



ACT TO ADAPT

Access to home adaptations for
people with motor neurone disease

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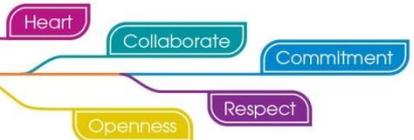
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Policy background

“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”





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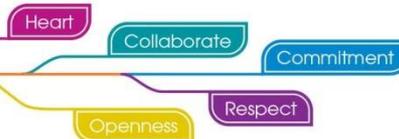
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Survey data: challenges finding an accessible home

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%)



Disabled Facilities Grants

- Means tested grant towards the cost of adapting a home
- Administered by local authorities in England and Wales, and NI Housing Executive
- Funded through annual national allocation in England
- Mandatory grant under the Housing Grants, Construction and Regeneration Act 1996
- Maximum mandatory grant £30,000 in England, £36,000 in Wales and £25,000 in Northern Ireland
- Authorities in England and Wales have discretionary powers to introduce extra or alternative support for home adaptations.

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Engagement findings

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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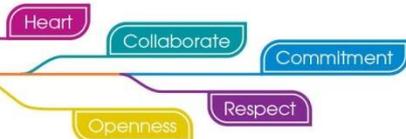
DFG delivery- timescales

- The Housing Grants, Construction and Regeneration Act 1996 contains mandatory time limits for stages of the DFG process
- Decisions to accept or reject DFG applications must be made within six months of receiving the application
- Following a positive decision, the work must be carried out within twelve months
- However, councils can defer payments by twelve months, in turn deferring the work
- These timelines are clearly unsuitable for people living with MND, a third of whom die within twelve months of diagnosis



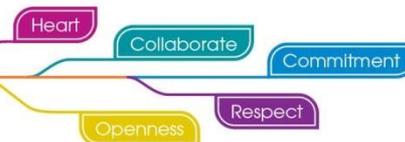
DFG delivery- timescales

- 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.



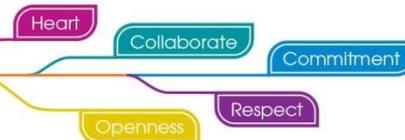
Spending on DFGs

- Significant local variation across the country
- English councils spent an average of 82% of their DFG allocation, but with wide variations between areas
- 60% of councils in England did not spend their full DFG allocation. 30% of councils spent 100% of their DFG allocation, and 10% spent more than their allocation.
- 14 of 22 Welsh councils spent over 90% of their allocation.
- The funding allocation process for local authorities is not transparent



Closed DFG cases

Reasons for closing cases	# of councils citing reason
Reason not recorded/data not held	187
Means test failed/contribution too high	73
Applicant died	41
Applicant moved home or left area	39
Applicant withdrawn	30



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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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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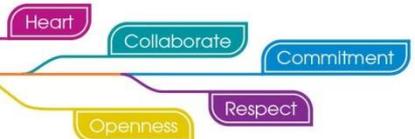
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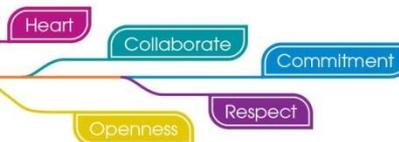
DFG delivery- best practice

- **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



DFG delivery- best practice

- **Warwickshire** Home Environment Assessment and Response Team (HEART) covering together the six district councils in Warwickshire.
- A review of fragmented services across district councils showed it was a 220-step process where 35% of people dropped out along the way
- Piloted an integrated service involving staff from housing, social care, strategic commissioning, integrated care and public health
- Officers are trained in skills of caseworkers, occupational therapy assistants and grant officers to provide a single point of contact and a simplified system for service users.
- As of 2018, the customer journey had reduced to 22 steps and the drop-out rate to 3%.



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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Recommendations: national government

- National governments must maintain a clear commitment to ongoing central funding for DFGs when current allocations end. This must continue to rise to reflect demand and demographic change
- National governments should review the mandatory means test to address key identified problems including:
 - The low savings threshold
 - Account not taken of real outgoings, including housing cost and the extra costs of disability
- Implement the Equality and Human Rights Commission's recommendation to require all new housing to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.

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