What the rehabilitation physician has to offer ....

Dr Margaret Phillips
Overview

• Today’s programme, and some of tomorrow’s, cover a lot of aspects of what the rehabilitation physician has to offer
• Boundaries
• Context
• Guidelines
What is the rehabilitation physician’s role?

Current practice

Neuromuscular guidelines group

Usual role of rehabilitation physician

Role of rehabilitation physician in NMD
Current practice

• Questionnaire to 230 BSRM consultants and associate specialists

• Aim was to ascertain:
  • The frequency and types of involvement of RM physicians in the rehabilitation of pwNMD
  • Opinions regarding future developments
Respondents

- 32 responses
- From 27 Rehabilitation Medicine services
Results of Questionnaire

- Rehabilitation clinics
- Joint clinics: neurology, paediatrics, orthopaedics, respiratory
- But
  - Only 6 saw > 50/year in clinic
Professions involved

- Large range of professions involved: some at the time of clinic, some that were referred to

- Some notable lack of provision:
  - Speech and language therapy
  - Psychology
  - Specialist nurse
  - Neuromuscular care advisor
  - Specialist neuromuscular occupational therapist
Investigations and outcome measures in clinic

- Investigations

- Outcome measures
  - none in 66%
  - Barthel in 12.5%
Facilities and Groups

• Groups

• Facilities
  • Gait analysis (10)
  • Wheelchairs
  • Specialist seating
Liaison with other specialists

- Large range
- 21 clinicians had neuromuscular patients using NIV on caseload
## Further development

- Pathways with services
- Commissioning
- Education
- Research

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Conclusions from questionnaire

• Not representative but indicative

• Shows what can be done

• That neuromuscular rehabilitation services are being provided in several places

• That many clinicians have some involvement and recognise a role
Rehabilitation practice in other countries

• Netherlands
• Denmark
• USA
What needs do pwNMD have?

- No studies on opinions of pwNMD regarding services

Derived from NM guidelines group discussions
Pathology

- Cardiac pathology
- Respiratory muscle pathology
- Pressure sores
- Contractures
- Brain pathology

Disease modifying treatment

Role

- Screening for and initiation of treatments concerning secondary pathologies
  - E.g. to reduce rate of development of cardiomyopathy and pathologies secondary to respiratory muscle pathology
- Knowledge of natural history and prognosis of specific conditions
- No direct involvement regarding DMT - but increased survival will have an impact.
Impairment

- Skeletal muscle strength & stamina
- Motor control
- Range of movement
- Joint stability
- Sensation
- Pain
- Depression & Anxiety
- Cardiac & respiratory function
- Swallowing
- Nutrition and hydration
- Bowel and bladder function
- Response to anaesthetics
- Cognitive and behavioural function

Role

- In depth knowledge regarding impairments
- Skills in addressing multiple impairments
- Differentiation of NMD and non-NMD related symptoms and signs
- Similarity with the range of impairments that a rehabilitation physician addresses in other conditions.
Impact of cognitive impairments

• Major factor in myotonic dystrophy
  • Executive functioning
  • Alertness
  • Drive

• Examples
  • DM1 across two generations - effect on household
  • People with DM1 in caring roles *
Activity

- Mobility
- Maintaining posture and body position
- Use of upper limbs
- Personal activities of daily living
- Communication

Role
- Experience in addressing these aspects of activity alongside rehabilitation teams
- Services usually in place - although often not specifically commissioned
Rehabilitation medicine pathways: minimising impact of health condition

• Local input across primary and secondary care
  ▸ Coordination
  ▸ Doing simple things right - ‘marginal gains’
  ▸ Prevention of complications / risk reduction
  ▸ Disability management closer to home
  ▸ Planning for acute illness
  ▸ Inreach during acute illness
  ▸ Advocacy
  ▸ Crossing the boundaries: primary to secondary to tertiary care
  ▸ Liaising with voluntary services
  ▸ Transition
Participation

• Employment, homemaking and voluntary work
• Education
• Starting and maintaining social relationships
• Starting and maintaining personal relationships
• Leisure activities
• Citizenship

Role
• Experience & skills in prioritising participation
• Experience and skills in negotiating goals and motivational techniques
• Established links & services
Lifecycle

• Progressive disability
• Transition
• Disruption of expected life narrative
• Understanding and implications of prognosis
• Pregnancy, labour & childbirth
• End of life care

Roles
• Negotiating and counselling through these lifecycle changes
• Minimising impact of health condition
• Knowledge of & liaison with relevant services
Location of services

- Most specialist neuromuscular services are tertiary, often regional

- Rehabilitation medicine services can provide a local service
  - links in with the specialist diagnostic service
  - specialist enough to address needs in daily life, reduce admissions and inreach when necessary
Summary

• Rehabilitation Medicine has a very relevant role in the care and rehabilitation for people with neuromuscular disease

• It can provide a bridge between highly specialised tertiary centres and good ongoing care close to home

• It integrates good management of the conditions with real world living