

**Who cares for the bereaved?  
A national survey of family caregivers  
of people with Motor Neurone Disease**

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## **Who cares for the bereaved? A national survey of family caregivers of people with Motor Neurone Disease**

### **ABSTRACT**

**Background:** Although Motor Neurone Disease (MND) caregivers are most challenged physically and psychologically, there is a paucity of population-based research to investigate the impact of bereavement, unmet needs, range of supports and their helpfulness as perceived by bereaved MND caregivers.

**Methods:** An anonymous national population-based cross-sectional postal and on-line survey of bereavement experiences of family caregivers who lost a relative/friend to MND in 2016, 2017, and 2018. Recruitment was through all MND Associations in Australia.

**Results:** 393 valid responses were received (31% response rate). Bereaved caregiver deterioration in physical (31%) and mental health were common (41%). Approximately 40% did not feel their support needs were met. Perceived insufficiency of support was higher for caregivers at high bereavement risk (63%) and was associated with significant worsening of their mental and physical health. The majority accessed support from family and friends followed by MND Associations, GPs and funeral providers. Informal supports were reported to be the most helpful. Sources of professional help were the least used and they were perceived to be the least helpful.

**Conclusions:** This study highlights the need for a new and enhanced approach to MND bereavement care involving a caregiver risk and needs assessment as a basis for a tailored 'goodness of fit' support plan. This approach requires continuity of care, more resources, formal plans and enhanced training for professionals, as well as optimising community capacity. MND Associations are well-positioned to support affected families before and after bereavement but may require additional training and resources to fulfil this role.

**Keywords:** Motor Neurone Disease; bereavement support; sources of support; social support; professional support; informal support; physical health; mental health; family caregivers; MND Associations; palliative care; compassionate communities, population survey.

### **BACKGROUND**

Motor neurone disease (MND), also referred to as amyotrophic lateral sclerosis (ALS) is a progressive, neurodegenerative illness involving a gradual but typically rapid rate of muscle wasting, weakness, and paralysis throughout the body. There is a high amount of variability in survival data and some individuals with MND live for many years before deterioration. However, death via respiratory failure commonly occurs

approximately 3-4 years post-onset and the median survival time is 2 years after diagnosis (1, 2).

Providing care for a family member with MND can have significant consequences given the usual relentless course of disease advancement and absence of cure (3, 4). Canadian research found that MND caregivers averaged over 40 hours of informal care per week (5). Distress was exhibited amongst 53% of these caregivers and was associated with the amount of care hours provided. Over 80% of individuals with MND live with their caregivers and unsurprisingly, research has reported connections between the physical and psychological functioning of both parties (5). Psychological sequelae such as anxiety and depression are already linked with MND caregiving (4, 6) and symptoms are associated with patient behavioural changes (7, 8). Caregiver burden levels are elevated amongst MND carers and increase with disease progression (9).

Given the inexorable mortality associated with MND, family caregivers will inevitably be confronted with bereavement. The bereavement process can be very distressing for MND caregivers; with some exhibiting anger and profound disappointment if there is a discrepancy between expectations and the actuality of the dying process (10).

Generally, bereavement can be associated with an increased risk of negative outcomes including spouse mortality, physical health problems, disability, suicide and suicidal ideation, medication abuse, hospitalisations (11), financial loss (12), social isolation and stigma (13). There are a number of mental health problems including the significant and lengthy post-loss dysfunction and impairment associated with Prolonged Grief Disorder (PGD) (14). Higher prevalence rates of PGD have been found amongst bereaved MND carers than in the general bereaved population (6, 15, 16).

Social support is generally considered to assist in safeguarding caregivers against negative bereavement outcomes (17). Sufficient external support can facilitate improved coping amongst bereaved individuals (14), but the support received by the bereaved is often insufficient in terms of quality and quantity (18). Rather than seeking formal assistance, the bereaved usually prefer to obtain support from within their social network due to the value placed on existing attachments, practical help from a tangible alliance and a perceived sense of belonging (19). Translating the needs of the bereaved and what they perceive to be helpful into effective support strategies remains a challenge (20) with some studies endorsing social and community based approaches to bereavement care that are flexible enough to account for 'goodness of fit' (21-23).

Most existing research includes caregivers from small clinic-based samples. There is a paucity of population-based research to explore the impact of bereavement, unmet needs, range of supports and their helpfulness as perceived by bereaved MND caregivers.

## **OBJECTIVES**

- To determine the self-reported physical, mental, and financial impact of bereavement
- To establish the extent to which the support was perceived sufficient to meet the needs of the bereaved
- To ascertain who provides bereavement support in the community
- To identify what sources of support were perceived to be the most or least helpful

## **METHODS**

Ethics approval was granted by La Trobe University Human Research Ethics Committee (HEC19022).

### **Study Design**

The study is a population-based, cross-sectional investigation of bereavement experiences of family caregivers who lost a relative/friend to MND between 2016-2018. Postal and on-line surveys were used to collect information from clients of the five state MND Associations in Australia (May-July 2019); online survey versions were collected and managed by REDCap electronic data capture tools hosted by La Trobe University (24).

### **Participants and Procedure**

A total of 1,404 study packages were posted to the five MND associations in Australia. These packages contained an invitation letter from the MND Association to the family, information sheet, the questionnaire, a list of family support services in case the respondent became distressed while completing the questionnaire, and a reply-paid envelope. Additionally, a link to the on-line REDCap survey was provided at the front of the questionnaire. The MND Associations then selected next-of-kin of clients who were bereaved in 2016-18 from their databases and mailed the study packages. Consent was implied by the return of the completed survey. No reminder letter was sent to reduce intrusiveness on the bereaved families. We chose a 6-months bereavement period to approach bereaved people as this period is the earliest required for a diagnosis of PGD, while 42 months is not likely to compromise the accuracy of recalled information. Clients were eligible to participate if a close family member or friend died in the specified timeframe, were able to read, understand and write in English, and were 18+ years of age.

### **Materials**

The questionnaire was adapted from a general bereavement survey (18) and tailored to MND-specific issues in consultation with a reference group comprising representatives from the MND Associations, two consumers and the project team which comprises skills in neurology, psychiatry, psychology, nursing and palliative care.

The questionnaire contained eight sections covering a range of experiences and unmet needs. It also included a validated risk assessment screening measure for

PGD, the PG-13 (14), measuring responses to separation, social/functional impairment and cognitive, emotional and behavioural symptoms. This tool was used to delineate the three risk categories of low, moderate, and high (18). When all 5 criteria (loss event, separation distress, >6 months bereavement, other emotional symptoms, and social/functional impairment) are present, high bereavement risk is established. A further categorisation of 3-4 criteria indicate moderate risk, and 1-2 criteria indicate low risk.

The supports bereaved people received were grouped into: professional, community and informal, according to the Public Health Model for bereavement support (18), which articulates a three tiered approach to bereavement risk and need for support: The low risk group (first tier, 36.7%) would need support principally from family and friends, the moderate risk group (second tier, 53.7%) would need support from the wider community and some general support from various professionals, and the high risk group (third tier, 9.6%) would need support from mental health services (6).

### **Analysis**

The data were analysed using STATA (Version 15) and SPSS (25). Descriptive and inferential statistics were conducted with frequencies calculated for the categorical variables and significance testing performed using chi-square or Fishers exact test when expected cell counts were less than 5. Significance was set at  $p < 0.05$ .

## **RESULTS**

393 valid responses were received (31% response rate). There was only 14.3% uptake of the online mode (56 of responses were online and 337 were postal). Females were more likely than males to use the online mode (95% vs 70%,  $p < 0.001$ ). Online respondents were younger (mean age for on-line survey was 51 years compared to 65 years for postal survey,  $p < 0.001$ ). There was no difference in educational status.

### **Profile of the bereaved and deceased**

Of the 393 bereaved carers (mean age 63.1, SD 12.7, age range 22-91 years), the majority were female (73.8%), retired (52.4%), widowed (71.2%) and Australian (78.8%). Their relationship to the deceased was mostly as a spouse/partner (72.2%) or child of the deceased (18.9%). The mean period of bereavement was 1.8 years (SD 0.8). Respondents cared for a median of 1.7 years, range 0.4 to 22.5 years, and 80% provided day to day hands on care. The mean age of the deceased was 68.4 years (SD 10.9), with an age range of 31-94 years. More than half of the deceased were male (59.1%). The median length of illness was 1.5 years, range 0.04 to 23.5 years (Table 1).

[Table 1 about here]

### **Self-reported impact of bereavement**

Different aspects of wellbeing were impacted by bereavement. Almost a third (31%) reported deterioration in physical health, 42% reported deterioration in mental health

and 27% experienced decline in their financial situation (Table 2). Conversely, about 20% reported improvement in all three aspects.

[Table 2 about here]

### **Sufficiency of support**

57% of bereaved respondents felt they received as much support as they needed. However, 38% reported that they were not fully supported in their bereavement. A further 5% stated that they did not need help. More in the high-risk group reported not having sufficient support (63%), while more in the low risk group reported having sufficient support (69%), ( $p=0.001$ ) (Table 3 and Figure 1).

[Table 3 and Figure 1 about here]

Over a half of those who reported not receiving enough support experienced significant worsening of their mental health ( $p=0.008$ ), and just under 40% reported worsening physical health ( $p=0.049$ ). Financial wellbeing was the least affected and differences were not significant (Table 4 and Figure 2).

[Table 4 and Figure 2 about here]

### **Sources of bereavement support accessed by MND caregivers**

The most frequently used sources of support were those in the informal category such as friends (98%), family (96%) and funeral providers (72%). In the community category, the most used services were those of the MND Associations (78%) and GPs (74%) followed by palliative care services (45%). Professional resources were the least frequently used, with case-coordinators (23%), counsellors (22%) and social workers (19%) the most consulted (Figure 3).

[Figure 3 about here]

All risk groups reported support from family, friends, and funeral providers to the same extent. There were significant differences between the grief risk categories in the use of some services: Compared to the low risk group, those in the high risk group used more of the following services: GPs (91% vs 68%,  $p=0.017$ ), MND Associations (84% vs 72%,  $p=0.039$ ), bereavement support groups (19% vs 9%,  $p=0.04$ ), counsellors (41% vs 15%,  $p=0.003$ ), psychologists (38% vs 13%,  $p=0.002$ ) psychiatrists (25% vs 4%,  $p<0.001$ ) and legal services (56% vs 34%,  $p=0.05$ ) (Figure 4).

[Figure 4 about here]

### **Perceived unhelpfulness of sources of bereavement support**

The extent to which these sources of support were rated as 'helpful' or 'unhelpful' varied. In the informal category, the supports which had the lowest rates of unhelpfulness were: family (11%), friends (18%), religious/spiritual advisors and funeral providers (26-28%).

In the community category, the highest rates of unhelpfulness were for school-based advisors (68%), nursing homes (56%), hospital and MND Associations (44%), palliative care services (38%) and community pharmacists (39%), GPs and allied health professionals (34-36%). The most useful were community groups which were seen to be helpful for 75%.

In the professional category, those reported as most unhelpful were case-coordinators, social workers, and psychiatrists (47-48%), followed by psychologists (43%), bereavement support groups and counsellors (34%).

[Figure 5 about here]

## **DISCUSSION**

This study provides new insights on the self-reported impact of bereavement on wellbeing and on the nature and extent of support received by bereaved MND caregivers.

### **Support and wellbeing**

Among the significant predictors of PGD was the insufficient support during the disease journey and a shorter period of caring which possibly reflects the lack of timely support and resources when the progression of disease is fast (6). Findings in this article further explain these predictors. Caregiver mental wellbeing was more adversely affected (42%) than their physical and financial wellbeing (about 30%). The 8% who reported their mental wellbeing 'got a lot worse' aligns with the proportions of PGD (8.7%) recently reported in this population (6). About 40% of MND caregivers did not feel they received enough support and this proportion is higher than the 29% of the general bereaved population who felt unsupported (6). Insufficiency of support was higher for those at high bereavement risk (63%) highlighting an association between lack of support and increased risk of grief complications in line with previous findings (6, 18). Not receiving enough support after the death adversely impacted on caregiver mental wellbeing. In fact, the prevalence rate of depression and anxiety in this population was 18.5% and 12.3% respectively (6). Perceived sufficiency of social support has been associated with a protective role against severe depressive symptoms during bereavement (26, 27), facilitates caregiver grief recovery (28) and reduces risk of grief complications (11, 17).

There was a statistically significant difference in observed frequencies of sources of support between the three risk groups (Fig.4). Most of the bereaved respondents in each of the three risk groups accessed support from family and friends in line with the general bereaved population, followed by MND Associations, GPs and funeral providers.

### **Community support**

MND caregivers accessed GPs for bereavement support (74%) more than the general bereaved population (56%), although 34% found them unhelpful. GPs play a pivotal role in facilitating a public health approach to support (20), particularly since bereaved



older adults tend to seek support for grief from primary care sources (29). Barriers to effective skills and capacity for bereavement support in the primary care domain are noted in the grief literature and suggestions for improvement have included training in a range of emotional and practical interventions (29). GPs report receiving little training for bereavement support (30), and lack specific guidelines to assist bereaved patients. Nevertheless, patients require continuity of care, information and timely referral to appropriate bereavement services (31, 32).

MND Associations were frequently accessed for support (78%) although 44% of respondents reported that these were unhelpful. These Associations play a central role in the delivery of case management and coordination of services to people with MND (PwMND) and their families (33). Emotional support is one of the primary expectations of service users in MND care (15, 34, 35) and MND Associations are in prime position to offer emotional support for caregivers before and after bereavement. However, these Associations need to be better resourced and trained to consistently implement this goal but funding challenges pose a continuous threat to their effective operation and viability. The drive to find a cure has been understandably the major focus of funding but PwMND and their families still need to be cared for physically and psychologically until a cure is found (33).

It is concerning that while 45% of respondents had used palliative care bereavement services, 38% of them found them unhelpful. This is similar to the 32% of the bereaved in the general survey who found them unhelpful (19). Studies demonstrate that palliative services generally adopt a blanket, non-tailored approach that lacks timeliness, consistency and continuity of care (36, 37). In a national survey of bereaved people in Australia, more people with cancer (64%) received palliative care in comparison to other non-malignant illnesses (4-10%) (36). The median contact time between palliative care services and patients was only one month. This reinforces the need for a palliative approach to MND care where knowledge and expertise is extended beyond the domain of specialist palliative care services to include the full scope of health and community-based services providing care, mostly at home, in order to meet the extensive range of needs of PwMND and their families, from diagnosis to bereavement (38).

### **Professional support**

More MND caregivers used professional services compared to the general bereaved population. This may be a reflection that most MND caregivers are in the moderate bereavement risk group and more of them are in the high-risk group compared to the general bereaved population (6). Access to professional mental health sources of support (counsellor, social worker, psychologist and psychiatrist) was more frequently reported by the high-risk group. However, it is also concerning that in this professional category the rates of unhelpfulness varied between 34% (counsellors and bereavement support groups), 43% (psychologists) and 48% (psychiatrists). Highly distressed bereaved individuals are less likely to engage with formal counselling services (39). Stigma is a factor for mental health issues, particularly amongst older bereaved individuals who are consequently less likely to accept a psychological diagnosis or mental health intervention (23). A bereaved individual's social network

can be influential in encouraging or discouraging engagement with mental health services (40, 41). The efficacy and helpfulness of various bereavement theoretical and intervention approaches for MND caregivers is untested and there remains a lack of proven treatments supporting the psychological well-being of this population (42).

### **Informal support**

The study confirmed previous findings that the vast majority of bereaved MND caregivers relied on their families and social networks for bereavement support, and this is the first study to quantify the extent of this support. This is in line with the public health model of bereavement support and the compassionate communities approach (18, 34), where these informal resources or assets are intrinsic in communities. Social support is a strong determinant of positive psychosocial outcomes following death (43) and is one of the few bereavement variables that is modifiable (44). MND caregivers were three times more likely to be in the high-risk group if they reported not having received enough support in general from all sources (6). Whilst informal sources of support were the mostly frequently used in this study, the capacity of supporters in such networks has been questioned (45) and promotion of methods to facilitate capability in this population requires attention (21, 23). While this paper only focussed on the range of support sources accessed, the rates of reported unhelpfulness could be due to a lack of a good fit between these sources and the needs of caregivers, particularly in the timeliness, amount, structure and function of support (21). Improving grief literacy in the community may help bridge the gaps in this fit between the provider and the receiver of support (46) and bolster the Compassionate Communities approach to bereavement care (19, 22).

### **Strengths and limitations**

MND Associations provided the most suitable recruitment method to reach those bereaved through MND as most patients in Australia are registered with their state Association (33). Overall, caregivers build rapport with these Associations during the caregiving period. Some stay connected during bereavement and continue to follow and support the activities of these Associations.

The non-respondents to the survey may have had different experiences to those reported in this study. There may be an under-representation of those who experienced poor bereavement outcomes, as in general this group tends to avoid involvement in such research (47).

The 31% response rate compares well with previous surveys for this population (33, 34) and higher than the 20% rate of general postal surveys. Our population-based large sample size of 393 compares well to smaller samples of 50 (48), 71 (49) and 40 (50) drawn from clinics in earlier studies. Population-based surveys have the added advantage of including non-service users.

### **Conclusions**

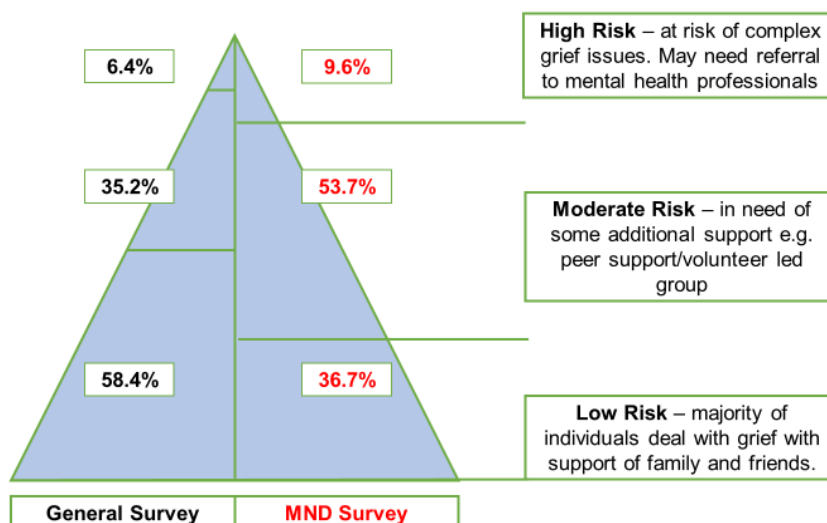
This study highlights the need for an enhanced approach to MND bereavement care based on risk and need assessment, specially that 63% of those bereaved through MND are in the moderate or high PGD risk group when the majority of the bereaved

from other causes usually experience normal grief (6) (Figure 6). While social and community- based approaches to bereavement care, such as the Compassionate Communities approach, remain the first port of call (19, 22), support for those bereaved through MND is needed over and above what is provided by their families and social networks.

It is striking that some of the sources that provided effective support during illness (GPs, MND Associations, palliative care services), were found wanting in bereavement. One possibility is that expectations of support and needs that were formed during illness were not met in bereavement. It could be that these supporters know how to care in illness but not in bereavement. Much professional bereavement care focuses on the identity and emotions of the bereaved person, less on strategies for getting through the experience. This issue surfaced in the accounts of bereaved people from an earlier population study in which we investigated ‘goodness of fit’ between needs identified and support provided (21).

From the professional support perspective, assessment of levels of risk is a pragmatic means of planning a tailored approach to care, which needs to be communicated to the bereaved as a “goals of care” map. Achieving a good fit between clinicians and the bereaved requires competent assessment, counselling, and clinical care proportional to need and may help improve the current perceived unhelpfulness reported in this study.

MND associations provide support during the illness experience for PwMND and their families and are ideally placed to do so in bereavement. Additionally, these types of organisations can connect both professional and community resources in a way that clinicians alone, or community actors, cannot. However, this requires MND Associations to include bereavement as an integral part of their role, expand the period of support and access additional training and necessary resources. They are ideally placed in the second tier of the public health model for bereavement support, depicted in the pyramid of the three risk categories (6) (Figure 6).



**Figure 6: A comparison of proportions in the three grief risk groups of the MND bereaved population and the general bereaved population, according to the Public Health Model.**

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## **Declaration of interests**

No conflict of interest

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