



The MND and Me Foundation's goal is to ensure all Queenslanders with Motor Neurone Disease receive equitable access to Non Clinical support services when and where they need them. We try to offer support services that deliver the right solutions, at the right time.

## **Service Offering:**

**Information Sessions** - It is important to have access to factually correct information about MND and the services and supports available. These sessions provide access to leading health professionals and MND Researchers. We try to have one Information Session per quarter. These sessions are video recorded and can be accessed at any time on our website.

Support Groups – These groups offer people impacted by MND the chance to spend some time in a supportive environment with like-minded people. They are only for people who are currently living with or providing care for someone living with MND. Attending a support group is a great opportunity to obtain information about services available in your local community, as well as to exchange practical advice and learn from each other in a relaxed, supportive and friendly environment.

Support Groups are currently being conducted in Cairns, Townsville, Gold Coast, Sunshine Coast, Ipswich, North and South Brisbane. The Support Group Calendar can be found on our website.

Carer Support Services – These services include Mindfulness Training Sessions and Current/Past Carer Lunches which are run at various times throughout each year.

**Child Psychology** - Funded access to child psychologists for children who have a parent/grandparent with MND. No GP referral is needed to access this service.

**i-Pad Connect Program** - Supply of i-Pads with specific communication applications pre-loaded to keep people connected with family and friends. A referral from a registered Speech Pathologist is required for this program.

**Voice Banking** – Voice Banking is a process where an individual who will likely experience difficulties using their voice in the future, records their voice through a website. This then creates an artificial voice, which can be used when and as needed to supplement or replace their natural voice.

Support may include supply of a USB head set and microphone and access to the required software program. A handy guide to the process can be found on our website.

**Equipment Hire** – Bridging the time gap between equipment prescription and delivery in the short to medium term. Where possible, we will fund the rental costs of necessary equipment until a more permanent solution is provided. A referral is required from an Allied Health professional (Occupational Therapist, Physiotherapist or Speech Therapist) to access this service.

**Emergency Grants** – These grants are provided when no other funding sources are available and urgent assistance is required for equipment or respite care. The maximum value of these grants is \$2,500. All grant applications must be received in writing with required supporting documentation.



'To Care and to Cure'

The MND and Me Foundation Limited (the Foundation) was established by Scott Sullivan, a husband and father of two children. Scott was diagnosed with Motor Neurone Disease in 2010 at the age of 38, and sadly passed away in April 2014.

The Foundation is a not-for-profit organisation that Scott formed to raise awareness of MND and its impact in the community. Scott saw a desperate need to assist people living with MND, as well as their families, to maintain their independence and quality of life for as long as possible.

The MND and Me Foundation Board – formed in 2011 – has assumed responsibility for governance and strategy of the Foundation to ensure the changing needs of people living with MND are met. The Board is united in the Foundation's mission To Care and To Cure. Until a cure is found, the Foundation will continue to help fund MND research and treatment initiatives to improve the lives of people diagnosed with MND.

It is also imperative that the Foundation provides the right solutions at the right time throughout the cycle of pre-diagnosis, diagnosis, living with MND and following a loved one's passing.

The Foundation works closely with corporate partners and other Australian MND and PND (progressive neurological disease) associations, in a financial and operational capacity, to provide care and services to people living with MND. This deliberate collaborative approach will help us ensure that no one faces MND alone.

Motor Neurone Disease in Australia is expensive. According to a Deloitte Access Economics Report in 2015 the total cost of MND in Australia was \$2.4 billion, which is equivalent to \$1.1 million per person with MND.



The MND and Me
Foundation's aim is to ensure
no Queenslander has to face
MND alone. We will strive
to be there to support them
when and where they need it.
People should not fall
between cracks in the
system.

#### **Fast Facts**

The MND and Me Foundation...



focuses on four key areas: Care, Research, Awareness and Community Engagement.



conducts specific events to drive MND awareness, fundraising and community participation (both within the MND community and the general public).



has provided over \$1,500,000 to MND research since the inception of the Foundation in March 2011



ensures Queenslanders with MND have timely access to much needed equipment, information, emotional support and care services.



is 100 per cent funded by corporate sponsorship and community donations.

All Queenslanders with MND (approximately 350 people) deserve equitable access to support services when and where they need them. While there are government funded support programs available, the huge variables associated with MND often mean these systems are too slow to react and struggle to keep up with the progressive nature of the disease.

### **Key Objectives**

- To assist people living with MND and their families, to gain access to health care providers and counselling services, and to provide funding for these services.
- To promote community awareness of MND and its impact on those living with the disease and their families/friends through public awareness campaigns and fundraising activities.
- To provide information about MND and its effects on people living with the disease, and their families and friends.
- To provide opportunities, forums and events whereby people living with the disease, their friends and families can meet with others in similar circumstances to share their feelings, challenges and achievements.
- To foster relationships and connections between the Foundation and similar organisations for the benefit of people living with the disease.
- To support research efforts by raising awareness about latest research initiatives and by contributing financially towards the funding of research.

#### **Service Offering**

We will continue to cultivate the Foundation's service offering to meet the changing needs of people living with MND. The Foundation's current service offering include:

- Supply of equipment (short/medium term)
   bridging the time gap between equipment prescription and delivery.
- Support Groups— currently available in Cairns, Sunshine Coast, Gold Coast, Ipswich, North and South Brisbane and Townsville
- Access to health professionals and research outcomes via Information Sessions
- Home improvement and support service grants for situations outside of the regular funding schemes eg NDIS and MAC
- Carer services Mindfulness Training and Past Carer Lunches
- Support coordination working out in the community to ensure access to funded support programs.
- Funded access to child psychologists for children who have a parent/grandparent with MND
- Supply of I-Pads and specific communication applications to keep people connected with family and friends.
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Contact us at the MND and Me Foundation today

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W mndandme.com.au E services@mndandme.com.au f www.facebook.com/MNDFoundation

# Our aim is to ensure that no Queenslander has to face MND alone.

## Support Coordination:

This service operates under the name of "Spark NeuroCare" and is run in partnership with MS Queensland to deliver state-wide Community based coordination support service.

Support provided includes:

- Advice, information and resources
- · Links to local service providers and suppliers of aids and equipment
- Referral to wellness and educational programs and events
- Referral to allied health services such as Physiotherapy, Occupational Therapy, Speech Therapy and Dieticians
- Ways to manage everyday life
- Assisting access to the National Disability Insurance Scheme (NDIS) or My Aged Care
- NDIS support coordination.

We have Support Coordinators working in the community helping people with MND in the following regions:

- Brisbane
- Ipswich
- Sunshine CoastBundabergWide BayRockhampton
- Townsville

- Gold Coast
- Toowoomba

An initiative of

Cairns







There is no membership fee required to become a member or receive services from the Foundation.

All support services we provide are free of charge except for some NDIS eligible services.

If you would like more information on the Foundation or to have a chat please don't hesitate to give us a call or visit our website.

( 07 3394 5333

mndandme.com.au