

<b>SUBJECT:</b>	<i>Agreement to sign the motor neurone disease (MND) Charter</i>
<b>RELEVANT MEMBER:</b>	<i>Councillor Patrick Hogan</i>
<b>RESPONSIBLE OFFICER</b>	<i>Martin Holt Head of Healthy communities</i>
<b>REPORT AUTHOR</b>	<i>Martin Holt</i>  <i>01494732055 martin.holt@chilternandsouthbucks.gov.uk</i>
<b>WARD/S AFFECTED</b>	<i>(All Wards);</i>

### **1. Purpose of Report**

To agree that the Council supports and signs the Motor Neurone Disease (MND) Charter which recognises and respect the rights of people with MND as set out in the Charter, and work towards the Charter's vision of the right care, in the right place at the right time. Members of the Healthy Communities PAG agreed to recommend to Cabinet that the Motor Neurone Disease Charter be supported.

### **RECOMMENDATION**

#### **1. To agree that Cabinet supports and signs the Motor Neurone Disease (MND) Charter**

### **2. Reasons for Recommendations**

To raise the awareness of staff and members of the impact of MND on carers and sufferers and to ensure that the council's policies and procedures enable people with MND to receive a rapid response to their needs and good quality care and support, ensuring the highest quality of life as possible and the ability to die with dignity. The MND Charter serves as a tool to help make this happen.

### **3. Content of Report**

3.1. MND is a devastating, complex disease and particularly difficult to manage. MND is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to move, talk and eventually breathe.

3.2. A person's lifetime risk of developing MND is up to one in 300. It kills around 30% of people within 12 months of diagnosis, more than 50% within two years. It affects people from all communities. It has no cure

3.3. The MND Association believe that if the right care is provided for MND it can save public services money in the long run. But more importantly, it can make a positive difference to the lives of people with MND, their carers and their loved ones.

3.4. The five points of the Charter and detailed in Appendix 1 are:

- The right to an early diagnosis and information
- The right to access quality care and treatments
- The right to be treated as individuals and with dignity and respect
- The right to maximise their quality of life
- Carers of people with MND have the right to be valued, respected, listened to and well-supported.

3.5. The impacts that District Council services can have on MND sufferers are identified in appendix 2, information for Councillors. The Council currently supports persons with disabilities in the following ways

	Impact	CDC/SBDC Position
Housing Adaptations	Adaptations funded via the DFG (Disabled Facilities Grants) programme can support MND sufferers to remain in their home and continue to access all facilities (bathroom, garden etc.). Appendix 2 highlights that in some areas there can be delays in the assessment and delivery of DFGs.	We have reviewed our processes and introduced a fast track grant process to speed up delivery of small adaptations such as stairlifts, showers and ramps. We work with clients and partners (including Occupational Therapists and contractors) to ensure adaptations delivered as speedily as possible, although there will sometimes be factors such as the need for planning permissions, lack of availability of contractors that can slow down delivery.
Social Housing	If the MND sufferer is living in social housing, the landlord may need to undertake adaptations or facilitate a move to more suitable accommodation if the property becomes unsuitable for the	Social Housing tenants can access DFG funding and landlords (i.e. Registered Provider landlords) can approve or directly undertake works, If a tenant has MND and needs to move on

	household's needs.	confirmed medical grounds, then he/she can be prioritised for rehousing via the Bucks Home Choice scheme and the landlord can also look to assist via their own internal Management Move scheme.
Housing Benefits	Persons in rental accommodation can face difficulties paying rent as well as other costs.	The introduction on Universal Credit means that the DWP (not the Council) is now responsible for administering new benefit claims for people seeking help with their housing costs. However, the Councils still administered Discretionary Housing Payments (DHP) which can provide additional help with housing costs in cases of particular hardship. Each application for DHP is considered on its individual circumstances
Council tax reduction	Persons on low income or claiming benefits may be able to claim 100% Councils Tax reduction	South Bucks District Council's Council Tax Reduction Scheme has a maximum of entitlement of 100% for taxpayers classified as vulnerable. If a customer is in receipt of certain qualifying benefits such as disability benefits they could be classified as vulnerable and then receive a maximum entitlement of 100% dependant on their income and eligibility.
Leisure, Transport, Parks	Ensuring full access to	The councils leisure

and Open Spaces	services assists in improving a person's quality of life	<p>facilities have disabled changing facilities and concessionary fees for disabled persons. The operator also supports the delivery of disability clubs Should the Chiltern Lifestyle Centre be built the facility will be fully accessible and designed to meet the needs of disable persons. The mix of community and leisure facilities will enable greater social interaction and opportunities to reduce social isolation and enable persons with NMD, their families and carers to participate.</p> <p>The financial support to Dial a Ride enables the opportunity for disabled persons to access transport.</p>
Planning	Ensuring full access to services assists in improving a person's quality of life	Planning advice and assistance enables applicant to apply via the portal.

3.6. Members are asked to recommend that the Council signs the Motor Neurone Disease (MND) Charter

**4. Consultation**

Not Applicable

**5. Options (if any)**

**5.1.** To agree to signing the Charter and to adopt policies that would support the aims of the Charter

**5.2.** To decline to sign the Charter

## **6. Corporate Implications**

Reports must include specific comments addressing the following implications;

- 6.1 Financial – there are no additional financial costs
- 6.2 Legal – the charter would assist the council in demonstrating its equalities duties

## **7 Links to Council Policy Objectives**

- 1. Delivering cost- effective, customer- focused services
- 2. Working towards safe and healthier local communities

### **Next Steps**

The Council would publicise that it has formally signed the Motor Neurone Disease (MND) Charter

<b>Background</b>	None, other than those referred to in this report.
<b>Papers:</b>	