

MOBILITY & BALANCE HELP SHEET



This Help Sheet explains how Machado Joseph Disease (MJD) affects mobility and balance, and provides information about appropriate support. This information is intended as a general overview and it is important to remember that each person with MJD needs to be assessed and supported according to individual need.

Mobility and balance and MJD

MJD is also known as Spino-cerebellar ataxia Type 3. The impact of MJD on muscles and balance is largely a result of the disease's effect on the brain's cerebellum. The cerebellum is located at the base of the brain and coordinates motor control, voluntary motor movement, balance, equilibrium and muscle tone. Damage to the cerebellum may lead to:

1. loss of coordination of motor movement
2. inability to judge distance and when to stop
3. inability to perform rapid alternating movements
4. movement tremors
5. staggering, wide-based walking (ataxic gait)
6. a tendency to fall
7. weak muscles
8. slurred speech
9. abnormal eye movements.

Ataxia is a general term for lack of muscle control and coordination and problems with fine motor control and posture. Gait ataxia is the most common neurological characteristic of MJD and is the first reported symptom in over 92% of people with the disease. Most people are wheelchair-bound and fully dependent for activities of daily living within 10-15 years.

Characteristic ataxia symptoms

- Tripping or stumbling at night.
- Adopting a wide base of support to get balance and walking with a staggering, ataxic or 'drunken' gait.
- Reaching for objects or walls to steady oneself or achieve balance.
- Avoiding night activities altogether owing to the combination of vision and mobility difficulties.
- Difficulty walking in sand or on uneven surfaces.

- As the disease progresses:
 - loss of muscle coordination
 - decreased strength and endurance
 - slow movements
 - spasticity and rigidity.

Support for people with mobility and balance difficulties

- Annual neurological assessments.
- Regular and needs-based occupational therapy and physiotherapy assessments and prescriptions for:
 - mobility aids
 - domestic aids and home modifications
 - individual exercise programs
 - customised footwear and orthotics.

Benefits of regular exercise programs include improvements in general physical function, health-related quality of life and balance, strength and gait. Exercising may help people cope with their disabilities, increase their self-esteem and foster in them a sense of being in control over the disease. Specific balance exercises may help reduce falls and injuries from falls.

Mobility aids

Mobility aids such as canes, walkers and wheelchairs can assist people with MJD to live more independently for longer and reduce the number of falls they have. As the disease progresses, different assistive devices will be necessary. Regular neurological and physical reviews are necessary. Remember that each person with MJD experiences the disease differently. Each individual's situation, including their home and community environment, must be taken into account.

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What carers can do

- Get to know the person you are caring for.
- Get to know the person's family and support network.
- Build a relationship of trust.
- Use communication aids effectively. Learn new skills as required.
- Use mobility aids appropriately. Make sure you have been instructed by a therapist in the safe and effective use of any aids the person is currently using.
- Follow instructions in the person's Individual Care/Management Plan to assist them with therapy, medication administration, use of aids and equipment.
- Remember to consider fatigue and environmental conditions.
- Be aware of occupational health and safety requirements.
- Observe the person in their daily activities. Take note of any changes in their mobility and balance.
- Communicate with the person about any changes they are noticing in their mobility and balance. Report any changes to the appropriate people, e.g. your supervisor, therapists, medical and allied health staff working with the person or MJD Foundation staff.
- Record details of mobility and balance issues as required within your work role.

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

MJD Foundation staff

Phone: 1300-584-122

Email: libby.massey@mjd.org.au

Your Health clinic doctors, nurses and health workers.