

Benign Spinal Cord Tumours- Survey February 2010

Below are the comments made by the people who have completed the Survey

No	Type of tumour and location	Treatment	Symptoms pre op	Symptoms post op	Rehab	Medication	Additional comments
1.	Ependymoma, L4		Nerve pain in legs	Nerve pain in legs	Radiotherapy, reflexology/osteopath/physio		
2.	Ependymoma, C7 to brainstem	Inoperable. No plans for surgery later				None	
3.	Intramedullary Ependymoma, C6/T2		Minor 'muscle' pain, then 2 weeks severe pain in back	Balance issues, loss of sensation in legs and feet, some nerve pain	Physiotherapy, acupuncture	Gaberpentin – beneficial in reducing the nerve pain experienced in two fingers	Thanks to a very skilled surgical team I am upright and walking and have resumed my full-time, very demanding employment
4.	Myxopapillary Ependymoma, T12/L3		Foot drop, hip pain, falling over	Backache, chronic fatigue	Physiotherapy	None	
5.	Intramedullary Ependymoma, neck	Tumour partly removed	aching in arm, losing balance, numbness in fingers	Tumour re-growth, will have surgery later	Radiotherapy	None	
6.	Intramedullary Ependymoma, T12/L1	Tumour partly removed, not grown again	Foot drop right foot, bladder and bowel dysfunction, left foot numbness, sciatica	Sciatica greatly lessened, still have remaining neurological difficulties	Physiotherapy for 9 months	None	Still experience back soreness, some days better than others, have MRI every 12 months to

							monitor possible re-growth and drop lesions.
7.	Schwannoma, L4		Lower back pain, pain down both legs, worse in left, tingling sensations in buttocks and left leg	Numbness in left foot, problems with bladder sensations, pain in lower back, tingling in buttocks and legs	Physiotherapy	Occasional pain killers	
8.	Intradural extramedullary schwannoma, T7/8		Started with pain in right side/back which spread to whole back and was very severe	Pain in the left side of back and some numbness on right chest/side area.	Physiotherapy	None	I would like to say thank you for this site – I have found it very interesting
9.	Schwannoma, Neck	Had surgery in 1970, 1976, 1982, 1992, 2003 for tumour regrowth;	Pain	Severe pain, weakness, numbness	Physiotherapy	Co-codamol, Diazepam, Amitriptyline – If I take as prescribed I may as well spend my days in bed as I am so drowsy	
10.	Schwannoma, C4/C5	Most of tumour removed, no regrowth;	Weakness, loss of balance, numbness in left arm and inability to tell hot/cold in feet	Burning pain right side, leg and foot, aching left arm, loss of balance, tiredness and palsy	Spinal cord stimulators, physiotherapy, biofeedback, acupuncture	Baclofen, Clonazepam, Duloxetine, Imitrex; Medication problems:	Tried many medications with little success and many side effects. Most medications,

						Tiredness mainly, bad interaction between Duloxetine, Baclofen and occasional Imitrex	such as Lyrica and Effexor caused withdrawal when stopping. Spinal cord stimulators failed and caused systemic infection. I suggest healthy lifestyle, yoga and meditation as a successful possibility.
11.	Astrocytoma benign inside spinal cord, in neck	All of tumour removed, except for one cell; Tumour re-grown, but no new symptoms;	back pain and sudden loss of balance		Physiotherapy	None	Had 1 st surgery at age 12, (now age 19), paralysed from stomach downwards but now almost completely rehabilitated. Surgery planned to remove 2 nd tumour.
12.	Meningioma, thoracic		Back pain, burning and tightness in legs, numbness from thoracic region, lack of balance, difficulty walking	None		None	

13.	Neurofibroma, L4/L5		Chronic pain, limited mobility	Numbness, pain, stinging pins and needles	Physiotherapy	None	Off all drugs now, rather be in pain than go near Morphine again! Body was dependent on Morphine as taking so much for so long (6 months).
14.	Hemangioblastoma, T3/T5		Numbness in left arm/hand, pain within abdomen, reduced mobility of motor functions	Burning left arm, hyper-sensitivity on chest and abdomen, lower right back pain, numb right foot and calf, poor balance, stiff neck	Physiotherapy, reflexology, acupuncture	Gaberpentin, Tramadol, Codeine.	None seems to really work
15.	Hemangiopericytoma, T5		Gradual paralysis from below chest	Disability right leg and foot and lack of sensation below chest	Physiotherapy	Oxycodone – very effective for severe pain	
16.	Type of tumour not known or stated Location: L1/L4	90% of tumour removed, another tumour being treated by radiotherapy;	Pain in back and down legs		Will have physiotherapy	Cocomanal, Dilflocec – Getting loads of cramps in legs and my bottom is totally numb on one side.	Doctors thought I had a disc problem until I had an MRI scan
17.	Type of tumour not known or stated Location: T5/T6		Pins and needles in hands	Still have the pins and needles in hands	None	None	

