



# Motor Neurone Disease Association of Tasmania Inc.

## Strategies: 2018 to 2020

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## Introduction

This document sets the strategic direction for the Motor Neurone Disease Association of Tasmania (MND Tasmania). It articulates our direction for the next three-year period from 2018 to 2020. It serves as a platform for the sustainability, effectiveness and efficiency of MND Tasmania by aligning everything that we do with our purpose and to achieve our vision:

### **A world without MND - care to cure**

The key strategies for the years 2018 to 2020 are:

- Develop and improve systems and processes to achieve sustainability, effectiveness and efficiency;
- Deliver quality services and support;
- Engage in and enhance partnerships; and
- Raise funds and raise our profile.

This document has been prepared by the board and we intend to develop it further as we consult with our stakeholders, including of course, members of MND Tasmania. As is well known, a plan is the start, success lies in making the plan work. The board has been working and continues to work on the underlying actions that take a plan to reality.

This document has been ratified by the MND Tasmania board 11/4/2018

## About us

MND Tasmania was founded in 1986, to assist people living with MND by providing information useful to stakeholders, assisting with equipment and home modifications, raising the profile of MND in the community and raising funds for research into MND.

The board of MND Tasmania comprises: president, vice president, public officer, secretary, treasurer and two ordinary members. All the members of the board are volunteers, who are elected at the annual general meeting (AGM) according the constitution. They serve until the date of the following AGM and are eligible for re-election at that and subsequent AGMs. The AGM is usually held in March each year.

# What is MND and Kennedy's disease?

## MND

Nerve cells (neurones) control the muscles that enable us to move, speak, breathe and swallow. Motor Neurone Disease (MND) is the name given to a group of diseases in which these neurones fail to work normally. Muscles then gradually weaken and waste, as neurones degenerate and die. Motor function is controlled by the upper motor neurones in the brain that descend to the spinal cord; these neurones activate lower motor neurones. The lower motor neurones exit the spinal cord and directly activate muscles. With no nerves to activate them, muscles gradually weaken and waste. MND can affect a person's ability to walk, speak, swallow and breathe. #

Amyotrophic Lateral Sclerosis (ALS), Progressive Muscular Atrophy (PMA), Progressive Bulbar Palsy (PBP) and Primary Lateral Sclerosis (PLS) are all subtypes of MND. Although MND is the widely used generic term in the United Kingdom, Australia and parts of Europe, ALS is used more generically in the United States, Canada and South America. MND is also known as Lou Gehrig's disease in the US after a famous baseball player who died of the disease. #

There is currently no cure or effective treatment for MND. People with MND have a median survival expectation of three years from the onset of symptoms.

## Kennedy's disease

Kennedy's disease (X-linked spinobulbar muscular atrophy [SBMA]) is an inherited disorder affecting the lower motor neurones. Due to similar symptoms, people are sometimes first misdiagnosed as having MND. Kennedy's disease affects adult males and the female gene carriers do not usually develop any symptoms of the disease. #

## Terms used in this document

As MND Tasmania supports people living with MND or Kennedy's disease, in this document, the terms:

- 'MND' refers to both MND and Kennedy's disease
- 'people with MND' includes those diagnosed with MND or Kennedy's disease
- 'people living with MND' includes people with MND or Kennedy's disease, their carers and family members

# Source: <https://www.mndaust.asn.au>; accessed 17 January, 2018

## **Our purpose**

**To support people living with MND, to share their experience and understand the challenges that they face**

## **Our vision**

**A world without MND: care to cure**

## **Our values**

Our values frame our decisions and our actions, which are aligned with our purpose. They are:

### **Integrity**

We are professional, accountable and reliable

### **People**

The people we serve are at the heart of everything we do

## **Our future**

Hope translated into effective treatments, better care and working tirelessly for a cure

## **Our strategies for 2018 to 2020**

In pursuit of 'care to cure' for everyone living with MND in Tasmania:

**Develop and improve systems and processes to achieve sustainability, effectiveness and efficiency**

**Deliver quality services and support**

**Engage in and enhance partnerships**

**Raise funds and raise our profile**

# What we do

## Disseminate information

- Gather and share advice on coping with MND
- Provide advice to people living with MND

## Engage in advocacy/lobbying

- Raise awareness of MND and optimise public contribution for care and research

## Assist people living with MND

- Create and nurture a caring link between people living with MND, by providing opportunities for interaction
- MND Tasmania and MND Victoria work together to provide the MND Advisor Service which provides state-wide support for members
- Needs-based support and assessment, home visits and referrals to appropriate care and support services as required
- Information, support and training for service providers for people with MND in Tasmania
- Free membership and bi-monthly newsletter from MND Tasmania and MND Victoria for people with MND in Tasmania

## Foster collaboration and research

- Foster and maintain links with MND Australia, MND associations in other States, other healthcare organisations and self-care groups
- Encourage and support relevant research initiatives

## Professional affiliations

MND Tasmania is a member of MND Australia, the peak MND organisation in Australia, and of the Neurological Alliance of Tasmania.

MND Tasmania has agreements with and works closely with community-based and not-for-profit organisations such as the Independent Living Centre Tasmania and FightMND, to optimise the quality of life for people living with MND and to promote and support research into MND.

MND Tasmania also works closely with a diverse range of health and human services at state and federal levels, including the medical, disability and aged care spheres, as well as specialists, general practitioners, neurologists, palliative care specialists, nurses, allied health, occupational therapists, physiotherapists and speech pathologists.

MND Tasmania currently has a memorandum of understanding with MND Victoria. MND Victoria assists us with providing the MND Support Service and administrative support which underpins the bimonthly newsletter, fundraising management and membership processing.

MND Tasmania currently has contracts with the Independent Living Centre Tasmania and FightMND to provide a communication equipment service for its members.