

29 September 2003

Consultation on the Definition of a Charity
The Board of Taxation
C/- The Treasury
Langton Crescent
PARKES ACT 2600

The Motor Neurone Disease Association of Victoria Inc wishes to make a submission in relation to the Definition of a Charity.

Background

Enclosed are two documents for your information, a leaflet entitled "Motor Neurone Disease - Some Facts" and a background paper entitled "Motor Neurone Disease - Some Background". In summary:

- ❑ MND is a progressive degenerative neurological disease that causes rapidly increasing levels of disability, and death
- ❑ Average life expectancy in Victoria from diagnosis is about 27 months
- ❑ Average age of onset is 59 years, however, the age range of onset is 40 to 70 years
- ❑ The rapid progression of MND creates high levels of disability and consequent needs for support — feeding, communication, movement, transferring, toileting, day activities etc. MND has a comprehensive impact on all aspects of living.
- ❑ While people of working age can remain at work after diagnosis, this is usually for a very short time, often only weeks of a few months.
- ❑ The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to those who are involved in providing the highly variable and complex care.
- ❑ Over 90% of people with the disease are supported by a spouse or carer in the home (Sach, 1995, 2003)
- ❑ Carer stress is a significant cause of hospitalisation and facility-based care/respite
- ❑ People living with MND are not traditional service users, and have rarely had involvement with the disability or community services sector.
- ❑ Research by Sach (1995, 1997, 2003) indicates that people living with MND **will not access services** unless they have confidence in the provider's knowledge of MND and its impact.

The Association - Structure and Leadership

The Association is governed by an elected State Council (Board of Directors) of 12 people elected by and from the Association's membership. Of the 12 places on the State Council, six are reserved for people living with MND or their close associates.

The Association has four full-time staff and eight part-time.

Services

The Association delivers four main services to people living with MND, their carers families and health professionals working with them, supported by administration and fundraising.

The services are:

- Equipment Loan
- Case planning and Assessment (Regional Advisors)
- Volunteers
- Information

The Association has registered and is supporting 100% of the projected cases of Motor Neurone Disease in Victoria. The Motor Neurone Disease Association of Victoria was established in 1981 and is a community-based organisation run by an elected State Council.

Membership of the Association is currently over 800, comprising patients, carers, former carers and interested people. The Association, as at 30 June 2003 was servicing 234 people with the diagnosis of MND. They receive a variety of services provided by the Association, including Family Support, information, equipment and volunteers. In 2002/2003, 350 people diagnosed with MND received support from the Association.

The Association moves in and out of the lives of people with MND as their needs demand. Given the relatively short life expectancy of people diagnosed with MND (27 months from time of diagnosis), the monitoring and reassessment of needs is an essential element in ensuring that they are able to appropriately access quality services when they need them. Our aim is to assist people to live as well as possible while living with MND. Transition management and facilitation is an effective mechanism to achieve this.

This transition process, or the role of being an interface between people with the disease and the service sector, is fundamental to effective service delivery for people with progressive degenerative diseases, and particularly MND.

The Definition of Charity

The Association is concerned about a number of issues in relation to the draft legislation and the definition of Charity.

The core definition

Section 4 Core Definition, (1) (c) states that a Charity “does not engage in activities that do not further, or are not in aid of, its dominant purpose:”

The dominant purpose of the Association is “*Provide and promote the best possible care and support for people living with MND*”. To achieve this dominant purpose, the Association provides direct support and services to people living with MND. In addition, the Association receives and raises funds to invest in research into the science, care and management of MND. The aim of this investment is to help find cause, treatment and cure of the disease, and to improve the care and management of the disease. The maximum amount the Association contributes to research is equal or less than 5% of total income.

The Association is concerned that investment of funds in research may be interpreted as not furthering its dominant purpose. The Association is of the view that investment in research of this kind should not be interpreted as being outside the dominant purpose of the Association and not endanger its status as a charity.

The Definition of Dominant Purpose

The Association is concerned that the words “ancillary and incidental to its purpose” in clause 6 (1) (b) should be interpreted widely to include investing in research as noted above.

The Definition of Public Benefit

Clause 7 Public Benefit states:

7(1) “A purpose ...is for the public benefit if and only if:

(c) it is directed to ... a sufficient section of the general community

Subclause 7(2) then states:

(2) “A purpose is not directed to the benefit of a sufficient section of the general community if the people to whose benefit it is directed are numerically negligible”.

This begs the question as to what is meant by “numerically negligible”.

The incidence of motor neurone disease is 2:100,000, or approximately 390 new diagnoses each year. At the same time, about 1170 people live with the diagnosis of MND at any point in time.

There needs to be further consideration of the notion of “numerically negligible”. While MND can identify a significant number of patients, many other disease and disability groups have much smaller numbers. The importance of their representative organisation being a charity and accruing the benefits of being a charity cannot be underestimated in the services and support they can provide.

It is our view that the term “numerically negligible” should be defined to ensure that it is clear that a charity which benefits a small section of the general community has a purpose for the public benefit.

Disqualifying Purpose

The Association is concerned that Clause 8(2)(c) will operate to prevent charities from attempting to influence the law or government policy, particularly in respect to funding and delivery of services.

On a liberal interpretation, there is nothing that could restrict the charities behaviour as long as the advocacy is undertaken in pursuit of its dominant purpose. However, on a stricter interpretation, it suggests that charities must restrict the resources they apply to such advocacy work. This would impose significant workload on charities which would have to record and monitor resource application to advocacy work in preparation for possible ATO audit.

The Association recommends that clause 8 be redrafted to remove the opportunity for alternative interpretation and ensure that there is no restriction on charities undertaking advocacy to change law or government policy so long as such advocacy was a part of its dominant purpose.

Additional Administrative Burden

Any requirement to record cost and value advocacy work undertaken as a result of adoption of the proposed definition of Disqualifying Purpose would be significant. For example, the Association has received a copy of the Form 990 required by the United States Internal Revenue Service and completed by a fellow MND organisation. That organisation has

indicated that this form is complicated to record and collect information for, difficult to prepare, and expensive to review by Auditors prior to submission. They have indicated that this form inflates their existing audit costs by approximately 50%, excluding data recording and retrieval. If the impact on MNDAV of such a review submission was required in Australia it would add approximately \$4,000 to audit and reporting costs, as well as costs of data recording and reporting.

Flexibility

Subject to changing the definition of Disqualifying Purpose as proposed above, the Bill does provide flexibility in a changing society.

Altruism

Adopting the concept of altruism in the dominant purpose would not impact on the Association. However, it must be recognised that altruism of a charity should not be used as an excuse or reason for Government not to fund such bodies or their activities.

We trust that this submission will add benefit to the discussion on the Definition of a Charity. The Association is available for further consultation and discussion if required.

A handwritten signature in black ink, appearing to read "Rodney Harris". The signature is written in a cursive, flowing style with a prominent initial 'R'.

Rodney Harris
Chief Executive Officer