



ACT TO ADAPT

Access to home adaptations for
people with motor neurone disease

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Motor neurone disease (MND)

- A progressive and terminal neurological disease
- Affects the functioning of motor neurones that enable movement, causing progressive weakness and ultimately paralysis in different parts of the body
- Highly variable rates of progression
- 50% of people with MND die within 2 years of diagnosis
- A small proportion may live much longer
- No cure, and limited treatment options
- No possibility of recovery or remission

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Policy background

“Everyone has the right to live in a safe and suitable home. For people living with MND, this means an accessible home that enables them to maintain their independence, dignity and quality of life as the disease progresses”



Survey data: challenges finding an accessible home

We surveyed 387 people living with MND. Survey respondents identified:

- Cost of adaptations (96%)
- Lack of financial help (39%)
- Length of time taken (25%)
- Availability of accessible homes (21%)
- Lack of support locally (23%)
- Lack of information (22%)



Engagement findings- DFGs

Issues identified:

- Lengthy waiting times- speed of MND progression not reflected in urgency of delivery
- DFG means testing seen as unfair: excludes outgoings required to live with and manage the condition. Savings threshold of £6000 seen as too low.
- Maximum DFG grant inadequate for major adaptations
- Shortage of existing accessible homes and lack of accessible/adaptable home registers
- Not knowing where to go for support and information
- Emotional impact of adapting/moving home while coping with the impacts of the condition.

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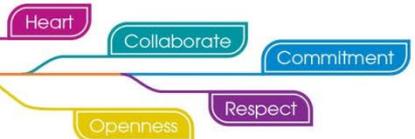
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DFG delivery- timescales

- 26% of local authorities in England do not process all DFG applications within nationally specified timeframes
- 42% of authorities did not pay all approved DFGs within one year
- Seven authorities in England reported that they funded projects within one year in 50% or less of all cases
- In Wales, 5 of 18 authorities did not process 100% of applications within six months
- Six authorities in Wales failed to make payments within one year in all cases, and three of these in less than 95% of cases.



DFG delivery- information

- Only 56 authorities in England and 4 in Wales held condition-specific data on MND in relation to home adaptations
- The rest stated that they did not hold the data, or that it would cost too much to extract. Several indicated that this was only held at OT or Social Services level, implying that in two-tier authorities this data is not usually passed on.
- Widespread lack of integration of home adaptations teams with wider health and social care systems
- Noticeable lack of information about the DFG process, or other accessible home options, on council websites across England and Wales.

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Recommendations: local government

Local authorities with responsibility for DFGs should:

- Put in place a transparent, fast-track, non-means tested process for adaptations under £5,000.
- Introduce a fast-track process for people diagnosed with terminal illness
- Review compliance with target timescales to ensure these are met in 100% of cases.
- Develop a policy using powers under the RRO 2002 to introduce discretionary support, which could include:
 - ‘Lean’ or no means tests for low-cost high impact adaptations
 - Increasing the cap on maximum grant
 - Removing the means test for common low-cost adaptations such as stairlifts

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Recommendations: local government

Local authorities with responsibility for DFGs should:

- Provide a single point of contact for disabled people to access information and support
- Build on good practice examples to integrate services, develop data sharing systems and introduce effective multi-disciplinary case management for home adaptations
- Improve their online information about DFGs, including publishing their assessment criteria, processes and other support options in accessible formats.
- Record the primary disability or health condition of DFG applicants in order to enable better evaluation and monitoring of how well they meet the needs of their local population

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DFG delivery- best practice

- **Eastbourne Borough Council and Lewes District Council** has increased the maximum DFG limit to £50,000, and removed the means test for works costing below £8,000. There is no means test for people leaving hospital or receiving palliative care
- Relocation expenses of up to £10,000 are available where moving is a preferable option.
- There is a non-means tested Hospital Discharge Grant of up to £3,500 for interventions including cleaning, decluttering and repairs

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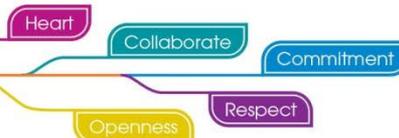
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DFG delivery- best practice

- **Sunderland City Council** used discretionary powers to make grants available without a means test up to the value of £8,000, where the applicant is receiving palliative care.
- Works costing less than £8,000 in other cases are subject to a 'lean' means test so that anyone with savings of less than £20,000 will be passported through.
- Relocation grants are available for tenants up to the value of £1,000 where this is a more cost-effective option.
- Loans available for qualifying work above the £30,000 limit, and for relocation where this is a more practical option



Disabled Facilities Grant (DFG) delivery: Guidance for local authorities in England

Motor neurone disease

Housing assistance polices can be used to respond to rapidly progressing and highly debilitating conditions such as Motor Neurone Disease (MND). Often people with MND want to continue to work during the early stages of the disease, which can make them ineligible for a DFG through means testing. But by the time they can no longer work an un-adapted home can make day to day activities very difficult to manage.

Some local authorities include provisions within their policy, such as:

- a fast-track process with no means testing for works up to £5,000.
- ignoring the earnings of the person with MND in the means test where larger scale works are assessed as being necessary and appropriate.

These provisions apply to a relatively small number of people but can have a significant impact upon their lives at a time of major upheaval.

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Local engagement 2022

- After conversations with Dartford they have committed to introducing a fast track process & free home adaptations up to £15,000 for private homeowners living with MND.
- In Sefton, Cabinet members considered a new charging policy and have approved the recommendation to waive charges for DFGs below £10,000. Council officers to arrange for the changes to charging to be published as soon as possible.
- In Wirral a discretionary grant scheme has been introduced where a financial assessment can be waived in certain circumstances and cases can be processed more quickly.

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