

The Rt Hon Elizabeth Truss MP
10 Downing Street
London SW1A 2AA

6th September 2022

Dear Prime Minister,

Congratulations on your election victory as leader of the Conservative and Unionist Party and appointment as Prime Minister. We look forward to working with you and your Health and Social Care Secretary to tackle the challenges facing families affected by dementia. We would welcome the opportunity to meet with you to discuss how dementia care could work for everyone in the future. We also invite you to visit one of our dementia specialist Admiral Nurse services to better understand the support our nurses provide to families.

Dementia UK is the specialist dementia nurse charity. Our clinical focus is on caring for the entire family affected by dementia, through our specialist Admiral Nurses who provide life-changing support and advice to families living with complex needs associated with all forms of dementia.

As you may be aware, there are over 900,000 people living with dementia in the UK and this is set to rise to over one million by 2025. This also includes approximately 70,000 people who have dementia diagnosed under the age of 65 years. Dementia was estimated to cost the UK around £25 billion in 2021 and is projected to almost double to £47 billion annually by 2050. Dementia can affect anyone and everyone; we will all know someone with dementia in our lifetimes. There currently isn't a cure for dementia so we must do everything that we can to better support families living with dementia, now and into the future.

However, historically dementia care has been a low priority at both national and local levels. We hope you can urgently lead change for a better system and outcomes for everyone affected by dementia. Below we lay out the challenges and solutions to this issue which we would welcome you considering as priorities for change.

Current challenges in dementia care

Too many families affected by dementia are falling through the gaps between health and social care. Families contact our Admiral Nurse Dementia Helpline and Clinics teams because they don't know what support is available to them, or how to access it. Too often people with dementia and their families are excluded or underserved by services because of their particular type of dementia, age, location, sexual orientation or cultural background.

People with dementia and their families face ongoing uncertainty and fractured support systems right from trying to get a diagnosis, through to post diagnostic support and end of life care. Without specialist support many families are left to struggle alone, with a very real impact on the health and wellbeing of the whole family. Hardworking mothers, fathers, older people and younger adults are often unable to hold down regular employment. They often don't receive the support necessary to help them balance work with their caring responsibilities, or continue to work while their condition is in its earlier stages.

Our vision is for dementia care in the UK to be transformed so that all families affected by dementia can access specialist and compassionate dementia support when they need it.

This means that dementia care needs to be more inclusive and better able to adapt as the condition progresses and when people's needs become more complex. This can be achieved by addressing:

- **how dementia care is commissioned and delivered** - we want families to have access to the right specialist support, at the right time, in the place where they live. This includes ensuring improved access to specialist dementia nurses to bring dementia support more in line with other conditions requiring specialist support, such as cancer
- **inclusion** - all families affected by dementia should have equitable access to quality care, regardless of their personal circumstances and dementia type
- **perception** - families living with dementia can still face discrimination and stigmatisation and this needs to end. Health and social care professionals and society more widely need to better understand dementia, and become more adaptive and supportive of the needs of people affected by dementia

Making this a reality

There is an urgent need to be bold and ambitious to ensure that there is fully funded and consistent dementia care across the country, supporting people right from pre-diagnosis and all the way through to end of life. We remain committed to engaging with your government to make the improvements needed. We would welcome the opportunity to work together in more depth on the forthcoming 10-year National Dementia Strategy and revised NHS Long Term plan.

We are also committed to growing the number of our dementia specialist Admiral Nurses, who have a vital role in supporting families living with complex needs. In England they work within the new Integrated Care Systems (ICSs) and help join up care and support for families while also sharing best practice in dementia care with other health and care professionals.

As an example of our support offer, the Great Western Hospital Admiral Nurse service in Swindon provides specialist support to families within the hospital setting as well as support in the community following discharge from hospital. They work to ensure better integration between health and social care to improve health outcomes and reduce the risk of avoidable hospital readmissions. The service recently won the Nursing and Midwifery Award at the NHS Parliamentary Awards in recognition of their vital support.

We look forward to meeting with you to discuss opportunities for improving dementia care and support, and to working together with you so no one has to face dementia alone.

Yours sincerely,



Dr Hilda Hayo
Chief Admiral Nurse and CEO Dementia UK