One year on, how is the Prime Minister’s challenge on dementia influencing your day-to-day work with people with dementia?

From left: Robert Holman, Norrms McNamara, Steven Common, Martin Brunet, Kelly Hierons, Pam Stopforth

It is a year since the Prime Minister David Cameron launched his ‘Challenge on dementia’, and with it a wide range of initiatives to better support people with dementia. In this issue we ask a range of people involved in dementia care to reflect on progress since March 2012.

One of the privileges of being a commissioner is talking directly with people with dementia and their carers. By listening to people who have dementia or the people who care for them, I get a good picture of what needs to improve. I feel very lucky to work in Camden – there is a shared commitment to enabling people with dementia and their carers to live a good quality of life and be valued as members of the community. In 2012, we talked to nearly 500 Camden residents and professionals about our Dementia Plan. People were keen to share their stories and learn more about dementia.

This hasn’t always been the case – but I think the stigma is lifting. The Prime Minister’s challenge has been crucial in stimulating a national conversation about the importance of diagnosis, good information, personalised care and inclusive communities. I’m particularly excited by dementia-friendly communities. I sense a real enthusiasm locally about supporting people with dementia to be active, influential citizens who are healthy and included within their communities. We will soon be talking to people in Camden about how we can make their local neighbourhood more dementia-friendly – for example, by making the physical space more accessible, looking at signage, or reducing isolation. I’m looking forward to helping make Camden an even more friendly place for people with dementia to live.

Robert Holman is a Strategic Commissioner, Mental Health Care for Older People for the London Borough of Camden

Since being diagnosed myself five years ago and realising there wasn’t that much out there for younger people with dementia, our campaign began to try and improve things. The Prime Minister’s dementia challenge last year was a great boost as it catapulted the illness of dementia into the eyes of the world. If you strip away the politics and get on with the job in hand, which is improving the quality of life not only for people with dementia but also their carers and loved ones, then the dementia challenge is just that, a challenge, but not something that is insurmountable.

It has to be community led and community driven. One of the most important things to remember is the two words we live by which are inclusion and engagement. To achieve this you must include people with dementia at every step, in every decision and every campaign. And I don’t mean by asking them to fill a questionnaire in (usually done by carers anyway) but to ask them on to your boards and steering groups. We have a voice, I have an opinion and more importantly I have a future, despite having dementia.

Norrms McNamara is a campaigner on behalf of all people living with dementia. He spoke at the launch of the Prime Minister’s challenge in London in March 2012

The simple answer has to be: some progress has been made, but much more is needed to fully meet the three key areas within the challenge. Pockets of improvement in health and care are clearly making a difference despite the impact of increasing demand on services in the context of widespread austerity measures and reduced resources. Closer links with local general practitioners and extending multidisciplinary working to include social care; reduced prescription of anti-psychotic medication, and increased community delivery of services have resulted in more timely intervention for people with dementia, a reduction of avoidable admissions to hospital and increased carer information and support.

Dementia care champions should improve things further together with newly appointed older people’s nurse practitioners working in care homes in the locality. Information and research is available but not always embraced by carer providers, either because of a lack of resources or awareness.

Services need to be innovative, effective and efficient but at the same time supported and publicised. Good practice needs to be shared and replicated more readily. Minimum standards across care providers should reduce discrepancies in care provision and help meet the rising expectations of people with dementia.

Steven Common is a specialist nurse in challenging behaviour at Bensham Hospital, Gateshead

I would love to say that the Prime Minister’s challenge has had a positive impact on my work, and the care for my patients with dementia. The political rhetoric around improving dementia care has been encouraging, and certainly helped to raise the profile of this much neglected condition, reduce stigma and bring a sense of optimism for the future. There is a healthy pride these days among those who work in dementia care, to complement the compassion and dedication that has always been there. This can only be a good thing, and is to be applauded. However, there has been nothing of substance to actually improve the care of those affected by dementia, many carers feel woefully unsupported, and the government’s proposal to incentivise GPs to conduct dementia case finding is about to make the whole situation much, much worse.

Robert Holman is a Strategic Commissioner, Mental Health Care for Older People for the London Borough of Camden

From left: Robert Holman, Norrms McNamara, Steven Common, Martin Brunet, Kelly Hierons, Pam Stopforth
The scheme risks harming patients with mild cognitive difficulties through unnecessary screening, while overwhelming the very service which is struggling to provide care for those who really need it. If GPs could instead be incentivised to work more closely with secondary care, supporting those who really need it, then the challenge might start to make a meaningful difference.

**Martin Brunet is a GP with the Binscombe Medical Centre in Surrey**

I have certainly seen some positive changes within my own locality and the services that have been piloted and set up to support people with dementia and their carers. We have seen the Admiral Nurse service set up providing vital support to carers in their own right, although unfortunately in some areas this funding has been cut. There have also been various support services set up specifically for people with dementia to enable them to remain living in the community and avoid admission into hospital.

All of these services are in response to the dementia strategy. Although I personally feel people are becoming more aware of dementia and the difficulties faced with supporting an ageing population, there are still limited services providing long-term support to carers through education and training, which I believe makes a difference.

Furthermore, there is a lot more work to be done to improve the dignity and compassion shown to people with dementia within services outside the mental health arena, including mainstream hospitals, GPs and residential care home facilities. Finally, let us also not forget the importance of raising awareness around other mental illnesses in older adults, such as depression, which have not had the same attention from government.

**Kelly Hierons is an adult social worker specialising in mental health for older people**

At PSS we have a longstanding commitment to dementia awareness. This was rewarded last year when our week-long dementia awareness campaign, which was run in partnership with Liverpool Hope University, resulted in the designation of 2013 as the ‘Year of Dementia’ in Liverpool.

Like our partners both locally and nationally we know there is still a long way to go to make the UK the dementia-friendly country we all dream of. But one year on we are continuing to push to make this dream a reality. As a team we don’t just lobby and campaign but we take hands-on action delivering innovative services that make a real difference to people’s lives. During 2012 we:

- introduced the provision of a befriending scheme that supports people with dementia to remain active within their communities whilst providing support in their own homes
- worked with Skills for Care to train volunteers to work with the befriending service to provide low level items of technology to promote the independence people with dementia and their carers
- facilitated training to the first cohort of PSS Dementia Coaches whose role it is to recruit Memory Mentors, individuals who understand and are aware of dementia, its symptoms and how it should be managed within the communities in which they live, work and socialise
- were recognised for our innovative model of community support ‘trio’ in North Wales which offers social activities and friendship to people with dementia.

**Pam Stopforth is Head of Development with the social enterprise PSS in Liverpool**