

# Support Grant Guidance

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## 1. Guidance

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This guidance is designed for Support Services staff based at Francis Crick House (FCH), Northampton, other national and regional staff, branches and groups to support with the evaluation and processing of support grant application forms.

## 2. Purpose

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The Articles of Association states that the objectives of the MND Association are for

*“the relief of persons who are, or who are suspected of being affected by Motor Neurone Disease and its associated conditions (the beneficiaries), by seeking to ensure that such persons and their families and carers receive such help and assistance as is calculated to relieve their need”.*

As such, those beneficiaries need not be in membership of the Association or known to a Branch and Group to benefit from an Association support grant.

The Motor Neurone Disease (MND) Association’s support grants enable people living with MND or Kennedy’s Disease, their carers, and families to access funds towards the cost of equipment, care and maximising quality of life.

This guidance identifies the circumstances in which a grant may be available to ensure:

- a. Appropriate use of available resources
- b. Equitable allocation of resources

This guidance will be reviewed annually or as required, by the Associations Directors and volunteer representatives from branches and groups. Approval will be through the Care Services and Research Committee and Board of Trustees to ensure consistency with the Association’s strategy as well as providing a framework to ensure the appropriate use of resources.

## 3. Types of Grant

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**A) This guidance is only applicable to the following categories of grants: -**

**MND Support Grant (Care) Grant** Maximum £1500 and category limits may apply – see Appendix B. Requires a health and social care professional assessment and must be processed by Support Services at FCH. Branches and groups will be contacted to ask if they wish to contribute and any support provided by a branch or group will be acknowledged, in writing, to the person receiving the grant.

**Quality of Life (QoL) Grant** Maximum £500 and can be funded directly by the local

branch or group or Support Services.

**Carer's and Young Carer's Grant (age 16 or over)** Maximum £500 in any 12-month rolling period and can be funded directly by the branch or group or Support Services. This grant can be applied for up to 12 months post bereavement.

**Children and Young Person's (CYP) Grant (age 18 or under)** Maximum £250 in any 12-month rolling period can be funded by the branch or group or Support Services. To qualify, the child or young person must reside with a person living with MND or have a parent/guardian living with MND. This grant can be applied for up to 12 months post bereavement.

**General notes:**

- A summary and flowchart of the four grants covered by this guidance can be found at **Appendix A**.
- Funding is limited and the maximum sums shown are for guidance only. We may award any amount up to the maximum for each grant category.
- In assessing the amount to be awarded, we will take in to account such factors as our overall grants budget, value for money and the impact of the grant on the applicant.
- For each individual applicant with MND, the combined amount of the Support Care and Quality of Life grants in any rolling 12 months will not exceed £3000 per person. Carer's, Young Carer's and Children and Young Person's grants are not included in this maximum.

**B) The following are not covered by this guidance:**

**Communication Aids grant (including voice banking)**

[www.mndassociation.org/communicationaids](http://www.mndassociation.org/communicationaids)

**Wheelchair Accessories grant**

[www.mndassociation.org/wheelchairs](http://www.mndassociation.org/wheelchairs)

**Cost of Living Support Fund payment**

[COST OF LIVING SUPPORT FUND FAQs NOV 2024](#)

These have a separate MND Association pathway to support which must be followed. The amounts awarded are dependent on each individual application.

## 4. Criteria

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The person on whose behalf the application is being made does not need to be a member of the Association; however, the benefits of membership should be communicated. This can be through the branch, group, or Support Services. The criteria in terms of who is supported and who can apply varies slightly for each grant.

The following criteria for accessing an **MND Support Grant (Care)** will be applied to all applications for funding and each application will be assessed on an individual basis:

- A health or social care professional has carried out an assessment that has identified a need for the provision of equipment or a service.
- Statutory and other sources of charitable funding have been thoroughly explored by the referring health or social care professional and evidence provided with the application.
- Statutory services will not provide the equipment or service, or it is anticipated that there would be an unacceptable delay in provision and evidence and confirmation of timescale is provided with the application.
- The equipment is not otherwise available through the Association's Equipment Loan service.
- An application form has been fully completed and includes at least one quote for the item or service requested.

The following criteria for accessing a **Quality of Life, Carer's, Young Carer's and Children and Young Person's grant** will be applied to all applications for funding and each application will be assessed on an individual basis:

- Anyone living with or affected by MND or their representative (this can include family members, Association Visitors (AV) and Area Support Coordinators (ASC)) may apply for a Quality of Life, Carer's, Young Carer's and Children and Young Person's grant.
- Carer's, Young Carer's and Children and Young Person's grants are all subject to age restrictions and these are set out in **Appendix A**.
- An application form has been fully completed and includes at least one quote or estimate for the item or service requested.

Any previous support that has been provided to a person living with MND through an MND Support Grant (Care) and Quality of Life grant in the last rolling 12 months will be considered when assessing the new request. The application form must, therefore, detail any Quality of Life grants that have been approved and paid directly by the branch or group.

### **Disclaimer**

Due to the scope and scale of **Quality of Life, Carer's, Young Carer's and Children and Young Person's grants** the following disclaimer must be used when awarding a grant:

*Please note that the Association is not a party to any agreement that you may enter with the service provider, it has not vetted the service provider, nor does it endorse the service provider or accept any liability for any loss that may be incurred or any responsibility for any issues or problems that may arise as a result of your dealings with the service provider.*

## 5. What Is Not Funded

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The Association will not normally provide a grant in the following instances:

- Equipment and adaptations that are a statutory responsibility
- Medicines/ drugs that are a statutory responsibility
- Medicines/drugs that are unproven treatments
- Retrospective funding
- Emergency healthcare needs
- Funeral costs
- Repayment of debt
- Legal costs
- Insurance policies
- Equipment for assessment for use by health and social care professionals unless with the express approval of the Director of Services and Partnerships

The Association may provide a grant in exceptional circumstances and the process is detailed in **Section 7**.

## 6. Application Process

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Application forms can be found on the Association's website:

[www.mndassociation.org/financialsupport](http://www.mndassociation.org/financialsupport)

Details are given on where to return completed application forms. If unsure, please contact Support Services. Applications received by Support Services will be processed within ten working days. These timescales are dependent on receipt of a fully completed application form. **Incomplete application forms will delay the process.**

### **For all applications received by Support Services/FCH:**

- All applications will be considered on an individual basis with part funding offered in the first instance. The person with MND and/or their family will be asked if they are able to contribute to the funding.
- The individual receiving a support grant will be given the opportunity to provide feedback to help the Association monitor and improve its processes.
- The Association will store all details of the support grant request and may share these with other Association representatives where this will provide better care and support for the person with MND. The individual may opt out of sharing information at any time.
- Once a decision has been made, the applicant will be informed of the decision.

### **Applications received and approved directly by branches and groups**

Such applications may take slightly longer to assess. Each branch/group should decide and document an appropriate mechanism for approving any applications made directly to them. For example, decisions can be made by key members rather than the full committee or

agreed in a meeting or by email as appropriate to the area. Some points to support branches and groups in making a timely decision:

- **Who should be involved?** – key members of the branch or group as agreed
- **Factors to consider** - is the application supported by local knowledge from an AV/ASC? Is the amount requested reasonable? Has the applicant provided evidence where appropriate? Has the applicant previously received a grant from the Association, branch or group?

If in any doubt, please contact the Support Services team who will advise.

Branches can pay individuals directly from their account whereas groups need to liaise with Support Services who will arrange for a BACS payment to be made on their behalf. To best support people with MND, their carers and families, a branch or group may be contacted by Support Services to ask if they are able to provide some funds out of area where resources are limited. Any support provided or received by a branch or group will be acknowledged, in writing, to the person receiving the grant. All information relating to decisions to fund in any category must be logged within the branch treasurer's quarterly report.

### **Urgent applications**

Due to the high volume of applications received by the Support Services team, from time to time, an application might need to be fast tracked and processed within five working days. In the following circumstances applications will be fast tracked. Please note this list isn't exhaustive:

- Person with MND has deteriorated rapidly and equipment or adaptation is needed to protect from risks such as falls and is unavailable from statutory service
- Funding is for something time critical for example travelling to appointment at short notice

## **7. Exceptions**

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The Association may provide a support grant in exceptional circumstances, even where the application falls outside the criteria outlined in this guidance. In these cases, applications will be reviewed via an exceptions process. This section describes the exceptional circumstance categories and the exceptions process.

### **Exceptional circumstance categories**

In the following circumstances, applications may be considered under the exceptions process:

- Service or equipment request falls outside of the support grant criteria
- Statutory services will not meet the request, even though required to do so (in these cases, where an application is approved, this will only be provided for an

interim period)

- Potential for breakdown in care between the person with MND and their carer
- Over-riding clinical factors exist for example the MND is progressing rapidly or there are other conditions that impact on the MND.
- Person with MND and/or main carer in severe financial difficulties
- Health or social care professional/ ASC or branch/group is aware of other exceptional circumstances.

### **Exception's process**

All applications submitted as an exception will be evaluated initially by Support Services and then by the Head of National Care using the MND support grant guidance and on a case-by-case basis. Detailed information which fully outlines the reason for the exception should be provided to aid the decision. The Head of National Care will review complex applications in consultation with the Director of Services and Partnerships, to provide Support Services with a decision, including any terms and conditions to the proposed grant.

Where an exceptions application has been declined, the person with MND and the requesting professional, where relevant, will be provided with the reasons for the decision made and will be signposted to other sources of information and/or support where appropriate.

Where an application has been approved the person with MND and the requesting professional, where relevant, will be informed of the decision, the value of the grant approved and any attached conditions.

Where an applicant for a support grant feels that they have been unfairly treated, they may refer to the Association's **complaints process** which can be found at [www.mndassociation.org/complaints](http://www.mndassociation.org/complaints)



## Appendix A

**MND Support Grant (Care)** up to a maximum of £1500 per application. Predominantly equipment or adaptations requiring a professional assessment. A funding guide can be found at **Appendix B**

An MND Support Grant (Care) must be accompanied by an assessment from the relevant Health or Social Care Professional. The person receiving the grant will be informed who has provided the funding (Branch or Group/ Support Services /shared).

Examples of funding would be contributions towards:

- Adaptations to property
- Stairlift rental/purchase
- Washer dryer toilet
- Respite care costs
- Riser recliner armchair

Included in support grant limit of up to £3000 in a rolling 12-month period.

**Quality of Life (QOL) Grant** up to a maximum of £500 per application. Serves to support both the person with MND and the family.

Does not require a professional assessment and enables the person with MND to purchase equipment, services or facilities which help maintain their independence, dignity, comfort and social connections. Can also be used to contribute to the cost of things which promote the well-being of the person with MND and immediate family.

Examples of funding would be contributions towards:

- Adaptations to the home not requiring an assessment
- Equipment not requiring an assessment e.g., mobility scooters, four wheeled walkers
- Support with essential garden and home maintenance
- Keeping connected e.g., tablets for accessing social media and video calls
- Hobbies and interests
- Special transport
- Accessible/adapted holiday venues

Included in the support grant limit of up to £3000 in a rolling 12-month period.

**Carer's and Young Carer's Grant** up to a maximum of £500 per application per rolling 12 months.

Supports the main unpaid carer (aged 16+) for someone with MND to allow them to take a break from caring duties and/or promote the well-being of the carer or young carer. Where two or more people share the role of main carer, any grant funding will be shared.

Examples of funding would be contributions towards:

- Hobbies and interests
- Keeping connected e.g., tablets for accessing social media and video calls
- Short breaks

Outside of £3000 support grant limit and can be applied for up to 12 months post bereavement.

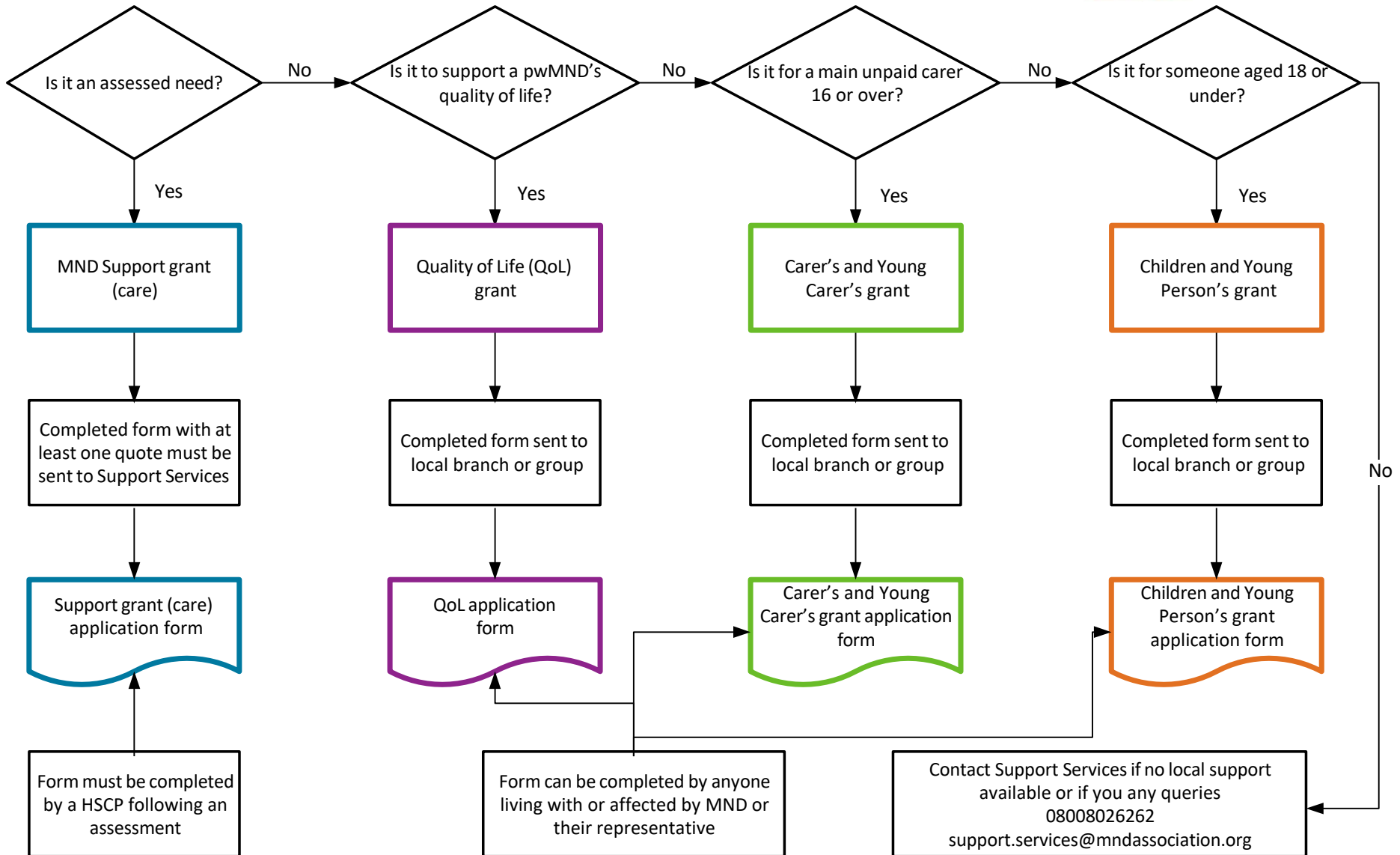
**Children and Young Person's Grant** up to a maximum of £250 per application per rolling 12 months.

Must be 18 or under and residing with a person living with MND or parent/guardian has MND. Examples of funding would be contributions towards:

- Driving lessons
- Hobbies and interests
- Keeping connected e.g., tablets for accessing social media and video calls
- Holiday/school trips

Outside of £3000 support grant limit and can be applied for up to 12 months post bereavement.

What support grant can I apply for?



## Appendix B

Support (Care) Grant Category	Guide £
Adaptations	*
Alarms/Telecare (purchase or rental)	£150
Bed and Bed Accessories (purchase or rental)	£750
Computer Access (purchase or rental)	£450
Environmental Controls (purchase or rental)	£500
Feeding Aid (purchase or rental)	£1000
Head Support (purchase or rental)	£150
Hoist/Lifting Equipment (purchase or rental)	£800
Mobile Arm Support (assessment)	£580
Personal Care	£500
Ramps (purchase or rental)	£750
Specialist Chair/Seating (purchase or rental)	£945
Stairlift (Straight/curved, purchase or rental)	£1500
Stair climber (purchase)	£500
Washer/Dryer WC (purchase)	£1500
Respiratory	£1000
Respite Care (at home or residential)	£1000
Vehicle (wheelchair accessible vehicle)	£1000
Vehicle Adaptation	£1000

\*Case by case basis

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