

Alzheimer's Society

Dementia and the need for integrated health and social care

Integrated health and social care is essential to the future of care and support for people with dementia. In the UK, one person develops dementia every three minutes (Matthews, F.E et al 2016) and it is estimated that around 850,000 people in the UK have the disease, a number that is set to rise to 1 million by 2021. 70% of people in care homes have dementia or severe memory problems, and people with dementia occupy 40% of hospital beds and stay 5 to 7 times longer than people over 65 without dementia

Dementia turns lives upside-down, there is currently no cure and almost everyone knows someone who has been affected. How dementia affects people is not simply due to the disease itself, but also as a consequence of how well they can access the care and support they need - too many people living with dementia face the condition alone, or they and their families struggle to access the services that they need, either because they are inadequate, or due to the fact that the current system that delivers that care and support is completely disjointed and overly complex. The complex nature of dementia and how it affects people means that care and support must also be provided in a highly personalised way that meets their individual needs.

From accessing post diagnostic support that can help people to carry on living well and independently in their own home, through to putting more complex packages of care in place, the experiences of people affected by dementia have highlighted that they often have to navigate through up to 20 different services to get the essential care and support they need. They depict a complex 'web' of people and services with whom they have to interact and navigate in order to get the care and support they need. This web encompasses the health and social care needs of the person with dementia and includes a range of services; from those directly related to day to day management and care, to managing direct payments, access to out of hours doctors, access to services regarding comorbidities or routine treatment, equipment services and other forms of support.

People living with dementia may get a diagnosis and medication through the NHS but, despite dementia being a medical condition, the symptoms people live with, particularly as their dementia progresses, can mean they need help with everyday activities – from washing and dressing to visiting the shops. This

means much of the support they need is through social care, resulting in them being disproportionately affected by failures in the current social care system; underfunded, uncoordinated or unavailable services, and an overburdened workforce that often lacks the appropriate knowledge and resources to meet their needs.

This is also costly – Alzheimer’s Society has campaigned on the issues people with dementia face in terms of the unfair burden of cost that results from having to pay for social care – and this, alongside how that care is accessed and provided regularly results in negative health outcomes.

Poorly integrated care and the lack of community provision often means people with dementia do not receive sufficient support until their needs reach crisis point, at which point they are often admitted to hospital. Once there, extended length of stay can often negatively impact their dementia and cause more rapid deterioration. This results in people with dementia experiencing delayed transfer of care (delayed discharge) due to the fact that their needs may have changed, but that systems aren’t coordinated well enough to get them where they need to be or provide the extra support they need. In addition to the impact on the person with dementia, this also has cost unnecessary cost implications for the NHS

From a practical, service provision perspective, better integrated health and social care provides an opportunity to improve quality, reduce unnecessary duplication and wastage of resources and increase both staff and financial efficiency. From the perspective of people affected by dementia, efficient, effective integrated systems will help to sustain and improve diagnosis and enable the delivery of comprehensive post diagnostic support and person centred care. This will support people with dementia to remain in their own homes for longer, avoiding unnecessary admissions, and will reduce the length of stay and adverse outcomes from delayed transfer of care that we know people with dementia experience.

Health devolution

It is clear to Alzheimer’s Society that devolution presents an opportunity to really drive integration forward, creating a modern health and social care system which is both cost-effective and tailored specifically to the needs of local communities. The devolution of Greater Manchester Health and Social

Care has given us a unique opportunity to create a joined up and consistent dementia pathway across the ten boroughs of Greater Manchester.

Dementia United and Alzheimer's Society agreed to formally work in partnership in January 2020, to develop programmes of work which aim to enhance the health and wellbeing of those living with or affected by dementia in Greater Manchester (GM), to benefit people across all ten boroughs.

Through this collaboration we aim to achieve the shared ambition to transform structures, systems, support and representation of people affected by dementia in GM ; together the partners will make GM the best place in the UK to live with dementia with sustainable and effective solutions. We will primarily:

(a) make best use of GM data systems and capability (including to generate real world evidence for post diagnostic care)

(b) support localities with the ambition to develop and expand the Alzheimer's Society Dementia Connect service, supporting people with an immediate referral post diagnosis with person centered care, lasting throughout their dementia journey;

(c) aim to develop and build on Dementia United's portfolio of work including, but not limited to; dementia friendly transport systems, improvements to end of life care, education and training and supporting underserved populations;

(d) be aligned to the themes of the Greater Manchester Health and Social Care Partnership transformation agenda

(e) Radically upgrade population health prevention;

(f) Transform community-based care and support;

(g) Standardise acute hospital care;

(h) Standardise clinical support and corporate functions; and

(i) Enable better care.

This collaboration will also offer the opportunity to develop new and wider partnerships with other key stakeholders, and to gather more information about the impact of dementia support on the lives of people living with dementia in the community. From diagnosis, people living with dementia find themselves having to navigate a range of services and professionals the aim of

the partnership is to create a model of care provision that works and is consistent throughout diagnosis, treatment and appropriate care provision.

This plan aims to create the greatest and fastest possible improvement to integrated health and social care in Greater Manchester, aligned to the themes of the broader "Dementia United" transformational plan. These themes are parallel to the NHS Well Pathway for dementia as well as underpinned by the NHS Long Term Plan ambition "We will go further in improving the care we provide to people with dementia and delirium, whether they are in hospital or at home."

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