

## Benign Spinal Cord Tumours - Survey - February 2012

Below are the comments made by the people who completed the survey:

	Type of tumour	Location	Year of surgery	Symptoms pre-surgery	Was all tumour removed	Has tumour grown again	Symptoms post-surgery	Radio-therapy	Treatment / rehab	Medication	Additional comments
1	Ependymoma	L2-L5	1997	Loss of feeling in legs. Severe lower back pain and pain around hips. Some loss of bladder control when the tumour was more mature.	Yes	No	Loss of some feeling in my left leg/foot which has never come back since the op 14 years ago.	Yes	Intensive physiotherapy	None	I was visiting my local hospital for 2 ½ years before being offered an MRI scan which showed the tumour up straight away.
2	Schwannoma	T8-T10	2010	Severe pain on right side of rib cage, numbness to soles of feet and heavy, weak legs.	Yes	No	No major pain, some heaviness in rib area, legs and arms when tired or overdone it.	No	None	Occasional Paracetamol	
3	Ependymoma	L1-5	2007	Severe back pain, numb legs and feet, no bladder control, weak legs.	Yes	No	Numb feet, pins and needles, weight gain, constant back ache.	Yes	Physiotherapy	None	
4	Ganglio Glioma	T12	1993	Left leg went numb and I fell over		Yes	Left leg paralysis, drop foot left, wobble walk, now use a manual wheelchair, awful pain- both nerve and muscle and skeletal, bowel and bladder problems, left foot problems Symptoms now: The same as post-op, but getting worse as it's been 18 years since operation.	No	Physiotherapy	Clonazepam, Imiprimine, Ibuprofen, Co-codamol,	Currently at pain clinic looking for more options to help with pain
5	Atypical meningioma	C1-C5	2000	Pain in neck and shoulder, pins and needles in left arm.	Part removed	Yes Have been told I may have further surgery.	Stiffness, pain, nerve damage. Symptoms now: Pain again, but in right shoulder and arm.	Yes	Physiotherapy; Had conventional radiotherapy plus Cyberknife in Germany	Over the counter medication.	Cyberknife in Germany was really good experience. Bought me 3 years before tumour has shown signs of growing again
6	Ependymoma	C2-C7	2011	Left forearm and toe numbness.	Yes	No	Nerve pain, numbness, weakness, fatigue, fine motor skills (hands), some balance issues.	No	Physiotherapy	Tramadol, Percocet, Citalopram, Colace, Fibre	Lives in the USA
7	Meningioma	C5-T1	2009	Loss of temperature sensitivity, numbness, leg spasticity, leg weakness, cramps in hand, arm and torso pain.	95% removed	No	Neck muscle weakness, weakness in left hand and wrist, occasional cramping in left hand, slight numbness in left arm.	No	Physiotherapy for 6 weeks after op. Went back to gym 3 months after surgery.	None	Lives in Australia 2 years after surgery living normal, active, healthy lifestyle. Constant improvement of left hand, and arm returning to almost full strength. Still occasional cramp in fingers.
8	Neurofibroma	T2	2008	Numbness and burning sensations down right leg, progressing to same symptoms in both legs, then great difficulty in walking and unable to lift legs.	Yes	No	Pain in shoulders, around op scar and in both armpits.	No	Physiotherapy	only painkillers as necessary	Only to thank hospital and staff for all their help and skill.
9	Not known	Lower back	2009	Very bad lower back pains, difficulty walking. Slept sitting upright for 6 months! Cramp in both legs not at the same time, shooting electrifying pains down my leg into the middle of my feet. Had trouble easing my bowels from pain. At times I couldn't move.	95%	Yes Will need more surgery	Slight twinges but 99% pain-free. Symptoms now: My shoulders seem to ache when I wash the dishes, my back aches more often and my legs ache frequently.	Will need to have	Slight physiotherapy for 2-3 days.	None	My tumour has re-grown sooner than expected but at a slow rate. I've been advised an op is very risky and am awaiting consultation on radio/chemotherapy.
10	Dermoid	Near bottom of spine	2011	My toes on left foot curling under and no feeling in foot, loss of balance, legs cramp up	Failed to remove it, just took piece for biopsy		Loss of balance and toes curling under. Your symptoms now: Leg cramps, foot purple, balance worse	No	Physio	Gaberpentine	
11	Meningioma	T5-6	2010	Severe explosive atypical migraines, dizziness, difficulty breathing, severe shoulder as well as ribcage thoracic pain, difficulty walking, bowel/bladder issues, feeling as though I would pass out prior to a bowel movement, numbness through leg and arm.	Yes	No	Severe thoracic pain impeded range of motion involved intensive acqua physio and ot. I have made significant improvements but I am nowhere near normal limits. I suffer from profound, severe, chronic and marked daily pain with compressed spinal nerve roots.	No	I have had physio (mostly acqua therapy) and ot. I receive pain management treatment but nothing helps for any extended length of time. It is severe profound daily constant thoracic pain which involves extremities. I receive thoracic acupuncture which helps get the pain down some. I've also had physio ultrasound core strengthening massage – no help.	Zanaflez, Lorazepam, Glycerin suppositories, Metamucil, Ibuprofen	Lives in the USA The rate at which the benign spinal tumour was diagnosed for me was lengthy I was misdiagnosed for years until I was unable to walk, falling, dizzy and severely impeded by explosive headaches due to CSF leaking out around my meningioma. It was horrific.

12	Ependymoma	Thoracic spine	2010 (diagnosed in 1997)	Increasing pain, some loss of balance	Part – biopsy	Yes	Chronic severe pain, difficulty sleeping, exhaustion, dead leg and back, curved spine, weak back, bowel and bladder problems, poor balance, walking impairment.	No	Neurodynamic physiotherapy helpful to free up stiffness and to ease movement. Efforts at pain control so far ineffective	None. Previously tried Gaberpentin, Pregabalin, and Ketamine without success. Could not tolerate side effects of Amytriptiline.	
13	Maxipapillary Ependymoma	Conus L1-L2	2012	Difficulty urinating, muscle wasting right calf, lower back pain	Vast majority	No	Too soon to tell, for the most part same as pre-op symptoms with a slight improvement in calf strength and urinating.	No	Acupuncture	None	Other than 3 month MRI booking and histology results I have had no real follow up or guidance.

**Below are the comments from people who have updated their previous surveys:**

	Type of tumour	Location	Year of surgery	Symptoms pre-surgery	Was all tumour removed	Has tumour grown again	Symptoms post-surgery	Radio-therapy	Treatment / rehab	Medication	Additional comments
14	Schwannoma	1 <sup>st</sup> tumour T8, 2 <sup>nd</sup> tumour L3/4	1989 & 2011	1st – pain under left ribs, 2nd - pains in left foot	1 <sup>st</sup> and 2 <sup>nd</sup> – Yes	Yes – 3 <sup>rd</sup> small tumour remaining	Numbness at the site of pain and in other areas. Itching near this	No	Physiotherapy	None	
15	Ependymoma	Lumbar and sacral	2007 and 2009	Back and leg pain	Most removed 1 <sup>st</sup> time, 2 nodules removed at 2 <sup>nd</sup> op and now controlled after radiotherapy.	Yes, after 1 <sup>st</sup> op	Leg pain (though not like before), numb foot and leg, backache	Yes	None. I did a lot of exercise classes to build up my leg muscles	None	Great to have a site where sufferers can chat about symptoms etc. The surgeons and oncologists are great, but they have not had the experience. Good to know you are not alone.
16	Schwannoma	C1-C4	2011	Neck pain and sensory issues which began in hands and then progressed through most of upper body. Sensory issues included hands feeling very cold but were actually normal temperature. Hands and upper body were losing sense of touch, numb, and I struggled.	In 2011 I had 3 operations. I still have remaining tumour.	No	Sense of touch restored. Accessory nerve injury to right shoulder was a complication of most recent surgery.		Am undergoing neurophysiotherapy for shoulder problems caused by accessory nerve injury	I have found a Tens machine effective with nerve pain management	
17	Unknown, waiting for biopsy results	T1-T5	Year tumour diagnosed: 2006 Year of surgery: 2012	Pain at site of tumour, chronic fatigue, neuropathic pain in forearm, altered sensation and weakness in 1 leg. Buzzing/tingling through legs, small numb patches across the body	Initially I was told it was totally removed then I was told there were small residual 'dots'.	No	Pain obviously from surgery, spasticity, spasms, numbness from chest down but I can feel things in a heightened or altered way, tight band feeling around chest and back. Relearning to walk and balance, but this is 4 weeks post op so early days!	No	Continuing with physiotherapy	Gabapentin, Baclofen, Oxycodon, Tramadol, Diazepam, Duclosate, Myraliax. Comments on medication: If I am late in my dosage spasticity is worse and so is the pain. Early days though post-surgery. It makes me sleepy too.	The immediate post-op MRI was inconclusive. I wait 3 months for confirmation. Initially I was told it was totally removed then I was told there were small residual 'dots'. I also had a syrxn which they drained I can only praise the neurosurgeon and hospital in the US. I had been told my tumour was inoperable but he proved them all wrong. He specialises only in scts. If you can get coverage then it's worth the trip
18	Chondrosarcoma	L1-L2	1996	Pain in leg and buttocks, numbness in feet and inability to move feet and legs properly.	Yes	Yes	Pain, numbness in legs and feet, lots of tripping over and unable to move legs properly	Yes	Physiotherapy, Reflexology, Homeopathy	Was previously on Gaberpentin but wasn't effective and I hated the way it made me feel (like a zombie). Now seeing a homeopath, which works	
19	Not known	Neck	1997	Tingling and burning in fingers of left hand	I was told it had all been removed at time of operation, but just found out that a small area remains.	No	Tingling and burning in left hand and wrist, also left shoulder. Some numbness down left side of body. Neck left sloping forward and difficulty holding my head up.	Yes	Small amount of physiotherapy	Amitriptyline and Co-codomol	
20	Hemangioblastoma	T3-T4	2006	Stiff neck, burning arms and chest. Loss of motor functions in left arm, jumping legs, burning feet, numbness in left arm and chest. Dramatic weight loss.	Yes, but damage left to spinal cord and nervous system.	No	Extreme burning and hyper-sensitivity to left arm, chest and lower right back. Numb, weak right foot, ankle and calf. Shooting nerve heat up and down spine. Limited movement in back and general constant pain.	No	Physio, ultrasound, tens, acupuncture, reflexology	Lidocaine patches, Gabapentin, Remedine, Was able to recover from Tramadol and drop anti-depressant	Hate having to be completely dependant on medication. Physically cannot function without meds.
21	Astrocytoma	C3-C6	1990 and 2001	Weakness in legs, bladder problems, pain in lower back	Part	No	Severe weakness in legs, altered sensation below waist, severe pain Symptoms now: Weakness in legs, poor balance, neuro pain, tiredness bouts.	Yes	Physio	Amitriptyline, Lyrica, Tramadol, Codeine	Had 2 tumours 1990 and 2001 but now only have to have 2 yearly scans Comments on medication: Tiredness problems with constipation