

SOCIAL & EMOTIONAL WELLBEING HELP SHEET



This Help Sheet explains the social and emotional impacts of Machado Joseph Disease and provides information about appropriate social and emotional support strategies.

Social and emotional wellbeing

The World Health Organisation's (WHO) definition of health includes the physical, social, emotional and cultural wellbeing of the whole community. Many health services in Australia use the phrase 'social and emotional wellbeing' when they talk about mental health.

Mental health

Mental health refers to how people feel about themselves emotionally, socially and spiritually. The World Health Organisation has defined mental health as a state of wellbeing where a person is aware of their own abilities to:

- cope with everyday life and the stressful things that may occur
- reach goals they have set
- be able to work and feel productive
- be a part of the community they live in.

Mental health includes having a sense of meaning in life and having control over decisions affecting your life. It can also relate to a sense of belonging and connection, and having access to treatment and support.

Mental health problems and mental illness

Mental health problems and mental illnesses refer to the range of disorders affecting thinking, moods and behaviours and consequently interfering with day to day life. A mental health problem is less severe than a mental illness but presents coping challenges. Coping strategies focus more on personal and social support and may not require clinical intervention. A mental illness must be diagnosed by a doctor or psychiatrist who assesses people's abilities to cope psychologically, socially and personally. Treatment of a diagnosed mental illness is prescribed by the doctor or psychiatrist in conjunction with personal and social support strategies.

Medications

Antidepressant and anti-anxiety medications may be used as part of a clinical treatment plan. Carers will be guided by clinicians and may need to support the person with MJD to take medications as prescribed. Carers are in an important role for observing, reporting and recording the person's response to medications.

MJD impact on social and emotional wellbeing

The gradual deterioration of nerves and muscles affects the capacity of someone with MJD to take part in many aspects of their daily life. Deterioration in strength, walking and balance, talking and being understood affects an individual's ability to look after themselves, maintain their homes and family, go to work, take part in community events, visit family members, etc. As the disease progresses, people become increasingly dependent on others. Adjusting to progressive loss of independence, while knowing that the disease only gets worse, inevitably affects a person's social and emotional wellbeing.

There is evidence that people with MJD have higher rates of depression, anxiety and apathy. Depression in people with MJD may be reactive to the physical incapacities, sleep disturbances and fatigue rather than the neurological damage of the disease process.

Supportive strategies

The MJD Foundation encourages people with MJD to 'Stay Stronger for Longer' and works with individuals and families to work out what the person needs in order to 'stay stronger for longer'. Staying stronger for longer will be influenced by:

- healthy living choices
- an adequate and nutritious diet
- appropriate exercise
- adequate rest
- recreation and stimulation
- strong and supportive relationships
- maintaining a person's role within their family and community
- being able to take part in family and community events and ceremonies
- programs and projects that foster empowerment, validation and strength.

Occupational therapy

Occupational therapy (OT) has been shown to improve the social and emotional wellbeing of people with MJD. A study of people with MJD taking part in an OT program over six months (weekly sessions for three months and then monthly sessions for three months) found significant reductions in depression. People who were the most depressed at the beginning of the program showed the greatest improvement.

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THE MJD FOUNDATION aims to provide a better quality of life for Indigenous Australians living with MJD. The MJD Foundation's five key areas of activity are research, advocacy, equipment, education and services. The social and emotional wellbeing of people with MJD, and their families, is supported by providing:

- equipment to assist people to be independent
- holidays to offer experiences of fun, excitement and fulfilment of dreams
- social outings for stimulation and enjoyment
- kin connection trips that enable people to 'go home' several times a year to keep connected to family and community (when they can no longer live in their community)
- MJD Therapy Programs (access to occupational therapy, physiotherapy, speech therapy and other forms of therapy to 'stay stronger for longer').

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

MJD Foundation staff

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Email: libby.massey@mjd.org.au

Your Health clinic doctors, nurses and health workers.