

# SLEEP DISTURBANCES HELP SHEET



This Help Sheet explains the effects Machado Joseph Disease (MJD) has on sleep patterns and provides general information to carers about appropriate support strategies.

## Sleep disturbances and MJD

People with Machado Joseph Disease have been shown to have higher rates of sleep disturbances, which affect their health, wellbeing and quality of life. Sleep problems include:

- restless leg syndrome and periodic limb movements during sleep
- REM behaviour disorder
- excessive daytime sleepiness
- night time awakenings and nightmares
- obstructive sleep apnoea
- insomnia.

MJD Foundation research on Groote Eylandt in 2008 showed that people with MJD had all of the above symptoms. These sleep problems were shown to affect daytime functioning capacity for those with MJD and also for their families and carers. **DEFINITIONS** Restless leg syndrome (RLS) is a sensorimotor disorder characterised by the urge to move one's legs owing to discomfort in them. Symptoms may start or worsen during periods of rest or inactivity and may be worse in the evenings or at night. The leg movements may provide partial or total relief.

### Definitions

**Restless leg syndrome (RLS)** is a sensorimotor disorder characterised by the urge to move one's legs owing to discomfort in them. Symptoms may start or worsen during periods of rest or inactivity and may be worse in the evenings or at night. The leg movements may provide partial or total relief.

**REM behaviour disorder (RBD)** is characterised by prominent motor activity and dreaming during rapid eye movement (REM) sleep. People with RBD often vocalise,

scream, swear and display violent or injurious behaviours during sleep. RBD tends to occur in the early morning hours, but can occur soon after falling asleep.

**Obstructive sleep apnoea (OSA)** is caused by obstruction of the upper airway. The throat is made up of a wall of soft tissue and as muscle tone relaxes during sleep, or is reduced by the effects of MJD, the wall of soft tissue collapses and obstructs the airway. OSA is characterised by repeated interruptions in breathing during sleep, lasting 20-40 seconds, and is often accompanied by snoring.

## Services for assisting people with sleep disturbances

The MJD Foundation recommends that anyone living with MJD have a sleep assessment (a referral can be made by a GP).

The MJD Foundation provides liaison and support for MJDF clients accessing specialist health assessments and services, including sleep clinics.

The MJD Foundation also funds sleep research so that the impact of the disease can be better understood and appropriate support strategies identified. In August 2008, the Adelaide Institute of Sleep Health visited Groote Eylandt to perform sleep studies on people with MJD. Individual assessments and annual reviews are conducted by specialist sleep physicians.

## Medications

Medications may be used for treating some symptoms of sleep disturbances. The effectiveness of medication needs to be monitored and people on medication need to be observed for side effects. In most cases, assistance with

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taking medications is provided by family members or carers. Carers need information about the medication, desired effects, possible side effects and the importance of taking the medication as prescribed (Right medication; Right dose; Right time; Right route).

As carers your role may require:

- assisting with medication administration within your job role and level of training
- observing sleep patterns and effects or side effects of medication
- reporting these to medical staff and/or the MJD Foundation staff
- recording details of any issues regarding sleep disturbances and medication as required within your job role, including reporting and recording any medication errors.

Remember that disturbed sleep will impact on the person's energy and fatigue levels. Disturbed sleep also has a major impact on the energy and fatigue levels of family carers.

Check communication about sleep issues and plan daytime activities accordingly.

## **Remember to:**

- always check documentation about sleep issues,
- communicate with other care staff across the 24hr cycle (hand-over reports and notes, respite worker feedback),
- communicate with the person about how they are feeling for the day,
- plan daytime activities accordingly, • develop evening and bed-time routines collaboratively to meet the person's needs within the resources and capacity of the care environment,
- seek advice and support if you need it.

## **Who can I talk to if I have questions or concerns?**

### **MJD Foundation staff**

Libby Massey 0417 279 120

Simone McGrath 0407 594 056

Your Health clinic doctors, nurses and health workers