



Code of practice on **Advocacy under Part 10 and related parts of the Act**

Your name: Ellie Munro

Organisation (if applicable): The Motor Neurone Disease Association

email / telephone number: ellie.munro@mndassociation.org / 020 7250 8449

Your address: David Niven House, 10-15 Notre Dame Mews, Northampton NN1 2BG

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

Contact details For further information:

Address: Sustainable Social Services Implementation Branch
Social Services and Integration Directorate
Crown Buildings
Cathays Park
CARDIFF
CF10 3NQ

email: sswbimplementation@wales.gsi.gov.uk

telephone: 029 20 82 6498

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 welcomes the statements in the code of practice about the importance of advocacy, different forms of advocacy and different points during a person's involvement with care services at which they may require an advocate. These statements are useful in establishing the principles of advocacy, and recognising the importance of ensuring that a person can participate fully in decisions about their social care.

We believe that a number of improvements should be made in order for this guidance to be fully comprehensive and to ensure that advocacy services are available to the people who need them, when they need them. These improvements are:

- Ensuring that the independent advocacy system is based on the principle of what is best for the person, not on the 'can only' principle, so that an individual and those involved in supporting them can make a real decision about who is most appropriate to provide advocacy, and that everyone who needs an advocacy service is able to receive one.
- Making sure that there is not undue pressure on friends and family to act as advocates, especially where this would be inappropriate
- Including the point at which a person with complex needs first comes into contact with the care system and points where a person may have their needs reassessed as a result of their deteriorating condition in the list of circumstances where advocacy should be considered
- Including the importance of promoting advocacy services in formats that are appropriate for and accessible to the individual.

All of these will help to further ensure advocacy is provided to people when they need it and in the manner they need it.

1. Do you agree that the Code identifies the people to whom advocacy must be provided?							
Agree	<input type="checkbox"/>	Tend to agree	<input type="checkbox"/>	Tend to disagree	<input checked="" type="checkbox"/>	Disagree	<input type="checkbox"/>
<p>What will further support this?</p> <p>The MND Association welcomes the clear guidance on when a local authority must consider advocacy needs.</p> <p>We believe that advocacy should, when appropriate, be a central part of the package of support provided to people with MND, and should be widely available to those who want it. As such, we have some reservations about the phrasing of the duty to provide advocacy services; sections 4.11 and 8.12 repeat the requirement that local authorities must arrange an independent advocate if an individual <i>can only</i> overcome the barrier(s) to participate fully with the support of that advocate (emphasis added), and if no other appropriate individual is available. We are concerned that this may mean that only the most extreme cases will be entitled to a local authority-provided independent advocate, and that pressure may be put on friends and family to act as an advocate instead, where that may not be appropriate. While there are clear guidelines to help local authorities consider circumstances where someone may not be an appropriate advocate, there is also inconsistency; section 8.7 says that "there will be occasions when this support [from informal and voluntary services] is not available" Availability does not equate to being appropriate, and the guidance must be clear on this.</p> <p>We believe that a principle of what is best for the person should replace the principle of 'can only' in this crucial matter; an independent advocate should be available to an individual as a matter of course, rather than in the most severe cases. A person or those involved in supporting them will then be better able to consider whether a friend or family member or a local authority-provided advocate is most appropriate, rather than an advocate being deemed appropriate at least in part based on their availability. We would also like reassurance that individuals will be able to challenge decisions made about entitlement to independent advocacy in good time if necessary.</p> <p>In addition, we ask the Government to amend its guidance to explicitly consider the needs of carers for advocacy services. A carer may face the same barriers to engaging and participating in decision-making processes, but may need advocacy services at different points to an individual receiving care.</p>							

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2. Do you agree that the Code identifies the range of circumstances where advocacy may be required?

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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What will further support this?

We broadly agree with the list of circumstances when individuals may require advocacy services, and appreciate that this is not a complete list. However, the Government should include in the list points at which a person needs a reassessment to determine their care needs as a result of a deterioration in their condition. This will be important to people with MND and a range of other progressive conditions, particularly at a point where a person may become eligible for local authority support where they weren't previously, or where they need greatly enhanced or different services to meet their needs.

This list should also explicitly include the point at which a person first comes into contact with social care services. The range of professionals that a person with MND may come into contact with when first arranging for social care provision can be overwhelming, and they may need extra support from an independent advocate to participate fully in decision-making.

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3. Do you agree that the Code identifies appropriate arrangements for publicising advocacy services?

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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What will further support this?

We welcome the requirement for local authorities and local health boards to map what existing advocacy services there are in their area, and recognition that people may need advocacy services to access the information, advice and assistance service.

However, people may also need other kinds of support to access the service, such as information in appropriate formats. For instance, people with MND may not be able to use standard telephony services if they can no longer speak, may need documents in formats online that are accessible using assistive technology or may need information, advice and support in their own home if they have acute mobility issues and cannot travel. The Government should include guidance on publicising advocacy services in a range of different formats suitable for the range of people who will need them.

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4. Do you agree that the Code will support local authorities to ensure advocacy is provided to support people to express their wishes and feelings?

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

Overall, the guidelines include useful statements on the importance of advocacy, different forms of advocacy and different points during a person's involvement with care services that they may require an advocate. Improvements mentioned above include:

- Broadening the qualifying criteria for when a person is entitled to local authority provision of independent advocacy services, and ensuring that there is a robust appeals process to challenge decisions about eligibility
- Making sure that there is not undue pressure on friends and family to act as advocates, especially where this would be inappropriate
- Including the point at which a person with complex needs first comes into contact with the care system and points where a person may have their needs reassessed as a result of their deteriorating condition in the list of circumstances where advocacy should be considered
- Including the importance of promoting advocacy services in formats that are appropriate for and accessible to the individual.

All of these will help to further ensure advocacy is provided to people when they need it and in the manner they need it.

Other

The Welsh Government is interested in understanding whether the proposals in this consultation document regarding part 10 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.

5. 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?

If specific communications needs are recognised and provided for, then this will have a positive impact on groups with disabilities including MND.

6. 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?

If specific communications needs are not recognised and provided for, then this will have a negative impact on groups with disabilities including MND.

7. 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.

8. 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.

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.