



Report on the provision of Housing
Adaptations for people living with
MND in Wales

Executive Summary

What is Motor Neurone Disease (MND)?

MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It can leave people locked in a failing body, unable to move, talk and eventually breathe.

A person's lifetime risk of developing MND is around 1 in 300. Six people per day are diagnosed with MND in the UK and it kills six people per day in the UK, this is just under 2,200 per year.

MND kills a third of people within one year of diagnosis and more than half within two years. It affects up to 5,000 adults in the UK at any one time. It affects people from all backgrounds. It has no cure.

What is Welsh Homes for MND?

Due to the progressive nature of MND, a person's condition will worsen over time. Eventually, people with MND will need specialist equipment to help maintain dignity and independence.

Most homes in Wales are not equipped to deal with the changing needs of people living with MND which is why the housing adaptations process is so important. However, the existing process has failed to adequately meet the needs of people living with MND and left many living in unsafe or inaccessible housing. Some people with MND have died while waiting for alterations to be made and the pandemic has worsened the situation in many cases.

[Welsh Homes for MND](#) hopes to see a streamlined adaptations process that works much better and faster for people with MND.

Our Findings

Our research has found the current adaptations process is not fit for purpose.

It is:

- **Lengthy**; the process from application to installation is far too long for people with rapidly progressing diseases like MND.
- **Financially unfair**; means-testing for adaptations further slows down the process but has also had a detrimental impact on the lives of people with MND and their families.
- **A postcode lottery**; different councils have varying definitions and processes leading to inequitable service provision across Wales.
- **Complex**; with service provision being so varied, combined with the fact approximately 70 organisations are delivering adaptations in Wales it is often difficult for people with MND to access accurate and up to date information.

At present, the adaptations process is complex, unjust, and inequitable; and most importantly, it is leaving people with MND in unsafe and inaccessible homes.

Our Recommendations

1. Apply a **no means tested, fast-track** process of housing adaptations for people living with MND
2. **Monitor and report on good practice and timely installation** of adaptations as set out in the Welsh Government's Housing Adaptations Service Standards

"I worry all day about the obstacles in front of me. How am I going to get in the shower? How am I going to get into the toilet? It is so tiring. Things are taking such a long time. We were under the impression that the adaptations would be installed much quicker."

Carol and Ken

Table of Contents

<u>Executive Summary</u>	2
<u>What is Motor Neurone Disease (MND)?</u>	4
<u>MND Association Key Asks</u>	4
<u>Housing Adaptations are Vital</u>	4
<u>The Current Adaptations Process</u>	5
<u>Challenges for People Living with MND</u>	6
<u>Means Testing</u>	7
<u>Fast Track Process</u>	9
<u>Models of Good Practice</u>	11
<u>Additional Suggestions</u>	13
<u>Conclusion</u>	13

What is Motor Neurone Disease (MND)?

MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, hearing and touch.

It can leave people locked in a failing body, unable to move, talk and eventually breathe. Over 80% of people with MND will have communication difficulties, for most this means a complete loss of voice.

Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.

A person's lifetime risk of developing MND is around 1 in 300. Six people per day are diagnosed with MND in the UK and it kills six people per day in the UK, this is just under 2,200 per year.

MND kills a third of people within one year of diagnosis and more than half within two years. It affects up to 5,000 adults in the UK at any one time.

It affects people from all backgrounds. It has no cure.

[More information is available here.](#)

Housing Adaptations are Vital

Housing adaptations are essential to ensuring people with MND can live safely, independently, and with dignity. They support the provision of care close to home, reduce pressures on frontline services such as health and social care, and enhance well-being for the individual and their families.

According to the recent Welsh Government Spending Analysis on Housing Adaptations, service users and carers reported that even small adaptations can have a positive impact on their quality of life. Feedback from service users suggests that, once completed, adaptations lead to increased or regained independence, with several respondents now able to do things independently for which they would have previously required carer assistance.

Adaptations make those who use them feel less restricted in their home. Respondents who had rails and ramps placed around their homes can now use them more fully and report increased confidence in moving around their homes.

MND Association Key Asks

1. To remedy the complex, unjust and inequitable system of access to housing adaptations in Wales, we are asking Senedd Members to put the case forward to the Minister to: **Apply a no means tested, fast-track process of housing adaptations for people living with MND**
2. **Monitor and report on good practice and timely installation of adaptations as set out in the Welsh Government's Housing Adaptations Service Standards**

Pat and Graham's experience:

Pat is 67 and has MND and lives with her husband, Graham.

"I'm dependent on my husband because it's getting hard. I have a brace on my leg and it's getting harder and harder to put my shoe on, especially since the last couple of falls."

Adaptations have been vital to both Pat and Graham's wellbeing and independence. Graham told us that:

"Things were tough before we had the shower room installed. The house wasn't suitable for Pat to have a shower and so I was lifting her in a potentially problematic way just so that she could get clean. The toilet was narrow with the sink in the doorway and the door was too tight to get a wheelchair in. If Pat wasn't using the commode chair, I would have to lift Pat onto the toilet."

"Since we've had the shower room installed, it's made a complete difference to the way we use the bathroom. It's got an extra wide door and



loads of space because they've opened up a different area. With the commode chair, the seat just slides over the toilet and the shower is in the same space so Pat just stays on the same shower chair and I manoeuvre her under the shower and I can leave her to it, whereas before I had to help her as there wasn't enough space. Pat now has the dignity of showering herself, which is the most important thing."

“Between May 2019 and February 2020 Ian was having to have bed baths because there was no way of him showering. From October 2020 until his death in February 2021, he lived and slept in the same chair, day and night, that was the only way he could be comfortable and happy.”

Julie and Ian

The Current Adaptations Process

The provision of housing adaptations reflects the principles set out in the Well-being of Future Generations (Wales) Act 2015 and Social Services and Well-being (Wales) Act 2014, and objectives set out in Prosperity for All and A Healthier Wales.

In April 2019 the Welsh Government published its [Housing Adaptations Service Standards document](#). The aim of the standards was to set out the level of services for the delivery and installation of a housing adaptation that service users can expect, regardless of their geographic location and tenure, can expect.

The service standards were intended to ensure service providers deliver housing adaptations in a consistent manner and to inform service users of the level of service they can expect when seeking support for a housing adaptation.

Adaptations are grouped into 3 categories:

- Small e.g. installation of grab rails or stair rails;
- Medium e.g. walk-in showers, stair lifts, ramps; and
- Large e.g. major structural changes to a property, including extensions.

However, according to the [2021 Spending Analysis](#) there appears to be a variation in the way that different sized adaptations are defined across Wales. This means that two people receiving the same adaptation but in different areas can be subject to different processes.

The Analysis did highlight that the above definitions may be particularly helpful in ensuring service users receive a uniform service regardless of their location, if adopted universally across Wales.

The [2019 Housing Adaptations Service Standards document](#) also states that performance monitoring data

will be submitted to the Welsh Government using the data collection methodology for ‘Housing Adaptations Data Monitoring’ which will help evidence progress on delivering the service standards. The data collected through this process will be published on an annual basis. However, no data has yet been forthcoming.

In the [Royal College of Occupational Therapists’ Report “Adaptations without delay”](#) they conducted a review of the current practice and identified two key findings:

- Current systems for delivering adaptations need to provide person-centred outcomes through a more integrated and collaborative approach to the assessment, design and installation of adaptations; and
- In terms of demand for adaptations, the most common are showers, stairlifts and ramps, often in situations that are simple and straightforward.

Challenges for People Living with MND

Many people living with MND are trapped in inaccessible homes because they cannot afford or cannot access support for the necessary housing adaptations. Some patients have died while waiting for alterations to be made, with the pandemic likely making the situation worse, robbing loved ones of valuable remaining time together.

The current funding system for providing housing adaptations in Wales is complex. This is a reflection of the evolution of legislation, the variety of funding regimes over a long period of time, and the involvement of multiple stakeholders in the care and support arrangements of disabled and older people. It is estimated that there are approximately 70 organisations delivering adaptations in Wales, spending nearly £60 million and assisting over 32,000 people. In addition, these figures do not capture the housing adaptations which are self-funded by individuals across Wales.

It is worth noting that these issues were raised 16 years ago in the [Jones Review of Housing Adaptations](#) (2005), including disabled facilities grants, in which the legislation around the Disabled Facilities Grant (DFG) and the administrative processes and systems arising from it was described as “very complicated”.

The range of different organisations providing access to adaptations further complicates the system and makes it difficult to implement and measure achievement against standards.

The current system for allocating funding is complex and inequitable. As will become clear in this report, the Welsh system of housing adaptations is a postcode lottery.

Means Testing

Overview

In March 2021, the then Minister for Housing and Local Government, Julie James MS, made a statement regarding housing adaptations and means testing:

“We know that reducing barriers so disabled people can maintain their independence, safety and good health allows them to continue to live at home with dignity, and it also reduces pressures on our health and social care services. From April 2021 it will be simpler for disabled people to get help with small and medium sized adaptations to their homes as we take measures to remove the means test from small and medium Disabled Facilities Grants (DFG).”

Responding to [a question](#) raised by Mabon ap Gwynfor MS in July 2021 regarding meeting the housing adaptation needs of people living with MND, the now Minister for Climate Change, Julie James MS, stated that:

“...she has increased support substantially to local authorities to ensure the means test is no longer applied to small and medium Disabled Facilities Grants (DFGs) and that all providers also now work to the same service standards which include consistent timescale to complete adaptations.”

We have worryingly discovered that some local authorities are relying on a strict interpretation of the statement made by the Minister in March in which she states that local authorities “can” rely on powers under the Regulatory Reform Order 2002 not that they “must” do so.



“Shame the country isn’t united on this, housing adaptations, all councils have different policies, and they should all be signing from the same hymn sheet”

Ces

From our advocacy work on behalf of those applying for adaptations it appears as though some local authorities will not disregard means testing until there is a legal obligation to do so.

Richard's experience:

Richard is 57 and from the Vale of Glamorgan. He has worked in agriculture and aviation all his life. He was diagnosed with MND in 2018 and uses a wheelchair to get around.

Richard has got personal experience of dealing with the financial impact of housing adaptations.

"One of the things I've struggled with is that I've actually had to pay for everything myself because when they did a financial assessment, social services and the local authority said anything in the house would have to be more than £152,000 before they'd give me a penny towards it. I've spent about £30,000 on trying to stay in this house. I've just been fortunate that I had that money because I worked hard all my life. That was my rainy-day money and I've had to use my pension for bits of it."

"The adaptations I needed have allowed me to stay in my own home and remain independent"

"I don't understand why I wasn't eligible for local authority support for housing adaptations, I've worked hard all my life to have a nice house and the value of that house was taken into account even though we've still got a big mortgage on it and I'm not earning a fortune and my wife doesn't earn that much."



Should Richard need any further adaptation, he will find it very difficult to afford the work.

Our Research



During May 2021 the MND Association sent Freedom of Information (FOI) requests relating to housing adaptation to all local councils in Wales. Out of 22 Councils, we received responses from 19.

10 of the 19 councils stated that they do not waiver means testing for DFGs and based on information we have received from people affected by MND, in addition to the FOIs, - which means that most councils are still applying a mean test.

8 councils stated that they do waiver the means testing under the following circumstances:

- For adaptations costing less than £800
- For adaptations costing less than £1,000
- For adaptations costing less than £5,000
- For adaptations costing less than £10,000
- Where the individual has a means tested benefit

Upon further inspection, it appears that on housing adaptations many councils' websites are unclear, confusing and limited in the information they provide. This makes them inaccessible to those who are lacking computer literacy.

While Swansea and Wrexham Councils' websites can be described as exemplars in the way they have clear, accessible, and transparent webpages explaining their processes, the general picture is that most are unclear on eligibility, with adaptation provision being distinctly inconsistent across Wales. Examples of disparity range from councils where DFG is means tested to Caerphilly Council where service users are actively encouraged to purchase the adaptations themselves.

There appears to be a distinct lack of understanding of the means testing waiver among Local Authority Officers. As the guidance has only recently changed this perhaps is to be expected, however, knowledge of the change in guidance should be reflected in the answers provided to the FOIs. Only one local authority, Bridgend County Borough Council, acknowledged that the Welsh Government were proposing changes to means testing.

It is notable that some local authorities waive fees but do so only up to a certain amount or do so as a result of external funding. There is evidentially no consistency across local authorities and a lack of widespread knowledge of alternative funding opportunities.

John and Yvonne's experience:

John & Yvonne live in Carmarthenshire. Yvonne was diagnosed with MND in 2012.

Just over two years ago it became apparent that to remain in their own home John and Yvonne would need a hoist in the bathroom, a hoist in the bedroom, and a specialist toilet. These adaptations would allow Yvonne to maintain her dignity and independence and would also allow John to remain as her sole carer.

"The Occupational therapist made the assessment and recommendations, I applied to Carmarthenshire County Council for a Disabled Facilities Grant.

It was a long process, lots of forms to fill in about our financial situation. We felt that we were not a priority and they clearly did not understand MND. I had to chase them for a response as they were taking so long to be told that we would have to pay the first £14,000. Their calculations were based on my income only and did not take into account mandatory monthly expenditure such as our mortgage payment, life insurance premiums, utility costs, community charges etc.

The amount calculated as my contribution was not only greater than the costs that would be incurred to make the necessary improvements but



was also not affordable, as it exceeded my limited amount of savings. It was therefore impossible for me to proceed on this basis."

The cost of the adaptations amounted to £11,000.

"We didn't have that sort of money to spare, this caused us to be very worried and concerned about the future. Because I had previously served in the Armed Forces a family friend suggested I apply to the Armed Forces Benevolent Fund (SSAFA), which we did, they were quick in their response. We needed £11,000, we received a total of £10,000 from SSAFA and MND Association. What will happen if we need further adaptations we don't know."

Fast Track Process

Overview

In 2018, the Wales Audit Office and the then [National Assembly for Wales Public Accounts Committee](#) published reports suggesting that national service standards would help overcome some of the variations and ensure disabled and older people receive the same standard of service irrespective of where they live, who their landlord is and whether they own their own home. However, it is unclear that they provide a measurable framework for the delivery of adaptations given the significant discrepancies between Local Authority service standards.

Despite welcoming the introduction of the Welsh Government's Service Standards, [the 2021 Welsh Government Spending Review](#) highlights the way in which the time taken to complete an adaptations process is measured differs between areas, leading to markedly varied waiting times. The most common variation is between starting points, with some providers 'starting the clock' at first enquiry (which is, in fact, in line with Welsh Government guidance) and others only doing so when the OT recommendation is made. In doing the latter, the aforementioned OT delays are masked, and delivery times look more impressive than they are in reality.

OTs themselves have noted delays caused by some housing associations querying the need for adaptation and often delaying or refusing permission, as well as growing concerns that the length of time taken by delivery organisations to process applications is rising, often because of financial pressures and staffing reductions. Overall, their experience is that local authorities have established more effective systems and processes to deliver adaptations than those used by most housing associations

For example, improvements in average waiting times have been seen where housing departments have their own OTs. However, only a small number of local authorities have developed integrated approaches to housing adaptations, drawing together grants, building surveyors and OTs into single teams.

Data collection and reporting around the effectiveness and efficiency of housing adaptations in Wales has historically been poor, resulting in an inability to draw comparisons between funding streams, understand variances in provision, scrutinise performance and examine impacts on service users.

The [2018 report of the Public Accounts Committee](#) also notes that despite the various sources of funding for housing adaptations, there is only a small range of national publicly reported performance indicators. The Committee

was also concerned that while discussions have been made on the merits of improved impact evaluation, no action has occurred on the part of Welsh Government to take this forward.

The Welsh Government's ENABLE programme brought together a number of programmes that were already in operation for delivering housing adaptations. These have largely

continued as before but ENABLE was designed to simplify them under one 'brand'. ENABLE is also a specific grant to local authorities to deliver small and medium adaptations more quickly and flexibly without need for recourse to DFG processes. It was designed to introduce more equitable standards and waiting times based on the level of adaptation rather than the grant needed. However, service standard discrepancies remain.

Consistency is key to future improvement. The adaptations process must be dependable and measurable across geographical area and tenure so that all recipients of adaptation services can expect similar levels of service.

Pat and Graham's experience:

"We've also had a stairlift and a ramp installed. It's all taken at least six months – eight months for the shower room – with an illness that never stands still".

"The thing with MND is that once your legs go, they're gone. It's not a fall, it's a collapse. If the ramp had been fitted earlier, the benefits would have been far greater. We would have been able to go out a lot more as Pat was stronger and a bit more mobile. But now that it's been fitted so much later on in the illness, the benefits are so much smaller. The biggest sadness for me is that in those six months where we waited, we could have done a lot more things together. We missed out on an awful lot."

Our Research



As part of our research into housing adaptation provision by local councils in Wales we also asked if they have a fast track process and, if so, what the eligibility criteria is.

From the FOI requests we made to local authorities we discovered that 14 out of the 19 have a fast-track system, although there is no consistency of eligibility criteria.

- 1 Local Authority informed us that they fast-track to prevent delayed transfer of care
- 5 Local Authorities fast-track applications for palliative care patients

- 5 Local Authorities fast-track palliative care patients to support hospital discharge
- 3 Local Authorities did so on the basis of priority set by Occupational Therapists.

5 Local Authorities informed us that they have no fast-track application system.

Due to the rapid and progressive nature of MND, fast track access to adaptations is key to ensuring people with MND can make the most of the time they have left.

Kathy and Tony's experience:

Kathy is 70 and lives in Caldicot with her husband Tony who has MND.

"The OT put in the application for a Disabled Facilities Grant (DFG) in November 2020, we had a phone call in the summer of 2021 to say that the work will start in August 2021".

"During the 10 months we have been waiting, Tony's arms and neck have got much worse. I shower Tony upstairs and its easier for me to get in with him. We've got mats down but I worry he's going to slip and there is no way that I'd be able to pick him up".

"I know how quick MND changes and so there have been times when I've thought, "Oh gosh, I wish they'd hurry up." The uncertainty of not knowing what was going to happen next, when I'd need to start getting things ready for builders has caused stress. When you don't sleep at night, this sort of stuff goes through your mind. You seem to be in limbo."



Models of Good Practice

In the 2021 Spending Review, reference was given to process-related good practice. The review highlighted the integration of teams and the use of properly recruited, trained and supervised trusted assessors for minor adaptations. This resulted in quicker, more aligned and streamlined processes. The review also mentioned that improvements have been made by ensuring procurement takes place through trusted contractors or framework agreements.

The key characteristic of a good service is that it is consistent across areas and tenures and, as a result, is one that ensures all service users receive similar levels of service.

A good service is one emphasises co-production by involving those in receipt of it at every step. This includes the initial conversations establishing need and desired outcomes to involvement in the design and implementation of the adaptation. This is buttressed by good communication, which helps those in receipt of adaptations better understand the length of time taken to install them.

The following local authority case studies are examples of good practice that we would like to see replicated across Wales.

Conwy Council

Occupational Therapists (OT) based in the grants team in Conwy pick up all palliative care referrals immediately. Referrals do not simply go on the waiting list; they are responded to within 2 to 3 days. When the OT is off work the duty OTs in Social Services will pick up the referrals ensuring there is always an immediate response. Their typical response as is follows:

Referrals to the Conwy Home Improvements Team are made via the Community OT. Contact is then made within 2 days and a home visit appointment is usually made within a week

The first appointment is sometimes undertaken jointly with the technical surveyor where possible but where this is not the surveyor can maintain a quick turnaround following their assessment.

Subsequently a technical surveyor can complete a design within a week and will then allocate it to contractors. The surveyor knows the workload of contractors and so will allocate typically to the cheapest - or second cheapest based on capacity to respond quickly.

Contractors typically come back within 2 weeks with pricing and a ramp installation can take 2 to 3 weeks and a wet room takes about 2 months.

Caerphilly County Borough Council

Prioritisation for allocation of assessment within Social Services is related to those in greatest need or at greatest risk.

There are 3 priorities:

Priority 1

This includes cases where intervention is essential to facilitate discharge from hospital and/or where clients have complex manual handling problems presenting significant risk to client and/or carers. This also includes clients with a terminal illness and very limited prognosis. The need to intervene quickly is essential to enable someone to remain/return to the community.

Priority 2

This includes clients with rapidly deteriorating neurological conditions, with a series of complex problems, where there is moderate risk to independence and enabling somebody to remain in the community.

Priority 3

This includes clients who have problems with activities of daily living where there is a threat to independence, but risk is manageable. These requests are dealt with in date order to ensure an equitable service to all residents of the borough.

DFGs are processed on a strict date order waiting list.

However, there are some exceptional circumstances when a recommendation can be accepted as a priority from Social Services. The criteria are as follows:

1. Hospital Discharge where intervention is essential to facilitate discharge and to prevent delayed transfers of care.
2. Terminal illness
3. Manual handling issues with significant risk to client and/or carer.
4. Imminent house renovation or refurbishment which would affect the adaptation work
5. Where a care package cannot be introduced until minor adaptations have been affected.

Additional Suggestions

The 2021 Spending Review raised a suggestion made in one of its stakeholder workshops that Welsh Government Service Standards could break expected timeframes down by adaptation size and then break down the timeframes for medium and large adaptations by the time it should take to see an OT and completion time thereafter. The Review mentions that some stakeholders considered it vital to measure the time it takes for an OT assessment to take

place as this can vary significantly across Wales. However, some argued this discrepancy was as a consequence of some Local Authorities experiencing more acute OT shortages than others.

Maximum effectiveness can only be ensured with alignment to Welsh Government Service Standards and guaranteed consistency across Wales.

Conclusion

Housing Adaptations play a vital role in ensuring the wellbeing and independence of people living with MND. However, it is clear that the system of means testing for small and medium works is still in use across many local authorities, despite Ministerial guidance to the contrary.

There appears to be lack of understanding across many local authority Officers as to the rules and guidelines which could be applied as well as alternative funding opportunities that are available.

This has led to many people living with MND spending significant amounts of their own money or savings in instances where they need not have done so. Many people who have wrongly paid for small and medium adaptations will now be unable to afford large adaptations.

Similarly, there is no consistency for the fast-tracking of applications across Welsh Local Authorities. While fast-tracking does occur in 14 of Wales' 22 Local Authorities, the criteria for such an occurrence is not uniformly applied resulting in a postcode lottery for services. Throughout this report the personal stories and experiences that have been highlighted represent a geographical spread across the whole of Wales.

As previously stated, MND kills a third of people within one year and more than half within two years. The delays experienced in receiving housing adaptations are robbing people of precious time with their loved ones as MND impacts upon their independence.

Despite these concerns, examples of good practice can be found in a number of local authorities and every effort should be made to replicate these across Wales.

Other elements of good practice have been identified, including integration of teams and the use of properly recruited, trained and supervised trusted assessors for minor adaptations as well as procurement arrangements

and co-construction with those in receipt of the adaptations.

People are not able to apply for adaptations until they need them. When people living with MND get to this stage they need adaptations quickly as MND is a rapid progressive disease. However, the system doesn't allow for this, the pace of progress being slow. Very often, by the time adaptations are installed, the disease has further progressed to another level in which approved adaptation needs have been superseded by more complex ones.

"Pete was diagnosed with MND in 2020. He had been stuck in the same room since losing the use of his legs in August 2020. Sadly Pete died in September 2021 while still waiting for the adaptations to be installed."

Selina

"I think there should be a system where when you're diagnosed with MND, the consultant informs the local authority. It's inevitable that people with MND are going to get worse. It's not a case of if, but when. People's needs for support are going to increase and it's no good waiting until they're absolutely desperate. If there was a way to join up health and social care from the point of diagnosis, I think it would save an awful lot of time."

Grahame



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