

## Appendix 5 - The role of councillors

### Who are councillors?

Councillors are elected by local people to represent them in a defined geographical area (called a ward, division or electoral area) for a fixed term of four years.

They are responsible for making decisions about, and monitoring, services provided by the council, on behalf of the local community.

Councillors are democratically accountable to residents of their ward, division or electoral area.

There are over 21,000 councillors in England, Wales and Northern Ireland.

### Why are councillors important to target?

Councillors are important because they

- are elected to represent people with MND and their families and
- particularly in England and Wales, have a say in many of the local services people with the disease rely on

### Services councillors have a say in

Service	How this affects people with MND and their carers
<b>Adult Social Care</b>	<p>Social care includes: paid care workers who come into the home to wash and dress the person with MND, or to help them continue to take part in leisure or social activities; the provision of some equipment – such as hoists – to help around the home; care homes where people with MND might move into if life at home becomes too difficult; as well as help with information and advice on accessing the right services.</p> <p>In England and Wales, social care is means tested. This means that not all people with MND will be eligible for ‘free’ social care provided by the council, it depends on their income. However, everyone should receive an assessment of their social care needs by the council.</p> <p>If you live in an area in England where there is a district council and a county council, then it is the county council that is responsible for decisions about social care.</p> <p>In Northern Ireland, health and social care services are joined up, and provided through the Health and Social Care Board and Trusts, not local councils.</p>
<b>Housing Adaptations</b>	<p>Adaptations to the home (private, rented or council) are often needed when the disease has progressed to the extent that it makes moving around the house and completing normal daily tasks difficult or impossible.</p> <p>Adaptations might include fitting accessible ramps and widening doors to allow for wheelchair access throughout the house; installation of a stairlift or through-floor lift to allow the person with MND to access the</p>

Service	How this affects people with MND and their carers
<b>Housing Adaptations</b> (cont)	<p>upstairs areas of their home for as long as possible; or the conversion of a bathroom to a wet room area.</p> <p>In England and Wales, adaptations can be fully - or partially-funded by a local council through a <b>Disabled Facilities Grant (DFG)</b>. This is paid for and administered by councils, and is means tested based on national criteria. If a person with MND qualifies for a DFG then a council-employed occupational therapist will make an assessment of what adaptations are required. In many areas, problems arise with DFG's when the assessment and/or adaptations take too long to complete.</p> <p>In Northern Ireland, grants for adaptations are the responsibility of the Housing Executive, not local councils.</p>
<b>Social Housing</b>	<p>People with MND who live in social housing may rely on the council to help them make adaptations to their flat or house, or re-house them in an accessible property, as the disease progresses (see above).</p> <p>In Northern Ireland, council housing is dealt with by the Housing Executive, not local councils.</p>
<b>Housing Benefits</b> (including Discretionary Housing Payments, local welfare payments and Council Tax Reductions)	<p>People living with MND who are in receipt of housing benefit can face difficulties paying their rent on top of other expenses.</p> <p>In England and Wales, local councils have a limited pot of money to provide short term assistance in those cases in the form of <b>Discretionary Housing Payments</b>. These payments are short-term. Each council determines who should be given a payment, and how much it should be.</p> <p>People with MND who are on low income or claiming benefits may also qualify for their local council's <b>Council Tax Reduction</b> scheme. This is means tested based on personal circumstances, income and savings. Eligible people can receive up to a 100% reduction in their council tax.</p> <p>In Northern Ireland, discretionary housing payments and benefits are the responsibility of the Housing Executive, not local councils.</p>
<b>Carers assessments and services</b>	<p>Caring for someone with a rapidly progressing terminal illness can be a stressful and exhausting role.</p> <p>Carers of people with MND have the right to receive a <b>carers' assessment</b> from the council. This gives the carer a chance to discuss their needs with social services. In many cases, this assessment does not happen (usually because it is not offered or a carer doesn't see themselves as such).</p> <p>Based on the assessment, the council can provide a range of <b>services</b> that will benefit both the carer and the person living with MND. These might range from respite care, to allow the carer a short period to recharge, to more simple things such as help with household tasks, provision of a computer or assistance with transport costs. The provision of carers services varies significantly.</p> <p>In Northern Ireland, carers' assessments and related services are provided by the local Health and Social Care Trust.</p>
<b>Blue Badge scheme</b>	<p>The Blue Badge scheme allows people with MND who have reduced mobility to park closer to their destination.</p> <p>In England and Wales, the scheme is now administered by local councils either through assessment based on national criteria, or on receipt of the Personal Independence Payment (PIP) mobility component.</p>

Service	How this affects people with MND and their carers
<b>Blue Badge scheme</b> (cont)	In Northern Ireland, Blue Badges are administered by the Road Service, not local councils. Qualification for a blue badge through PIP is not yet in place/confirmed in NI.
<b>Public health</b>	Local authorities in England are responsible for public health. This includes measures to prevent disease, prolong life and promote good health. For example, helping people to quit smoking and take up a healthier lifestyle. It can also include measures which promote <i>quality</i> of life and wellbeing, for example, initiatives to improve support at the end of life and after bereavement.
<b>Local Transport Leisure and Recreation Facilities Roads and Footpaths Parks and Public Places Local Planning</b>	Ensuring full access to these services will be important to people with MND, as they help to achieve the quality of life aspiration of the Charter. Full disabled access to these facilities should be expected.

Other council services may include public health, waste and recycling, regulation of local business, education services, electoral registration, environmental health and libraries.

## Who is responsible for these services?

Councillors are the key decision makers: they set the priorities and local policy for the local area. The decisions they make are then implemented on a day-to-day basis by staff members employed by the council, who are called officers.

Councillors retain overall responsibility for ensuring the services organised and delivered by officers meet the needs of local people.

In England, since the Health and Social Care Act 2012, councillors also have a say in some health matters too.

## How do decisions get made in councils?

Most councils, in England and Wales, have a leader (or an elected mayor) and a cabinet who make the big decisions. Councillors not in the cabinet are known as backbenchers, and their role is to scrutinise the decisions.

It can be useful to find out what role your local councillors have. Find out by looking on the democracy section on the council's website. You will see a list of councillors and the positions they hold.

Look out for councillors who are members of council committees or boards dealing with health, wellbeing and adult social care (in England and Wales). These have an important role in making decisions about services used by people with MND and their carers.

## Different types of local government in England, Northern Ireland and Wales

In Wales, a single council delivers all local services in each area. In Northern Ireland there is also only one council per area, but health and social services are provided separately by Health and Social Care Trusts.

In England, the structure of local government is more complex, but it is worth taking the time to understand what system your area has.

If you live in London or many of the larger cities of England (like Birmingham, Manchester, Leeds or Liverpool), you will have a **London Borough** or **Metropolitan District Council** (MDC). These councils provide all local services, so their councillors have an important role in issues affecting people with MND.

If you live in a large to medium-sized town or city like Reading or Nottingham, you'll probably have a **unitary or**

**'single tier' authority.** These councils also provide all local services. Some counties like Cornwall, Shropshire and Northumberland have also moved to having only one unitary council.

If you live in a rural or semi-rural parts of England, your local government might be split between a **county council** and **district or borough council**. County councils cover large areas, like Devon or Kent, and provide about 80 per cent of services for that area. District and borough councils cover smaller areas and provide more locally based services. If you have both in your area, we'd recommend you prioritise the county council, as they have more influence over the services used by people with MND.

As well as local councils, the UK also has around 10,000 **parish, town and community councils**. These form the most local level of local government and are responsible for things like: allotments, bus shelters, car parks, public toilets, cemeteries, footpath lighting, litter bins, local halls and community centres, parks and public ponds, public clocks and war memorials. We are not prioritising councillors of these very local councils in this campaign, but there would be no harm in finding out who they are and asking them to adopt the Charter!