



Department
of Health &
Social Care

From Helen Whately MP
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The Rt Hon Penny Mordaunt MP
By email to: penny.mordaunt.mp@parliament.uk

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Dear Penny,

Thank you for your correspondence of 9 November on behalf of your constituent, Ms [REDACTED] about Huntington's disease. I apologise for the delay in replying.

I was very sorry to read of [REDACTED] death and of the experiences she describes. I can appreciate that this situation has caused a great deal of distress and I hope she will accept my sincere sympathies at what must still be a very difficult time.

The Westminster Hall debate on 9 November highlighted the physical and psychological impacts of Huntington's disease, the effect it has on family members and the need for better coordination of care. The Government is committed to improving the lives of those living with Huntington's disease.

NHS England's Neurosciences Clinical Reference Group is working on improving services for people with all neurological conditions. Neurology commissioning arrangements are fragmented, which means that navigating services can be a complex and bureaucratic experience, resulting in delays to accessing care at specialist neurology and neuroscience centres. Through its Neuroscience Transformation Programme, NHS England is developing a new definition for specialised neurology and a model for neurology services. This will make it easier for integrated care systems to reduce inequality of access and match knowledge and skills to patient needs much earlier. It will help speed up initial diagnosis and allow specialist interventions to be made available closer to the patient, rather than at specialist centres. In addition to this programme, NHS England is developing a neuropsychiatry service specification that, when finalised, will outline the multi-disciplinary approach to caring for patients with complex neurological conditions such as Huntington's disease.

To improve how we care for patients with a rare disease, we published the *UK Rare Diseases Framework* in January 2021, building on 2013's *UK Strategy for Rare Diseases*. The framework commits to helping patients get a final diagnosis faster, increasing awareness of rare diseases among healthcare professionals, better coordination of care and improving access to specialist care, treatments and drugs. All four nations of the UK agreed to publish their own action plan within two years of the framework's publication, and each nation set up a delivery group or implementation board to agree and monitor its action plan. The *England Rare Diseases Action Plan 2022* is available at www.gov.uk/government/publications/england-rare-diseases-action-plan-2022. It sets out 16 specific, measurable actions for the next year.

We are aware that more needs to be done to improve the coordination of care for people living with rare diseases. We will continue to undertake community engagement during the development of England's second action plan.

Regarding [REDACTED] experiences in his first care home, any form of abuse or neglect is unacceptable. We are bringing forward measures to provide a greater understanding of practice and provision at a local level, including independent assessment of local authorities' delivery of their Care Act responsibilities by the Care Quality Commission (CQC). How local authorities engage with carers and individuals is a key concern that we expect to form part of these assessments. The Health and Care Act 2022 includes provisions for the CQC to assess the performance of local authorities' delivery of their adult social care duties, as set out under the Care Act. The CQC has been working with local government, the care sector and people with care and support needs to develop a framework for these assessments, including how to consider local authorities' responsibilities to carers.

Furthermore, [REDACTED] may be interested to know that on 24 January, the Secretary of State for Health and Social Care announced that the department will develop and publish a major conditions strategy. The strategy will set out a shift to integrated, whole-person care, building on measures already in place through the *NHS Long Term Plan*. Our approach will use the best evidence for ways to tackle the major conditions that contribute to the burden of disease, including mental ill health, in England. It will combine our commitments on mental health, cancer, dementia and health disparities into a single, powerful strategy. A joined-up strategy will ensure that mental ill health is considered alongside physical health conditions, so that any interactions will be taken into account, and care will be better centred around the patient.

Yours,



HELEN WHATELY