



AFFILIATIONS

Associate member of  **mnd**
Australia

Other Memberships



**INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS**



Neurological Alliance
of New Zealand



**FUNDRAISING
INSTITUTE OF
NEW ZEALAND**

MATATIKA MĀTAURANGA KAITAUTOKO



- Not for profit founded in 1985
- National Office in Auckland.
- Staff based at National Office:
 - General Manager
 - Support Service Team Leader
 - Administrator
 - Fundraising and Accounts
 - Communications Manager
 - Grants Administrator
 - Research Advisor



- 7 Support team members
- Health/Education backgrounds
- Team members all part time 24-35 hours/week
- Cover 2, 3 or 4 DHB's each
- Work from home offices
- Monthly team meetings via ZOOM
- Team training days in Auckland once or twice a year

Support Team



Referrals



Health Professionals/
Allied Health, The
person with MND/
Family ...



We respect that some
people choose not to
engage with MND NZ



Some folk need time,
Others want us there
immediately

Support service provides support for

- People with MND
- Their caregivers
- Families/Whanau
- Health Professionals working with people with MND



Our client support includes:

- Home Visits
- Email, text and phone follow up between visits
- The option of Skype/ZOOM calls with those in outreach areas
- Liaising with HP's, Allied Health, Rest Homes and community service providers, NASC, TALKLINK
- Providing information and support for extended family and friends



MND Support Role

- Very different to HP or Allied Health – our aim is to complement these services by collaboration → REFER.
- Listen – to needs/concerns of client and loved ones.
- Provide information.
- Help our clients navigate health system.
- Support health professionals.
- Promote communication with wider team.
- Facilitate contact with other people with MND.



Contact with others

- Support groups – mindful of dynamic, not suitable for all
- Smaller meetings depending on need – e.g. widows/
widowers
- Linking spouses/ carers with similar issues
- Linking through email if both parties request and agree
- MND NZ Forum
- Social media forums - 😊 or ☹️ [In Holland ...]



Resources

- Information pack for clients
- “A Problem -Solving approach” - booklet for health professionals
- Talking to Young People Pack
- Newsletters. MND interest updates
- Facebook
- **Website www.mnd.org.nz *******



MND NZ Research Network

- Established in 2017 to facilitate interaction [MND biomedical and clinical researchers, HP's etc].
- Led by Dr Emma Scotter.
- Based at Centre for Brain Research.
- Website provides centralized location to provide information on all MND research in NZ.
- Prompt new research through increased interaction.
- MND NZ supports research through fundraising and through raising awareness.



MND Registry

- Launched in May 2017.
- Collects clinical, demographic , contact and genetic information (if known).
- Data stored anonymously in secure online database maintained by Australian Registry.



MND Registry Aim

- Facilitate growth of MND research in NZ.
- Help guide future development of Support Services.
- Connect people with MND to researchers here and overseas.



8% ☹️

Regular Fundraisers

- Cuppa Tea for MND
- Main fundraiser – Walk 2 d’feet MND



Most common question –
What Next ?
& How long?



and KG

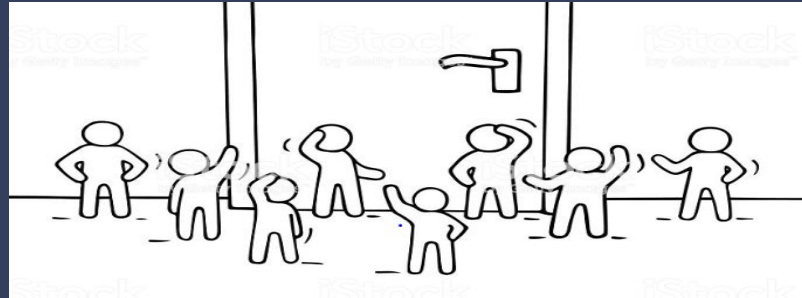
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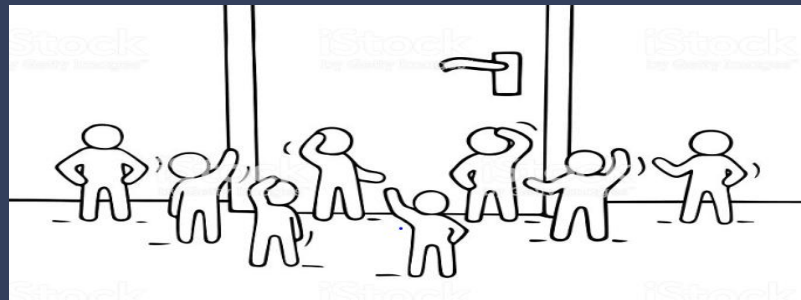
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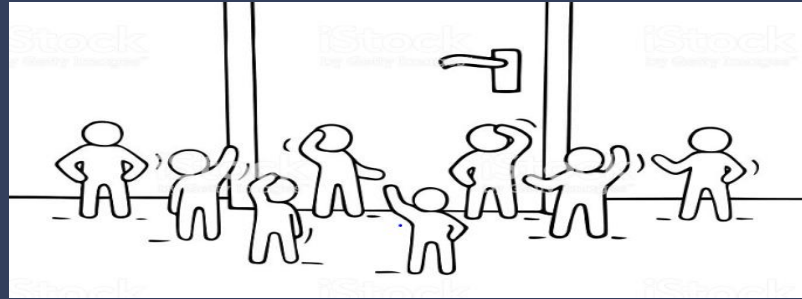
- Can be overwhelming for the person with MND having so many people involved.





- We can only do our best within the limitations of :
 - the health system
 - resources
 - support networks,
 - client's own choice
 - and the unpredictable nature of MND itself.





- Communication is the key.



This is such an individual journey.
People have the right to choose and do what works for
them,
even if it might seem unconventional to us,
BUT we don't promote – just listen.



We are always mindful that:

- Needs of PwMND, their carers and family need to be taken into account.
- MND robs the person of physical function- by including them in decision making and planning of management of their symptoms/needs

we can empower them to have more control over their life.



Our support for Caregivers is an important focus of our work

- Change in lifestyle and role.
- Altered family function/dynamic.
- Ongoing grief & loss
- Sense of self & identity changes.
- Anxiety & Helplessness.
- Little/no control over personal decision making.
- Loss of Privacy.
- Exhaustion.
- Both Physical Health & Psychological wellbeing impacted.



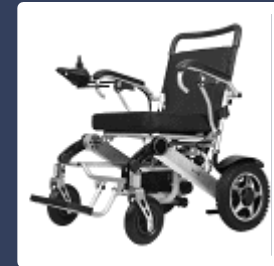
Main Perth 2019 Symposium learnings for us

- Cognitive Changes
- Nutrition and weight management

Emphasis was on :

- Multidisciplinary care
- Working together rather than in silos
- Proactive approach – getting things in place prior to need

JF



Although our work is very sad at
times,
It is also so rewarding and fulfilling.

It is a privilege and blessing to be
allowed into these beautiful families
and to have the opportunity to walk
beside them.

Our clients are inspirational people
and we learn so much from them.

None of the team would change what
we do for anything.



*“Her smile lights
up the world.”*



