

Benign Spinal Cord Tumours- Survey February 2011

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

People who have had surgery:

No.	Type and location of tumour	Surgery	Symptoms pre op	Symptoms post op	Treatment since surgery	Medication	Additional comments
1	Ependymoma C4-C6 Intramedullary	Surgery in 2003 All removed, leaving only syringes; has not grown again	Initially neck and back pain, nausea and vomiting, then pins and needles in arms, and constipation followed by severe neck/back pain, weakness and neuralgia in arms and legs until I could barely walk or use my hands.	Initially, severe neck/back pain, fatigue, weakness, reduced sensation in hands/feet, poor balance, tinnitus, muscle spasms, tingling in hands/legs. Now all above remain to a lesser degree apart from pain, tinnitus and fatigue which can still be bad.	Physiotherapy, OT initially. Tried acupuncture for pain (under duress!) but it was nonsense.	Amitryptaline nightly and Ibuprofen, Paracetamol, Codeine as required. If I forget to take Amitryptaline the neuralgia can be unbearable. Side effects of this drug through blurring to vision.	My condition goes up and down but once I start to feel unwell or tired all my symptoms increase dramatically. I hold down a full-time office job, but it is a struggle. Just one day without any tinnitus or pain would be a luxury.
2	Schwannoma C6/C7	Surgery in 2010 Almost all removed	Pain in arm/hand/legs. Pins and needles in hands, feet, face and parts of my back and neck. Headaches and insomnia.	Pain in arm, hand and fingers. Numbness in hand and arm. Leg pain and neck stiffness. Pain at the site of surgery. Electric like shock pains in arm/hand and legs. Weakness in arm/hand and same side leg.	Physiotherapy	Neurontin, Morphine and sleeping tablets. Neurontin made me gain weight, but have managed to lose most of it in past 2 months.	
3	Neurofibroma (isolated) T3/T6	Surgery in 2008 Part removed,	Great difficult walking, inverted left foot, bilateral pins and needles (particularly in the feet),	Severe chest pain (now felt in the right side as the rest is numb), muscle cramps and tightness in	None	None	

		has not grown again	burning pain in calves, loss of balance, numbness, severe chest pain, 'tight' pain around waist/ribcage, constipation, urine retention.	stomach, chest and ribs, numbness in upper back, left chest and underside, coccyx and right foot, pins and needles in the hands, constipation.			
4	Neurofibroma C3/4/5	Surgery in 1993 Part removed, has grown again I've had two surgeries and am about to have a third	Left sided neuropathy leg and arm. Incontinence (urinary), sexual dysfunction, numbness of both hands and various areas of torso. Neck and shoulder pain.	Increasing paralysis of left arm. Weakness of left leg, neuropathy in both legs. Pain in shoulder.	Physiotherapy, acupuncture, Bowen technique	Occasional Carbamazepine	
5	Ependymoma C2/C5 intramedullary Grade 2	Surgery in 2004 Most removed. has not grown again	Tingling pain, right upper limb. Increasingly more difficult to hold pen to write as time progressed. Heightened awareness of heat in right hand when picking up pan lids, etc. Lacking sense of touch.	Paralysis for several weeks. Rehabilitated to walk again. Still only able to walk short distances without support. Brown-Sequard Syndrome, Hands most debilitated, particular fine motor control.	Four months rehabilitation on spinal ward, physio for six months, following in short blocks.	Amitryptiline 25/50g per night. Tramadol 50g per night, Paracetamol /Ibuprofen as and when.	
6	Myxopapillary Ependymoma L1/L4	Surgery in 2004 All removed, has not grown again	Severe back pain, sciatica, pain passing stools, difficulty and pain walking and driving	Numbness at base of spine and in buttocks. Severe constipation for 2 weeks, tiredness.	None		Excellent pre- and post op care from NHS
7	Schwannoma T8	Surgery in 1989	Pain behind front lower ribs on left side	Tired shoulder/back muscles	Physiotherapy I now swim and	Paracetamol occasionally	I had my 1st surgery in the States and don't

		All removed (I think all), has grown again. Not had surgery for new tumour only just diagnosed. I now have pains in left foot.		Not had surgery for new tumour only just diagnosed. I now have pains in left foot.	practice yoga and Pilates, plus walking		know who is best to see here. Only seen rheumatologist so far.
8	Epidermoid T11/L2	Surgery in 2008 Part removed, has not grown again	Weak legs, numb foot, balance problems and hesitate in urinating	Slight numbness in foot.	Physiotherapy		
9	Astrocytoma C1/C5	Surgery in 2005 60% removed, has grown again	Very stiff and painful neck and shoulders	Weakness in left hand, neck pain, neck dropping to one side.	Physiotherapy, use of a neck brace Surgery to re-straighten vertebrae, disrupted when resecting tumour in cord. One year of chemotherapy. Further resection of tumour, radio, two further drains of a cyst that remains which was causing pressure symptoms in the area underneath the brain stem.		Just wish to note that the main problem now is not solid tumour, but the cyst within the tumour remains as it is attached to motor and parasympathetic function. It has been drained twice.
10	Ependymoma T5/T6	Surgery in 2009	Problem with leg muscles in right side, strongly affecting my	Problems with dorsalflex action and hip flexers in right leg. Loss of feeling	Physiotherapy	Lyrica 75 mg, Cymbalta 60 mg. Just started Baclofen 10	Live every day to your fullest.

		All removed, has not grown again	walking and everyday movements. It was an effort to lift my leg to put on a pair of socks in the morning.	in left leg, starting to come back. I walk with a cane and a brace for my right leg. I have a tightness all the time around my mid section, and now it is starting to drop.		mg. The Lyrica and Cymbalta seem to help with the tingle feeling and day to day living with the tightness	
11	Ependymoma, grade 2 C7/T3	Surgery in 2009 All removed (as far as I'm aware). Don't know (if grown again), having another MRI	Numbness in lower back and left thigh and sensory problems feeling temperature	Numbness and sensory feeling from my chest down to my feet	Physio in spinal unit and having Reiki	Diclofenic (now stopped)	Have been feeling really emotional lately and worried that I won't get feeling back.
12	Chordoma Neck C2	Surgery in 2005 Part removed, has grown again. Had another op on 19.8.2010	None	Numbness on left side, deafness in left ear, weak left leg	Cobalt 60 radiotherapy Physiotherapy	Pregabalin 75 mg Helps with sleep	Had to wear a halo vest for 9 months. I think I was misdiagnosed in 2004.
13	Cyst Nervous system top of spine	Surgery in 1995 Cyst was drained, not removed	Very bad headaches	My nerves have been affected in my hands and feet and neck is not very flexible	None	Amitryptaline and Co-codomal	

People who haven't had surgery:

No.	Type of tumour and location	Date diagnosed	Symptoms	Reason for not having surgery	Surgery at a later date?	Medication	Additional comments
14	Astrocytoma Neck	January 2008	Tickly right forefinger, less well-developed muscle on right hand side, poor circulation to right hand – results in extra layer of skin on palm.	Position of tumour means that surgery or even biopsy could paralyse me	No	None	
15	Not yet diagnosed C6/C7	October 2010	Upper left shoulder/back pain that radiates to left arm and fingers. Minor loss of muscle strength on left arm.	Just diagnosed. Neural surgeon recommended observation for 3 months and get another MRI before deciding to do surgery.	Yes	none	
16	Not sure, possibly Astrocytoma C1/C3	December 2009	Biceps clamping up, pain in hands, very poor grip, neck cracking and severe pain when waking in morning	Far too dangerous. High percentage of full loss of body.	No	Diazepam, Amitryptiline, Co-codomol Very good for pain control.	
17	Astrocytoma or Ependymoma T6	November 2010	Upper back of chest across back area aching in night and first thing in the morning. Problems with aching hands and pins and needles in arms at night.	Specialist due to see me again in 6 months to monitor situation after full brain and spine mri scan. Was informed too risky to even try to get a biopsy of it.	Yes	Diclofenic and Paracetamol. Most painkillers seem not to make any difference. Am taking Diclofenic for lower back problem. No medication seems to help.	Any offers of advice or support as I have 2 issues, lower back disc problems AND an upper back internal spinal tumour
18	Schwannoma L5	November 2010	Weakness, numbness, burning sensation, pins and needles in left hand, buttocks and left and right	I feel the risks versus the pain are too high at the moment and can deal with the pain for now,	Yes	Amitryptiline. Makes me even more tired	This forum is fantastic and has been such a help

			leg, though left is much worse, pain in hips, tiredness and exhaustion, restless sleep.	especially as pain may still be there post op.		during the day but does help a little to relax at night	for me and my husband, family and friends, and has helped me to make an informed decision about surgery! Thank you all
19	Probably Ependymoma. Maybe Astrocytoma C5 syrxinx at C7	January 2010	Sometimes my left hand and arm feel weak, but they haven't lost their strength. It's only the feeling. My feet feel numb from time to time and sometimes my right leg or both hurt. But everything is endurable so far.	Because my symptoms were very slight. An occasional tripping on my right foot. The finding was unexpected. They were looking for a hernia in the neck. At the end the stiffness I'd been suffering was due, mostly, to the stress, but the tumour was there.	Yes	None	
20	Neurofibroma Neck C2/3/4	January 2011	Sore neck. Partial numbness and tingling sensations in hands, right arm and part of torso.	Urgent but not an emergency. Expecting op to happen in March 2011. Awaiting date.	Yes	None	I have been told that without surgery I will be completely paralysed, possibly unable to breathe, within a year.