



DementiaUK

Helping families face dementia

**Only together:
towards better
specialist
dementia
support**



Only together: towards better specialist dementia support

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Introduction

Too often, people living with dementia are left facing this condition alone, or with inadequate, temporary or sporadic support. Health professionals, including GPs (General Practitioners), can and do provide support. But frequently these professionals and other health services are overworked and under-resourced, and as a result unable to adequately help with many of the challenges faced by families.

This situation has real consequences on the health, wellbeing and finances of both the person with dementia, and any family members or carers supporting them. Too often we hear of families left alone to cope without the information or support to best help the person with dementia, or protect their own health, wellbeing or financial situation.

We can't improve this situation alone. The Covid-19 pandemic has shown the fragility of the current system – which was already under immense pressure in 2019, as suggested by our *Facing it alone: experiences of dementia support*¹ research. This paper *Only together: towards better specialist dementia support* is our starting vision, and the beginning of our campaign for better services.

Only together can we make sure that people affected by dementia can have a single, clinically trained point of contact to help them find the support they need, when they need it. Only together can we make sure that people affected by dementia can ask for, and receive the tailored information they require, at all stages of the dementia journey. And only together can we work to plug the gaps in specialist dementia support across the country.

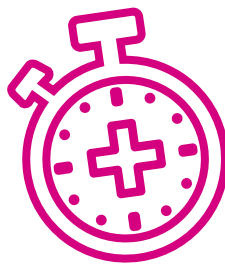


The current challenges

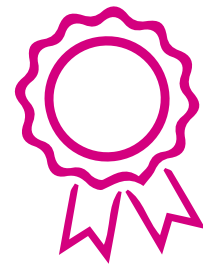
Dementia UK and our network of Admiral Nurses (dementia specialist nurses working in a variety of settings) have been working with families affected by dementia for over 30 years. However, aside from the individual experiences of families, there are systemic challenges in the provision of dementia care. For example:



More people are receiving a dementia diagnosis than ever before. Around 1 million people are projected to have dementia in the UK by 2025²



The health service, and GPs in particular, are under unprecedented pressure. In all the UK nations, health services are under severe strain from rising demand (not just for dementia cases) as well as financial pressures



Best practice is not the reality on the ground. There is good practice and guidance on what people with dementia and their families should be offered, including the NICE Quality Standard on Dementia and NICE Guidance³. However, too often this is not what families receive

The latter two issues have only been worsened by the impact of Covid-19 on the UK health and social care systems. Not only has this placed an additional physical risk on people with dementia who may be vulnerable⁴, but the psychological and emotional effects of Covid-19 have been devastating. Lockdowns from March 2020 onwards posed an additional layer of complexity for families affected by dementia⁵. This has only been heightened by the closure of many respite and support services⁶ leaving many families feeling alone, abandoned, and/or uncertain about the impact of future local or national lockdowns impact on the availability of support services⁷.

Our *Facing it alone*⁸ research shows that many families affected by dementia want and need more support. GPs and other health professionals are committed to helping, but are too often undersupported, overworked and lack specialist services locally which could help families.

Only together

Our vision and next steps for specialist dementia services

The fundamental principle behind our vision for specialist dementia services is that people affected by dementia should be able to receive the information and specialist support they need, when they need it, in the form they need it. In other words, dementia support needs to be truly person-centred.

Indeed, having the information and specialist support needed is not just about making sure the needs of the person with dementia are known and addressed. This means that people affected by dementia – both the person living with their diagnosis and their families – can make choices about how to spend their time, and plan ahead for the progression of the condition. This also helps to make sure everyone involved in caring has their health and wellbeing needs addressed. Having the right support available can help preserve relationships, reduce stress, and minimise the risks of financial hardship as a knock-on effect of the condition.

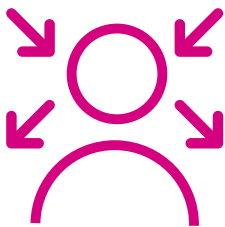
What does this mean in practice? Drawing from our research, we will focus on two key recommendations for improvements in specialist dementia care going forward into 2021.





a) Tailored information

Information needs to be tailored to individuals' needs in terms of quantity, detail and the timing for when it is given. People affected by dementia need to know about the condition's likely progression, impacts on relationships, benefits, and many other factors. But many family members who responded to our survey reported that a diagnosis can feel initially overwhelming. Phasing when information is shared can help people 'digest' material at the right time. A short information resource was welcomed as a starting point, with links to other information that people can use in future, with support from professionals as needed.



b) Single point of contact

When faced with a dementia diagnosis (or even any life-changing illness), there are often many professionals to meet or involve. For anyone unfamiliar with the health service, this experience can feel bewildering and exhausting. Some patients and families also report falling through the gaps between services, particularly those with complex cases. Instead, as a standard, families should have a clinically trained professional as their single point of contact.

Dementia UK can help. Every day, we give specialist advice, support and interventions to families living with dementia in the UK through our Admiral Nurses, our Helpline and information resources. We also are expanding our network of Admiral Nurses working in local areas. These clinical professionals help families locally, as well as provide specialist training, advice and professional support to other health and social care professionals such as GPs. In some cases, Admiral Nurses working in local areas may be able to provide a single clinical point of contact for families dealing with complex dementias, subject to availability.

There are clearly many other recommendations that could be made, and would need to be applied in improving services. Among other aspirations, we would like to see families affected by dementia have support every step of the way – before, during, and after diagnosis – as well as improve GPs' capacity to offer longer appointments. But we appreciate these aspirations will take time, resources and long-term partnership working.

What can you do?

Ensuring that all families affected by dementia have a single, clinical point of contact and tailored information whenever they need it will be a long and challenging process. But we can start now. We are launching our Only together campaign to work with families, GPs, Admiral Nurses and other professionals to deliver better specialist support for families affected by dementia. We will be working on these changes across the UK, and call on others to begin making these improvements wherever they are based.

On our campaign website ➡ www.dementiauk.org/onlytogether we outline a range of actions families, GPs, and other health and social care professionals can take, including:



sharing your experiences and best practice with us to disseminate around the country



highlighting where provision is lacking, or where more support could be needed;



and crucially working with us in local areas to improve specialist dementia services

What will we do?

We will work with local areas to help them improve support and coordination: depending on capacity of our national and local Admiral Nurses, we can support local GP surgeries or other services to better understand and support families affected by dementia. We would be happy to work with local providers to develop Admiral Nurse services in varied settings. We will also provide new and existing information resources to any local GP surgery, memory service, or other service supporting people affected by dementia.

We are ready to work to improve support for families in whatever way is needed. Dementia is a condition which provides significant challenges to health and social care systems in the best of times, but can be exceptionally difficult for people affected, including family members. We can all be stretched too thin by the twin impacts of dementia and the Covid-19 pandemic. But only together can we build better support and services for everyone affected by this condition.



About us

Dementia UK provides specialist dementia support for families through our Admiral Nurse services, our Admiral Nurse Dementia Helpline, and via our wide range of information resources. We are an independent national charity entirely funded by donations, and receive no government funding. More information about us and our Admiral Nurses can be found on our website: www.dementiauk.org

Footnotes

1 Available at <https://www.dementiauk.org/onlytogether>

2 See Alzheimer's Research UK (source from 2014) Dementia Statistics Hub, available at: <https://www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk/>, accessed on 17th February 2020

3 See <https://www.nice.org.uk/guidance/ng97> and <https://www.nice.org.uk/guidance/qs184> for more information.

4 Suarez-Gonzalez A, Livingston G and Comas Herrera, A (2020) *The impact of the COVID-19 pandemic on people living with dementia in UK*. Available online: <https://ltccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>, accessed 18th October 2020

5 Vaitheswaran, S., Lakshminarayanan, M.M., Ramanujam, V., Sargunan, S. and Venkatesan, M.S. (2020). *Experiences and needs of caregivers of persons with dementia in India during the COVID-19 pandemic—A Qualitative Study*, The American Journal of Geriatric Psychiatry

6 Greenberg, N.E., Wallick, A. and Brown, L.M. (2020). *Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia*. Psychological Trauma: Theory, Research, Practice, and Policy, 12(S1), p.S220

7 These points are explored more widely in: [currently in press] Oliver, E., Goss-Hill, B., Anson, M-J., Johnstone, R. (2020) *Increasing need for dementia specialists within primary care settings as a result of Covid-19*, Journal of Nursing Management

8 Available at <https://www.dementiauk.org/onlytogether>



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

**Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm**



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Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).