# A lifeline not a luxury.

## Delivering accessible homes for people with Motor Neurone Disease.

November 2025

MND Association

Unlock the door

# Contents

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**Front cover:** Charlotte, who is living with motor neurone disease.

All quotes in this report are from people living with or affected by MND, who responded to our survey.

# Foreword

**Many people are shocked to learn that people with motor neurone disease (MND) are spending their final months trapped in homes that no longer meet their most basic needs. For some, that means sleeping in their kitchen because they can't reach their bedroom. For others, it means risking a fall every time they use the toilet, or going months without being able to wash safely.**

One person having to endure these conditions would be unacceptable. But the tragic reality is that these are not isolated stories; they are the everyday reality for many people with MND. As this report lays bare, right now there are many hundreds of people with MND whose housing robs them of both their dignity and the chance to make the most of the time they have. This is not inevitable. It is the result of an outdated system that moves far too slowly for people whose conditions progress rapidly, and it is unacceptable that this has been allowed to continue.

I hope that as you read this report, you feel the same sense of anger and injustice as I did. We need to harness this sense of injustice to drive our campaigning for change. There is much that needs to change. But the most urgent and lifechanging reform is simple: people with progressive and terminal conditions, such as MND, must be guaranteed a fast-track route to deliver the home adaptations they need.

For someone whose condition may progress significantly in a matter of months, waiting a year or more for vital adaptations is just not good enough. MND won't wait for bureaucracy to catch up, and so people living with MND shouldn't have to either. Fast-tracking is vital to ensure that no one spends their final months trapped in an unsafe and unsuitable home.

That is why we are campaigning for fast-tracking to become standard practice across England, Wales, and Northern Ireland, to deliver the support that people living with progressive and terminal conditions need, when they need it. We recognise that achieving these changes isn't something we can do alone. It will require the collective effort of many individuals and like-minded organisations. I hope this report inspires you to get involved.

**Tanya Curry**
Chief Executive
Motor Neurone Disease Association

# Executive summary

**Few diseases are as devastating as motor neurone disease (MND). It is a progressive and incurable condition which affects the brain and central nervous system, eventually leaving people unable to move, speak, swallow and ultimately breathe. A third of people with MND die within a year of diagnosis, and more than half within two years.**

As MND progresses, timely home adaptations are critical to maintaining good health and wellbeing for as long as possible. Without them, people already trapped in failing bodies can find themselves trapped again in inaccessible homes, leading to isolation, injury, illness and emotional distress.

An accessible home can prevent isolation, reduce accidents, slow physical and mental health decline, and help avoid unnecessary hospital admissions. The Government's Better Care Fund policy framework acknowledges that home adaptations are crucial in helping people stay healthy and maintain independence longer, supporting the shift from illness to prevention and from hospital to home.[1]

However, the survey data and personal testimonies set out in this report demonstrate that countless people with MND struggle to get the support they need to adapt their home before it is too late. In response to a survey, **52% of people living with MND said they were dissatisfied** with the key source of support available for home adaptations: the Disabled Facilities Grant (DFG).

When applying for a DFG, people with MND are often forced to spend the last months or years of their lives battling a long, complex and dispiriting process. The average time from submission of a DFG application for a large adaptation to completion of the works is 289 days in Wales, 357 days in Northern Ireland and 375 days in England. As someone with MND surveyed for this report said, **"The whole process consumes you from start to finish."**

For people living with MND, a rapidly progressive condition, these lengthy timescales mean **adaptations often arrive too late to make a difference.** This report calls for the introduction of formal fast-track processes for people living with progressive and terminal conditions, that ensures adaptations are delivered in time to be of real benefit.

People living with MND also find themselves excluded from support due to a means-testing process that takes no account of the financial costs that arise from living with the condition. Survey data found that **51% of respondents considered the means test "very unfair"**, with 30% reporting it delayed their application by months. For people with a short life expectancy, these lost months can mean missing out on the opportunity to benefit from adaptations altogether. That is why this report calls for the means test to be waived for people with progressive, life-limiting conditions such as MND.

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[1] Better Care Fund policy framework 2025 to 2026.

Even when people living with MND are approved for DFG funding, they may discover that the funding available will not cover the adaptations required. The maximum DFG has been capped at £30,000 in England and £36,000 in Wales since 2008. If the caps had risen in line with inflation, they would today be £49,000 and almost £59,000 respectively. The cap in Northern Ireland is £35,000, set in August 2022. Further inflation since 2022 means that the equivalent cost in 2025 would be almost £40,000.

The failure to uplift DFG caps to reflect inflation, and the increased cost of works, mean that successive governments have presided over a steady erosion of the level of real-terms support available to disabled people to enable them to live safely and well at home. 33% of people living with MND told us that the funding they received through a DFG was inadequate to fully cover the adaptations they required.

**These issues result in many people with MND being trapped in their own home — isolated, unsafe and unable to access a home environment suited to their needs.** Another survey respondent described what happens to people with MND when the system fails them:

**“My husband couldn’t wash properly for over six months. I used to wash him by the kitchen sink as I obviously couldn’t get him upstairs. [He] ended up in a hospice for care… We managed to get him home for Christmas and he died two months later.”**

This report draws on evidence from Freedom of Information requests to local authorities, a survey of people with lived experience of MND and the DFG system, and interviews with occupational therapists. **It shows that DFG delivery is a postcode lottery, impacted by unacceptably long wait times, unfair and inconsistent means testing, and variable approaches to the application of the means test and grant levels.** These issues prevent many people with MND from making urgently required adaptations to their homes, putting them and their carers at risk of worse health outcomes, avoidable accidents and a drastically reduced quality of life.

This report also addresses the ongoing failure to build new accessible housing, which is needed to ensure the housing stock better matches the accessibility needs of the population as a whole. Currently, only 1.4% of houses built between 2020 and 2030 in England will be suitable for a wheelchair user. Despite previous government commitments to take action, there is still no legally required proportion of housing that must be built to be fully habitable by wheelchair users in England and Wales.

# Recommendations

**Local recommendations**

- Local authorities in England and Wales, and the Northern Ireland Housing Executive, should implement formal fast-track processes for people with progressive conditions such as motor neurone disease. These processes should ensure rapid decision-making and delivery of adaptations, supported by training and education for staff so that fast-tracking is applied consistently and appropriately.
- Local authorities in England and Wales, and the Northern Ireland Housing Executive, should waive the means test for adaptations of all sizes for people with progressive, life-limiting conditions such as MND.
- Local authorities in England and Wales, and the Northern Ireland Housing Executive, should be required to keep a register of accessible social homes.

**National recommendations**

- The UK and Welsh Governments should strengthen guidance to local authorities to set a clear expectation that they establish and introduce formal fast-track processes for DFG applications from people living with progressive conditions such as motor neurone disease. They should work with local authorities to support a consistent approach to fast-tracking, including by establishing transparent monitoring and reporting of fast-track processes, standards, and timelines at the local level.
- The UK and Welsh Governments should strengthen guidance to local authorities to set a clear expectation that they waive the means test for adaptations of all sizes for people with progressive, life-limiting conditions such as MND. They should actively engage with local authorities to monitor and report on progress towards this goal.
- The UK Government, the Welsh Government and the Northern Ireland Executive should increase the mandatory Disabled Facilities Grant (DFG) cap to at least £50,000. The cap should be reviewed annually and uplifted in line with inflation.
- The UK Government must ensure that the new formula for allocating DFG funding to local authorities accurately reflects the level of housing accessibility need in each local authority area.
- In England, the Government should require both social and private developments to meet M4(2) specifications, as it previously committed to do. In Wales and Northern Ireland, the Lifetime Homes Standard should be extended to private sector developments.
- England and Wales should set a target for a minimum of 10% of new builds to be to the M4(3) wheelchair accessible standard or equivalent.
- Reviews into the Disabled Facilities Grant system should be carried out in Wales and Northern Ireland. The recently completed review in England should be published in full.

# Methodology

**This report brings together evidence from a literature review on the DFG system; responses to requests made under the Freedom of Information Act; responses to a survey of people with experience of MND and the DFG system; and interviews conducted with occupational therapists.**

Under the Freedom of Information Act, a list of questions concerning the administration of DFGs was sent to all local authorities in England and Wales, as well as the Northern Ireland Housing Executive, from June 2024 to March 2025. As home adaptations in Scotland are delivered through a separate system, we do not address Scotland in this report.

The survey was sent/advertised between February and April 2025 to people registered to receive communications from the Motor Neurone Disease Association, and features input from 114 respondents in England and Wales. The questions concerned various aspects of the DFG application process and invited multiple-choice responses as well as qualitative comments.

Interviews were conducted through a session with four occupational therapists in the South East of England in May 2025, and with one occupational therapist and a senior housing surveyor in the North East of England in June 2025.

Sources used in the literature review are cited in the bibliography, with online resources accessed between May and August 2025.

# Section 1: Motor neurone disease and the Disabled Facilities Grant

## The needs of people with motor neurone disease

Few diseases are as devastating as motor neurone disease (MND). It is a progressive and incurable condition which affects the brain and central nervous system. As the disease advances, people can lose the ability to move, speak, swallow and eventually breathe. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will develop a rare form of dementia. A person's lifetime risk of developing MND is up to 1 in 300, and there are around 5,000 people in the UK living with MND.

As their disease progresses, people living with MND typically require significant adaptations to their homes. These adaptations are urgent health interventions that enable people to access and use essential facilities in the home, such as bathrooms, kitchens and bedrooms. Home adaptations can reduce the risk of accidents, prevent hospital admissions, and enable proper care to be delivered in the home. They can also enable entry and exit from the home, making it possible for people to maintain social connections, attend medical appointments, and participate in community life.

Home adaptations are essential to maintaining health, wellbeing, dignity and independence. **Given the condition's potential for rapid progression, people living with MND need a home adaptation system that is fast and responsive to their changing needs.**

There is a growing body of evidence linking a lack of home adaptations to poorer health and wellbeing outcomes. A longitudinal study of disabled adults in England over an 11-year period found that home adaptions reduced the likelihood of falls by 3%, pain by 6%, and poor health by 4% for adults with severe mobility impairments.[2]

> **"The adaptations we fundraised and put in are completely vital to my survival and wellbeing. Without them I'd be trapped inside, stuck downstairs and have no usable washing facilities. It's not about 'I prefer to have them' — I totally need them."**

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[2] "Home modifications and disability outcomes: A longitudinal study of older adults living in England", Chandola and Rouxel, Lancet Regional Health May 2022.

The UK Government's Better Care Fund policy framework recognises that home adaptations play a crucial role in helping people stay well and remain independent for longer, and help support the shift from sickness to prevention, and from hospital to home.[3]

Despite the central importance of accessible housing and timely home adaptations to maintaining health and wellbeing for people living with MND and other serious health conditions, there is growing evidence that many people experience great difficulty accessing the adaptations they need. This report draws on survey data, Freedom of Information data and personal testimonies to demonstrate that a high proportion of people living with MND struggle to access support for home adaptations, which is primarily delivered through the Disabled Facilities Grant (DFG) process in England, Wales and Northern Ireland.

A survey of people living with or affected by MND carried out for this report showed that more than half of respondents were "dissatisfied" or "very dissatisfied" with the DFG process overall. **A third of people with MND responding to the survey found that the grants they received were inadequate to cover their home adaptation needs.** People living with MND also shared experiences of unfair means-testing processes that exclude people with significant support needs, while substantially delaying the grant process. Freedom of Information data shows that the assessment and installation of large adaptations over the last three years took around a year on average; an unacceptable and unworkable timeframe in the context of the speed of MND progression.

This report provides further evidence that the DFG system does not meet the needs of many people with disabilities, particularly those living with progressive, life-limiting conditions such as MND.

### Background — the Disabled Facilities Grant

The Disabled Facilities Grant (DFG) is a means-tested capital grant available in England, Wales and Northern Ireland, which can help with the cost of adapting a home for people with a range of disabilities, mental health or age-related needs. It is administered by local authorities in England and Wales, and by the Housing Executive in Northern Ireland. It provides funding for adaptations such as installing a stairlift or through-floor lift, creating a level-access shower room, widening doorways, providing ramps and hoists, installing handrails and ramps, or creating a ground floor extension.

A person will qualify for a DFG if they can demonstrate that specific home adaptations are necessary and appropriate to meet their needs, including moving around and getting in and out of their property, and that the work is reasonable and practicable. Under these circumstances, a local authority has a mandatory duty to offer a DFG, providing financial eligibility criteria are met by way of a means test. The mandatory grant is capped at £30,000 in England, £36,000 in Wales and £35,000 in Northern Ireland, with local authorities able to provide additional funds above the cap at their discretion.

> **"[Now that] the adaptations are done, life is more bearable and I don't feel I'm impacting on my wife's health — physically, mentally and emotionally."**

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[3] Better Care Fund policy framework 2025 to 2026 — GOV.UK

The legislative framework for DFGs is set out in the Housing Grants, Construction and Regeneration Act 1996 for England and Wales, and the Housing (Northern Ireland) Order 2003 in Northern Ireland. Both make the award of a grant mandatory — a statutory duty — where the required conditions are met.[4] These include confirmation, often via an occupational therapist, that the works are necessary and appropriate to meet the person's needs, and that the adaptations are reasonable and practicable given the property's condition. The Act also provides for regulations to set the maximum grant amounts for each nation; these grant amounts are subject to change through secondary legislation.

Local authorities may choose to provide discretionary assistance above these limits. This discretionary power is supported in England and Wales by the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002[5] , which enables councils to offer additional help such as top-up funding, minor adaptations, or alternative forms of housing assistance, provided they publish a Housing Assistance Policy setting out the scope and criteria for such support.

In Northern Ireland, the Housing Executive operates a similar discretionary policy, allowing additional assistance beyond the statutory maximum where justified by need and available resources.[6] National guidance emphasises that, while the mandatory grant process is governed by statute, discretionary measures should reflect local priorities, support independent living, and align with wider health and social care strategies such as the Better Care Fund.

There has long been recognition that the DFG system does not meet the needs of many people with disabilities. For example, an independent review of the DFG in England commissioned by the UK Government in 2018 (the External Review)[7] found it lacking in many respects. It characterised the DFG process as “difficult to navigate” and criticised the wide variation in length of time between approval of grant to completion of work. It found that delays to the DFG process “appear to have a detrimental effect on health, mental wellbeing, and fear of falling”. Most of the review's recommendations have never been implemented.

More recently, an inquiry by the UK Parliament Levelling Up, Housing and Communities Select Committee in May 2024 identified “many shortcomings with the current DFG system, which ultimately leads many applicants to drop out entirely.”[8] It described a postcode lottery of support, an overly-complex means test which penalises disabled people who remain in work, and found that the DFG upper limit is inadequate to cover all home adaptation needs. In Wales, the Equalities and Human Rights Commission has found “unacceptable delays” within the DFG process.”[9]

It describes the means testing system as overly complex and sometimes inequitable, and criticised a “fragmented” delivery system and a lack of available information for service users.

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[4] Housing Grants, Construction and Regeneration Act 1996 (c. 53).
Housing (Northern Ireland) Order 2003, Article 50. Statutory Rule of Northern Ireland No 412.

[5] The Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 (SI 2002/1860).

[6] Northern Ireland Housing Executive, Home Improvement Grant Policy Manual (Draft Version GRS 1 — April 2022), section 5 Disabled Facilities Grants.

[7] University of the West of England (2018), Disabled Facilities Grant (DFG) and Other Adaptations — External Review.

[8] Levelling Up, Housing and Communities Committee (2024), Disabled People in the Housing Sector, p.4.

[9] Welsh Government Social Research, A Review of Independent Living Adaptations — Executive Summary, pp. 2-3.

# Section 2: Impact of the DFG on people with MND

## Delays and fast-tracking

The Disabled Facilities Grant (DFG) process is simply too slow to meet the needs of people with motor neurone disease (MND). With a condition that can progress in a matter of months, long application and installation times mean that adaptations often arrive too late to make a difference, or not at all.

There is a statutory six-month time limit for a decision to be made on a DFG application. However, the time taken for works to be completed is expected to be far greater. For example, the Welsh Government's service standards anticipate medium adaptations taking 26 weeks and large adaptations taking 70 weeks — more than a year.[10]

Given that people with MND generally have a life expectancy of two to three years, with only 10% living longer than 10 years post-diagnosis,[11] both the statutory six-month time limit and the expected timeframes for installation are far too long for someone with MND to wait. In many cases, a person's accessibility needs will progress significantly during that time-frame, so that by the time the adaptations are delivered, they are no longer adequate.

The need for quick and forward-looking work is made clear in the following, from an individual whose wife has MND:

> **"You need to get things done and get them done quickly. Because the moment you do something, it quickly becomes out of date."**

Delays often result in the process from application to installation taking far longer than six months. The Communities and Local Government Select Committee noted in 2018 that "our predecessor Committee [concluded] that [the DFG process] was 'slow and cumbersome', so we were interested to return to the issue. Once again, we heard that it was a 'clunky process' and that waiting times for implementation varied significantly between local authorities, ranging from days and weeks in some places to two or three years in others."[12]

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[10] Welsh Government (2019), Housing Adaptations Service Standards, p. 8.

[11] NICE (2015), Quality Standards and Indicators Briefing, p. 3

[12] Communities and Local Government Committee (2018), Housing for Older People p. 20

Responses to our FOI requests showed, on average, that the assessment and installation of large adaptations over the last three years took around a year. Concerningly, the time taken to complete a large adaptation has increased by 13% over the three-year period, with the average waiting time rising to over a year by 2023/24. In the context of a rapidly progressive and terminal condition such as MND, these timeframes are unacceptable.

Small adaptations generally include items like grab rails, lever taps, or minor adjustments; medium adaptations cover things like stairlifts, level-access showers, or ramps; and large adaptations include major works such as extensions, through-floor lifts, or significant bathroom/kitchen remodelling.[13]

**Average duration of the DFG process in England**

| | Av. days from application to approval | | | Av. days from approval to installation | | | Total: Av. days from application to installation | | |
|---|---|---|---|---|---|---|---|---|---|
| Year | Small | Medium | Large | Small | Medium | Large | Small | Medium | Large |
| 2021/2 | 75 | 92 | 145 | 85 | 120 | 188 | **160** | **212** | **333** |
| 2022/3 | 86 | 101 | 143 | 106 | 127 | 211 | **192** | **228** | **354** |
| 2023/4 | 76 | 111 | 157 | 92 | 118 | 218 | **168** | **229** | **375** |

In Wales the completion of DFGs often takes a significant amount of time. The Wales Centre for Public Policy notes that in 2018/19, the average time from application to the completion of works was 207 days (roughly seven months), but that increases to 298 days (roughly ten months) in Flintshire.[14]

**Average duration of the DFG process in Wales**

| | Av. days from application to approval[15] | | | Av. days from approval to installation | | | Total: Av. days from application to installation | | |
|---|---|---|---|---|---|---|---|---|---|
| Year | Small | Medium | Large | Small | Medium | Large | Small | Medium | Large |
| 2021/2 | 44 | 59 | 148 | 75 | 125 | 239 | **119** | **184** | **387** |
| 2022/3 | 39 | 52 | 44 | 63 | 125 | 227 | **102** | **177** | **271** |
| 2023/4 | 36 | 44 | 72 | 65 | 112 | 217 | **101** | **156** | **289** |

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[13] ADRA (2025). Making a request for adaptations.

[14] Wales Centre for Public Policy (2021). Disabled Facilities Grants: Changing the Means Test, p. 26.

[15] Not all 17 local authorities which responded provided usable data for each element.

There are also substantial delays in completing DFG works in Northern Ireland. In October 2024, the Northern Ireland Executive provided the following evidence of the average time taken for DFG works to begin:[16]

**Average duration of the DFG process in Northern Ireland**

| Av. days from recommendation to inspection | Av. days from inspection to approval | Av. days from approval to plans and documents provided by applicant | Av. days from documents provided to work starting | Total: Av. days from recommendation to work starting |
|---|---|---|---|---|
| 28 | 18 | 292 | 19 | **357** |

This is almost two months longer than the average in England, which was roughly six months on average in 2023/4 — even for large adaptations.

Data released by the Northen Ireland Executive in February 2025 revealed that over 1,000 Northern Ireland Housing Executive social housing tenants were waiting for adaptations to their homes. Of the 373 properties awaiting major adaptations, almost 15% (55) had been waiting between 19 and 24 months and just over 10% (38) had been waiting between 25 and 30 months.[17]

The causes of delays are complex and numerous, given different local authorities' varying processes and circumstances. These can range from a lack of join-up between a local authority's social care and housing departments, to a lack of availability of occupational therapists. Indeed, the occupational therapists we spoke to noted the differences in provision across the district and borough councils within their county.

The testimonies of people living with MND, as well as survey data from people living with MND in England and Wales, demonstrate that these lengthy timeframes have a significant impact on people awaiting vital home adaptations. Among respondents to our survey:

- 21% waited between 3-6 months for DFG approval post-occupational therapist assessment, while 16% waited longer than six months.
- Following approval, 21% of respondents waited more than six months for work to be completed.
- 39% of participants did not benefit from expedited processes or said that, if they did, these were nonetheless slow.

The real impact of these delays is evident from the accounts of those affected:

> **"My [relative living with MND] has fallen on the stairs before the grant was approved."**

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[16] Northern Ireland Department for Communities (2024). AQW 16027/22-27.

[17] Northern Ireland Department for Communities (2025). AQW 20442/22-27.

These delays are concerning, given that 151 local authorities in England who responded to our FOI requests (76%), claimed to have some form of fast-track application process for applicants with urgent needs. In most of these (106), the process simply meant that an occupational therapist could grade an application as “urgent” or “high need,” which in theory should result in prioritisation of the application.

In practice, however, this informal system leaves too much room for interpretation and inconsistency, meaning that people who should be fast-tracked are not always treated as such. One local authority stated that “all applications are dealt with as a priority,” which means that none are. The absence of clear, formalised processes and standards means that fast-tracking is applied unevenly and unreliably, leaving people with progressive, life-limiting conditions at risk of long, harmful delays.

## Examples of best practice in local authorities

**Gateshead Metropolitan Borough Council**

Gateshead has introduced a formal fast-track assessment route for people with neurological conditions, including MND. All such cases are automatically categorised as urgent, and those assessed as palliative are treated the same way. This ensures applications are prioritised without delay or ambiguity, offering a clear and consistent process that responds to the urgency of progressive and terminal conditions.

> **“They said that because of my diagnosis of MND and my lack of mobility I would go to the top of the queue. This was back in May last year (2024), it has still not started [as of February 2025].”**

**Cardiff Council**

Cardiff has developed a formal fast-track pathway for people with urgent needs, including those with MND. Referrals identified by community occupational therapists are treated as urgent, with a technical visit arranged within 48 hours of receipt. Cases are then prioritised with contractors to accelerate delivery. Where ground-floor facilities are required, Cardiff uses modular extension pods, which can be installed much faster than traditional building methods. This approach shows how structured fast-track processes, supported by innovative solutions, can provide timely and effective adaptations for people with progressive conditions.

In interviews, occupational therapists said that processes vary significantly across England and Wales, and that fast-track procedures were used inconsistently. The number of staff involved in the fast-track procedure varies between areas, as do staff members’ levels of awareness of and training relating to MND. As a result, they explained, the success of a fast-track process often depended upon the persistence of the occupational therapist. They also noted factors external to any fast-track process that affected delivery speed, such as contractor and home improvement agency delays.

In Northern Ireland, there is currently no fast track process for specific conditions; applications are only expedited where there is an identified ‘health and safety risk’. However, at the time of writing this report, the Northern Ireland Housing Executive had agreed to implement a fast tracking process for home adaptations for people with MND, subject to formal sign off by the Northern Ireland Executive. This is a particularly welcome development and represents a significant and positive step forward for people living with MND.”[18]

### Defining a fast-track process

For people with MND, “fast-tracking” cannot mean simply expediting one part of the Disabled Facilities Grant process. Without clear standards, local authorities may implement inconsistent or partial approaches that fail to deliver meaningful impact. A robust fast-track system should apply across all stages of the adaptation journey. The key stages of the DFG process are defined as follows by Foundations, the national body for Home Improvement Agencies, Handyperson Services and the Disabled Facilities Grant in England:

| Stage 0 | Stage 1 | Stage 2 | Stage 3 | Stage 4 |
|---|---|---|---|---|
| First contact with service | First contact to assessment and identification of the relevant works | Identification of the relevant works to submission of the formal grant application | Grant application to grant approval | Approval of grant to completion of works. |

Local authorities should aim to meet the following maximum target times for fast-tracked applications:

| Stage | Description of stage | Target Timeframe (maximum) |
|---|---|---|
| 1 | First contact to assessment and identification of the relevant works | 5 days for simple adaptations<br>20 days for more complex adaptations |
| 2 | Identification of the relevant works to submission of the formal grant application | 25 days for simple adaptations<br>45 days for complex adaptations |
| 3 | Grant application to grant approval | 5 days for both simple and complex adaptations |
| 4 | Approval of grant to completion of works. | 20 days for simple adaptations<br>60 days for complex adaptations. |

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[18] Gordon Lyons (3 March 2025). Disability Housing Adaptation Schemes — Oral Answers, Northern Ireland Assembly.

This sets the target timeframes at 55 days (about two months) for simple adaptations and 130 days (just over four months) for complex adaptations. These timelines are consistent with existing best practice guidance.[19] It is also important to acknowledge that achieving expedited timelines will in most cases require waiving the means test for people with progressive, life-limiting conditions, a point explored further in the next section.

To make fast-tracking effective in practice, governments must do more than just encourage local authorities to act. They need to issue clear, authoritative guidance that explains what fast-tracking entails in practice and ensures it is understood consistently across all local areas. This guidance should be supported by strong communication from the centre, so that expectations are not misinterpreted or diluted by local variations. Importantly, governments must also monitor the effectiveness of these processes by collecting and publishing data on delivery, allowing progress to be tracked over time. Without this leadership, there is a real risk that fast-tracking will remain patchy, inconsistent, and unreliable for those with the most urgent needs.

## Recommendations

### Local

Local authorities in England and Wales, and the Northern Ireland Housing Executive, should implement formal fast-track processes for people with progressive and terminal conditions such as motor neurone disease. These processes should ensure rapid decision-making and delivery of adaptations, supported by training and education for staff so that fast-tracking is applied consistently and appropriately.

### National

The UK and Welsh Governments should strengthen guidance to local authorities to set a clear expectation that they establish and introduce formal fast-track processes for DFG applications from people living with progressive and terminal conditions, such as motor neurone disease. They should work with local authorities to support a consistent approach to fast-tracking, including by establishing transparent monitoring and reporting of fast-track processes, standards, and timelines at the local level.

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[19] Welsh Government, (2019). Housing Adaptations Service Standards, p.8.

## Means testing

DFGs are means-tested to determine household eligibility for support. The formula for the means test is similar across England, Wales and Northern Ireland and mirrors the calculation of entitlement to Housing Benefit: the assumed weekly needs of the household are calculated and surplus income is identified. That surplus amount is then used to calculate how large an "affordable loan" the claimant could secure to contribute towards costs, with the DFG reduced accordingly.

In its 2024 report, the Levelling Up, Housing and Communities (LUHC) Select Committee found that "the current DFG means test is unnecessarily complex and leads many applicants to drop out of the DFG process entirely."[20]

This is supported by the findings of our patient survey: 41% of respondents found the means-testing process "difficult" or "somewhat difficult". Responses included:

> "Process not supported… nothing explained."

> **"No help to do it. If wrong, takes you to end of queue every time."**

> "Stressful to say the least. Having recently been diagnosed and asked all these questions was very stressful."

The means test contributes to further delays to the DFG process. Thirty percent of respondents to our survey told us that the means test contributed to delaying their DFG application. Fourteen percent stated that the means test delayed their application for a DFG by up to a month, 10% reported a delay of between one month and 12 months, and 6% reported a delay of more than 12 months.

> **"Waiting for a downstairs wet room meant that I had to struggle to climb the stairs to the upstairs bathroom. I did crumple on the stairs regularly, leaving my wife helpless to get me up and having to wait for assistance. This left me feeling very upset and embarrassed."**

The delays incurred by the means test seem to be so well understood that they can discourage people from even applying for DFGs. One contributor who cares for his wife, who has MND, told us:

> **"We have had no actual experiences with the DFG except to be discouraged to apply as we have been informed it will be means tested…We were also advised that the system is very longwinded and takes an age!"**

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[20] Levelling Up, Housing and Communities Committee (2024), Disabled People in the Housing Sector, p. 23

## Means testing

Many respondents to the patient survey found the means test to be unfair: 51% said it was “very unfair” and 16% said the process was “somewhat unfair”. Some of the responses to the patient survey evidence the ways in which the test can be a blunt tool:

> “Was means tested and disallowed. This means I cannot get adaptations even though they are needed.”

> **“Adaptations cost us £70k. As my husband still received sick pay we were told we earned too much and had funds to borrow up to £80k on a loan! Our friends and family helped us raise £40k to cover the costs of the main adaptations rather than take on debt when our financial future was unclear. We then saved for less essential adaptations like ramps in the back garden.”**

> “If it wasn’t for my family and a couple of friends we would have totally gone under.”

The DFG means test fails to take account of the significant and unavoidable extra costs of living with MND. Research by the MND Association and Demos has shown that people with MND face average additional costs of more than £14,500 per year, driven by expenses including home adaptations, mobility aids, specialist equipment, increased energy use, transport to medical appointments, and professional care. This is an average figure, with some households paying significantly more to manage the impacts of the disease.[21] Other studies have found that these costs can exceed £250,000 over the course of the illness.[22]

These outgoings are non-discretionary and can quickly erode household finances, meaning that an income level which appears adequate on paper may in reality be insufficient to cover both daily living costs and essential home adaptations.

The means-testing calculation assumes that homeowners will be able to secure a larger loan than tenants, on the basis that homeowners will be able to increase their mortgage and therefore borrow more affordably.[23] However, this assumption is wholly unrealistic for people living with a terminal, progressive condition. Taking on debt is often not feasible when life expectancy is short and financial stability is already under strain. If a partner is also required to give up work to provide full-time care, household income is further reduced, making loans entirely out of reach.

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[21] Motor Neurone Disease Association (2023). Through the Roof.
Motor Neurone Disease Association (2017). MND Costs.

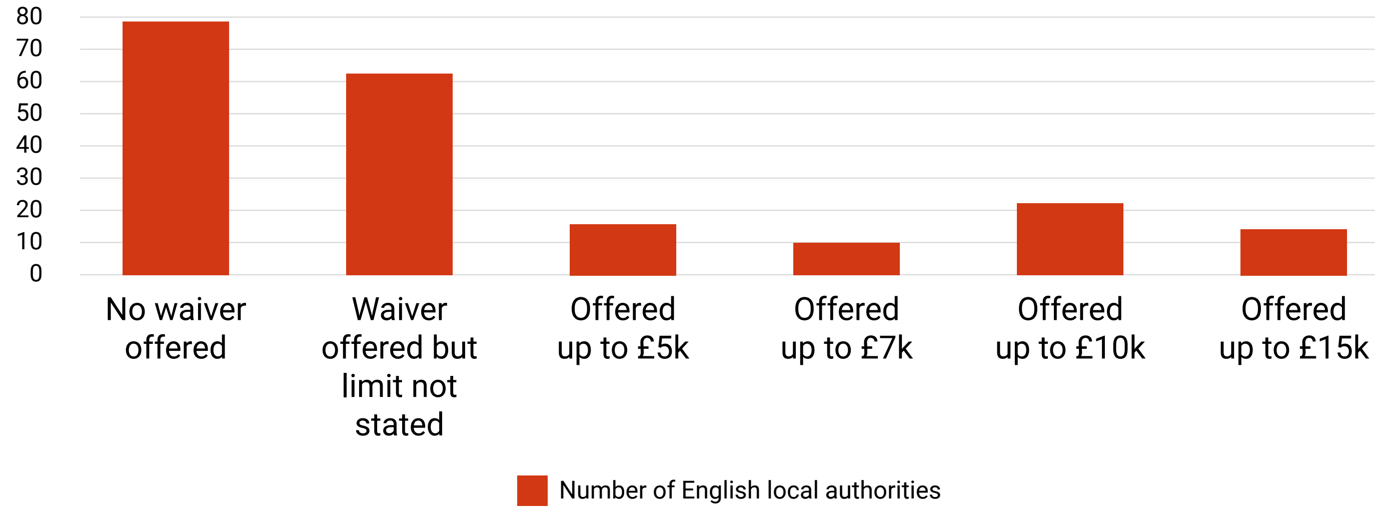
[22] Demos. Motor Neurone Disease Survey. 2019.

[23] University of the West of England (2018), External Review, p. 165

In response to criticisms of the means test, the Government, in its March 2025 response to the LUHC Committee's 2024 report, laid the burden on local authorities, saying "local authorities have a significant degree of flexibility…in relation to the means test."[24]

The variation in local authorities' approaches to waiving the means test is highlighted in the responses to FOI requests. Indeed, 40% of local authorities in England did not offer any form of means test waiver. Of the 118 local authorities which would waive the means test, 50% only do so for claims below a value of £15,000, and 13% would only do so for claims below a value of £5,000.

**Policy of Waiving Means Test — English Local Authorities**



As such, these policies would not apply to those requiring the most expensive adaptations of the sort that may be required by some people with MND. This was corroborated by our patient survey: 68% of respondents were subject to a means test.

There are examples of positive practices at the local level: 26 local authorities in England noted that they waive the means test for applicants with life-limiting or rapidly progressing conditions, or those requiring palliative care.

As one survey respondent explained:

> **"Leeds City Council made a political/ policy decision not to means-test adults with terminal conditions."**

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[24] Housing, Communities and Local Government Committee (2025), Disabled People in the Housing Sector — Government Response, p. 11.

However, as another respondent pointed out, this is a postcode lottery. Meanwhile, FOI responses show that a number of these exemptions to the means test for those with life-limiting or progressive conditions are then only applicable for works which cost under a certain amount, thereby excluding more extensive and costly adaptations.

**Best practice example:**
**Plymouth City Council**

**Plymouth City Council's Independent Living Assistance Policy states that where a client is terminally ill or has a life-limiting, fast-progressive condition (based on a social care needs assessment), DFG applications are classified as emergency adaptations. In these cases, the application is not subject to any means testing process. Emergency applications are fast-tracked through to completion without having to go through a prioritisation process.**

Worryingly, one occupational therapist interviewed for this report highlighted that an English local authority intended to introduce a means test, having previously not employed one, with the intention of deterring DFG applications. Separately, an FOI response from a Welsh local authority revealed that they are considering reintroducing the means test for medium-sized DFG applications due to high demand.

It is deeply concerning that there are thoughts of means testing being introduced or reintroduced at the local level. For people with progressive, life-limiting conditions such as MND, these changes risk creating additional financial and administrative barriers to accessing essential adaptations.

### Disincentivising work

The application of the means test penalises people with MND who wish to keep working for as long as they can. If their income is above the threshold, they may be deemed able to fund adaptations themselves and ruled ineligible for support. Yet this is a false assumption. For people with MND, earning capacity can collapse suddenly as the disease progresses, or because a partner has to leave work to become a full-time carer.

This trap discourages people from maintaining employment, even though staying in work is often vital for financial security, self-esteem, and mental wellbeing. Instead of supporting independence, the system incentivises early exit from the workforce and premature reliance on welfare support. In practice, the means test undermines government objectives to keep people in work for as long as possible, while increasing long-term public expenditure through lost tax revenue and greater demand on NHS and social care services.

The Government itself acknowledged this problem in its 2022 guidance for local authorities on DFG delivery, noting that people in the early stages of a condition may be ineligible because they are still working, yet by the time they stop work they are in urgent need of adaptations.[25] In reality, people living with rapidly progressive conditions such as MND may urgently require major adaptations even while they are still in work, as their condition can deteriorate rapidly regardless of employment status. People with experience of MND highlighted this issue in the survey:

> "We were disqualified from getting any help at all because my husband wished to continue to work: having an income disqualified us but we didn't have any savings at all at that time to pay for the adaptions, so he endured some 18 months of falls and dangerous transfers, and I had to lift him in and out of bed and onto the toilet, and off the floor each time he fell, that whole time, risking my back."

**"We had to crowd-fund the costs because we didn't have any savings to cover them and couldn't get a DFG because my husband wanted to continue working as long as he could to stay sane."**

The partner of a man living with MND in Northern Ireland described being denied urgent adaptations because she and her partner were still working:

**"[My partner] returned home from hospital and slept in our kitchen on a hospital bed. All of his equipment — commode, wheelchair etc — was jammed into our kitchen. Our home was in turmoil, and we had to hold it together for the sake of our two boys. We needed a downstairs bedroom and bathroom built ASAP. We applied for financial aid to have this building done. We were turned down for any assistance as we both worked. We were told to reapply when our circumstances changed. As far as we were concerned they had already changed dramatically and we didn't have time to wait!"**

The solution offered by the Government in its guidance is again that the responsibility lies with local authorities, pointing to the measures that some local authorities have implemented following the MND Association's Act to Adapt campaign: "Some local authorities include provisions within their policy, such as…a fast-track process with no means testing for works up to £5,000 [or] ignoring the earnings of the person with MND in the means test where larger scale works are assessed as being necessary and appropriate."[26] However, given the variation in local authorities' policies and the limitations to the support that even the most generous authorities offer, stronger guidance and more active engagement by central government is required to support consistent adoption of means test waivers across the country.

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[25] MHCLG/DHSC (2022), Disabled Facilities Grant Delivery: Guidance for Local Authorities in England, p. 18.

[26] Ibid.

## Alternative funding streams in Wales, and lessons for the means test

In Wales, funding streams besides the DFG are available which do not require a means test. While the Rapid Response Adaptations Programme (RRAP) is only used for small adaptations[27] and the Enable programme only for small and medium-sized adaptations,[28] the Physical Adaptations Grant (PAG) is available to those in social housing and who need medium-sized or large adaptations — thereby in theory covering the same scale of works as a DFG, without any limit in principle on the cost of a single adaptation.[29]

Analysis of these means test-free programmes has been far more positive than that of the DFG system. An independent review commissioned by the Welsh Government in 2015 found that, while "there are still unacceptable delays" within the DFG system, "the PAG [and] Rapid Response Adaptations Programme…pathways stood out as simple, quick and effective systems, in stark contrast to the problems associated with the DFG pathway and the complexity of the adaptations system as a whole."[30]

In a further repudiation of the means test, as of April 2021 the Welsh Government directed local authorities to remove the requirement for a means test in the case of "small" and "medium"[31] DFGs.[32] When announcing the end to means testing for small and medium-sized DFG applications, the then Minister for Housing and Local Government, Julie James MS, did so in the context of wanting to "continue to improve access to adaptations for those who need them, as well as reduce waiting times."[33]

This measure was estimated to cost local government in Wales, collectively, an additional £238,000 while saving each individual authority between £6,000 and £10,000 in annual administration costs. Evidence was cited from the Wales Centre for Public Policy that the amount saved on administration costs would be "roughly equivalent" to the amount that would be spent as a result of not means-testing small and medium works. While those with progressive, life-limiting conditions such as MND would likely require larger, costlier adaptations, waiving the means test in their case would only marginally expand the exempt demographic.[34]

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[27] AgeCymru (2025), Disability Equipment and Home Adaptations in Wales, p. 27.

[28] Welsh Parliament (2024), Home Aids and Adaptations — a Guide for Constituents, p. 3.

[29] Welsh Government Social Research (2015), A Review of Independent Living Adaptations, p. 44

[30] ibid, p. 2

[31] House of Commons Library (2023), Disabled Facilities Grants for Home Adaptations, p. 32.

[32] Welsh Parliament (2024), Home Aids and Adaptations- a Guide for Constituents, p. 4. Note: broadly, 'small' adaptations are things like stair rails and small ramps which do not require home modification; 'medium' adaptations are things like walk-in showers and large ramps — things that may require major home modification but which don't require planning permission; and 'large' adaptations are those which require structural change/planning permission, such as an extension or through-floor lift. See Welsh Government (2019), Housing Adaptations Service Standards, p. 10.

[33] Julie James, Minister for Housing and Local Government (2021). Written Statement: Removing the Means Test on Small and Medium Disabled Facilities Grants.

[34] Ibid.

## Recommendations

### Local

Local authorities in England and Wales, and the Northern Ireland Housing Executive, should waive the means test for adaptations of all sizes for people with progressive, life-limiting conditions such as MND.

### National

The UK and Welsh Governments should strengthen guidance to local authorities to set a clear expectation that they waive the means test for adaptations of all sizes for people with progressive, life-limiting conditions such as MND. They should actively engage with local authorities to monitor and report on progress towards this goal.

### The DFG cap

In England, the maximum mandatory DFG has been capped at £30,000 since 2008, although local authorities are able to top this up using their discretionary powers.[35] The Bank of England, using the Consumer Price Index, estimates that goods and services costing £30,000 in 2008 would in 2025 cost more than £49,000. The DFG cap in Wales, of £36,000, has similarly not risen since 2008, with inflation making the equivalent level in 2025 almost £59,000.

The DFG cap in Northern Ireland has been increased in recent years. Before 2020, the standard DFG cap in Northern Ireland was £25,000. However, since June 2020 it has been increased three times — first by 8.5%, then by 12% in September 2021, and by another 12% in August 2022 — such that it is currently £35,000. This was in recognition of "rising construction costs and challenges in the construction industry."[36] Further inflation since 2022 means that the equivalent level in 2025 would be almost £40,000.

**The failure to increase the maximum DFG caps in line with inflation means that successive governments have presided over an ongoing real-terms decline in the support provided to disabled people to maintain their health, wellbeing and quality of life in their own home.**

As it stands, the DFG cap is likely to be sufficient for the adaptations required by many conditions. The External Review shows that, in England, across DFGs provided for all conditions, the majority of works (57% in 2015/16) cost less than £5,000, and only 8% of DFGs were over £15,000.[37] The average spending per DFG in Wales is far below the cap, at £9,600.[38]

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[35] MND Association (2019), Act to Adapt — Access to Home Adaptations for People with Motor Neurone Disease, p. 9.

[36] Northern Ireland Housing Executive (2022), Response to FOI_22-23_198.

[37] University of the West of England (2018), External Review, p. 47

[38] Welsh Government (2025), Assistance for Housing Improvement: April 2023 to March 2024 (Headline Results).

However, for people with the most serious, life-changing conditions such as MND, a maximum grant of £30,000 or similar may be insufficient and must be increased if it is to provide the level of adaptation which they require. For instance, extensive home modifications such as installing a through-floor lift, creating fully wheelchair-accessible bathrooms, or widening multiple doorways can quickly surpass this limit. A 2017 report by Demos, in partnership with the MND Association, states that "adaptation costs can extend…into the tens of thousands of pounds (and in rare cases, hundreds of thousands of pounds)."[39]

The External Review notes that the cost of an extension would, in a number of areas, have exceeded the DFG cap in 2016/17: in the South West of England it would have cost almost £35,000, while in London it would have cost £55,000.[40] These excesses will have increased since then due to inflation. The Review also notes that "the drive to stay within the grant limits may affect the quality of what is achieved…the average number of adaptations over £30,000 has been decreasing in parallel with reductions in funding and does not seem to reflect changing levels of need."[41]

Respondents to our patient survey attested to the fact that the cap was often not sufficient: 33% said that the DFG they received only "partially covered" their adaptations with "significant out-of-pocket personal costs"; "barely covered" them; or "did not cover the required adaptations at all." In summary, 58% of people thought the DFG cap amount was "somewhat unfair" or "very unfair".

Many people responding to the survey raised the issue of adaptation costs exceeding the DFG cap:

> "Adaptations cost us £70,000."

**"The total amount of work was £100,000 and [I was] awarded £30,000."**

> "£66k or thereabouts of our own money towards a small side extension, driveway and decking."
>
> "I was told I could be supported with [a] maximum amount of £30,000 but I need a wet room which will cost approximately £80,000. I have no means of raising £50,000. The lady at [the Council] said this was the start of a slow process which may take many years. I feel my only option is to move to a flat."

Another person with lived experience of MND explained that the adaptations required for his wife were going to cost between £80,000 and £100,000. Reflecting on this, he said:

**"Our home has been our home since 2004. It's the only house the kids have ever lived in. I want it to be as free [as possible] for [my wife] to do what she wants when she wants. I don't believe anyone in that situation should be thinking about the financial burden."**

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[39] Demos (2017), MND Costs: Exploring the Financial Impact of Motor Neurone Disease, p. 37.

[40] University of the West of England (2018), External Review, p. 40

[41] Ibid., p. 49

While local authorities can top up the maximum DFG amount at their discretion, this is drawn from their own wider funding. As such, and in a time of significant pressure on local government finances, there is great variance in the availability and amount of these top-ups. Freedom of Information responses from local authorities in England show that only 59% provide discretionary top-ups, and these are often only up to certain levels.

Fifteen responding local authorities stipulated the maximum value of those top-ups, demonstrating that discretionary top-ups will still often not make up the shortfall: two would offer up to £30,000, one would offer £25,000, three would offer up to £20,000, four would offer up to £15,000 and five would offer up to £10,000. Similarly, in Wales, of the two local authorities which specified the extent to which they would top up the DFG with their own funds, the maximum for one was £15,000 and for the other was £14,000.

In Northern Ireland, however, in cases where the £35,000 DFG cap is insufficient, the centralised Housing Executive can spend another £50,000 per DFG (again, raised from £25,000 in recognition of inflation) where necessary, meaning that the maximum that can be awarded under particular circumstances is now £85,000.[42] While this may not be sufficient in every case in which a complex adaptation is required, it recognises the scale of what can be necessary.

Overall funding for DFGs from the UK Government should be increased such that a raised cap does not put undue pressure on local authorities. Without additional funding, local authorities will have to continue diverting funding from other services, at a time when local government as a whole continues to face significant financial pressures. The Local Government Association found in March 2025 that 20% of local authorities were not very or not at all confident that they had sufficient funding to deliver all of their statutory duties in 2025/26, rising to 50% when looking ahead to 2026/27.[43]

The DFG Performance Report published by Foundations shows that local authorities in England averaged six maximum-value DFGs per year.[44] If we assume this number remains constant across 292 councils, and all such grants were increased from the current £30,000 cap to £50,000, the additional cost for England would be around £35 million per year.[45]

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[42] Northern Ireland Housing Executive (2022), Response to FOI_22-23_198.

[43] Local Government Association (2025), No More Sticking Plasters.

[44] Foundations DFG Performance Report 2025

[45] Calculation based on data from the Foundations DFG Performance Report showing an average of six maximum-value DFGs per local authority per year. The total number of councils is drawn from the DFG 2025—26 Allocations Table, and was confirmed as 292 by email from Foundations. The estimated additional annual cost assumes 6 maximum-value grants × 292 councils × £20,000 (difference between the current £30,000 cap and proposed £50,000 cap) = £35.04 million.

Accessible homes have profound mental health and wellbeing benefits for people with disabilities.[46] One study, which included interviews with scores of people who had had large adaptations made to their homes, notes that "the power of major adaptations to transform lives is even greater and more dramatic than that of the smaller adaptations."[47] They were noted to have had positive impacts on many aspects of the interviewees' psychological wellbeing, including their self-respect, ability to take part in family life, and their sense of independence and freedom.[48]

The economic benefits of enabling people with disabilities to safely remain in their homes are also significant: it can reduce falls and other accidents which result in costly hospital care; it can prevent people from needing to move into care settings; and it can allow them to remain in work. Care & Repair Cymru, a charity which promotes safe housing for older people, estimates based on a controlled longitudinal study carried out by Swansea University that **every £1 spent on such adaptations saves the health and social care services £7.50.**[49]

It is more difficult to quantify the economic benefits of large adaptations due to a lack of studies[50], especially those relating specifically to the circumstances of those with MND. However, the Equalities and Human Rights Commission notes that "timely provision of adaptations can result in considerable cost savings, as they help to avoid lengthy stays in hospital, or the need for more intensive housing options such as care homes."[51]

**Adequately resourcing DFGs would be in line with the UK Government's intention, as laid out in its flagship 10 Year Health Plan,**[52] **to move from a policy of treating sickness to one of preventing sickness.**

## Recommendations

The UK Government, the Welsh Government and the Northern Ireland Executive should increase the mandatory DFG cap to at least £50,000. The cap should be reviewed annually and uplifted in line with inflation.

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[46] University of the West of England (2018), External Review, p. 54

[47] Heywood et al (2001), Money Well Spent: the Effectiveness and Value of Housing Adaptations, p. 21.

[48] Heywood et al (2001), Money Well Spent, pp. 17-18

[49] Welsh Government Social Research (2015), A Review of Independent Living Adaptations, p. 104.

[50] University of the West of England (2018), External Review, p. 54

[51] Equality and Human Rights Commission (2018), Housing and Disabled People: Britain's Hidden Crisis, p. 40.

[52] Department of Health and Social Care (2025), Fit for the Future: Ten Year Health Plan for England.

## The apportioning of the DFG budget

In Northern Ireland, funding for DFGs is administered centrally by the Northern Ireland Housing Executive, so there is no need for the budget to be distributed between local authorities. In Wales, meanwhile, local authorities are not provided with DFG-specific budgets but are expected to fund them from their overall budgets.[53]

In England, however, the budget for DFGs is funnelled through the Better Care Fund and then distributed to local authorities using a formula which takes into account the number of claimants of disability-related benefits; the proportion of the population aged 60 or over; and the proportion of the housing stock that is not owned by local authorities.

However, both the External Review and the LUHC Committee have argued that the current distribution formula in England does not allocate funds fairly, based on local need.[54]

This is evidenced by the results of our FOI requests, which show that 44% (87 of 198) of local authorities in England had used 100% or more of their DFG budget allocation in 2023/24. Of these 87, 40 had used more than 100%. Meanwhile, others had used notably smaller amounts: dozens had used between one third and two thirds of their budget.

The External Review recommended that the formula instead be based on "the number of people with a disability, income (from benefits data), tenure split (from [the Department's] data) and regional building costs."

In July 2025, the Government opened a consultation on the way they allocate DFG funding to local authorities in England.[55] The consultation proposes that two new elements be added to the formula. The first is that the prevalence of disabled children be disaggregated from the prevalence of disabled adults, on the basis that children's applications are not means tested and their adaptations are often more expensive. The second is a recognition of the variation in building costs between regions, which is a welcome inclusion of the External Review's recommendation. The Building Costs Index shows regional disparities in the costs of delivering adaptations. Taking this into account will enable more accurate distribution of DFG funding across local authorities.

This consultation is a welcome development and presents an opportunity to ensure that the funding formula better reflects local housing need. More efficient allocation of DFG funding that local authorities can fulfil their statutory duty to provide DFGs wherever the need exists.

### Recommendation

The UK Government must ensure that the new formula for allocating DFG funding enables local authorities in England to provide DFGs in line with local need.

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[53] Welsh Government Local Government and Housing Committee (2025). Welsh Government Draft Budget Scrutiny 2025-26, p. 6.

[54] Levelling Up, Housing and Communities Committee (2024). Disabled People in the Housing Sector, p. 24

[55] Ministry of Housing, Communities and Local Government (2025). Changing the Way Government Allocates Disabled Facilities Grant Funding to Local Authorities in England.

## Calls for a fundamental review of the DFG

In England, successive Governments have committed to reviewing the DFG since 2021, with the most recent commitment made in August 2025. This followed legal action — which the Government settled out of court — which claimed that the failure to increase the DFG limit undermined the purpose of the relevant legislation and discriminated against particular groups of disabled people. The December 2021 White Paper, "People at the Heart of Care: adult social care reform", included the first post-2021 commitment to raise the DFG upper limit. In late 2024, the Government formally agreed to review the cap following legal action.[56] In 2025, through written parliamentary answers, it confirmed both the review of the upper limit and a separate review of the funding allocation method, and by mid-2025 it launched a public consultation aimed at reforming how DFG funds are allocated.[57]

At the time of this report's publication, the Government has confirmed that an internal review of the cap has been has been carried out and they have no plans to publish the review or its findings.

The underlying issues for people with MND in accessing a DFG to meet their needs are complex, as demonstrated in this report. The first step towards addressing these issues would be for each nation to undertake a fundamental review of how the DFG is designed and how successfully it operates within their jurisdiction, and for those reviews to be made publicly available to support transparency and accountability.

### Recommendation

Reviews into the Disabled Facilities Grant should be carried out in Wales and Northern Ireland. The recently completed review in England should be published in full.

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[56] Department of Health and Social Care. People at the Heart of Care: Adult Social Care Reform White Paper, (2021).

[57] Local Government Lawyer, (2025). Government to review upper limit on Disabled Facilities Grant after judicial review settled.

Department for Levelling Up, Housing and Communities, (2025). Changing the Way Government Allocates Disabled Facilities Grant Funding to Local Authorities in England: Consultation.

# Section 3: Building for the future

## The stock and standard of accessible homes

In England, new homes must be built to the M4(1) — or "visitable dwelling" — standard. This is intended to make reasonable provision for people — including wheelchair users — to access and use the building, for example by having access to sanitary facilities on the entrance level. However, the Habinteg Housing Association, which developed these standards, has said that M4(1) homes are "only 'visitable' in the loosest sense" and "not sufficiently accessible for most older and disabled people."[58]

In 2020, the then Government launched a consultation on accessible homes and, almost two years later, agreed to the recommendation that new homes should be built to the higher M4(2) — "accessible and adaptable dwellings" — standard. This would provide, among other things, "room to turn a wheelchair in a hall… a workable bathroom…step-free access to the front door [and] potential for a shower."[59] However, by March 2024, the LUHC Committee was "deeply concerned" that the Government had since "made little progress towards implementing this policy in practice."[60] In its response, in February 2025, the current Government noted that this was a "commitment made by the previous Government" — though it did state that it "intends to set out its policies on the accessibility of new homes in the near future."[61]

By December 2024, the Government already released a revised National Planning Policy Framework (NPPF) — the foundational document for one of the Labour Government's flagship manifesto pledges to build more homes. There is scant mention in the NPPF of accessible homes and, where there is, it references the pre-existing accessibility standards.

As such, it is unclear when the Government will issue updated guidance on the building of accessible homes; whether the commitment to the M4(2) standard will remain; and, if it does, how it would be recommended or required given the recent issuing of the revised NPPF.

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[58] Communities and Local Government Committee (2018). Housing for Older People, p. 35

[59] Ibid., p. 35

[60] Levelling Up, Housing and Communities Committee (2024). Disabled People in the Housing Sector, p. 14

[61] Housing, Communities and Local Government Committee (2025). Disabled People in the Housing Sector — Government Response, p. 5

If M4(2) standards are not implemented, Habinteg has calculated, we may arrive at a point at which only 29% of homes built between 2020 and 2030 will have been built to any recognisably accessible standard.[62]

Raising accessibility standards is also an economically sound measure. M4(2) and, to an even greater extent, M4(3) houses are designed to be "futureproof", able to accommodate subsequent adaptations in a manner which would be difficult to do retrospectively in a home with lower accessibility standards.[63] Meanwhile, the Director of Planning at the Home Builders Federation told the LUHC Committee that "the development industry is relatively relaxed about M4(2) becoming a baseline", while the Vice Chair of Habinteg noted that **building a three-bedroom, semi-detached house to M4(2) rather than M4(1) specification would cost, on average, just £1,400 more.**[64]

The importance of future-proofing homes is exemplified by one respondent to our survey:

> "After discussing what was needed, we all said it was not feasible, mainly because they need to take into account the worst scenario, which is a tip-and-turn wheelchair which needs a 1.5 metre turning area. We are in a two-bed bungalow and, as a lot of internal work would need to be done, there could be unexpected problems. The building was [not able] to accommodate the works that would be required. The builder said that they do find that a lot of properties built from the 1960s onwards are not ideal for conversions of this kind. And newer builds with even smaller rooms and wooden dividing walls etc. cannot be [adapted] at all to accommodate the worst scenario of a tip-and-turn wheelchair."

In Wales, meanwhile, the Government requires all publicly funded developments to be built to the Lifetime Homes Standards,[65] which is considered to be broadly equivalent to England's M4(2) standard.[66] However, there is no published data on the number or proportion of publicly funded developments that meet this requirement. Without transparent monitoring, it is not possible to verify compliance or track delivery over time.

In Northern Ireland, since 1998 all new social housing has had to meet the Lifetime Homes Standard[67], while grant-aided social housing must meet additional accessibility standards.[68]

Neither Wales nor Northern Ireland, though, impose standards on private developments which guarantee genuine accessibility.

## Recommendation

In England, both social and private developments should be required to meet M4(2) specifications, as previously planned. In Wales and Northern Ireland, the Lifetime Homes Standard should be extended to private sector developments.

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[62] Habinteg (2021). Forecast for Accessible Homes 2020. p. 12.

[63] Communities and Local Government Committee (2018). Housing for Older People, p. 36

[64] Ibid., p. 37

[65] Equality and Human Rights Commission (2018). Housing and Disabled People: Britain's Hidden Crisis, p. 27

[66] Habinteg Centre for Accessible Environments, Lifetime Homes.

[67] Equality Commission for Northern Ireland (2019). Equality in Housing and Communities, p. 18.

[68] Northern Ireland Housing Executive (2021). Older People's Housing Strategy 2021 — 2027, p. 27.

In England, the higher M4(3) standard — "wheelchair user dwellings" — is optional. Similarly, in Wales, the Wheelchair Housing Design Standard — which is similar to, though not as prescriptive as, the M4(3) standard — can be used entirely at local authorities' discretion.[69] Consequently, at the end of 2023 only half of England's adopted and draft local authority plans contained any target for M4(3) homes,[70] and Habinteg estimates that only 1.4% of houses built between 2020 and 2030 will have been built to M4(3) standards.[71]

This further reduces the availability of housing suitable for people living with disabilities, and increases the need for costly, time-consuming DFGs. Data from the English Housing Survey shows that around 400,000 wheelchair users in England are living in homes that are neither designed for nor adapted to their needs.[72]

The Executive Director of the Royal Institute of British Architects told the LUHC Committee that "perhaps 10% to 15% [at M4(3) standard] is where we are going to have to get to", with many other stakeholders issuing a call for 10% of all new builds to comply with M4(3).[73]

There is an economic case for improving housing stock. Research by Habinteg and the London School of Economics shows that **the average additional cost of building a home to M4(3) specifications is £22,000, which would be heavily outweighed by the costs saved by the state elsewhere.** Due to reduced social care expenditure, the availability of an M4(3) specification home would save the state £94,000 over the course of 10 years in the case of a working-age wheelchair user, and over £101,000 in their later years.[74]

In recognition of the need for more accessible housing, Northern Ireland's Minister for Communities announced in March 2025 a target for 10% of new-build starts to be wheelchair accessible.[75] England and Wales should follow this socially necessary and economically prudent lead.

## Recommendation

England and Wales should set a target for a minimum of 10% of new builds to be built to the M4(3) standard or equivalent.

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[69] Equality and Human Rights Commission (2018). Housing and Disabled People: Wales's Hidden Crisis, p. 10.

Welsh Government (2021). Mandatory Quality Standards for New Homes, para. 4.22.

Welsh Government (2024). The Welsh Housing Quality Standard 2023, p. 29.

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### Accessible housing registers

It is crucial that local authorities have a comprehensive understanding of the amount of accessible social housing in their areas. Firstly, this allows authorities to track whether they have sufficient accessible housing to meet their population's needs. Secondly, it allows them to identify suitable homes when it is necessary for residents with additional needs to be relocated. Better tracking of accessible social housing would also provide a useful data point when determining how funding for DFGs should be allocated between local authorities (as covered above), and would enable Governments to assess their need for accessible housing at the national level (as discussed below).

The Northern Ireland Housing Executive has an in-house Accessible Housing Register (AHR) for social housing which tracks the amount of accessible housing across Northern Ireland. According to the Housing Executive's 2024 Housing Investment Plans, "to date a total of 18,398 properties have been surveyed and assigned an AHR classification code."[76]

In Wales, despite the Welsh Government encouraging the development of AHRs, responses to Freedom of Information requests to local authorities show that, of the 17 respondents, seven do not keep a register at all, with another two not keeping a register because they do not have any social housing stock.

The picture is similar in England: as of March 2024, just 21% of local authorities kept an AHR.[77]

Despite a recommendation from the LUHC Committee that the Government "require all local authorities to keep a register of accessibility of homes in their own housing stock and require local authorities to keep a detailed record of all accessible social housing within their local authority area,"[78] the current Government stated in February 2025 that it did "not believe that mandating accessible housing registers is the appropriate action to take."[79]

The absence of comprehensive registers has real consequences. In London, for example, the London Assembly's Housing Committee recently warned that **thousands of disabled Londoners are stuck in unsuitable housing because boroughs do not keep adequate records of which homes are accessible.**[80] The Committee concluded that without a systematic register, people in urgent need face long waits, repeated assessments and unnecessary moves, while accessible stock sits empty or is let to households who do not need it. This postcode lottery mirrors the situation across England and Wales, where the lack of accessible housing registers compounds delays and inequities in the DFG system.

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[76] Northern Ireland Housing Executive. Housing Investment Plans.

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Accessible homes must then be ring-fenced for disabled people who need them, with a dedicated pool of emergency accessible housing that can be allocated quickly when someone becomes suddenly unable to live safely in their current property. Without ring-fencing, scarce accessible homes risk being allocated to households without accessibility needs, further reducing availability for those in crisis.

## Recommendation

Local authorities in England and Wales should be required to keep a register of accessible social homes and ring-fence accessible housing stock for disabled residents.

# Conclusion

**This report has presented clear evidence that the current DFG system does not meet the needs of people living with motor neurone disease (MND). The combination of outdated funding caps, an unfair and inconsistently applied means test, and excessive delays for delivering adaptations is leaving many individuals in unsuitable and unsafe living conditions.**

The challenges outlined are not new. Reviews, inquiries and lived experiences have repeatedly highlighted the same structural problems. Despite this, meaningful reform has been slow or absent. The result is a fragmented and inequitable system, where access to timely support depends heavily on geography, local authority discretion, and personal financial circumstances.

Fixing the DFG is not a complex policy challenge; the solutions are known. Raising the funding caps to reflect current costs; removing the perverse and punitive means test that penalises people for working, saving, or drawing on their pension; streamlining application processes; and mandating accessible housing registers are practical steps that can be implemented with immediate impact. These are not optional improvements. They are urgent public health measures that address fundamental flaws in the system and directly impact the physical safety and mental wellbeing of people living with MND.

Above all, the system must guarantee a national fast-track route for those with progressive, terminal conditions. For people who may live only months after diagnosis, delays of months or even weeks can mean adaptations arrive too late to be of benefit. Without fast-tracking, the DFG will remain incapable of serving those most in need.

The benefits of reform extend beyond individuals to wider society, the NHS and social care services. Maintaining good health and wellbeing, reducing hospital admissions, and delaying or avoiding entry into residential care will reduce costs across health and social care systems. A more responsive and fair system will also reduce the administrative burden caused by protracted applications, appeals and discretionary workarounds.

Policymakers now face a clear choice: continue with a system that is failing those with the most urgent needs, or take decisive action to create a DFG process that is fit for purpose. The evidence in this report demands a comprehensive response. Anything less will be a continued disservice to people living with or affected by motor neurone disease. A fairer, faster, and more consistent DFG, with an end to punitive means testing and a clear fast-track process, is not just reform; it is a matter of dignity, safety and justice.

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