

**Use of coping strategies in MND/ALS: association with demographic and disease-related characteristics**

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## Abstract

### Objective

Understanding the use of coping strategies and which factors are predictors of strategy utilisation might help clinical staff anticipate which coping strategies individuals are more likely to utilise. In this study we assess coping strategy use in the Motor Neurone Disease (MND, also known as Amyotrophic lateral sclerosis (ALS)) population, and examine associations of demographic and disease variables with individual coping strategies.

### Participants and Methods

233 participants with MND/ALS were recruited into the ongoing Trajectories of Outcomes in Neurological Conditions (TONiC) study from MND clinics across the United Kingdom. Participants completed a questionnaire pack collecting data on demographics and a range of patient reported measures including the Coping Orientations to Problems Experienced scale. Associations between demographic and clinical characteristics and coping strategies were examined by simple and multiple ordinal logistic regression.

### Results

The most commonly used strategy was Acceptance, followed by Active Coping, Planning and Positive Re-interpretation and Growth. The least used strategies were Substance Use, Turning to Religion and Denial. Ten out of the fifteen strategies showed statistically significant associations with demographic and clinical characteristics. Most markedly, females were found to utilise Restraint, Seeking Instrumental Social Support, Seeking Emotional Social Support, Focus on and Venting of Emotions, Behavioural Disengagement, and Mental Disengagement more than males.

### Conclusion

Clinical staff should be aware of several disease and demographic characteristics that are associated with use of potentially maladaptive coping strategies or the underutilisation of coping strategies that may lead to better psychosocial adjustment.

Keywords: Amyotrophic Lateral Sclerosis, coping, Motor Neurone Disease, psychological adjustment, quality of life, TONiC

## Introduction

Motor Neurone Disease (MND, also known as Amyotrophic lateral sclerosis (ALS)) describes a group of diseases characterised by progressive degeneration of the motor neurones controlling voluntary muscles. This leads to widespread muscle weakness and wasting, affecting voluntary movement, speech, swallowing and breathing. Most people with MND die of respiratory failure within 3 to 5 years of symptom onset<sup>1,2</sup>. Currently there is no cure available and thus the main focus of care is on treating symptoms and improving quality of life. Previous studies have found that quality of life in MND is substantially affected by psychological factors and support from family and friends<sup>3-7</sup>. The constantly changing stresses of a progressively disabling, incurable and terminal condition like MND place considerable demands on patients' coping abilities.

Coping involves 'cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'<sup>8</sup>. There are two main groups of coping strategies, those that alter the situation that is causing distress (problem-focussed strategies) and those that reduce or manage the emotional response to the stressor (emotion-focussed strategies)<sup>8</sup>. These two types of coping are complementary and are generally used together<sup>8</sup>, including in MND<sup>9,10</sup>. Both cross-sectional and longitudinal studies have found that coping capacity and the strategies used affect depressive symptoms and quality of life<sup>5,6,9,11,12</sup>.

The role of coping strategies in adjustment to MND has been the focus of a number of small studies<sup>6,9,12</sup>. The use of support and positive action have been found to correlate with lower levels of depression and anxiety, whereas avoidance and venting were positively correlated with increased levels of anxiety<sup>12</sup>. Similarly, patients who use positive action, positive thinking and independence were found to have fewer symptoms of depression<sup>9</sup>. The use of a group of coping strategies

consisting of active coping, acceptance, planning and positive reframing has even been suggested to increase survival <sup>13</sup>.

Despite the evidence for the positive or negative impact of individual coping strategies, little is known about association between demographic and disease characteristics and the strategies patients turn to. One study by Montel and colleagues with 49 MND patients showed that age affected the use of emotional support, venting, positive reframing, planning, and humour, and that acceptance, positive reframing and humour were used more with increasing disease duration; onset type and functional status also showed some associations with strategy utilisation <sup>14</sup>. Other studies have not found any correlations of strategy use with demographic characteristics or have found changes in these over time <sup>10,12</sup>. The conflicting evidence may be due to the small sample sizes or the different instruments used in these studies. In order to increase the understanding of overall coping strategy use in MND patients and which factors affect the probability of an individual turning to a certain strategy, we address these questions using a very large population sample in the UK who completed the generic and broad 'Coping Orientations to Problems Experienced' (COPE60) questionnaire <sup>15</sup>.

## **Methods**

### *Data Collection*

Participants with MND were recruited into the ongoing Trajectories of Outcomes in Neurological Conditions (TONiC) study from specialist clinics across the United Kingdom. Following informed consent, participants completed a questionnaire pack, which could be done with the assistance of a caregiver acting as scribe if the patient could not write. Demographic and disease-specific data, as well as a range of patient reported measures, were collected in the pack. Demographic data included age, sex and marital status, where 'single', 'widowed' and 'divorced' were combined to 'not married'. Disease specific data included time since diagnosis ('disease duration'), onset type and

functional ability in the limb, bulbar and respiratory domains captured by the ALS Functional Rating Scale Revised (ALSFRS-R)<sup>16</sup>. Confirmation of the clinical diagnosis, onset type and disease duration were additionally collected from a health care professional familiar with the patient's case. Ethical approval was granted from the relevant local research committees (reference 11/NW/0743).

### *Coping*

Amongst the patient reported measures was the Coping Orientations to Problems Experienced (COPE60)<sup>15</sup> inventory, which was used in this study to assess 'dispositional coping', i.e. the extent to which the respondents usually use certain coping strategies. The inventory consists of 15 scales with 4 items each and includes problem focused coping strategies (active coping, planning, suppression of competing activities, restraint, seeking of instrumental social support), emotion focused coping strategies (seeking of emotional social support, positive reinterpretation and growth, acceptance, denial, turning to religion) and other coping strategies (focus on and venting of emotions, behavioural disengagement, emotional disengagement, humour, substance use). Table S1 in the Supplementary Material defines each of the 15 strategies.

Participants report their responses to each item on a 4-point Likert scale (1 = I usually don't do this at all, 2 = I usually do this a little bit, 3 = I usually do this a medium amount, 4 = I usually do this a lot). The responses to the four items of any one scale are summated such that the use of each coping strategy is scored 0-12. For statistical analysis we collapsed these scores into 5 groups ('Not at all', 'A little', 'More than a little', 'A moderate amount', 'A lot') in order to ensure that groups are more reasonably populated (see Figure 1).

### *Data Analysis*

Overall coping strategy use was assessed using the following summary measures: mode, median, 25% and 75% percentiles, minimum and maximum value.

Rasch analysis<sup>17</sup> was applied to the ordinal response data of the ALSFRS-R in order to arrive at interval level scales for the three domains: bulbar, limb and respiratory.

Ordinal logistic regression with cumulative logits was used to assess the associations of coping strategy use with demographic and disease specific characteristics. Proportional odds were assumed where this agreed with the available data. The proportional odds assumption was tested using a likelihood ratio test with a cut-off for significance at  $p < 0.01$  and, where the test was significant, the parameter estimates for the different levels were investigated to ensure that the proportional odds assumption was only rejected if there were clear differences in the effect of the covariate on strategy usage at the different levels and a clear trend was recognisable. This was done to ensure that the assumption of proportional odds was only rejected if there was strong evidence against it.

Univariable ordinal logistic regression was carried out initially. For coping strategies where one or more covariates were statistically significant at the 5% level, a multiple ordinal logistic regression model was developed using forward selection. In all cases, significance was assessed using a likelihood ratio test.

The statistical analysis was conducted using R version 3.3.1 and the `vglm` function of the VGAM package<sup>18</sup> with the 'cumulative' and 'reverse=TRUE' VGAM family function options. Only complete cases were included in the analysis.

## **Results**

267 individuals completed the pilot phase pack, which included the COPE60, of which 233 participants had complete coping and covariate data. Missing data was primarily an issue in the disease specific information (see Table 1); coping data was incomplete in 5 individuals. Table 1 shows the demographics and disease characteristics of the study population.

### *Overall coping strategy use*

While every strategy was used to some extent, frequency of use varied widely. The most commonly used strategy was *Acceptance*, with 79% of the individuals endorsing usage with a 6 or more on a scale from 0 to 12, including 16% of the study population who endorsed it with the maximum score of 12. This was followed by *Active Coping*, *Planning* and *Positive Re-interpretation and growth*. The least used strategies were *Substance Use*, for which 82% reported use as 0, *Turning to religion* and *Denial*. Table 2 show summaries of the overall usage of the 15 different coping strategies.

#### *Associations with demographic and disease specific characteristics*

Results from the univariable and multivariable regression analyses are given as odds ratios with 95% profile likelihood confidence intervals (Tables 3 and 4). Likelihood ratio test p-values from the univariable regression are given in Table S2 in the Supplementary Material.

#### Problem-focussed strategies

*Active coping* is used more by those with better bulbar function (1.08 (95%CI: 1.01, 1.16)). The use of *Restraint* was associated with both sex and functional ability in the respiratory domain. Females were 1.79 (95%CI: 1.08, 2.95) times as likely as males to use this strategy at higher levels and there was less usage of *Restraint* with increasing functional ability in the respiratory domain (0.868 (95%CI: 0.771, 0.977)). Similarly, *Seeking of instrumental social support* was used at higher levels by females compared to males (1.83 (95%CI: 1.13, 2.97)). The use of *Planning* and *Suppression of competing activities* were not found to be significantly associated with any of the covariates tested.

#### Emotion-focussed strategies

In the univariable analysis, *Seeking of emotional social support* was found to be associated with sex and disease duration. However, in the multiple regression marital status was found to be significantly associated with *Seeking of emotional social support* after sex was adjusted for, whereas



disease duration was no longer a predictor. Females were 2.38 (95%CI: 1.44, 3.94) times as likely to report *Seeking emotional social support* at higher levels compared to males, and married individuals were 2.07 (95%CI: 1.15, 3.72) times as likely to utilise this strategy at higher levels compared to individuals without a spouse. The utilisation of *Positive re-interpretation and growth* and *Denial* were found to increase with greater functional ability in the motor domain (1.06 (95%CI: 1.01, 1.1) and 1.07(95%CI: 1.02, 1.12), respectively). *Turning to religion* was found to be utilised at higher levels with increasing age (1.04(95%CI: 1.01, 1.06)). There was no evidence that the use of *Acceptance* is associated with any of the covariates tested here.

#### Other strategies

The utilisation of *Focus on and venting of emotions* was found to be associated with sex, age and functional ability in the bulbar domain. Venting was used less with increasing age and better bulbar function (0.964 (95%CI: 0.943, 0.985) and 0.91(95%CI: 0.848, 0.976), respectively). Females were 2.63 (95%CI: 1.6, 4.35) times as likely to use this strategy at higher levels compared to males. *Behavioural and Mental disengagement* were used more by females compared to males (2.05 (95%CI: 1.24, 3.37) and 2.62 (95%CI: 1.58, 4.33), respectively). *Mental disengagement* was used less with longer disease duration (0.795 (95%CI: 0.647, 0.976)). *Substance use* was found to be strongly associated with onset type; limb onset patients were 3.06 (95%CI: 1.15, 8.14) times as likely to use it at higher levels compared to bulbar onset patients. The number of individuals with respiratory onset disease was too low to be able to assess differences in usage compared to bulbar onset. There was no evidence that the utilisation of *Humour* is associated with any of the covariates tested here.

#### Discussion

This is by far the largest study undertaken to assess the strategies which patients use to cope with the physical and psychological challenges of MND. It demonstrates that people with MND draw on a

very diverse repertoire of strategies, varying from those considered positive and beneficial, such as *Acceptance*, to those typically considered maladaptive, such as *Substance abuse*.

The original work on the COPE60 posited “acceptance to be particularly important in circumstances in which the stressor is something that must be accommodated to”<sup>15</sup>; the current inability to cure or slow MND makes it an exemplar of a stressor which must be accommodated to. In this study *Acceptance* is the most frequently used strategy, in keeping with results from a French population studied by Montel et al.<sup>14</sup>. Coping through acceptance has been shown to predict more positive adjustment to the diagnosis of cancer<sup>19</sup>, and to reduce anxiety and depression in multiple sclerosis<sup>20</sup>. In chronic pain from muscular dystrophy, multiple sclerosis, post-polio syndrome, or spinal cord injury, pain acceptance related to less emotional distress<sup>21</sup>.

While there are many different patterns of use of the different coping strategies, our results show that use of different strategies is significantly associated with factors, which are readily evident in clinical care. These include demographic variables, like age, gender, and marital status, and disease characteristics, such as limb or bulbar onset. Understanding of this can help the clinical team intuit which coping strategies may be more readily accessed by the patient.

We found that females are more likely to *Seek emotional social support* and to *Seek instrumental social support*, i.e. assistance or information about what to do. Social support in MND has been associated with better quality of life<sup>22</sup>, so these significant gender differences in use of social support may imply gender differences in behaviours supporting quality of life. However, the reality may be more nuanced. In common with much previous research, the COPE60 addresses in-person social support, and may under-estimate seeking social support through new means such as social media or the internet, which have been shown to be more frequently used for support seeking by males<sup>23</sup>.

In this study females were more than twice as likely to report greater use of three strategies which may impede their ability to engage with problem solving; these are *Behavioural* and *Mental disengagement*, which refer respectively to withdrawing from efforts to achieve a difficult task or psychological disengagement from the task, and *Focus on and venting of emotions*, or concentrating upon and venting emotional distress. Greater use of behavioural disengagement has been associated with depression, although whether depression leads to disengagement or vice versa could not be determined<sup>24</sup>.

*Restraint* refers to coping through holding back attempts to act until their use appears opportune. We found that females use this strategy to a greater extent than males but whether this reflects self-control or lack of confidence to act remains uncertain. Patients with worse respiratory function also use *Restraint*. Patients using *Restraint* may benefit from discussion and advice from professionals to help them decide whether they can act and when.

In keeping with previous research, both religion<sup>14 25</sup> and venting of emotions<sup>9</sup> were little used but our larger sample size allowed detection of clear age differences in use of these coping strategies; religion was used more with increasing age and venting of emotions less. We did not find other differences in strategy use by age, unlike earlier work with a smaller sample size (n=49) which found that emotional support, venting, positive reframing, planning and humour were used more by patients aged under 55 years.

Use of particular coping strategies is constrained by the patient's ability to successfully employ a strategy, which may be influenced by their personal situation or disability. We found that the capacity for *Seeking emotional social support* is strengthened by having a partner; married people were over twice as likely to use this strategy at higher levels compared to people of the same sex who are not married. Patients with better motor function were more likely to use *Positive re-interpretation and growth*, where the situation is depicted in a positive light; and *Denial*, where the situation is not acknowledged; both strategies are more viable for patients with less impaired

function and greater independence. For those who retain the ability to speak, it is easier to access the coping strategies of *Active coping* through negotiating problem-solving behaviours. While *Substance Use* was rarely cited as a coping strategy, if used it related to alcohol excess and was over 3 times more common in limb compared to bulbar onset patients.

The current cross-sectional results do not allow us to formally assess any causal links between disease characteristics and coping strategy utilisation. Neither can we determine whether use of coping strategies changes over time, but the influence of disability may be anticipated to alter with disease progression. Earlier work found that longer disease duration was correlated with acceptance, positive reframing and humour<sup>14</sup>, which the authors suggested might reflect patients adjusting to the condition. Our analysis shows that with longer disease duration patients are less able to mentally disengage as a means of coping, and they are more likely to turn to religion, though overall use of religion for coping remains infrequent.

Furthering the understanding of the use of coping strategies will help clinicians to understand which strategies patients may be more likely to utilise, based on their personal and disease characteristics. Consideration of these data remind clinicians that not all strategies are feasible for people with MND due to their personal situations or the disabilities arising from their disease. Conversely, patients with particular demographic or disease profiles are more likely to utilise strategies associated with worse outcomes and may need additional support. Targeted advice on coping may improve coping capacity and facilitate psychosocial adjustment.

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### Conflict of interest

The authors report no conflicts of interest.

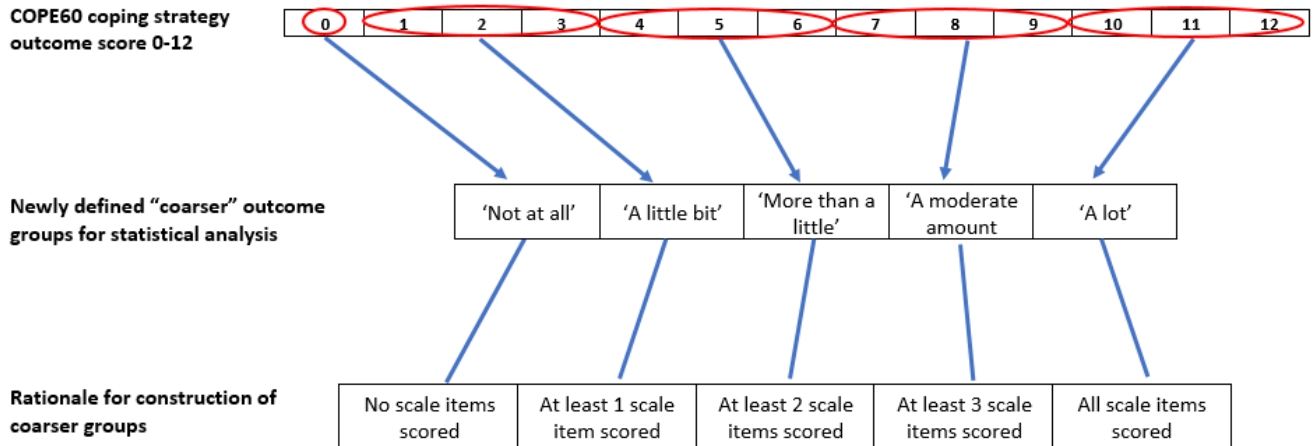
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## Figures

Figure 1: Method for collapsing COPE60 outcome scores into groups for analysis



## Tables




**Table 1: Demographics of the study population**

	Summary statistics in the study population	Number of individuals for whom these data are missing
N	233	
age (mean (sd))	64.42 (11.09)	0
sex = M (%)	148 (63.5)	0
status = married (%)	183 (78.5)	5
duration (median [IQR])	18.10 [8.70, 41.00]	17
onset_type (%)		16
Bulbar	61 (26.2)	
Limb	169 (72.5)	
Respiratory	3 (1.3)	
ALSFERS-R bulbar (median [IQR])	8.16 [5.89, 12.00]	1
ALSFERS-R motor (median [IQR])	13.19 [9.85, 16.66]	1
ALSFERS-R respiratory (median [IQR])	11.09 [9.55, 12.00]	5



Table 2: Coping strategy usage summary

	0	1	2	3	4	5	6	7	8	9	10	11	12
Planning							M						
Active coping							M						
Restraint							M						
Suppression of competing activities					M								
Seeking of instrumental social support	M												
Seeking of emotional social support					M								
Positive reinterpretation and growth							M						
Acceptance													M
Denial	M												
Turning to religion	M												
Focus on and venting of emotions	M												
Mental disengagement					M								
Behavioural disengagement	M												
Humour	M												
Substance use	M												

Symbol/ Shading	Indicates value of:
	Minimum to maximum response
	First to third quartile
	Median
M	Mode

**Table 3: Odds ratios and 95% profile likelihood confidence intervals resulting from the univariable regression analyses.**

All figures are rounded to 3 significant digits and significant results are highlighted in red.

	Sex=male	Age	Marital status=married	Log(disease duration)	Onset type=Limb	Onset type=Respiratory	ALSFRS-R bulbar	ALSFRS-R motor	ALSFRS-R respiratory
planning	0.844 (0.523,1.36)	0.985 (0.964,1.01)	0.856 (0.488,1.5)	0.998 (0.819,1.22)	1.06 (0.625,1.79)	9.77 (0.809,118)	1.07 (0.999,1.14)	1.03 (0.988,1.07)	1.08 (0.967,1.21)
Active coping	0.883 (0.544,1.43)	0.99 (0.969,1.01)	1.01 (0.57,1.78)	1.06 (0.869,1.3)	1.17 (0.689,2)	2.15 (0.257,17.9)	<b>1.08</b> <b>(1.01,1.16)</b>	1.02 (0.979,1.06)	1.06 (0.944,1.19)
Restraint	<b>0.595</b> <b>(0.362,0.977)</b>	1.02 (0.994,1.04)	0.748 (0.42,1.33)	0.956 (0.781,1.17)	1.24 (0.722,2.13)	3.35 (0.399,28.2)	1.02 (0.95,1.09)	1.01 (0.965,1.05)	<b>0.881</b> <b>(0.784,0.99)</b>
Suppression of competing activities	0.686 (0.419,1.12)	0.997 (0.976,1.02)	1.27 (0.712,2.25)	0.857 (0.699,1.05)	1.01 (0.589,1.73)	1.75 (0.206,14.8)	0.998 (0.931,1.07)	1.04 (0.995,1.08)	0.966 (0.861,1.09)
Seeking of instrumental social support	<b>0.547</b> <b>(0.337,0.889)</b>	0.992 (0.972,1.01)	1.13 (0.642,1.98)	1.05 (0.862,1.28)	0.935 (0.553,1.58)	1.09 (0.136,8.73)	1 (0.939,1.07)	1.01 (0.969,1.05)	1.01 (0.901,1.13)
Seeking of emotional social support	<b>0.499</b> <b>(0.307,0.81)</b>	0.987 (0.967,1.01)	1.58 (0.899,2.78)	<b>0.817</b> <b>(0.669,0.996)</b>	0.771 (0.456,1.3)	0.966 (0.121,7.7)	1 (0.94,1.07)	1.02 (0.976,1.06)	1.02 (0.911,1.14)
Positive reinterpretation and growth	0.775 (0.479,1.25)	0.982 (0.962,1)	0.761 (0.433,1.34)	1.01 (0.831,1.24)	1.14 (0.671,1.93)	1.45 (0.18,11.7)	1.06 (0.987,1.13)	<b>1.06</b> <b>(1.01,1.1)</b>	1.02 (0.913,1.15)
Acceptance	0.841 (0.517,1.37)	1 (0.98,1.02)	0.666 (0.374,1.19)	0.93 (0.761,1.14)	1.52 (0.895,2.59)	5.57 (0.466,66.6)	1.04 (0.973,1.12)	0.991 (0.95,1.03)	1 (0.893,1.12)
Denial	0.729	1.01	0.96	0.866	0.817	0.643	1	<b>1.07</b>	0.997

	(0.447,1.19)	(0.987,1.03)	(0.541,1.71)	(0.706,1.06)	(0.478,1.4)	(0.0738,5.61)	(0.934,1.07)	(1.02,1.12)	(0.888,1.12)
Turning to religion	0.628 (0.369,1.07)	1.04 (1.01,1.06)	0.792 (0.427,1.47)	1.22 (0.971,1.53)	0.94 (0.521,1.7)	3.31 (0.411,26.6)	1.01 (0.938,1.09)	1.06 (1.01,1.11)	1.03 (0.908,1.18)
Focus on and venting of emotions	0.36 (0.219,0.593)	0.971 (0.95,0.992)	1.12 (0.637,1.98)	0.922 (0.756,1.13)	0.554 (0.325,0.943)	0.339 (0.0404,2.84)	0.919 (0.859,0.984)	1.01 (0.971,1.06)	1 (0.892,1.12)
Behavioural disengagement	0.489 (0.297,0.805)	1.01 (0.991,1.03)	0.763 (0.429,1.36)	1.08 (0.882,1.32)	0.832 (0.486,1.42)	0.283 (0.0321,2.5)	0.942 (0.879,1.01)	0.972 (0.932,1.01)	0.92 (0.819,1.03)
Mental disengagement	0.371 (0.224,0.614)	0.981 (0.96,1)	0.802 (0.453,1.42)	0.779 (0.635,0.955)	0.629 (0.368,1.08)	0.48 1(0.0569,4.07)	0.944 (0.881,1.01)	1.02 (0.975,1.06)	0.963 (0.858,1.08)
humour	1.07 (0.666,1.73)	0.987 (0.966,1.01)	0.767 (0.438,1.34)	1.05 (0.861,1.28)	1.29 (0.764,2.18)	5.24 (0.645,42.6)	1.03 (0.964,1.1)	0.997 (0.957,1.04)	0.993 (0.887,1.11)
Substance use	0.811 (0.411,1.6)	0.972 (0.944,1)	0.692 (0.323,1.48)	1.06 (0.799,1.42)	3.06 (1.15,8.14)	1.48e-06 (0,Inf)	1.09 (0.982,1.21)	0.977 (0.921,1.04)	0.953 (0.815,1.11)

**Table 4: Odds ratios and 95% profile likelihood confidence intervals resulting from the multiple regression analyses. All figures are rounded to 3 significant digits.**

	Sex=male	Age	Marital status=married	Disease duration	Onset type=Lim b	Onset type=Respiratory	ALSFRS-R bulbar	ALSFRS-R motor	ALSFRS-R respiratory
Planning	-	-	-	-	-	-	-	-	-
Active coping	-	-	-	-	-	-	1.08(1.01, 1.16)	-	-
Restraint	0.559(0.339, 0.924)	-	-	-	-	-	-	-	0.868(0.771, 0.977)
Suppression of competing activities	-	-	-	-	-	-	-	-	-
Seeking instrumental social support	0.547(0.337, 0.889)	-	-	-	-	-	-	-	-
Seeking emotional social support	0.42(0.254, 0.695)	-	2.07(1.15, 3.72)	-	-	-	-	-	-
Positive reinterpretation and growth	-	-	-	-	-	-	-	1.06(1.01, 1.1)	-
Acceptance	-	-	-	-	-	-	-	-	-
Denial	-	-	-	-	-	-	-	1.07(1.02, 1.12)	-
Turning to religion	-	1.04(1.01, 1.06)	-	1.38(1.08, 1.76)	-	-	-	1.08(1.03, 1.14)	-

Focus on and venting of emotions	0.38(0.23,0. 627)	0.964(0.94 3,0.985)	-	-	-	-	0.91(0.848 ,0.976)	-	-
Behaviour al disengage ment	0.489(0.29 7,0.805)	-	-	-	-	-	-	-	-
Mental disengaga ment	0.381(0.23 1,0.631)	-	-	0.795(0.64 7,0.976)	-	-	-	-	-
Humour	-	-	-	-	-	-	-	-	-
Substanc e use	-	-	-	-	3.06(1.15 ,8.14)	1.48e- 06(0,Inf)	-	-	-



## Use of coping strategies in MND/ALS: association with demographic and disease-related characteristics

### Supplementary Material

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Table S1: COPE-60 Inventory scales and concept definitions

<b>Scale</b>	<b>Activities undertaken by individual</b>
<b>Active coping</b>	Taking steps to try to remove or circumvent the stressor or to ameliorate its effect
<b>Planning</b>	Thinking about how to cope with a stressor
<b>Suppression of competing activities</b>	Putting other tasks aside in order to deal with the stressor
<b>Restraint</b>	Waiting until an appropriate opportunity to act presents itself
<b>Use of instrumental social support</b>	Seeking assistance or information
<b>Use of emotional social support</b>	Seeking sympathy or understanding
<b>Positive reinterpretation and growth</b>	Reframing the stressor in positive terms
<b>Acceptance</b>	Accepting the reality of a stressful situation
<b>Turning to religion</b>	Using faith for support
<b>Focus on and venting of emotions</b>	The tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings
<b>Denial</b>	Denying the reality of the stressor
<b>Behavioural disengagement</b>	Reducing one's effort to deal with the stressor
<b>Mental disengagement</b>	Using alternative activities to take one's mind off a problem
<b>Substance use</b>	Using alcohol or drugs to reduce distress
<b>Humour</b>	Making jokes about the stressor

Derived from <sup>1 2</sup>

Table S2: P-values from the likelihood ratio test comparing models with one covariate to models without explanatory variables. Values are rounded to three significant digits and values <0.05 are highlighted in red.

	Sex	Age	Marital status	Disease duration	Onset type	ALSFRS-R Bulbar	ALSFRS-R Motor	ALSFRS-R Respiratory
Planning	0.488	0.14	0.574	0.982	0.116	0.0552	0.181	0.172
Active coping	0.611	0.334	0.983	0.547	0.691	0.0244	0.353	0.338
Restraint	0.0379	0.158	0.319	0.666	0.405	0.609	0.775	0.0329
Suppression of competing activities	0.132	0.765	0.419	0.139	0.85	0.949	0.0881	0.569
Seeking instrumental social support	0.0142	0.443	0.67	0.621	0.96	0.895	0.634	0.875
Seeking emotional social support	0.00487	0.222	0.106	0.045	0.62	0.89	0.426	0.73
Positive reinterpretation and growth	0.293	0.0882	0.344	0.897	0.848	0.115	0.0092	0.686
Acceptance	0.483	0.915	0.149	0.478	0.13	0.242	0.659	0.979



Denial	0.213	0.454	0.889	0.166	0.737	0.982	0.00183	0.967
Turning to religion	0.0882	0.00594	0.464	0.0868	0.475	0.76	0.0176	0.608
Focus on and venting of emotions	4.75e-05	0.00677	0.693	0.441	0.068	0.0147	0.555	0.994
Behavioural disengagement	0.00493	0.253	0.348	0.447	0.425	0.0957	0.191	0.157
Mental disengagement	9.12e-05	0.0857	0.455	0.0149	0.218	0.0975	0.434	0.517
Humour	0.77	0.209	0.359	0.625	0.269	0.379	0.903	0.9
Substance use	0.547	0.053	0.356	0.667	0.0255	0.0943	0.434	0.561

### References

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2. Litman JA. The COPE inventory: Dimensionality and relationships with approach- and avoidance-motives and positive and negative traits. *Personality and Individual Differences* 2006;41:273–284.