



Calvary

Getting Comfortable **with comfort for people with ALS/MND**

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State-wide Progressive Neurological Diseases Service (SPNDS)

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Continuing the Mission of the Sisters of the Little Company of Mary

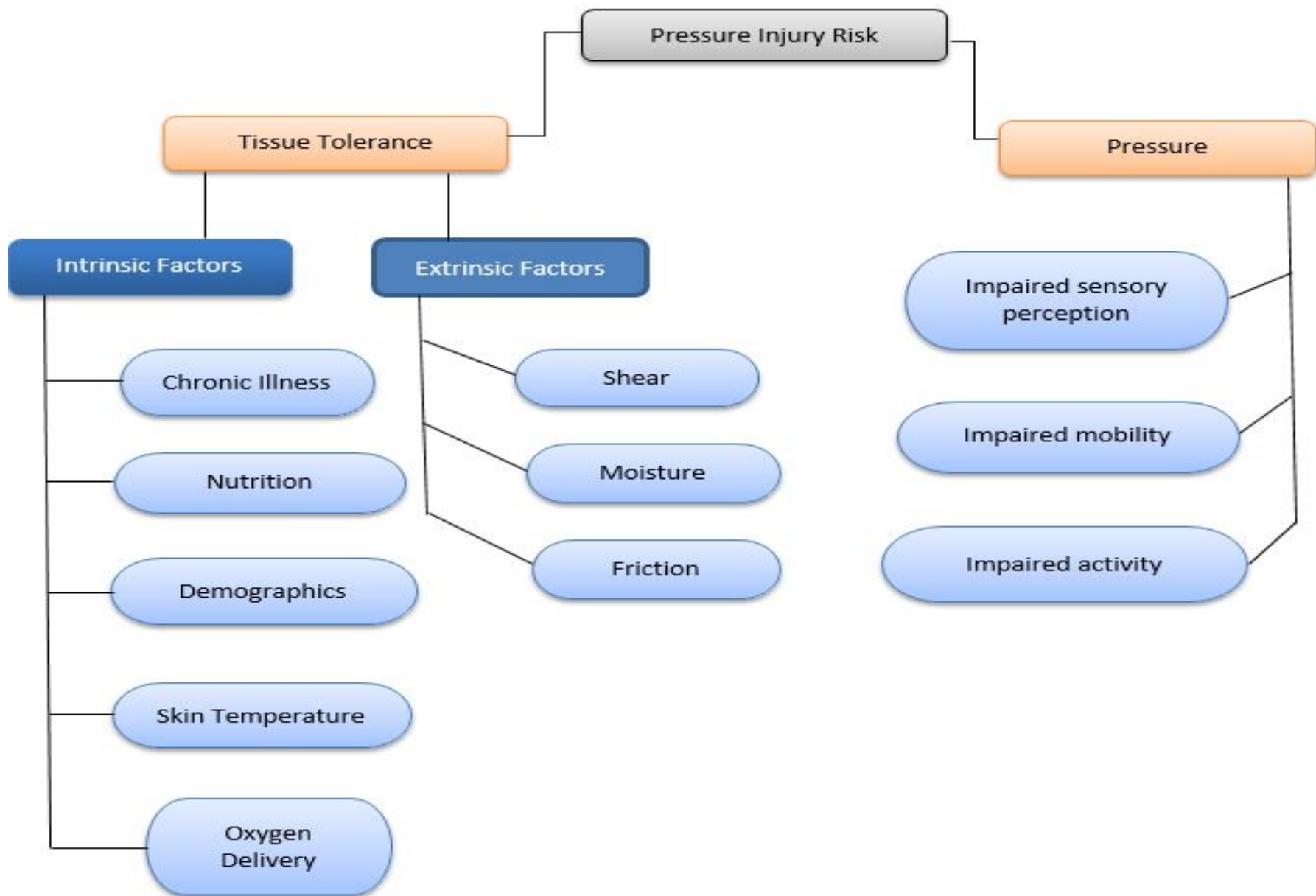
“I can’t get comfortable in bed...”

- Discomfort is a common issue reported
- Complex, thorough assessment is essential
- Don’t assume it is pressure related
- Use a team approach
- Think beyond equipment
- Positioning strategies
- Medication
- Psychological interventions



What is causing the discomfort?

- Immobility and inability to change position
- Unable to sleep in preferred/premorbid sleeping position
- Spasticity or low tone causing traction on joints
- Cramps and fasciculations
- Fear and anxiety
- Muscle wasting



Do not assume discomfort is pressure related

- No significant comorbidities
- Continence is managed
- Well cared for
- Early access to equipment to manage comfort and pressure risk
- Contact with health professionals
- Education to carers

Physical causes of discomfort

Motor Neurone Disease Pain Pathway - Physical Pain

TYPES OF PAIN

MUSCLE CRAMPS

- Massage/ stretch muscles from carers
- Aromatherapy
- Drink tonic water (contains quinine)
- Bananas, oranges and citrus fruit juices (magnesium imbalance)
- Warmth

- Quinine Sulphate
- Magnesium
- Vitamin E
- Verapamil

SPASTICITY

- Position
- Passive exercise
- Active within limitations
- Warmth
- Pressure above and below joint

- Physiotherapy
- Tizanidine (Zanaflex)
- Baclofen
- Hydrotherapy
- Botulinum toxin

CONSTIPATION

- Dietary intake
- Fluid intake
- Exercise- passive
- Review of current medication
- Regular review of bowel habits and monitor any change
- Abdominal massage
- Linseed seeds

- **Laxatives**
- Movicol
- Senna & Lactulose
- Dulco-Lax
- Laxative on commencement of opioids

SPASMS

- Exercise
- Positioning

- Baclofen
- Dantrolene
- Diazepam
- Sub lingual Lorazepam
- Tizanidine (Zanaflex)

SKIN PRESSURE

- Positioning
- Regular turning
- Correct moving and handling techniques
- Preventative measures

- Pressure mattresses/ cushions
- Appropriate beds/ chairs
- Use of hoists
- Diclofenac Sodium (Voltarol)
- Morphine (Oramorph)
- Amitriptyline

MUSCULO SKELETAL

- Passive exercises prior to transfers for immobile patients
- Exercise
- Positioning
- Correct moving and handling techniques

- Physiotherapy
- Hydrotherapy
- Non steroidal anti inflammatory medications
- Paracetamol
- Tramadol
- Joint injections
- Morphine
- Orthotics- splints
- Collars
- Tens
- Complementary/ Alternative Therapy

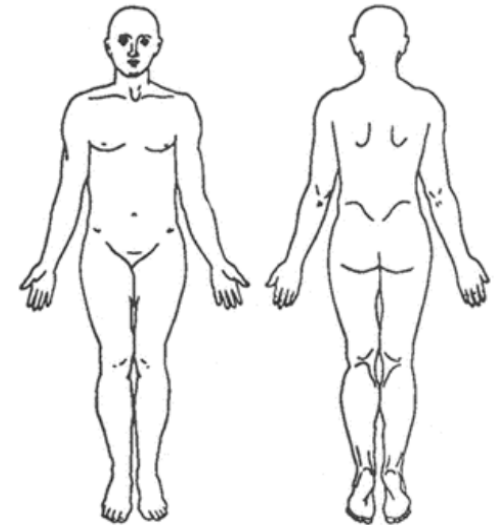
REGULAR REVIEW OF ALL TYPES OF PAIN

Psychological impact of discomfort

- Psychological distress can manifest and amplify physical discomfort
- Factors to consider
 - Pre-morbid personality
 - Family dynamics and relationships
 - Coping strategies
 - Adjustment to diagnosis
 - Emotional state- fear, grief, anger and frustration
 - Loss of control, anxiety, depression

Assessing discomfort

- **Subjective**
 - Pain or discomfort type (sharp, burning, aching etc.)
 - Severity (ask to rate out of 10)
 - Location
 - Timing (intermittent, constant)
 - Daily routine
 - Premorbid pain (lower back pain etc.)
 - Screen for pressure injury risk factors
- **Objective**
 - Posture
 - Skin appearance
 - Joint mobility and tone
 - Observe carer transfer technique

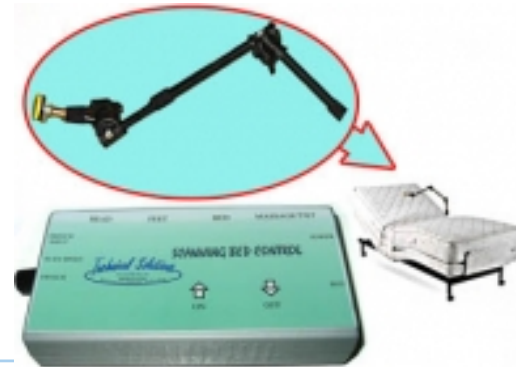


Now what?

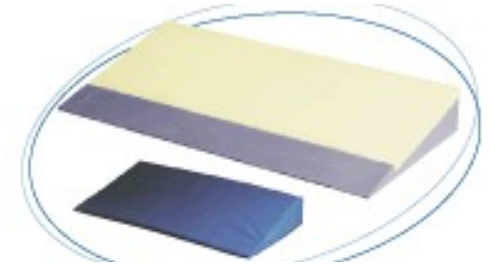
- Compile the information and determine the key issues
- **Discomfort**, rather than pressure is more commonly the target of interventions
- A combination of different strategies and interventions
- Trial and error may be required- everyone is different

Bed mobility

- Bed mobility/ re-positioning
- Approach hospital bed discussions with care and sensitivity.
- ‘Electrical controlled beds’
- Bed control location or Scanning bed controller (an environmental control unit) can provide independence via ‘hands free’ control
- Sleeping in recliners



Aids and equipment options



Aids and equipment options

- Bedsticks
- Bed cradles
- Sheets with satin insert panel
- Mattress overlays and pressure mattresses
 - Memory foam overlay
 - Mattress with Roho inserts
 - Alternating air mattress overlay
- Hospital beds
- Spenco heel booties
- Transfer equipment (hoist, slide sheets)



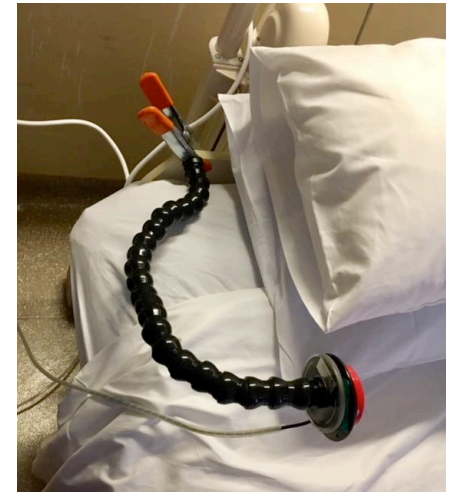
Practical strategies for managing comfort

- Shoulder care education
 - Positioning and gentle ranging exercises
 - Transfer technique
- Optimise the person's independence with mobility in bed or chair
- Carer education with transfer technique and equipment
- Regular repositioning regime
- Passive joint movements



Practical strategies for managing comfort

- Medications to target cause of discomfort
 - Anxiety
 - Pain
 - Spasticity, cramps
- Psychological interventions
- Music Therapy
- Call bell set up
- Quick release strap for NIV mask



TIP: Take photos and provide written instructions of recommendations with positioning devices and techniques to ensure carry over between carers

Presented to clinic reporting inability to get comfortable in bed

Background

- 56 year old with Lumbar onset MND
- Sleeping with wife in Queen bed, nil aids
- Independent with 4WF

Assessment

- Discomfort and difficulty turning and repositioning himself bed
- Blankets get caught
- Max wishes to remain sleeping in bed with wife
- Vital for his role as a husband
- Maintain intimacy with his wife

Max



Recommendations

- Sheet with satin panel
- Bedstick
- Bed cradle
- Medications to improve comfort
- Future consideration hospital bed with pressure mattress and companion bed



Jenny reports shoulder and back discomfort in bed

Background

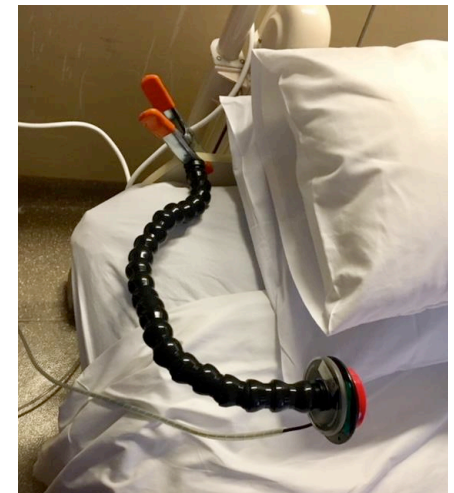
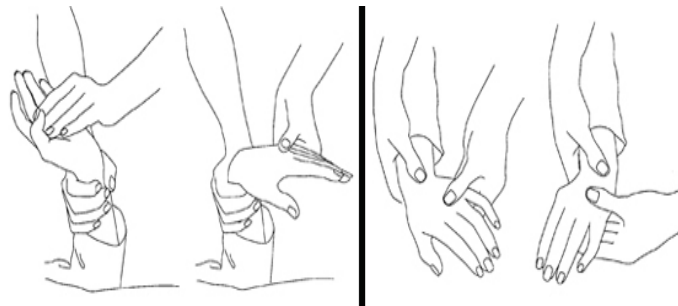
- 65 year old lady with bulbar onset MND
- Lives with her daughter
- Independent nil aids
- Endurance is limited by fatigue
- NIV use overnight
- PEG inserted
- Lost 8kg in 6 months
- Hand weakness

Assessment

- Sleeps on her back with 2 pillows
- Neck is flexed
- Shoulder blades and spine dig into the mattress
- Poor sleep feeling frightened about what is happening
- Unable to call out to daughter
- Anxious about difficulty removing the NIV mask
- Fatigue and reduced appetite

Recommendations

- Remote Call bell with buddy button
- NIV mask adapted with a quick release strap
- Memory foam overlay
- Discussed equipment
- Gentle shoulder exercises joint ranging
- Clinical psychology
- Music Therapy
- Dietician
- Medication



Pain in shoulders and back in recliner

Background

- 72 year old man with cervical onset MND
- Proximal upper limb weakness
- Assistance with all transfers and with mobility

Assessment

- Shoulder pain
- Observed sitting in recliner chair
- Finding it more comfortable to sleep in recliner chair than in bed
- Flaccid tone at shoulder and pain at joint end range

Recommendations

- U-shaped positioning cushion
- Shoulder care education
- Gentle shoulder exercises
- Tilt in space powered wheelchair
- Medications
- Sleeping in recliner is ok



Take home messages

- Discomfort is a common issue
- Many possible causes of discomfort
- Discomfort is not always caused by pressure
- Thorough assessment required
- Ensure effective management strategies
- Combination of repositioning, equipment and medications is often most successful
- MND is a moving target

Be flexible and review regularly as needs will continue to change

References and resources

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