

Regulations and code of practice in relation to Part 4 of the Act (direct payments and choice of accommodation) and Part 5 of the Act (charging and financial assessment)

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Responses should be returned by **31 July 2015** to:

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Introduction

Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales. 30% of people with the disease die within 12 months of diagnosis. There is no cure.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

Summary of response

The MND Association believes that the regulations and code of practice provide a relatively clear framework for charging, financial assessment and related issues, a useful level of standardisation and a level of discretion for local authorities to provide more generous support in certain cases which is welcomed.

We are concerned, however, that the financial eligibility threshold is set at a level that is extremely restricted, and that people with MND with very little means, disability-related costs and a limited or lack of ability to earn will still struggle to afford their care and other costs. People with MND will face increased costs relating to heating, food, clothing, equipment and housing adaptations among other things, as well as their care costs; financial eligibility must be set at a level that provides adequate care to those who face hardship, rather than just the most extreme cases. We are also concerned that flexibility in the guidance around flat rate charges, charging for prevention and charging arrangement fees to those in receipt of a direct payment, will do little to discourage local variation, will reduce uptake of services that save the system money and will ultimately leave a person with less to spend on care.

Charging for care and support - general

1. Do you agree that the regulations and code of practice provide a clear framework for financial assessment and charging of recipients of care and support?

Agree	<input type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>
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Please provide details of anything that you consider has not been included or has been included incorrectly.

The framework is relatively clear and provides a level of standardisation which is helpful, along with a level of discretion for local authorities to provide more generous support in certain cases.

The MND Association is concerned that the financial eligibility threshold is too restrictive, and that people with MND with very little means, increasing disability-related costs as their disease progresses and a limited or lack of ability to earn will still struggle to afford their care and other costs. People with MND will face extra costs relating to heating, food, clothing, equipment and housing adaptations among many other things, as well as their care costs; financial eligibility must be set at a level that provides adequate care to those who face hardship, rather than just the most extreme cases. As such, we urge the Welsh Government to reconsider the threshold to take into account a wider range of people affected by devastating costs as a result of an MND diagnosis.

We are also concerned that flexibility in the guidance around flat rate charges, charging for prevention and charging arrangement fees to those in receipt of a direct payment, will do little to discourage local variation, will reduce uptake of services that save the system money and will ultimately leave a person with less to spend on care. These concerns are described in more detail in relevant sections below.

Financial assessment and determination of charges

2. Do you agree that the financial assessment arrangements identify the relevant forms of income and capital care and support recipients will have that should be taken into account?

Agree	<input checked="" type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>
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Are there any forms of income or capital not identified? If so, how should these be treated for the purposes of determining a charge?

We feel that the financial assessment arrangements do identify the relevant forms of income and capital involved in a financial assessment.

Financial assessment and determination of charges

3. Do you agree that the arrangements for determining a charge strike an appropriate balance between minimising the impact upon care and support recipients with low financial means, while allowing local authorities to obtain a contribution towards the cost of provision?

Agree	<input type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input type="checkbox"/>	Disagree	<input checked="" type="checkbox"/>
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What will further support this?

We recommend that the Government to bring the minimum income amount at least in line with the average extra cost of disability, estimated by the Extra Costs Commission as £550 per month. Assuming the maximum level of award for a single person claiming Income Support and excluding allowances for flat rate charges, the minimum income amount currently falls short of this by £126. People with MND can expect are expected to face higher disability-related costs as a result of the severity of the condition and related needs, so we welcome the level of discretion allowed to local authorities to increase the minimum income amount, and hope that local authorities act accordingly. However, to avoid local variability and to offer a fairer system to people facing hardship as a result of costs relating to their disability, a more realistic estimate of disability-related costs must be made and applied at a national level.

We are unconvinced by guidance on the subject of flat rate charges. While there is a clear intention to protect individuals from circumstances where they are subject to numerous flat rate charges without an assessment of their ability to pay for them, and without these counting towards the £60 maximum weekly charge for care and support, we believe that there will remain circumstances where people find themselves in financial difficulty, without much scope for recourse. This also lays the system open to considerable local variability, where what might be charged for at a flat rate in one area is not in another, and so counts towards one person's maximum weekly care bill, but not another person's. This is contrary to the aims of this collection of guidance and regulations. We urge the government to remove this distinction in order to avoid this problem altogether. If a person is deemed as in need of means-tested support, then this should cover support for all costs.

Choice of accommodation

4. Do you agree that the choice of accommodation arrangements for those entering residential care provide them with additional choice over their accommodation?

Agree	<input type="checkbox"/>	Tend to agree	<input checked="" type="checkbox"/>	Tend to disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>
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Please provide details of anything that you consider would provide prospective residents with more choice.

The guidance is very clear that this choice of accommodation must be a real choice, and that a local authority, rather than an individual, must bear the burden of extra costs where the local market means that accommodation suitable to a person's needs is only available at a higher price. This is very welcome, particularly for people with MND whose choices may be extremely limited by the specialist care that they need in a care home setting. Every effort should be made to provide people with MND the same level of choice as people with other illnesses, needs and disabilities through the market-shaping processes referred to in the code of practice, including commissioning of specialist neurology services for care home settings.

We welcome the recognition that assessments of cost differences should only be made between two of the same type of care home. There must also be a clear delineation between care homes and other residential settings in order to make sure that needs are met appropriately. A hospice, for instance, does not offer a viable alternative setting to a care home and should not be treated as a means of discharging a local authority's responsibility for meeting needs.

Deferred payments

5. Do you agree that the revised deferred payment arrangements for those entering residential care with property will enable them to have an improved choice over the timing of any sale of this to pay for such care?

Agree	<input type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input type="checkbox"/>	Disagree	<input checked="" type="checkbox"/>
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What will further support this?

The revised deferred payment arrangements will allow a very small proportion of people more control over the timing of selling their property to pay for care in a care-home setting. A person will have to have assets, excluding their main or only home, of less than £24,000, earnings of less

than £25.50 per week and will have to have been living alone or with someone who is not their partner, child under 18 or other close relative over 65 in order to qualify. This is extremely limited, and does not offer a real choice or a real financial solution for those who need one.

It is not clear from either the code or the regulations whether a local authority has discretion to offer deferred payment arrangements to other people. The Government should stipulate this clearly in the guidance, and make the case for doing so clearly to local authorities. People with MND and their families will greatly benefit from the extra time and control in arranging their affairs that an arrangement would offer.

Prevention and assistance

6. Do you agree that the different arrangements to charge for prevention and assistance strike an appropriate balance between promoting take up of these such services enabling local authorities to recover some of the costs of providing or arranging them?

Agree	<input type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input type="checkbox"/>	Disagree	<input checked="" type="checkbox"/>
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What will further support this?

We are particularly concerned that the regulations allow a local authority discretion to charge for preventative services at a flat rate. We strongly believe that this is wrong in principle, as well as setting up difficulties for operation in practice. Preventative services by their very nature save the health and care system money, which should be reflected in the commissioning of these services; funding should come from the whole system, rather than from the individual in need of the service. While we appreciate that the statutory guidance attempts to guard against charging acting as a barrier to uptake of these services, we do not see how this can possibly be avoided. This is self-defeating, and we urge the Government to reconsider its guidance and practice on this issue. At the very least it should define what constitutes a preventative service, to avoid services being re-classified as such in order to enable a flat rate charge to be levied, and define which of these should be chargeable with clear justification, in order to provide transparency on the matter.

Other

The Welsh Government is interested in understanding whether the proposals in this consultation document regarding parts 4 and 5 will have an impact on groups with protected characteristics. Protected characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief,

sex, and sexual orientation.

- 7. Do you think that the proposals in this consultation will have any positive impacts on groups with protected characteristics? If so, which and why/why not?**

It is encouraging that the Government has taken into account the extra cost of disability in its financial assessment regulations to some extent. However, it does not go far enough. To truly make a positive impact on this protected group the Government must recognise and respond to evidence from recent research that puts disability-related extra costs at a much higher level than that provided.

- 8. Do you think that the proposals in this consultation will have any negative impacts on groups with protected characteristics? If so, which and why/why not?**

Aside from falling short of the level described above, we do not believe that these proposals will have a negative impact on the lives of people with disabilities.

- 9. Re-balancing the care and support system to deliver the new legal framework will require reprioritisation of resources. What are the key actions that need to be taken to achieve this?**

The system will require initial funding from health and social care partners to establish regional partnership boards and arrangements. The social care system itself will need ongoing, sustainable funding in order to both provide the care and support that people need to achieve well-being outcomes, and to realise potential cost savings to the health system. This includes funding to fill gaps in local advocacy services in order to meet statutory requirements, and funding for specialist services to ensure that people with MND have real choice. Ultimately the funding of social care saves the whole system money, and any reprioritisation of resources must reflect this. Joint funding arrangements recognise this to some extent in some areas, and further joint funding of social care services will deliver further savings to health and other services.

- 10. We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to tell us about them.**

We are extremely concerned about regulations allowing local authorities to seek reimbursement relating to arrangement fees from people in receipt of a direct payment. There is very little in the code of practice providing further information, limits or other recommendations on this issue, beyond exemptions as a result of statutory requirements elsewhere. We believe that

this essentially amounts to the 'top-slicing' of a person's direct payment, and risks leaving them with less to spend on necessary care services. We believe that this should be part and parcel of services that a local authority is obliged to provide a person with a direct payment, and not an opportunity to add extra costs or compete with private providers.

Responses to consultations may be made public – on the internet or in a report. If you would prefer your response to be kept confidential, please enter YES in the box.