

NUTRITION HELP SHEET



This Help Sheet provides general information about nutrition for people with Machado Joseph Disease (MJD). It is important to remember that each person with MJD needs to be assessed and supported according to individual need.

Background

Weight loss and malnutrition are common in people with Machado Joseph Disease. The symptoms of MJD are complex and interrelated. While research has shown that weight loss might be a feature of the disease, associated causes of weight loss and malnutrition include swallowing difficulties, reliance on others for food preparation and needing assistance with eating. Fatigue and mood symptoms also influence appetite and eating habits.

Someone with MJD may also have other health issues and illnesses, may spend periods of time in hospital and experience complications that affect their nutritional health.

As soon as symptoms are noted, the person needs to be assessed and a management plan to maintain weight and nutrition should commence.

Screening, assessment and management planning

The assessment and management planning for nutritional health will involve the person with MJD, their family/carer and a team of health professionals including:

- speech pathologist
- dietician
- health centre staff (medical officer, nursing staff, Aboriginal health workers)

Regular reviews are required as the disease progresses.

Weight loss

Weight loss is caused by a prolonged imbalance between energy intake and energy output. People with MJD have lower body mass index (BMI) scores than the normal range. Weight loss in people with MJD may be a symptom of the disease itself, and may also be a side effect of other physical, emotional and social impacts of the disease.

Malnutrition

The World Health Organisation says malnutrition essentially means 'bad nourishment'. Clinically malnutrition is characterised by too much or too little intake and absorption of protein, energy and micro nutrients. Frequent infections and disorders may result. Malnutrition can contribute to pressure sores, falls, poor immune function and wound healing. It will affect organ function, mental state and quality of life. Someone who is malnourished has an increased risk of disease and early death.

Dysphagia

Dysphagia (difficulty swallowing) usually leads to a reduced oral intake of food. People with swallowing difficulties may experience anxiety and panic during meals, embarrassment and avoidance eating, especially in front of others. The MJD Carer Help Sheet on Swallowing Difficulties provides more information on this topic.

Social and emotional wellbeing

People with MJD have high rates of depression, anxiety and apathy. It is thought that depression is reactive to the impact of MJD rather than being neurological damage or the disease itself. Please refer to the MJD Carer Help Sheet on Social and Emotional Wellbeing for more information. Remember also to consider factors such as family issues, homesickness, income, housing, climatic conditions that may be affecting someone's emotional state, eating habits and their nutritional status.

What carers can do

Assist the person to:

- eat and drink regularly and at a time, place and pace that creates the best opportunity to enjoy their food
- eat a range of healthy food from all food groups

NUTRITION HELP SHEET



- keep eating orally (by mouth) for as long as possible
- adhere to a modified diet if prescribed, making it as appealing as possible
- use eating aids and utensils if prescribed
- drink adequate fluids, using thickened fluids if prescribed
- maintain a healthy weight range
- attend appointments with dietician or speech pathologist to monitor nutrition issues.
- report any changes to appropriate people, eg. your supervisor, dietician, medical and allied health staff working with the person
- monitor and record details of nutrition and weight as required in your work role.

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

MJD Foundation staff

Leah Clarke (Darwin)	0499 334 856
Jill Turner (Groote Eylandt)	0499 330 207
Mark Kilpatrick (Alice Spings)	0499 330 238
Wyam Morris (Cairns)	0499 771 143

Your Health clinic doctors, nurses and health workers.

Be aware of general care principles:

- get to know the person you are caring for and their likes and dislikes regarding food and drinks
- make meal times enjoyable and relaxed
- present food in an appealing way
- use communication aids effectively so you can talk to the person about what they want to eat and drink
- use eating aids and utensils appropriately. Make sure you have been instructed by a therapist
- follow instructions in the person's Individual Care/Management Plan to assist them with safe positioning, food and fluid intake, medication administration
- remember to consider fatigue and environmental conditions and plan eating and drinking times that meet the person's needs
- make sure you have the time needed to assist the person to eat at the pace they can manage safely
- observe the person's eating and drinking patterns. Notice any changes
- communicate with the person about any changes they are noticing in their eating and drinking preferences and enjoyment