OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Sleep routine and Management

Many people with Huntington's disease report that their sleep patterns are affected and sometimes are awake most of the night, then continually catnap or doze throughout the day.Many find themselves experiencing long periods being awake or asleep. This irregular routine can be disruptive to family life and mean individuals potentially miss important things in their lives because they sleep through them(Goodman, Barker 2010, Morton, Wood et al. 2005). Often people cannot change this pattern of behaviour.

The involuntary movements associated with Huntington's disease can generate a variety of challenges; falls risk, friction burns and entrapment. As the disease progresses, individuals will spend more time in bed. They might develop contractures or pressure sores if they are unable to change position regularly.

1. Sleep patterns

1.1 The occupational therapist can give advice on sleep hygiene especially if the person is in the early stages as this can help people set up good behaviour patterns for later in the disease
1.2 Create a quiet restful environment in the bedroom, such as no TV, phones or computers which may stimulate and distract
1.3 Consider what is eaten and drunk before bed; avoid alcohol, coffee or a full meal, instead have a light snack
1.4 Lightweight duvets/bedding or placing a cooling fan in the bedroom may be useful as many individuals report being too warm. Alternatively, there are now available all-in-one pillows, fitted sheets and duvet sets that people may prefer if involuntary movement means that their bedding gets thrown off and they get cold in the night
1.5 Create a bedtime routine and keep this consistent, such as a bath, changing into night clothes, reading
1.6 Families can be given advice and be supported to understand and manage their expectations about the person's sleep patterns
1.7 Encourage exercise and increase participation of meaningful activity
1.8 Avoid naps in the day, which can affect a good night sleep
1.9 Check what medication a person is on as some medications have a negative effect on sleep, refer to GP as required

2. Risk assessment

2.1 An individual risk assessment should be carried out on the suitability of any transfer or mobility equipment, beds or mattress and any bed rails in combination with the bed occupant
2.2 Document and review your risk assessment regularly

3. Bed mobility

3.1 Consider a person's cognitive as well as physical abilities such as the ability to follow instructions, maintain grip or organise movements when assessing for equipment to aid transfers
3.2 Consider a high-low adjustable profiling bed. This may facilitate transfers, aid positioning, manage falls risk and aid safe manual handling
3.3 Break down activities into smaller stages, i.e. rolling over in bed, moving from lying on back, on to side, up to sitting
3.4 Use equipment such as slide sheets, manual handling belts, bed levers, stand hoist or hoist to assist with positioning and transfers

4. Safety

4.1 Minimise trip hazards or injuries by the removal of clutter and re positioning of furniture near the bed
4.2 Consider use of foam padding/pipe lagging on any surfaces likely to cause injury
4.3 For someone who is prone to falling out of bed consider the use of a double bed or a high low bed
4.4 Consider the position of the bed, such as alongside a wall or in a corner to reduce the risk of the person falling out. However this needs to be assessed carefully due to potential impact on manual handling issues if carers need to access both sides of the bed

4.5 If using a low bed assess the risk of entrapment, under the bed
4.6 If hand controls are present ensure they are out of reach or locked to prevent trapping or crush injuries
4.7 Consider a falls mat/crash mat to be used on the floor but be aware this may pose a trip hazard
4.8 An audio floor sensor pad, infrared or visual monitors can be used to indicate when a person has got out of bed and can be useful for carers. Sensors which go under the mattress need to be used with caution as involuntary movements can trigger them
4.9 Bed side wedges could be considered if the individual frequently rolls out of bed, these are strapped on to the mattress before making the bed
4.10 Assess the risk of suffocation and ligatures if using pillows with sheets or sleep systems to maintain posture

5. Bed rails

5.1 Refer to local policy on use of bedrails and NHS patient safety resources
5.2 If bedrails are being considered they must be risk assessed on an individual basis. The person with Huntington's disease should be involved in the decision, wherever possible. It is also very important to determine the views of the carers
5.3 If bed rails are used the person's capacity to make decisions about their safety in bed should be recorded. If they lack the capacity, a best interest decision can be made and then deprivation of liberty safeguard assessor should be contacted
5.4 When doing your risk assessment, think about entrapment e.g. the gap between the bed rail and mattress or the bed rails themselves. Also, consider the need for padded bed rails, padding to the head and footboards, skin integrity and friction burns. You should also think about the risk of climbing out of bed if bed rails are used
5.5 If a person has a lot of involuntary movements, you may want to consider a cocoon, but check these can be used with air mattresses and/or profiling bed
5.6 No piece of equipment can remove all the possible risks; for some individuals supervision may be needed at all times when the person is in bed

6. Posture

6.1 To support posture in bed the use of lateral wedges, T- rolls, wedge pillows, rolled towels and specialist sleep systems can be used
6.2 A profiling bed that has a 4-section profile action can reduce slipping by applying the knee break so that the knees are bent to reduce slipping down the bed. This must be considered when there is a need to elevate the head end of the bed
6.2 The ability to profile a bed may aid respiration in the later stages and can minimise the risk of aspiration if a person is being PEG fed in bed or returns to bed for rest periods after a meal. For a person being PEG fed the minimum requirement is that they are sat up at an angle of no less than 45 degrees to reduce risk of aspiration

7. Skin integrity

7.1 Liaise with appropriate care professionals i.e. tissue viability nurse
7.2 Consider the type of mattress for the pressure relief requirements of the person e.g. pressure relieving foam, dynamic air flow mattress
7.3 Consider the impact of the mattress on transfers e.g. air flow mattress which can be placed on static mode
7.4 Use a bed positioning schedule to ensure position is changed, for example side laying and supine

References

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National Patient Safety Agency (2007c) Safer Practice notice (17): Using bedrails safely and effectively and Medicines and Healthcare Products Regulatory Agency (2006) Device Bulletin 2006(6). Safe use of bedrails. Available at www.mhra.gov.uk

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European Huntington's Disease Network Clinical Guidelines for Physiotherapists http://www.euro-hd.net/html/network/groups/physio/physiotherapy-clinical-guidelines-en.pdf?tm=1442404448

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