

## Support Funds applicant guidance

### What are the MND Association Support Funds?

A diagnosis of MND or Kennedys can be tough and our Support Funds are here to help. We offer four different Support Funds that can be used flexibly to best meet yours and your family's needs and to enable you to feel better equipped to manage your condition.



#### The four Support Funds are:

- Everyday living
- Technology and innovation
- Wellbeing – individuals, carers, children and families
- Cost of living

### Core principles

The principles that underpin the Support Funds are:

**Equity:** Support is needs-based, non-discriminatory, and tailored.

**Transparency:** Clear eligibility, process, and communications.

**Empowerment:** Supporting independence and wellbeing

**Efficiency:** Simplified procedures

### Assessment criteria



The MND Association Support Funds are not means tested.

Assessments of Support Fund applications are based on:

#### Need

- A need which is urgent for example equipment which isn't provided by the NHS or the local authority
- The cost of a good/service being higher than expected and a Support Fund will enable you to access this – for example cost of living related spend such as higher bills and food costs



1 If you have any questions about our Support Funds, you can contact us by email at [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) or by phone at 0808 802 6262.

## Impact

The support fund will have a demonstrable impact on your wellbeing and will help you to achieve one or more of the following:

- I can cope better with MND
- I feel less isolated or lonely
- I can do the things that are important to me
- I feel less anxious about things
- I can make special memories with my family



**Support Funds do not need to be repaid and are not considered by the Department of Work and Pensions as income.**

## Am I eligible?

To be eligible for all Support Funds, you will need:

- to have a confirmed, or suspected diagnosis of MND or Kennedy's disease. The confirmed or suspected diagnosis has to be made by a neurologist, and we will ask for confirmation of this.
- to live in England, Wales or Northern Ireland however there is no minimum time for this, and you do not need to have been in receipt of government benefits to be eligible.

Your usual place of residence can be a residential property, a care home, nursing home or other facility as long as it is in England, Wales or Northern Ireland.

The Wellbeing Support Fund is also available for the main unpaid carer and children who may be living with the person with MND, or their parent/legal guardian has MND, as long as the person with MND lives in England, Wales or Northern Ireland.

For example, this means that if the main unpaid carer, or children lived in England but the person with MND lives in Scotland we would be unable to support.



## What can I apply for?

Below are some examples of how the four different Support Funds can be used.

### Everyday living



- Seating
- Contributions towards adaptations
- Wheelchair accessories eg risers, powerpacks, attendant controls
- Equipment rental – stairlifts, wheelchairs, seating, ramps
- Respite
- Physiotherapy

### Technology and innovation



- Banked voice downloads (including voice build and repair services)
- Text to speech communication aids and apps
- Contributions towards alternative wheelchair controls such as eyegaze driving
- Specialist assistive technology for the home
- Specialist software



**Applications to the Everyday Living and Technology and Innovation Support Fund must be supported by a qualified Health and/or Social Care Professional. This is because the Health and/or Social Care Professional will have to assess the equipment, service, adaptation or technology as being appropriate for the person with MND**

### Wellbeing – individuals, carers, children and families



- Holidays, breaks and trips (in the UK or abroad)
- Counselling for over 25s
- Home and garden maintenance and improvements (eg cleaner, gardener, furniture)
- Driving lessons
- School trips and other activities
- Self care (eg haircuts, beauty treatments)
- Complementary therapies



**The Wellbeing Support Fund is available to the main unpaid carer and children up to 18 months post-bereavement.**



## Cost of living



- Food costs
- Household bills (e.g. energy bills)

## Is there a limit to what I can apply for?

Each Support Fund has a different limit and covers a different range of goods/services (detailed at **Appendix A**) and we may consider requests up to the limit.



For people living with MND or Kennedy's disease there is a rolling 12 month limit of £4000. The Cost of Living Support Fund and Wellbeing applications for carers, young carers and children/young people is outside of this limit.

## How do I apply?

Please complete, or speak to your health or social care professional about completing, the relevant application form which can be found on our [website](#).

Return the application form by email and you will receive an automated email to confirm your application has been received. We will process your application within 10 days and will be in touch to confirm the outcome or discuss any further information that we might need.

Support Fund applications are assessed on individual applicant needs, previous applications made, and available budget. Our support may not always cover the full amount needed.

## Can I apply for any of the Support Funds retrospectively?

Yes, it is possible to apply for support funds up to six weeks retrospectively and we have developed a simple framework, at **Appendix C**, detailing the circumstances in which applications can be made retrospectively.



## Is there anything you won't fund?

We are unable to provide funding towards the following:

- Equipment and adaptations that are the responsibility of the NHS or local authority
- Medicines/ drugs that are the responsibility of the NHS
- Medicines/drugs that are unproven treatments
- Medicines/drugs that are not yet NICE approved but proven
- Repayment of debt
- Legal costs
- Insurance policies



### **Important Disclaimer – applicable to all Support Funds**

Please note that the Association is not a party to any agreement that you may enter into with a 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.

## What if I need more support?

If you are in a more complex situation and our Support Funds are unlikely to fully meet or resolve your needs, we may still be able to help.

Our [Benefits Advice Service](#) can discuss your ongoing needs and ensure you are maximising your income and will explore all benefits and entitlements you might be eligible for.

[Lightening Reach](#) and [Turn2Us](#) both offer a simple way of searching through financial support available.



## Appendix A

**Everyday Living** Up to a maximum of £2000 per application. Equipment or adaptations requiring a professional assessment. A funding guide can be found at Appendix B

An application must be accompanied by confirmation of suitability from the relevant Health or Social Care Professional.

Examples of funding would be contributions towards:

- Adaptations to property
- Ramps
- Hoists
- Stairlift rental/purchase
- Washer dryer toilets
- Respite care costs for overnight and weekend carers
- Riser recliner armchair rental/purchase
- Wheelchair accessories and add-ons
- Powered wheelchair rental
- Mobile arm support rental/purchase
- Physiotherapy

Included in support fund limit, for people with MND, of up to £4000 in a rolling 12-month period.

**Technology and Innovation** up to a maximum of £1000 per application

An application must be accompanied by confirmation of suitability from the relevant Health or Social Care Professional.

Examples of funding would be contributions towards:

- Non specialist communication aids\*, apps and accessories
- Voice banking (repair, build and design)
- Alternative wheelchair driving controls eg eyegaze
- Environmental Controls/Assistive Technology for the home
- Voice amplifiers
- Boogie boards

\*iPads, Android and Windows devices for use a text to speech communication aid

Included in support fund limit, for people with MND, of up to £4000 in a rolling 12-month period.



## Wellbeing 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 (not requiring assessment), 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, main unpaid carer, young carer (up to age 19) and children (up to age 18) of, or living with, the person with MND.

- Up to a maximum of £750 per application for people with MND
- Up to a maximum of £500 per application for the main unpaid carer or young carer, up to the age of 19, per rolling 12 months
- Up to a maximum of £250 per application for children/young people, up to the age of 18, per rolling 12 months

Funding for carers, young carers, children and young people is available up to 18 months post bereavement.

Examples of funding would be contributions towards:

- Equipment not requiring an assessment e.g., mobility scooters\*, four wheeled walkers, lightweight wheelchairs
- Essential garden and home maintenance/improvements/furniture/white goods
- Keeping connected e.g., tablets for accessing social media, online banking and video calls
- Hobbies and interests
- Special transport including taxi's
- Accessible/adapted holiday venues
- Complementary therapy
- Headset microphones for voicebanking
- Driving lessons
- Holidays/trips – transport and accommodation
- Counselling for adults
- Spa/pamper days
- School trips and other school/extra curricular activities
- Toys and games

\*please check the class of the mobility scooter as it may be liable for road tax

Included in support fund limit, for people with MND, of up to £4000 in a rolling 12-month period

## Cost of Living up to a maximum of £500 per application per calendar year.

Does not require a professional assessment and enables the person with MND to apply for funds towards household bills without the need to send a quote or other proof of costs.

Outside of the support fund limit, for people with MND, of up to £4000 in a rolling 12-month period



## Appendix B

Everyday Living (max £2000 per application)	Guide £ (up to)
Adaptations	*
Profiling Bed and Bed Accessories (purchase or rental)	£2000
Environmental Controls (purchase or rental)	£1000
Feeding Aid (purchase or rental)	£2000
Head Support (by exception only)	£200
Hoist/Lifting Equipment (purchase or rental)	£1000
Mobile Arm Support (assessment)	£1000
Personal Care	£500
Ramps (purchase or rental)	£1000
Specialist Chair/Seating (purchase or rental)	£1000
Stairlift (Straight/curved, purchase or rental)	£2000
Washer/Dryer WC (purchase)	£2000
Respiratory	£500
Respite Care (at home or residential)	£1500
Vehicle (wheelchair accessible vehicle)	£2000
Vehicle Adaptation	£1000
Wheelchair Accessories	£1500
Wheelchair Rental	£1000



Technology and Innovation (max £1000 per application)	Guide £ (up to)
Communication Aid (iPad, Android or Windows based)	£400
Communication Text to Speech App	£200
Voicebanking – voice download	£250
Alternative wheelchair driving controls	£1000
Voice amplifier	£100
Boogie boards – LCD writing tablet	£50
Communication Aid Accessories (case, stylus ,keyboard)	£150

\*Case by case basis



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## Appendix C

As a guide the timeframe for considering retrospective applications, across any Support Fund Category that meets the criteria below, is within **six weeks** of equipment/service having been paid.

Criteria	Rationale
<b>Urgent need</b>	<ul style="list-style-type: none"> <li>- Applicant at risk from safety aspect</li> <li>- MND progressing rapidly</li> <li>- Potential breakdown in care</li> </ul>
<b>Delay from health and social care professional or person applying on behalf of the applicant</b>	<ul style="list-style-type: none"> <li>- Sick leave</li> <li>- Annual leave</li> <li>- Thought they had sent it (human error)</li> <li>- Application submitted to the wrong place/got email address wrong - have evidence to show this</li> <li>- Application missing in post</li> </ul>
<b>Rental renewal</b>	Consider retrospectively in the scenario where first time applying for this (may have been covering cost themselves previously and no longer able to do so) and it has been sent late by the health and social care professional
<b>Emergency call out charges / repairs</b>	<ul style="list-style-type: none"> <li>- Stairlift repairs</li> <li>- Riser recliner chair repair</li> <li>- Washing machine repair</li> <li>- Vital everyday equipment/items the applicant needs</li> </ul>
<b>Transport costs e.g. taxi</b>	<ul style="list-style-type: none"> <li>- Attending appointments with little to no advanced warning</li> <li>- To enable to access community/shops e.g. to purchase gas/electric / food / phone credits</li> <li>- Anything that could put the applicant at risk of isolation</li> </ul>
<b>Everyday essential items</b>	For example a new washing machine which has to be purchased at short notice.

