

February 2009 : This attachment shows the actual comments made by the people who completed the survey – we hope you find the information useful.

.No	Type of tumour	Symptoms pre op	Treatments and Rehab	Symptoms post op	Medication	Comments
1	Ependymoma	Loss of use of fingers, severe neck pain	Radiotherapy and physiotherapy	Difficulty walking, neuro disturbances Walking affected, recently become much worse. I walk with a stick. Balance not good. Loss of some feeling in legs and feet. Am constantly tired. During op had laminectomy in neck. This affected posture and I can't stand straight. This gives me frequent backaches.	I have taken Baclofen (a few years apart) gave up due to side effects	
2	Schwannoma	Severe neck pain, loss of control of right hand side of body. Sleeping difficult, bowel problems	Physiotherapy & acupuncture	Nerve root lost in op. Damage to right hand and arm. Weakness in left hand. Sensations in legs and feet. Balance problems	Mainly Amitryptiline (at night for 5yrs) and Diclofenac (still take occasionally)	As I found most medication made me feel unwell – now try and listen to my body and stop activities when pain starts or moving position.
3	Not known	Tingling, burning in left hand especially fingers	Radiotherapy, physiotherapy	Tingling and burning in left side at lesser level. Some numbness, Balance not good	Co-dydrammol and Amitryptiline. No bad effects	
4	Ependymoma	Nerve type throbbing pain in back and legs	none	Nerve damage to foot and buttock at lesser level. Back	Co-codamol when pain is bad. Was on Tramadol – had symptoms weaning	It is good to be able to write about what has happened to me (us) as it

				pain (ache) Constipation	myself off this drug (breathless and sickness)	seems difficult for others who haven't been through it to understand
5	Pilocytic Astrocytoma	Loss of sensation, back pain, muscle weakness, stumbling	3 months rehab, physio, aromatherapy and massage	Some paralysis, neuropathy, spasms, stiffness, tiredness	Amitryptiline. Side effects: feeling tired and loss of function	
6	Ependymoma	Numbness in left toe, tingling sensations in neck and face	Hydro-therapy, Physiotherapy, sports injury massage and acupuncture	Partial lack of sensation from chest down, especially feet, weakness in arm and shoulder, back ache	Pregabalin daily, Co-dydramol or Co-codamol as required. Was on Gabapentine And advised to change to Pregablin but still side effects: tiredness and unable to concentrate	I don't know what I would have done without this website for support an information and would like to thank you for all the work you put into it
7	Mesenchymal Chondrosarcoma (benign)	Pain in lower back and numbness and weakness in left leg	Physiotherapy	Numbness in left foot and leg, unsteady on feet on uneven/ slippery surfaces	none	
8	Ependymoma	Severe back/hip pan, floppy right foot, difficulty walking, night fevers and severe burning pain, bladder dysfunction	Physiotherapy	Loss of feeling to parts of left buttock, leg and outer foot. Pain in operated area, bowel and bladder dysfunction. Upper abdominal pain, slow digestive system. Tiredness. Odd nasty shooting pains and odd sensations. Night fevers	Painkillers as required. Lying down and resting has a better effect on my pain since my operation	
9	Meningioma	Numbness. Spasticity	Physiotherapy (2wks)	Paralysed 50% down right hand	Lodine, Co-codamol	

				side, mobility and bowel problems. Cannot use right hand.		
10	Ependymoma	Foot drop, hand spasms, pain in arms, problem walking	Physiotherapy	Pain in hands and forearms, hand spasms, crackles in legs, 50% numb from breast bone down, difficult with fine motor skills in hands (especially when cold)	Amitryptiline, Gabapentin, Paracetamol. Tablets don't help that much	
11	Intramedullary	Back pain	Physiotherapy, leg and knee brace, acupuncture	Less mobility, more pain, more disability	Morphine slow release Amitryptiline, Gabapentin, Baclofen, Oxynorm liquid, Co-codamol. Tablets keeps pain bearable most days but effects of medication is disabling: tired, bad memory, slow reactions, disturbed sleep	
12	Meningioma	Numbness and tingling in feet and legs	Physiotherapy	Numbness, weakness in legs and upper body	-	
13	Intradural extramedullary paraganglioma	Chronic back pain, worse lying down, numbness in does, walking gradually worse in last few	Physiotherapy for a few months	Weakness in right leg	none	Although diagnosis and surgery was traumatic the end outcome was positive as chronic back pain resolved by surgery

		months				
14	Ependymoma	Muscle twitches and spasticity. Weakness. Stiff leg muscles. Overnight neck pain.	N/A	No operation	Ibuprofen (400mg) and Tizandidine Hydrochloride. The latter controlled muscle twitches and lessened spasticity	
15	Hemangioblastoma	Weakness in legs, crawling sensation in back, legs and arms. Pressure pain from back into chest. Fatigue	N/A	No operation due to location	Amitriptyline, Diclofenac, Duhydrocodeine	Have been told tumour unchanged but symptoms are progressing.
16	Possible Astrocytoma or Ependymoma (opinion divided)	Chronic pain in back. Hypersensitivity in right forearm, numbness and tingling in right breast and feet	N/A	Tumour tangled up – operation too risky	Tramadol (300mg) and BuTrans skin patch (20 micrograms)	I had waiting. I feel like stuck between a rock and a hard place. I have been told surgery may not help pain and even make me worse but in the meantime I wait to get worse before I have surgery.
17	Ependymoma	Weak leg and foot drop, pins and needles	Physiotherapy, hydrotherapy, botox	Left leg paralysed	Baclofen. There is the benefit that spasms reduced.	Although paralysed after the operation, now walking with sticks and good quality of life. I know I will get on better with positive thinking and a lot of hard work.
18	Intramedullary tumour	Weakness in right leg, pain in leg, leg stiff and tight.	Small amount of Physiotherapy	Weakness in right leg, pain in leg, leg stiff and tight	Gabapentin, Amitriptyline, Morphine patch, Tramadol.	I have been told they want to try me on a Ketamine infusion . I think this website is good

		Not able to keep shoes on.				and it makes you feel that you are not alone with your pain
19	Intramedullary Ependymoma	Numbness in hands and feet, tripping over. Tiredness	3 sessions of Physiotherapy – 4 mths after surgery	Nerve damage in surgery, still numbness etc., weight gain, tired after 10mins walking.	nothing	
20	Intramedullary Ependymoma	Severe neck pain, numbness of fingers	Intense rehab for 1yr – physio and occupational therapy	Neurological damage, clumsy hands, nerve pain in forearms, poor sensitivity and touch sensation in arms, legs and back. Poor proprioception. Tiredness.	Have stopped all medication	
21	Ependymoma	Stiff and crunchy feeling in neck. Loss of feeling in left finger tips. Neck pain.	Some physio and acupuncture	Pain and stiffness in neck/shoulders. Neuropathy in different parts of the body, bad in left hand and forearm, muscle wastage. C1-C5 fusion means I can no longer move my head. My neck/head has a forward slant to it – cord tethering at the site of surgery – causes pain.	<p>Voltarol (15mg) Pregabalin (300mg) MST Morphine (60mg) (In the past I have been on Tradadol and Coproximal) Pregabalin is a must for me for neuropathy – I find it very hard without it. Have use Gabapetin. MST Morphine is very tiring and can feel drugged at times. Currently need it all for pain relief</p>	

22	Ependymoma and brainstem Syringomyelia	Unable to swallow, sneeze or cry. Numbness in left foot	6mths physio and acupuncture	Continuing pain, muscle spasm	Diazepam. It relieves muscle spasm	My tumour was over 6 inches in length and had a syring attached.
23	Intramedullary Ependymoma	Pain in elbow, arm and hand.	N/A	N/A	Gabapentin and Morphine. Don't notice that Gabapentin is doing any good but morphine helps take the pain out of my hand and arm	My tumour hasn't grown in the past 2 years but the cysts that go with it are increasing. My neurosurgeon may look into widening the spinal cord
24	Ependymoma	Weakness in legs, lack of balance, falling. Pain in back, also in trunk and legs at night. Headaches	Physiotherapy	Back pain, numbness in leg and groin. Sluggish bowels. Fatigue.	Tramadol	I struggle to get any information from the hospital which makes everything more worrying. My operation was cancelled 3 times over a week while I set in a hospital bed waiting for it. No-one even bothering to tell me or stop my "nil by mouth". In the end the operation took 8hrs
25	Intradural Schwannoma	Pain in lower back, bad first thing am, pins and needles in fingers and toes	None	Tired if walk too much followed by pain in lower back and hip area.	Co-codamol, Tradadol, Voltarol. I try not to take anything as I hate the drugged feeling I have when I am trying to work.	
26	Intramedullary Ependymoma	Severe headaches, neck pain and numbness	Physiotherapy and acupuncture	Numbness on left side of body	Nurofen and painkillers from time to time.	Your website is a great help, keep up the good work and thanks.

27	Astrocytoma	Neuropathic pain and tingling in arms and legs – worse in evening. Constipation	Radiotherapy followed by physiotherapy, hypnosis, and after radiotherapy had psychological therapy	Neuropathic pain, numbness in legs and bottom	Amitriptyline (50mg at night) Pregabalin (100mg), Beprenorphine patch (20mcg) Sienna 7.5mgs) Normacol plus. Amitriptyline helped at first then as symptoms go worse tried other drugs but got bad constipation. Not found the ideal pain relief.	
28	Ependynoma	Symptoms only started 3 wks before surgery. Numb feet, legs and moved up the body.	Radiotherapy, physio, acupuncture, reflexology, pilates.	Very tired, pain the upper shoulder and back. Mobility problems (latter slowly improving)	Oxycontin, Gabapentin. Took a long while to fin the correct tablets and level of dose. Worth being open minded and keep asking questions	It is a long slow process but listen to your body. It is so rare that no one knows the outcome and you have to handle your tumour your way. Don't take "no" for an answer.
29	Intramedullary	Mild neck ache at D7/8 and burning in both hands	N/A			
30	Never named (benign tumour)	Loss of sensation in legs/hands/torso	None	Same as pre surgery plus neuropathic pain	Pregabalin 50mg, Butrabs 1pmcg patch Previously Amitriptyline, Dothepin	Nothing really takes the edge of the pain. Suffered fatigue, drowsiness, difficulty concentrating, dry mouth. But I can stand and walk (after a fashion) drive and work full time. I have adapted and concentrate on what I can do.

31	Myxopapillary Ependymoma	Sore back, stiff legs, knees locking up and bladder problems	None	none	Tradadol – works wonders but makes me dizzy and I don't sleep well	
32	GCT Osteoclastoma	Lower back pain/partial paralysis	Radiotherapy – full dosage (twice)	Partial paralysis and numbness of legs, progressive leg weakness	None	Progressive weakness in leg. (MRI and CT unable to help more)