Response to the review of the Priority Services Register

Introduction

i. 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. Half of people with the disease die within 14 months of diagnosis. There is no cure.

ii. 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.

About MND and energy use

i. The profoundly disabling effects of MND are increasingly addressed via technological solutions that require power. A person's loss of mobility can be countered through the use of hoists, often powered, to move them around inside the home, and through profiling beds and riser-recliner chairs to ensure they are comfortable. They will often also have a powered wheelchair, into which may be integrated computer systems for communicating (sometimes controlled by tracking eye movement) and for controlling the home environment (for instance turning lights on and off). Stairlifts or through-floor lifts may also be installed, as may a Clos-o-mat (washing and drying) toilet.

ii. People with MND will often have to set their heating high in the winter, as they cannot move about easily to keep warm.

iii. Powered equipment can also be used to meet the medical needs of people with MND, and in some cases prolong life. The loss of the ability to cough and swallow means the person cannot control secretions in the mouth and throat; this can be addressed with the use of suction units and cough assist machines. Declining respiratory function can lead firstly to sleep-disordered breathing, which significantly impairs quality of life, and eventually to death; the use of non-invasive ventilation (NIV – a device to pump air into the lungs) is recommended for NHS use to address this. Powered feeding pumps may also be used for a person who can no longer swallow.

iv. An uninterrupted power supply is therefore of vital importance to people with MND: not only does it make possible the maintenance of daily living at the most basic level, but for some people it is essential in order to keep them alive. Many of the powered items have batteries, but obviously their capacity is finite. A prolonged power outage for a person who is reliant on NIV has the potential to prove fatal.

v. Our central recommendation in respect of any reform to the Priority Services Register is that it must enable electricity distributors to identify people with extreme levels of need, even among the broader cohort of vulnerable customers. In the context of the changes proposed by Ofgem, we recommend that this should be done at least in part through the proposed new system of coding, so that people with high levels of need are consistently recognised by all distributors.

vi. Of course, an effective response from distributors to power outages must follow from this: where possible this should involve swift reconnection in the event of a planned outage, and channels of communication and information that people can access easily. Evacuation of a person with MND should only be considered as an absolute last resort: moving someone who is reliant on powered equipment can be challenging and distressing, and if they are relocated to a general healthcare setting such as an accident and emergency department, they may find that the staff are unfamiliar with MND and provide unsuitable care such as insisting the person lies flat or administering oxygen, both of which are dangerous for people with MND whose breathing is impaired.

vii. We respond below to selected questions from the consultation paper.

Question 1: Do you agree that energy companies should be required to offer non-financial services with the aim of equalising outcomes for customers?
Yes.

Question 2: Do you agree that we should continue to prescribe a minimum set of services? Do you support the proposed list of services?
We agree, and we support the proposed list of services.

Question 4: Do you agree that we should move away from requiring energy companies to provide services to disabled, chronically sick and pensionable age customers to an approach which requires energy companies to take reasonable steps to identify and provide appropriate services to any customer with safety, access or communication needs?
Most people with MND will meet one or more of the current PSR criteria: they are chronically sick, usually disabled and often of pensionable age (MND is more common among older people). On balance, however, we would support a move to more sophisticated criteria: the breadth of the existing categories creates a risk of people with MND, whose levels of need are often high, being lost among large volumes of customers with lower levels of need. We support an approach that allows for high levels of need to be recognised and prioritised.

One potential danger with this approach is that the register could become hard to access: our experience of reform to the benefits system shows that the introduction of apparently reasonable eligibility criteria can in practice throw up barriers to access, often because the administration of the service is poor and individual staff misunderstand the criteria or develop an unsympathetic attitude towards recipients of the entitlement. Criteria for inclusion on the register must be kept as simple as possible, and as many ways of meeting the criteria (such as by production of evidence of entitlement to benefits, or other paperwork that the person is likely to possess already) must be available. To achieve this while targeting the register effectively will be challenging, and require careful design in close consultation with affected groups.

Question 5: Do you agree that energy companies should be required to maintain a wider register of consumers that they have identified as being in a vulnerable situation?
Yes.

Question 6: Do you agree that suppliers, DNOs and GDNs should share information about customers' needs with: a) each other? b) other utilities?
Yes; information should be shared among DGOs, GDNs and other utilities.

Question 8: Do you agree that we should stipulate the minimum details that we expect energy companies to share, for example that names and phone numbers must be shared where they are available? Is there any other information that should be shared and for what purposes?
Yes. The minimum information proposed seems appropriate.

Question 9: Do you agree that energy companies should agree common minimum 'needs codes' to facilitate the sharing of information?
Yes. A new coding system will be necessary to ensure that levels of need are recognised.

We can see several further issues that will need to be considered, however. The first is how the system will record changing levels of need: MND is a rapidly progressing condition, and while a person may have moderate respiratory problems when they register, for instance, these may have become profound several months later.

The transition from the old system of coding to the new one will also require consideration: will all currently registered customers have to be contacted and re-coded?

Finally, it is unclear that the sharing of records as proposed in the consultation paper will create a single record for each customer; instead, it appears to create the potential for multiple and potentially conflicting records, held by different companies. A central repository for all records may be necessary.

Question 10: Should information about a customer's needs be shared with their new supplier when they switch?
Yes.

Question 11: Do you agree that a single cross-industry brand will raise awareness of priority services?
Yes.

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