

Relief of symptoms in end stage neurological conditions

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Plan

- Introduction
- Impact on the individual
- Assessment
- Symptoms- interventions and team management
- Conclusions

Introduction

- Neurological symptoms often affect function but also impact on passive care and comfort
- Unfortunately LTNC common
 - MS, PD, MND, MSA
- Management should be holistic
 - focussing on maintaining autonomy
 - supporting the individual and their carers in decision making
 - providing information and ensuring co-ordination of care



Effective liaison between neurology, primary and palliative care services is essential

Symptom prevalence

Symptom prevalence and severity in people severely affected by MS.

IJ Higginson et al. J Palliative Care 2006;22-3;158-165.

- Of 18 symptoms, PwMS reported a mean of 9. Six of which were moderate, severe or overwhelming.
- Commonest- 'difficulty using legs', 'fatigue', 'difficulty using arms'
- Pain, nausea, constipation and breathlessness- similar prevalence to studies in people with cancer

Symptoms

- Spasticity and spasms
- Neuropathic pain
- Bladder and bowel dysfunction
- Speech and swallow difficulties
- Respiratory problems
- Mood and cognitive dysfunction

Impact on the individual

- Active function
 - Self care, feeding, typing/ writing, reading
- Passive function
 - Washing, dressing, positioning
- Social functioning
 - Accessing the community, seating, communication
- Pain, discomfort
- Sleep
- Mood, self image

Assessment

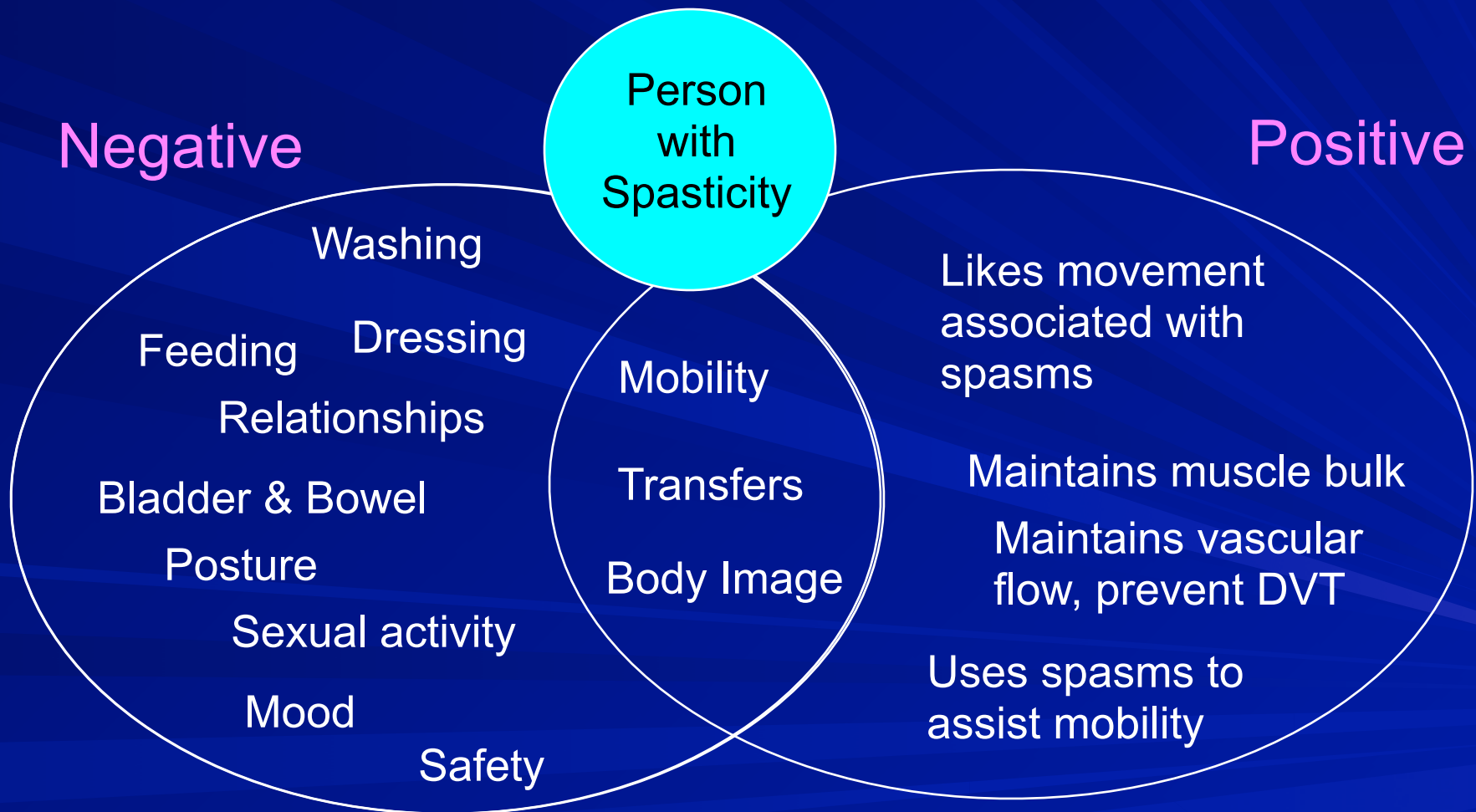
- Talk to:
 - The individual and their families/ carers
 - Community teams, therapists, district nurses, day centres etc.
- History
 - 24hr routine
 - Previous and current interventions (drugs, therapy, seating, orthotics, TENS)
- Hands on and measurement
- Set a goal of treatment

Spasticity and spasms

- Discomfort, pain, stiffness
- Impact on transfers, seating, washing, dressing
- Development of contractures, pressure sores



Impact of Spasticity and Spasms



Remember spasticity can be useful..

Spasticity Assessment

- Information gathering
- MDT assessment
- Effect of spasticity, spasms on daily activities incl sleep, mood, participation
- Assess patient expectations
- Look for trigger factors

Triggers and noxious stimuli



Skin



Bladder



Splints



Orthotics



Bowels



Pain, skin



Seating & positioning

Measures



- Tone - Ashworth (1964)
- Range of movement - Goniometry
- Spasm scale - (Penn et al 1989)
- Visual analogues of pain, comfort, leg stiffness
- Description of position in W/C- photos
- MAIN PROBLEM



GOAL



Goal

OUR GOAL FOR
THE WEEK



Options for Spasticity Management

MILD
SPASTICITY

SEVERE
SPASTICITY

→ Ongoing Medical, Therapy & Nursing →

Oral
Medication

Inpatient
Rehabilitation

Focal
Treatments

Intrathecal
Baclofen

Intrathecal
Phenol

Surgical
Options

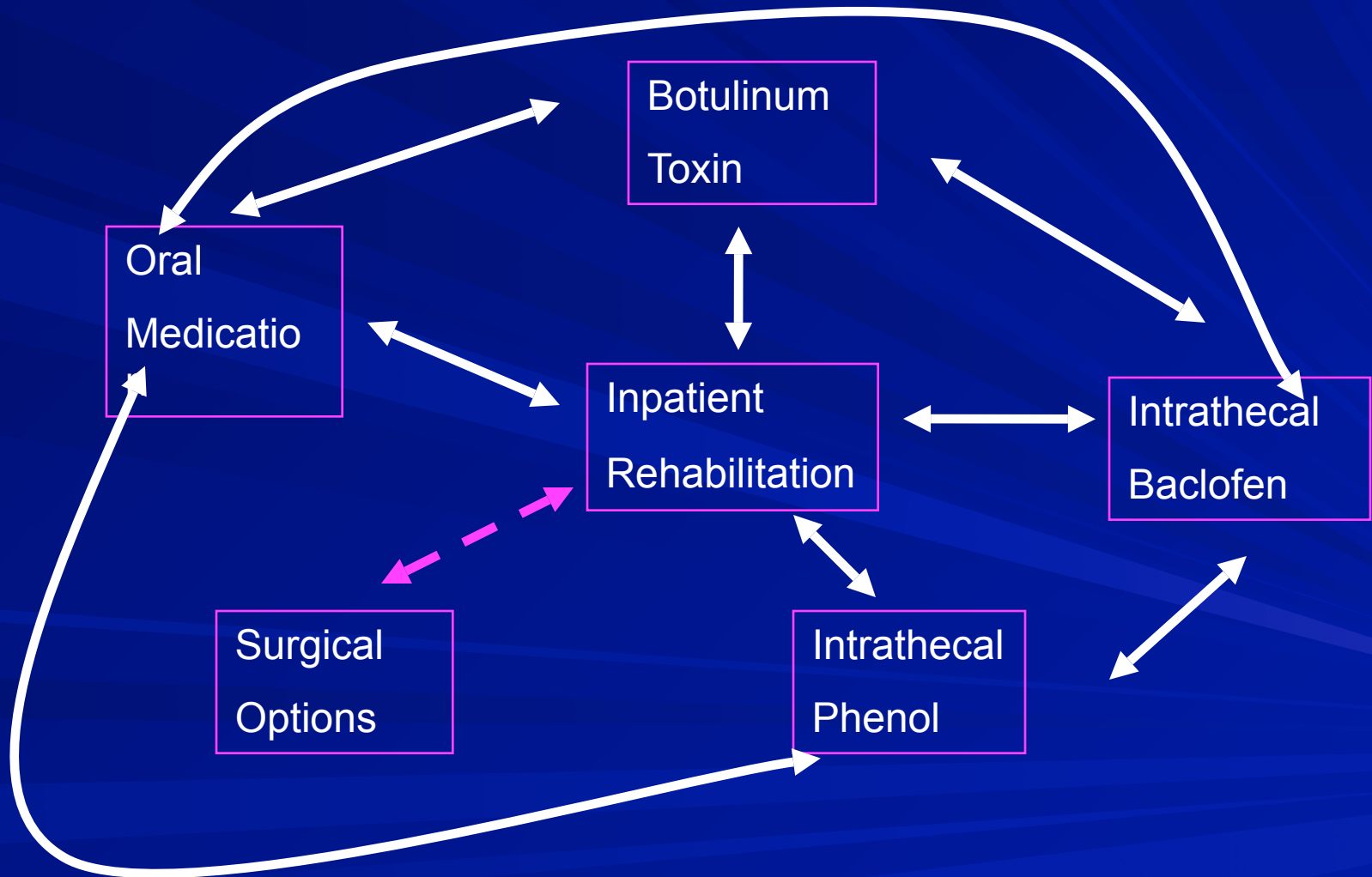
Primary

Teamwork

Secondary

Intermediate

Spasticity Management



Individualised Treatment Plan

■ Education

- What is spasticity?
- Contribution of spasticity to current problems/function

■ Management of trigger factors

■ Physical management programme

- Positioning, Seating, Standing, Stretches, Strengthening

■ Pharmacological treatment

Pharmacological Therapies

■ Generalised

- Baclofen, Tizanidine, Dantrolene, Benzodiazepines, Gabapentin



■ Focal

- Botulinum toxin
- Regional nerve blocks

■ Intrathecal

- Baclofen
- Phenol



Issues with Oral Drugs

■ Optimisation of effects

- Timing, drug choice

■ Side effects

- Including fatigue, cognition

■ Blood monitoring

■ Exposing weakness

- Trunk and lower limbs

■ Mechanism for monitoring effect and adjusting dose

Remember- the aim is to improve function and minimise complications, not simply to reduce spasticity



Optimisation

Getting the most out of the drugs

■ Timing

- Tablets on waking.. Not with breakfast
- Adjust to activities eg. Car travel, work patterns, therapy, sexual activity



■ Drug choice

- Take advantage of other drug actions
 - Clonazepam and sedation- for nocturnal spasms
 - Gabapentin- for neuropathic pain



■ Mechanism for monitoring effect and adjusting dose

- Patient and carer education, treating therapists, GP

Combining drugs

Start low and go slow

■ Start first choice drug

- Increase according to effect or tolerance
- Stop titration when desired effect achieved or side effects occur
- If no effect at full tolerated dose, withdraw

■ Add in 2nd drug

- Repeat process

What if the drugs don't work?

Review trigger factors and physical management programme before escalating therapy

Other treatment options:

- **Focal treatments**

- Chemical neurolysis or botulinum toxin

- **Intrathecal baclofen**

- **Intrathecal phenol**

- **Surgery**

Intrathecal baclofen



Pros

- Extremely effective
- Flexible dosing
- No systemic side effects (particularly CNS)
- Consistent treatment
- No drug interactions
- Allows reduction of oral medications
- Can be combined with morphine or bupivacaine

Cons

- Surgical procedure
- Risk of complications
 - Catheter issues, infection
- Potential risks (can be fatal)
 - Overdosing
 - Withdrawal (missed refill apt)
- Limited battery life
- Minimal effect on upper limbs
- May compromise walking
- Body image issues

Intrathecal Phenol

- Phenol injected via lumbar puncture at ~L2
 - Protein coagulation & necrosis
 - Axonal degeneration
- Indiscriminate destruction of motor and sensory fibres
 - Through positioning target motor nerves

Selection Criteria

- Severe lower limb spasticity
- Oral Medication, physiotherapy, nursing no longer effective
- ITB not appropriate
- Bladder & bowel dysfunction with effective management programme in place
- Aware of potential sexual dysfunction
- Sensory impairment of lower limbs
- Local anaesthetic trial successful

Efficacy

25 patients

- Goals of treatment;

- Increase ease of care

- Comfort

- Positioning in bed or wheelchair

- Marked reduction in tone, pain, spasm intensity and frequency. Increased ease in positioning, hoisting, hygiene and dressing

Managing Severe Lower Limb Spasticity - Can Intrathecal Phenol still have a role? Jarrett L et al. (2002) J Neurol, Neurosurg & Psychiatry. 73 (6):705-9.

Pre and post phenol



Neuropathic pain

- Common problem in neurological conditions
 - 28-86% of people with MS
 - 8% post stroke, 5% moderate- severe
- Varied clinical presentation
 - Muscular pains
 - Dysaesthesiae, hyperpathia, allodynia
 - Shooting pains
 - Visceral pain

Impact of pain

- Interferes with mobility, seating, washing and dressing, social functioning
- Poor sleep pattern
- May contribute to development of depression

- Questionnaire study of 180 people with MS:
 - 66% had current pain (<3 mths), legs commonest site
 - Top 3 interference ratings for pain were 'sleep', 'recreational activities' and 'enjoyment of life'

The scope and nature of pain in persons with MS DM Ehde et al, Mult Scler 2006;12:629-638.

Pain management

- Before treating, consider other causes
 - E.g. Back pain in wheelchair users
 - Immobility, spasticity

 Physical programmes, heat pads, TENS, NSAID's

- Drug treatment for neuropathic pain
 - Gabapentin, pregabalin, carbamazepine, tricyclics
 - Newer anticonvulsants: lamotrigine, levetiracetam, oxcarbazepine

Bladder and bowel dysfunction

Very common, particularly with spinal cord involvement

- Bladder symptoms:
 - Frequency
 - Urgency
 - Incontinence
 - Hesitancy, retention
 - UTI's

Causes:

- Detrusor hyperreflexia
- Sphincter dyssynergia

Bladder and bowel management

- Must assess **residual volume** before treatment
 - **No residual** → Anticholinergics, DDAVP, botulinum toxin
 - **Residual present** → Intermittent self catheterisation, indwelling catheter
 - **Consider suprapubic catheter**
- Bowel- establish routine
 - Oral agents; lactulose, senna, movicol
 - Suppositories/ micro-enemas
 - Loperamide for urge incontinence

Speech and swallow difficulties

- Dysarthria- facial or bulbar muscular weakness
- Dysphasia- stroke, mass lesions
- Dysphagia- acutely following stroke, TBI or insidiously with mass lesions, MS, MND, PD, MSA etc
 - Incidence probably underestimated

Speech/ swallow management

■ SALT

- Exploration of communication aids
- Language therapy
- Education
 - Risk and dangers of aspiration
- Compensatory mechanisms
 - Chin tuck, head turning to swallow
 - Dietary modifications

■ Percutaneous gastrostomy

Respiratory problems

Multisystem Atrophy, MND

■ Education

- Awareness of issues
- Treatment options

■ Non-invasive positive pressure ventilation (NIPPV)

- May be acceptable to individuals not wishing to have invasive ventilation
- Positive effect on quality of life in MND (vitality domain of SF-36), improving daytime somnolence, increasing appetite, relieving morning headache and dyspnoea

A prospective study of quality of life in ALS patients treated with noninvasive ventilation. RA Lyall et al. Neurology 2001;57:153-156.

Mood and cognitive dysfunction

- Both common in neurological disorders
- Neuropsychological assessment
 - Useful to define extent of dysfunction in memory, attention, speed of processing, language and executive function
 - Guides strategies for orientation and decision making
 - Important to consider regarding advance directives
- Mood
 - Common in MS, PD
 - Psychological support or cognitive behavioural therapy
 - Medication; beware side effects e.g. bladder

Conclusions

- Effective symptom control at all stages of neurological conditions is essential
 - Education
 - Specialist nursing/ therapy intervention and support
 - Pharmacological measures
 - Invasive treatments (intrathecal phenol, NIPPV)
- ➔ Co-ordinated MDT with the individual central to the management process, actively involved in monitoring the impact of symptoms and in the effectiveness of therapeutic interventions

Acknowledgements

- To all of the patients who consented to their photos being used to help with education and training of health professionals
- To you all for listening....

Any questions?