ECNO
Edinburgh Centre Neuro-Oncology

Living with a spinal cord tumour: Post operatively

Synopsis:

- Living with a spinal cord tumour post-operatively
  - Fatigue, sleep, pain, spasticity
  - bladder, erectile dysfunction
- Role of neurological rehabilitation
  - “What can I do now?”
- Peer-reviewed web sites

Managing fatigue…

- One of the most common side effects of tumour itself, surgery, meds.
- Don't dismiss it – talk to your doctor, why?
  - Anaemia, or infection can be the underlying cause
- Simple steps how to manage fatigue:
- Fatigue: simple steps:
- Stay active as you can. But exercise should be done in moderation, and not to the point of exhaustion. Walking is an exercise that has been found helpful in various cancers as well.
- Have a rest: if you feel like napping, do so for 30-45 mins, but don't overdue it, as it can disturb your sleep cycle at night. (about problems of sleep we will briefly discuss later in the talk)
- Be practical about fatigue: think: what can I do, how can I adjust? Basically plan ahead; don't be afraid to ask for help at home etc. Or do not stand when you can sit, adjust your environment… Etc etc…
- Eat well and drink plenty of fluids: have small regular meals; have carbohydrates (pasta, fruit and whole grain breads) provide long lasting energy reservoir. But if you have poor appetite, eat plenty of fruits and vegetables.
- Consider a trial of amantadine 200mg OD

How do I know if I have insomnia?

American Academy of Sleep (2005) criteria:

- Complaints of difficulty initiating sleep, maintaining sleep, or waking up too early
- Sleep difficulty occurs despite adequate opportunities for sleep
- At least one of the following during the day:
  - Fatigue
  - Difficulty concentrating or remembering
  - Difficulty interacting with others or completing work
  - Irritability
  - Decreased motivation
  - Daytime sleepiness
  - Headache or problems with stomach or bowels
  - Worries about sleep

Management strategies for insomnia

- Sleep hygiene

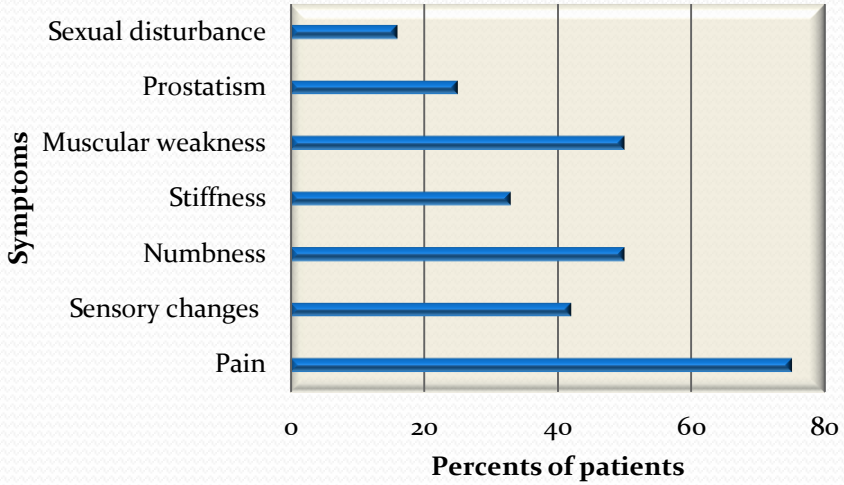
Principles of sleep hygiene

- Don't go to bed until you feel sleepy
- 20 minute 'toss and turn' rule (if you aren't asleep in 20 minutes, get out of bed and do another relaxing activity for 20 minutes then try to go to sleep again
- Avoid excess day time naps
- Establish regular day time routine
- Reserve a room for sleep only (if possible)
- Avoid caffeine, alcohol and nicotine, coca cola drinks etc
- Have a warm bath and a warm milky drink at bedtime
- Take regular exercise but avoid late night hard exercise
- Monitor your sleep with a sleep diary

- But SE: amnesia, daytime somnolence, decreased vigilance

Management of pain

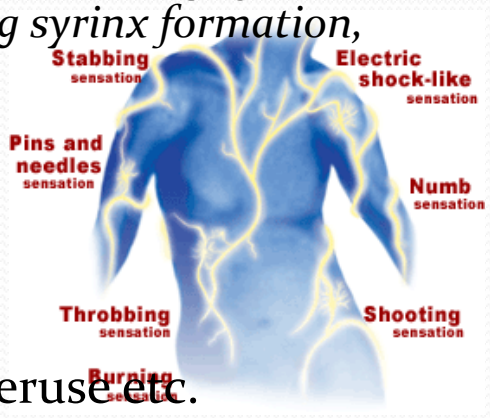
- Remember my previous presentation on symptom prevalence?



- Pain was the most common presenting symptom, with over 70% of patients complaining of it

- Neuropathic pain (aka stabbing, burning or tingling)
  - Impaired 'communication'
  - Impaired communication between the nerves which were damaged by the spinal cord lesion and the brain. In neuropathic pain, basically, it means that the brain misunderstands the afferent signals from around the area of the spinal cord the injury ocurred and results in pain sensation from the area below the level where otherwise patient has little or no sensation at all. So this is why a patient can feel neuropathic pain in an area which otherwise has no sensation or has only numbness.

NB: if pain starts months/years after the surgery (or the nature and severity of it suddenly changes), this may be due to a new medical problem eg syrinx formation, tumour recurrence.



- *Musculoskeletal pain*
  - *Problems in muscles, joints and bones*
  - *Back and neck pain – common in those with spine fusion*

  Musculoskeletal pain due to muscle injury, strain or overuse etc.

  Back and neck pain: in spine fusion, as increased motion occurs above and below the fusion.

- *Muscle spasm pain*
  - *Occurs when muscles and joints are strained from spasticity*

Pain management: caveats

- Pain reduction of at least 30% is generally accepted to be clinically meaningful result.
- Coexistent depression / anxiety
- Interdisciplinary therapeutic approach

- Coexistent depresson and anxiety may hinder the pain management and should be identified and treated accordingly.
- Interdisciplinery: pharmacological and non pharma ie Cognitive Behavioural Therapy, physical and occupation therapy (to help with splint, home aids and devices etc).

Bandolier

"Evidence based thinking about health care"

Complementary and Alternative Therapies

This site is intended to gather the best evidence available about complementary and alternative therapies (CAT) for sufferers and professionals. The principal mechanism will be by searching for systematic reviews and meta-analyses of complementary and alternative therapies, and providing abstracts of them. It contains stories from Bandolier, plus abstracts of systematic reviews, meta-analyses, or other studies about CAT. We are able to do this because of generous initial sponsorship from an unconditional educational grant from the BUPA Foundation.

The nature of evidence

- **Why bogus therapies seem to work**
- **Acupuncture trials from around the world**
- **Why systematic review of homeopathy is absurd**
- **Homeopathy: systematic review of systematic reviews**
- **Bias in critical appraisal - the example of acupuncture for stroke rehabilitation**

Safety concerns

- **Ayurvedic herbal medicines and heavy metals**
- **Ephedra adverse reactions**
- **Homeotherapy and adverse effects**
- **Harm from acupuncture**
- **Herbal therapies and safety**

For add-on benefit:

- Get treatment for other medical problems
- Physical exercise: advice from physiotherapist
- Reduce stress, distract yourself
- Keep a record of pain
- Do not self-medicate with alcohol

Remember: chronic pain is not hopeless. Try various strategies, try not to be discouraged if one treatment does not work. Often neuropathic pain is difficult to treat, and a complex approach is to be taken.

A complete pain relief may not be possible, living better despite pain is a realistic goal.

- Overall health can have a big impact on pain. Urinary tract infections, bowel problems, skin problems, sleep problems and spasticity can make pain worse or harder to treat
- Doing regular physical exercise can reduce pain as well as improve mood and act as a distractor.
- Keep a record : record what makes pain worse/better

Erectile dysfunction

Bladder dysfunction

- Reflex bladder vs flaccid bladder.
  - Assessment by urologist
  - Medical treatment:
  - Drugs for **urinary frequency**: oxybutinin, tolterodine (act by increasing bladder capacity by diminishing unstable detrussor contraction)
  - For involuntary muscle spasm: diazepam, baclofen, dantrolene
  - Acidification of urine (ascorbic acid or cranberry juice)

- Reflex bladder – UMN bladder, lesion above T12 level. The bladder reflexes are still intact, and so when the bladder is full it may empty automatically. Since the nerves above the sacral portion of the spinal cord are not connected to the brain, the patient will not have awareness of the bladder being full.
- Flaccid bladder, lesion below T12 (LMN bladder): all reflexes are lost and the bladder will have no muscular tone. When overfilled, the dribbling incontinence may occur. Again the patient does not have awareness of full bladder.

The role of neuro-rehabilitation: “what services are available for me?”

- Briefly, what financial support is out there?
- Community services: OT/psychol/counselling
- And lastly, PHYSIOTHERAPY
  - Updates

Financial Help

- **Statutory Sick Pay** (unable to work for <28wk)
- **Disability Living Allowance (now Personal Independence Payment)** (disability >6 mo)
  - Mobility component (£18/wk - £49/wk)
  - Care component (£18/wk - £70/wk)
- **Attendance Allowance** (£53 - £75/wk)
  - *NB: the other benefits you get can increase if you get AA*
  - **Carer's Allowance** (for those >16y) (£59/wk)
- **Disabled Facilities Grant**
  - From your Local Council

https://www.gov.uk/browse/benefits/disability

Adaptations and Equipment

- Occupational therapy (OT) assessment
  - Request via local social services department
- The Work Step Programme (suggested by a patient)
- Disabled Living Centres (www.assist-uk.org)
- Disability Living Foundation (www.dlf.org.uk)
- DRIVING:
  - Return to driving? – needs to have an assessment of driving ability (www.mobility-centres.org.uk)
  - For anything else on motoring: www.direct.gov.uk/motoring

Physiotherapy!!!!

Important message!!!

Rehabilitation teaches you to recover the lost function, and not merely to compensate the loss!!!

Updates re: rehabilitation

- Pathway to rehabilitation and rehab specialist services

Links to other organisations

- **Links to other organisations:**
- **Spinal Injuries Scotland** is Scottish voluntary organisation concerned with new and long term spinal injured people, their relatives, friends and those involved in the management, care and rehabilitation of the injury. **http://www.sisonline.org/**
- **Spinal Injuries Association** represents all spinal cord injury interests regardless of how the impairment occurred, whether or not it has resulted in full or partial paralysis **http://www.spinal.co.uk/**
- **NHS Greater Glasgow and Clyde**provides a wide range of health care for people in Glasgow and Clyde, a range of acute services across the whole of Glasgow, and a number of specialist services on a tertiary basis for the West of Scotland or the whole of Scotland. **http://www.nhsggc.org.uk/content/**
- **International Spinal Research Trust** is a pioneering charity. Its aim is to find ways to repair spinal cord injury and to reverse the paralysis that results from it. Based in the UK and recognised as a leader in its field, Spinal Research funds groundbreaking projects at scientific and medical institutions around the world. **http://www.spinal-research.org/**
- **Walking on Air** a charity for a unique recreational opportunity (gliding). **http://www.walkingonair.f9.co.uk/**
- **Options** an association to aid and assist the rehabilitation and re-integration of spinal cord injured individuals by enabling them to fulfil their sporting and recreational potential. **http://www.options-sport.org/**
- **Momentum Skills** enables and empowers more than 1300 disabled and excluded people every year to identify and achieve their life goals. http://momentumskills.org.uk/our-services
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- **Lots of research summary on ependymoma tumours; https://cern-foundation.org/**
- **Spinal Cord Tumour Forum**