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Standards of care physiotherapy



Marleen van den Hauwe
PT University Hospitals Leuven
NMRC Leuven, Belgium



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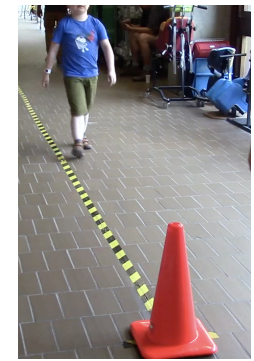
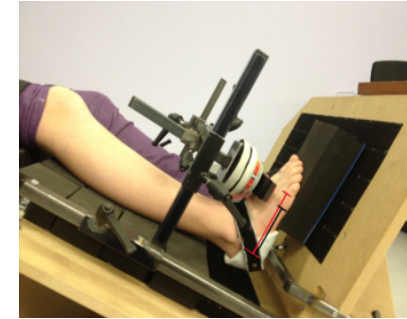
Herestraat 49
B - 3000 Leuven

www.uzleuven.be
tel. +32 16 33 22 11

UNIVERSITY HOSPITALS LEUVEN

- **Assessments**
 - Muscle strength
 - Range of motion
 - Functional timed testing
- **Interventions**
 - Prevention of contractures
 - Exercises and activities
 - Assistive technology and adaptive equipments
 - Respiratory therapy

- Muscle strength:
 - Manual Muscle Testing
 - Hand Held Myometry
- Joint Range:
 - Goniometry
- Functional Performance (every 6 months)
 - NSAA
 - Timed tests
 - 6MWT



- North Star Ambulatory Assessment (NSAA)
 - 17 items
 - unidimensional functional scale for ambulant boys with DMD
 - robust scale
 - >10 points change over a period of time is clinically meaningful

Test Item	2	1	0
1. Stand	Stands upright, still and symmetrically, without compensation (with heels flat and legs in neutral) for minimum count of 3 seconds	Stands still but with some degree of compensation (e.g. on toes or with legs abducted or with bottom stuck out) for minimum count of 3 seconds	Cannot stand still or independently, needs support (even minimal)
2. Walk	Walks with heel-toe or flat-footed gait pattern	Persistent or habitual toe walker, unable to heel-toe consistently	Loss of independent ambulation. May use KAFOs or walk short distances with assistance
3. Stand up from chair	Keeping arms folded. Starting position 90° hips and knees, feet on floor/supported on a box step.	With help from thighs / push on chair / prone turn or alters starting position by widening base.	Unable



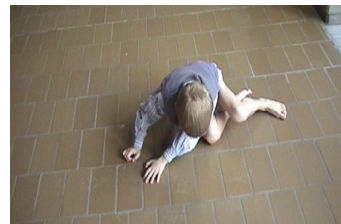
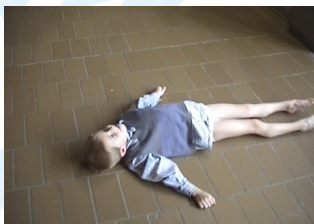
item 13: stands on heels

• Timed Function Tests (TFT)

- high validity and reliability
- predictive value regarding functional motor changes

1. Time to stand from a supine position (>30sec: loss of ambulation over the following 12 months)

NSAA equivalent grade	Test grade	Detail
<input type="checkbox"/> 0	<input type="checkbox"/> 1	Unable to stand from supine, even with use of a chair
<input type="checkbox"/> 0	<input type="checkbox"/> 2	Assisted Gowers – requires furniture for assist in arising from supine to full upright posture
<input type="checkbox"/> 1	<input type="checkbox"/> 3	Full Gowers - Rolls over, stands up with both hands “climbing up” the legs to achieve full upright posture
<input type="checkbox"/> 1	<input type="checkbox"/> 4	Half Gowers - Rolls over, stands up with 1 hand support on leg
<input type="checkbox"/> 1	<input type="checkbox"/> 5	Rolls to the side and stands up with one or both hands on the floor to start to rise but does not touch legs
<input type="checkbox"/> 2	<input type="checkbox"/> 6	Stands up without rolling over or using hands on legs



2. Time to run/walk 10m (>12sec: loss of ambulation over the following 12 months)



Test grade	Detail
<input type="checkbox"/> 1	Unable to walk independently
<input type="checkbox"/> 2	Unable to walk independently but can walk with knee-ankle foot orthoses (KAFO) or support from a person
<input type="checkbox"/> 3	Highly adapted wide based lordotic gait. Cannot increase walking speed.
<input type="checkbox"/> 4	Moderately adapted gait. Can pick up speed but cannot run
<input type="checkbox"/> 5	Able to pick up speed, but runs with a double stance phase, i.e. cannot achieve both feet off the ground
<input type="checkbox"/> 6	Runs and gets both feet off the ground (with no double stance phase)

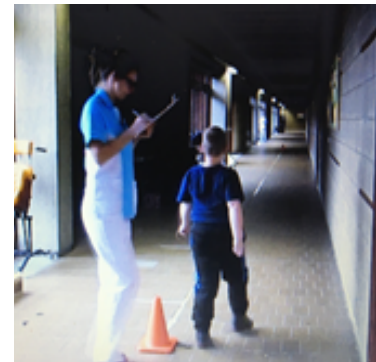
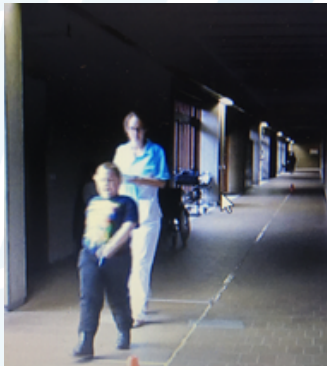
3. Time to climb or descend 4 standard-sized stairs (>8sec: loss of ambulation over the following 12 months)



Method used to climb stairs	
<input type="checkbox"/> 1	Unable to climb 4 standard stairs
<input type="checkbox"/> 2	Climbs 4 standard stairs "marking time"(climbs one foot at a time, with both feet on a step before moving to next step), uses both arms on one and both handrails
<input type="checkbox"/> 3	Climbs 4 standard stairs "marking time"(climbs one foot at a time, with both feet on a step before moving to next step), uses one arm on one handrail
<input type="checkbox"/> 4	Climbs 4 standard stairs "marking time"(climbs one foot at a time, with both feet on a step before moving to next step), not needing handrail
<input type="checkbox"/> 5	Climbs 4 standard stairs alternating feet, needs handrail for support
<input type="checkbox"/> 6	Climbs 4 standard stairs alternating feet, not needing handrail support

- 6 minute walk test (6MWT)

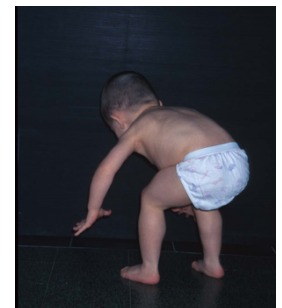
- most sensitive available endpoint for clinical trials
- improves or remains stable over the first 7 years
- baseline 6MWT <325m demonstrates a greater decline over 6 months



- Bayley-III scale
 - infants and young children (<3 years)
 - to detect early developmental delays



- Other assessments for young children
 - NSAA
 - AIMS
 - Hammersmith Functional Motor Scale Expanded
 - Gross Motor Function Measure or MFM



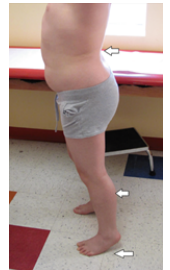
- Brook upper limb
- Elbow flexion
- Grip Strength
- PUL (upper limb test)
- EK scale



- **Assessments**
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- **Interventions**
 - Prevention of contractures
 - Exercise and activity
 - Assistive technology and adaptive equipment
 - Respiratory therapy

Interventions

- Prevention of contractures and deformities
 - stretching
 - orthotic devices
- Exercise and activity
- Assistive technology and adaptive equipment



Stretching

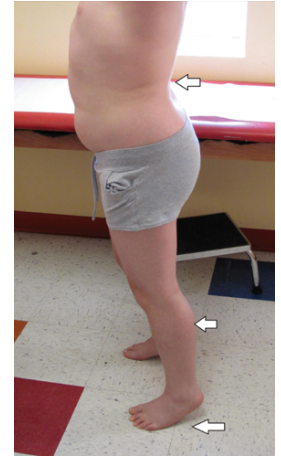
- to prevent or minimise contractures and deformities
- daily preventive home stretching 4-6 times per week
 - start before the loss of passive ROM
 - stretch to full range of motion
 - ambulatory phase: ankle – knee – hip
 - later: fingers – wrist – neck

Stretching



Orthotic devices

- night AFO's
 - in ambulatory phase
 - start at young age (better tolerated)
 - stretching effect (larger than stretching alone)
- day AFO's
 - stretching
 - positioning
 - non-ambulatory phase
- wrist/hand splints
 - stretching wrist and long finger extensors
 - non-ambulatory phase



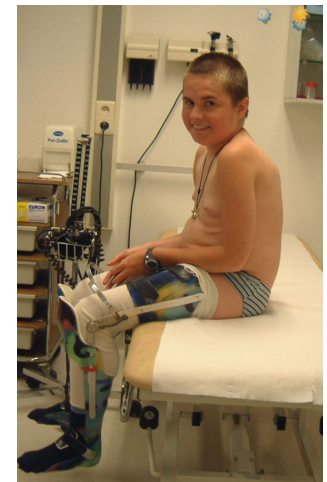
Orthotic devices

- serial casting
 - to increase the length of muscle (increase of the number of sarcomeres in animal models)
 - in ambulatory phase: to prevent decline in motor function
 - improves passive dorsiflexion
 - in late ambulatory phase: before revalidation with KAFO's
 - improves dorsiflexion, knee and hip extension



Orthotic devices

- KAFO's
 - late ambulatory and non-ambulatory stages
 - provide a suitable base of support for proximal lower limb weakness
 - multidisciplinary decision and management
 - careful selection of good candidates (we have seen both positive and negative results)



Orthotic devices

- KAFO's
 - tailored tuning of the splint is crucial
 - orthotist needs to understand in detail the effects of biomechanical control
 - revalidation with people expert in neuromuscular diseases



Orthotic devices

- standing frame
 - start in ambulatory phase
 - at school or at home
 - later power wheel chair that accommodates standing



Exercise and activity

- prescribed, monitored and guided by physiotherapist
- to prevent sedentary/immobile lifestyle, social isolation and overweight
- regular, concentric, low resistance and submaximal anaerobic exercise and activity
- allow adequate rest
- CAVE:
 - effect of exercise on muscle degeneration !!!!
 - overexertion and overwork



- recommended exercises:
 - swimming and cycling
 - adapted sports
- for older boys:
 - assisted cycling
 - robotic-assisted movement



Assistive technology

- Mobility assistance: to maximize mobility and independence with functional activities
 - manual wheelchair
 - ambulatory phase
 - e-motion wheelchair
 - late ambulatory phase and non-ambulatory phase
 - power wheelchair
 - non-ambulatory phase



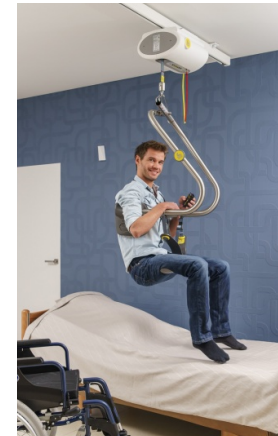
Assistive technology

- Mobility assistance:
 - attention for good positioning in wheelchair with special focus on spine and pelvis (to prevent spinal curvatures)
 - spinal orthosis is generally not recommended
 - lumbar support
 - good frame size
 - cushioning to avoid ulcers
 - re-evaluate every six months: bad position -> loss of function



Assistive technology

- transfers
 - transfers board
 - mechanical lifts
 - specific transferring education (attention fractures during transfers!)

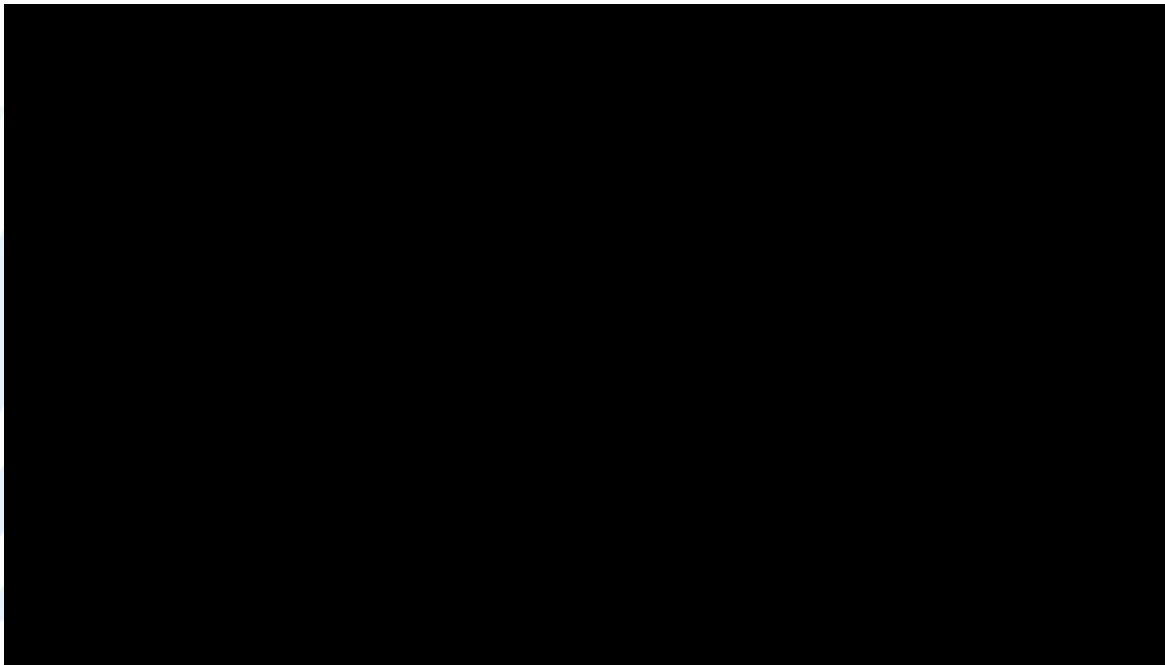


- specialized trays, input devices and software (computer)



Assistive technology

- Arm support



Respiratory therapy

- decrease of chest wall mobility and fibrosis of intercostal muscles
 - restricted patterns of breathing
 - decrease of cough strength
- FVC <60% pred: initiate use of lung volume recruitment techniques and exercises
- FVC <50%, PCF <270L/min or MEP <60cm H₂O: initiate assisted cough techniques and exercises





Thank you for your attention!



marleen.vandenhauwe@uzleuven.be