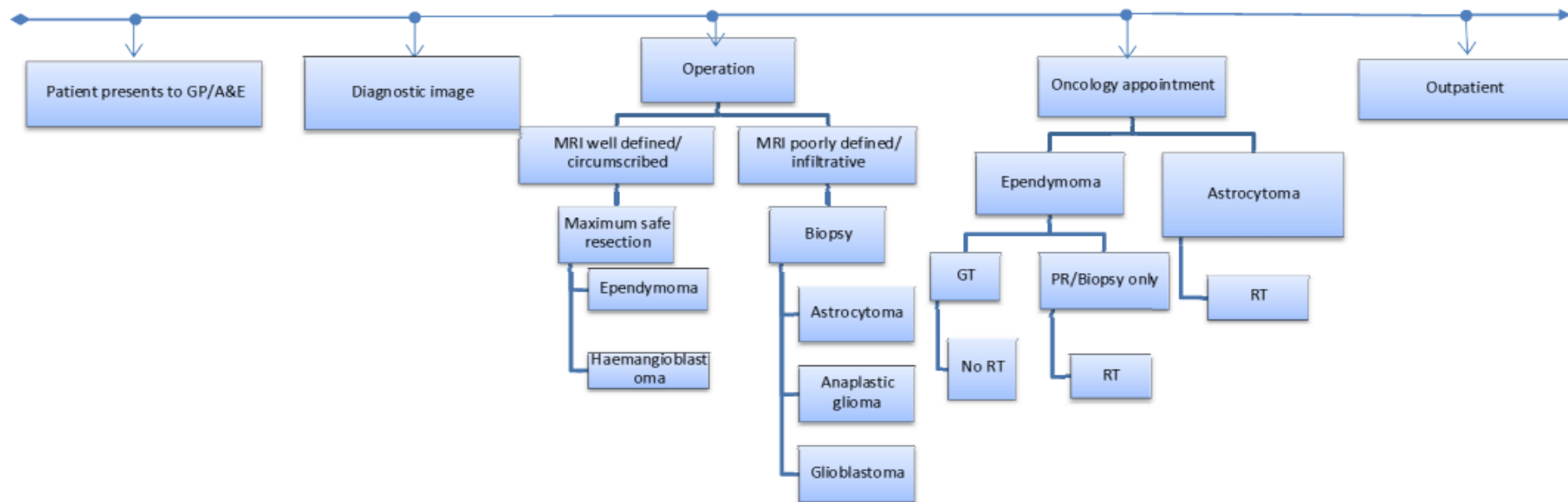


- Symptom duration ranged from 10 days to 20 years (mean 40 months)

Clinical signs (*what a doctor detects*)



A patient's journey:



Duration from GP to MRI Dx:

- Those patients, who presented to their GP with motor +/- sensory disturbances, were referred to a neurologist within a few weeks/months
- Or a recent change in symptom severity > speeded up referral.
- For those patients with a disturbance of predominantly sensory modality, the speed of referral ranged from a couple of years to a few decades.

Patient information needs:

- Patients received inadequate information about the aetiology, risk of recurrence, or complications caused directly by tumour or its treatments

At one time I saw a lot of different consultants and was in and out of hospital partly due to side effects of treatment and medicines. It was a very distressing time, as neither my husband, nor relatives/ friends had enough information to inform and help me. With hindsight I am not sure that enough is known about these tumours or the devastating effects radiotherapy can have. (Patient 2).

- Unfortunately, the great majority of patients did not receive additional information relating to any aspect of their disease other than technical information, eg. *disability insurance, benefits, housing and social/psychological support*
- Limited knowledge about charity groups for such patients.

- The majority of patients sought additional information from other sources other than their treating physician. The Internet was the most common and available source. **Yet, no Internet sites were particularly useful.**
- No leaflets were given (as not available through ECNO).
- A few patients searched the WWW for the complementary therapies:
 - *We came across a number of therapies that may be beneficial such as shark cartilage, mushroom 'maitake' – which based on some anecdotal reports were found to reduce the growth of a spinal cord tumour. However these products are expensive as they are required for a long-term use. Also the availability of these things can be an issue. (Patient 8).*

Navigating through the NHS:

- The majority of patients were **dissatisfied** with the service they had received in the Primary Care. – GPs had limited knowledge of the condition;
 - *My GP had no idea what I had and still does not.*
 - *As a GP diagnosis of such a tumour would have been impossible. After diagnosis the GP had very little knowledge of the condition. The time taken from initial GP visit to MRI referral was too long. Further damage or serious health deterioration could have occurred.*
 - *At least 6 GP visits, plus x3 GP visits at home. New pain killers every time. I was in agony for over 18 months, surgery may have been prevented or a lesser operation done.*

ECNO

- ECNO has a specialist nurse practitioner, Shanne McNamara.
 - She was the point of contact should need be (dedicated telephone service, also email); for example:
 - Telephoning the nurse reduced the anxiety, was helping to cope with the disease knowing that if new symptoms developed, the concerns would be dealt with by a professional immediately.
 - Alternatively, patients emailed their questions and concerns prior to a consultation with their physician so that the consultation could then focus around the main issues of concern.

- Frequency of follow-up:
 - Satisfied.
 - Gained reassurance from a clinic attendance.
 - *As long as I was told to come back in a year's time, to me this meant that everything must be ok.* (Patient 4)
- However, patients themselves are more likely to detect tumour recurrence.
 - Large RCTs failed to provide convincing evidence that intensity or form of follow-ups affect survival or QoL.



Thus, essential to explain signs and symptoms to look out for if tumour recurrence!!!

Summary:

- Long symptom duration prior to Dx
- Non specific symptoms – Pre-op status best predictor
- Inadequate informational support:
 - Technical
 - Non technical
- No peer-reviewed written materials available, eg. leaflets, FAQs
- 1/3 relapse after 3 years – a significant morbidity
 - Ψ benefit of follow-up appointments
 - A need for continuous rehabilitation input, not just following surgery
 - Remove obstacles in obtaining information – identify, tackle, treat!

A patient story:

I had experienced pain for nearly 2 years before the tumour was discovered ...the pain would come and go in my lower back and legs but in aug 2011 the pain stayedthis is when I first went to doctors ...I was sent for a spinal x ray ..nothing showed up ...I went back to doctors again, this time was sent for an ultra scan ...nothing showed up ...in dec 2011 ...I went back to doctors and complained and said I was not happy as the pain was a lot worse and was now in my feet as well and I could not walk without pain ...was referred to ABCD Hospital...trauma clinic appointment was 28th Feb 2012 ...within 5 mins of being examined they told me the signal from my brain was not reaching my legs ...had MRI on 8th march 2012 and was called up to hosp on the 9th march 2012....and told I had a tumour on the lower part of my spine in side spinal canalhad operation on the 10th april 2012 ...and was told my tumour was an ependymoma I was given no information at all on the tumour....my consultant said lose some weight...

Cont.

when I met with the consultant prior to my operation the only information I was given was that if I did not have the operation to remove the tumour I would be paralysed from the waist downhe said he was 99% certain the tumour was benign ...but would know more when it was removedhe wrote down every thing that could go wrong as a result from the surgeryhis manner was abrupt and he was more interested in the fact I was overweightI felt intimidated ...and felt I could not ask any questions ...it was sign this consent form and I was dismissed... the day after my operation he walked in the ward in front of my sister and said ..your tumour was not what I thought it was ..its at the lab u will get the results in 4 daysthen he said lose some weight and walked off ...4 days later he came back on the ward....he said your tumour produces seedlings so there is a chance it can come back and you can get a brain tumour if it does ...then he said lose some weightI didn't feel able to ask any questions because I felt so ill after surgery and was in shock when he mentioned the tumour could come backI don't feel it was ever explained to me why the tumour can come backI was never told how the outcome of the operation could change my lifefor example ...not ever being able to return to workbeing in more pain after the operation than before the operation ...it was never explained how it could effect my life emotionally ...the fact I would suffer from depressionand feel like life was not worth livingand wanting my old life back but knowing it would never happenI was never told about the impact it could have on my life ...not just physically but emotionally ...I was given no information on how I would manage financiallyI was given some information from the macmillan nurses but the rest I had to find out from friends and family and the internet ...

Glossary

- Extradural – outside the dura mater of the spinal cord. These are usually metastatic from other sites of origin eg prostate
- Intradural extramedullary – these arise within the dura but outside the actual spinal cord tissue eg meningioma, schwannoma
- Intramedullary – these tumours arise within the spinal cord itself.



Thank you 😊