

# MND COSTS



**When MND strikes, people's worlds are turned upside down**



People with MND are being forced to fund care themselves and wipe out their savings because:

- Benefits and entitlements are not enough to cover the costs MND incurs.
- Accessing financial support can be too difficult and overwhelmingly complex to apply for and the system can also be too slow to respond. This is resulting in some people getting support when it's too late, in some cases after the person with MND has died.
- Not enough people are being made aware of the financial support they are entitled to.

Until now the costs of MND and the impact on people with MND and their families has been largely hidden, and not fully seen or understood by those with the power to change it.

**We are campaigning to end the financial hardship faced by people with MND and their families**

Join the campaign at [www.mndassociation.org/mndcosts](http://www.mndassociation.org/mndcosts)

## What is motor neurone disease (MND)?

A fatal, progressive disease that can leave people locked in a failing body, unable to move, talk and eventually breathe.



*You know you can't... even things like going to the pictures, or going out for a meal. You have to think twice, and if we do go out it's always Wetherspoon's.*

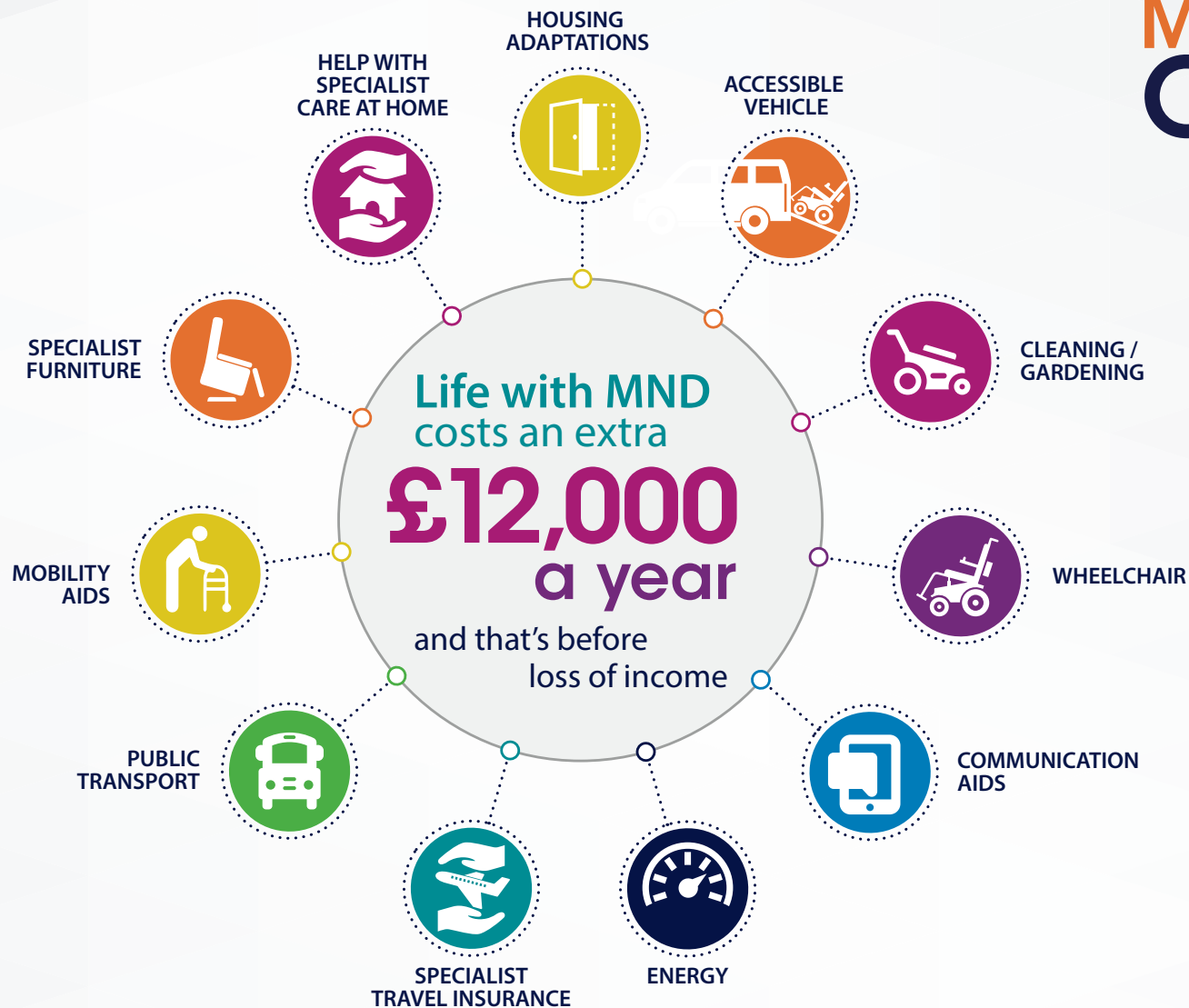
## The issues

- Not enough financial support\* to help people cope with the costs of MND.
- Not enough people are aware of what financial support they are entitled to, especially around bereavement benefits.
- There is a stigma about applying for disability benefits.
- The system can be too slow to respond.
- Financial support can be based on income and overwhelmingly complex to apply for.
- The unpredictable nature of MND can make it hard to plan and cope financially.
- The financial impact increases over time as the disease progresses.
- The financial impact is particularly hard on working age adults, especially those with children.



\*Financial support - for example, benefits such as: Personal Independence Payment, Disability Living Allowance, Attendance Allowance, Employment and Support Allowance, Carers Allowance; Disabled Facilities Grants and NHS Continuing Healthcare

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Life with MND is tough enough without being pushed into financial hardship

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# The effects

- Families are wiping out their savings to get the support they need, or going without vital support because they can't afford it.
- There is significant under-claiming of disability benefits by people with MND.
- Financial support is being provided too late, in some cases after the person has died.
- Bereaved carers and families struggle to cope financially after their loved one has died.



Nearly **25%** of people living with MND are not receiving disability benefits that they are entitled to.



*...I'm warming myself with blankets because I looked at the electric and I've got about £10 left on there... at 1.20pm the heating comes on because I'm cold... If my blanket falls down I can't put it on...*



*It's a question of whether I actually want to go to work every day and leave him, or do I want to spend more time with him, because obviously time is of the essence.*



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*...I had to max out credit cards and get an overdraft. Now I'm struggling to pay bills so have to work extra shifts to be able to eat.*

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*...in the long term I will have to move from our family home as I will not be able to afford to live here for much longer.*

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*...the thought of all that – the good job going; the money going...relying on the wife's wages and state benefits, was very, very stressful.. I was having sleepless nights, worrying about the finances.*

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## Life with MND is tough enough without being pushed into financial hardship.

Over the last few years, we have been campaigning against many of the cuts and threats by the government to vital disability benefits for people with MND and their carers. These threats have not abated.

We need to step up our campaigning to ensure the benefits system and financial support services provided by the government are accessible and provide people with MND with the financial support they need.

Together, we can change this by raising awareness, mobilising others and putting pressure on politicians to act!

Play your part in helping to improve the lives of people with MND, their carers and families by joining the campaign today at [www.mndassociation.org/mndcosts](http://www.mndassociation.org/mndcosts)

## Our Principles

**What we believe good financial support for people with MND and their carers should look like.**

1. It must take into account the progressive, often rapid, and terminal nature of MND.
2. People need to be provided with information about the range of financial support available to them and how to access it.
3. People should feel able and comfortable to claim the benefits and entitlements available to them.
4. Decision makers must recognise that some people of working age cannot work, and will never return to work.
5. People should not lose out on financial support on the basis of their age.
6. People should be exempt from unnecessary reassessments for benefits and entitlements.
7. Services must take into account the fact that MND creates significant extra costs.

## For more information:

Visit the website: [www.mndassociation.org/mndcosts](http://www.mndassociation.org/mndcosts)

Email us: [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)

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