

Housing Adaptations

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If you have Multiple System Atrophy (MSA) it is likely that, at some point, you will need to consider making changes to your home. These changes will hopefully enable you to continue living there. Good planning will help ensure that the changes made will continue to meet your needs as the MSA progresses.

Key Points to Know

The advice of an Occupational Therapist (OT) should always be requested. The MSA Trust has a Guide for OT's working with people with MSA.

Help may be available with the cost of adaptations, or with the help of moving to a more suitable property. It is essential to ask about financial help before incurring any costs or instructing architects and builders.

Because adapting your home can be a lengthy process it is important to start thinking about it at an early stage – well before the need arises. The grants application process, applying for planning permission (if needed) and choosing and organising builders will all take time.

In England, Wales and Northern Ireland you may be eligible for a means tested Disabled Facilities Grant (known as a DFG). Different systems operate in Scotland and the Republic of Ireland and there are minor differences between the DFG systems in England, Wales and Northern Ireland.

VAT relief may be available on building works, See for more information:

<https://www.gov.uk/financial-help-disabled/vat-relief> or call the HMRC on 0300 123 1073.

This factsheet aims to explain how to obtain the help you may need when planning adaptations to your home.

What Might I Need?

MSA affects balance and co-ordination which can make moving around difficult. Eventually a person with MSA may be unable to walk, stand or transfer from standing to a chair or bed.

MSA can also affect arm function, continence, vision, speech and swallowing. Each of these difficulties, to a greater or lesser extent, needs consideration when thinking about housing needs.

Although MSA is a variable condition and affects everyone differently, many people will need to consider the following points. These are just examples and what you require will depend upon your home, your family, how you organise your life and how your MSA affects you. An OT will assess your needs in conjunction with you, your family and other professionals.

- Access in and out of the property: Pathways into your home need to be wide enough to accommodate a wheelchair and should not be shingle or gravel as this is hard to push a wheelchair over – or even to walk on. Access needs to be step free, so many properties will need to have a ramp installed. If you have a vehicle, thought needs to be given to how you will get to the vehicle and in, and out of it from where it is parked.
- Access around the property: The property needs to be wheelchair accessible with spacious doorways and passageways. It should be step-free between rooms.
- Single floor living: For most people with MSA single floor living is the easiest option. Stair lifts are not usually a good option because of the difficulties of transferring on and off them. It can also be difficult to remain balanced and safe whilst on a moving stair lift. Stair lifts are not recommended for people who experience sudden drops in blood pressure. Family carers need to be very careful when assisting people to transfer. What a family may consider safe may not be judged so by staff at professional care agencies. This could mean that professional carers are not able to assist a person to use the stair lift so the person is unable to access a different floor of their home. A wheelchair accessible through-floor lift (one that goes through the ceiling to the floor above) may be a viable option. This is if your home is spacious enough to accommodate the lift and the upstairs rooms are large enough to move around in a wheelchair. When a lift is not suitable, you may wish to consider staying on the ground floor in your home. This often requires installation of a bathroom and bedroom, depending on space available. Extensions are costly adaptations, and it is important to note that a full grant is usually not enough to cover the total cost.
- Bathroom: Decisions need to be made about whether a bath or shower is preferred and how you will access this. A wet room can be a good option. Showers should be level access. Seats and grab rails may be needed. There needs to be room for a carer to assist you, and for any equipment that you may need, such as a shower chair. Bathroom doors should open outwards so you are not stuck if you fall.
- Kitchen: Think about how much you will use the kitchen. Might surfaces need to be lowered, taps changed, space made for sitting down? Will meals be eaten in the kitchen?

- **Bedroom:** In the later stages of MSA some people require a profiling, adjustable bed and this requires more space than a regular bed. There may need to be room for a hoist for transfers from bed to commode or wheelchair. A free-standing portable hoist, or a gantry hoist (floor-standing frame) do not require any major adaptations to your home. They should be provided through your OT. However, flooring may need to be considered for ease of movement of a portable hoist. A ceiling track hoist is a fixed piece of equipment that uses a track in the ceiling to allow easier movement between areas. This involves less manual handling. Your OT can advise which hoist system would be the most suitable for your needs.
- **Lounge:** Many people with MSA find a riser recliner arm chair comfortable. There needs to be room to facilitate transfers in and out of chairs.
- **General:** Good flooring, lighting, heating and an adequate supply and positioning of electrical sockets are also important. Extra storage may be needed for equipment and some electrical equipment will need charging. Space may be needed for a carer to sleep and/or for your computer or communication aid (if you use one) to be set up.

Considering these needs can be daunting but it is the role of the Occupational Therapist to assist with appropriate planning. You can refer yourself to your local Social Services Department for Occupational Therapy support. Alternatively, do contact us and we can support you in making this referral.

Housing adaptations can take months to be approved and completed, and can be very disruptive. The impact of this on the person living with MSA and family should be considered. Often equipment will be provided first and these can be really useful in the earlier stages of MSA and also while you are waiting for the installation of a major adaptation. Equipment is often loaned free of charge (for example, commodes, shower seats and profiling beds) and minor work (for example, the fitting of grab rails) is also often free. However, it is important to consider the long term and changing needs of someone living with MSA. Being able to voice your wishes and contribute to the choices that need to be made is also very important. Therefore, it is recommended to discuss possible equipment provision and adaptations with your Occupational Therapist as early as possible.

Adaptations - England, Wales and Northern Ireland

Disabled Facilities Grants (known as DFG's) are available to some people who need to adapt their home. DFG's are available to owner occupiers, landlords and to people who live in private rented accommodation. If you live in a property owned by the council or by a Housing Association, contact them in the first instance.

The person applying for the DFG must be either the owner or tenant and the person with the disability must plan to live in the property for the 'grant period' (usually five years).

DFG's are means tested grants. The means test looks at household income and at household savings over £6,000. DFG's cover things like the fitting of ramps, adding ground floor bedroom and bathroom facilities, adapting a kitchen and installing a through-floor lift. To find out more about applying for a DFG speak to your Local Authority OT. Only works that meet the criteria and 'assessed need' can be considered.

It is always important to apply for a grant, even if you do not think that you will receive funding. This is so there is a record of the work needed and who funded it. This could be helpful if further adaptations are required.

Local authorities must make a decision on your DFG application within six months. The maximum DFG in England is £30,000, in Wales it is £36,000 and in Northern Ireland it is £25,000.

In England and Wales a local authority can offer additional help through their discretionary powers (for example, an interest free loan secured on your property) if necessary.

In Northern Ireland discretionary grants are different. To obtain more information about these grants in Northern Ireland contact The Northern Ireland Housing Executive on 03448 920900 or see: www.nihe.gov.uk/index/benefits/home-improvement-grants.htm

You can read more about DFG's at: <https://www.gov.uk/disabled-facilities-grants>.

Adaptations – Scotland

In Scotland local authorities can provide grants, loans and other help to homeowners if a property needs adapting. Grant assistance must be given if the adaptations are “essential to a disabled person’s assessed needs and the work is structural or involves permanent changes to the house (except for extensions for living accommodation in the existing structure or any other structure)”.

Grants also have to be given for standard amenities that meet the needs of a disabled person (for example, a toilet or a wash hand basin). The grant will be for 100% of the approved costs if a disabled person (or someone in their household) receives certain income related benefits (these do not include Attendance Allowance or Personal Independence Payment). In other cases the grant covers 80% of the approved costs. There is no upper limit to the size of the grant, it depends on a person’s ‘assessed needs’. Needs are usually assessed by a local authority OT.

Tenants can also apply for help subject to certain conditions. A booklet called ‘Funding Adaptations to the Home’ is available online (see the link below) or call 0131 244 3748. There are different versions of the booklet for homeowners, local authority tenants, private tenants and housing association tenants.

See: <https://www.citizensadvice.org.uk/scotland/housing/repairs-and-improvements-s/housing-grants-and-loans-s/>.

Adaptations – Republic of Ireland

Mobility Aids Grant Scheme:

The Mobility Aids Grant Scheme can help older or disabled people with the cost and installation of things like grab rails or a level access shower. The maximum grant is 6,000 euros and this can be for up to 100% of the cost of the work. The scheme is administered by local authorities. You can get OT advice from your local authority or independently (which can be paid for from the grant).

Further grants can be applied for when a need arises.

Grant applications are prioritised according to need. For example, those with a terminal illness will have a high priority.

To qualify, household income must be under 30,000 euros per year.

Housing Adaptation Grant for people with a disability:

A housing Adaptation Grant is available where changes need to be made to a home to make it suitable for a person with a disability or mental health difficulty to live in.

The grant can help you to make changes and adaptations to your home. for example, making it wheelchair-accessible, extending it to create more space, adding a ground-floor bathroom or toilet or in some cases, the provision of heating.

The scheme is administered by local authorities. It is means tested with household income over 30,000 euros a year assessed. The maximum grant is 30,000 euros unless your house is under a year old in which case the usual maximum is 14,500 euros.

The grant is expected to cover all adaptation needs but a further grant can be applied for in the future if needs change.

Grant applications are prioritised according to need and categorised as 1, 2 or 3 with level 1 being the highest priority. Grants are subject to local authority funding and they may not always pay the full amount. In this case you may be able to get a local authority home improvement loan.

Housing Aid for Older People Scheme:

The Housing Aid for Older People Scheme is used to improve the condition of an older person's home. In general, it is aimed at people 66 years of age and older, who are living in poor housing conditions. However, in cases of genuine hardship the local authority may assist people age under 66. It covers essential repairs to make a property habitable, for example, re-wiring. The maximum grant is 8,000 euros which can cover up to 95% of the cost of the work.

For further information on Housing adaptation grants visit www.citizensinformation.ie.

What if I don't meet the criteria for assistance, or what I require isn't eligible for grant help?

Do ask your Occupational Therapist and local council about local schemes that may exist to help in these situations. Other grants may exist for some aspects of work (for example, energy efficiency boilers/heating systems).

See <https://www.disabilityrightsuk.org/housing-grants> for details of other schemes.

Please contact the MSA Trust for information as we may be able to help locate voluntary organisations that could help if the amount needed is modest.

Home Improvement Agencies

You may also get help from a home improvement agency. Home improvement agencies (HIAs) are not-for-profit organisations run by housing associations, local authorities and charities. They help homeowners and tenants with things like applying for grants and other sources of funding and finding builders. They may organise the fitting of minor adaptations and security measures (for example, grab rails, key safes and door viewers).

In England 'Foundations' can put you in touch with your local HIA. Their telephone number is 0300 124 0315 or see: wwwFOUNDATIONS.UK.COM.

In Wales, Care and Repair Cymru can put you in touch with a local service. Their telephone number is: 0141 221 9879 or see: WWW.CAREANDREPAIR.ORG.UK.

Care and Repair Scotland can offer information. See: WWW.CAREANDREPAIRSCOTLAND.CO.UK or telephone 0141 221 9879.

The MSA Trust's Contact Details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://WWW.MSATRUST.ORG.UK/SUPPORT-FOR-YOU/HCPs/>.

We also have Social Welfare Specialists that can assist you with housing enquiries and give information about welfare benefit entitlements.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591 | E: support@msatrust.org.uk | W: WWW.MSATRUST.ORG.UK

REVISION DATE: 05/24 | REVIEW DATE: 05/27 | VERSION: 1.0

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References for this information sheet are available by contacting support@msatrust.org.uk.

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