

The Brexit vote has many implications for people with dementia, their families, the workforce in care and health services, employers, local authorities and dementia researchers.

First, most experts predict a challenging economy and possible recession. State funded social care, already stretched, does not fare well under austerity budgets, but self-funders are also facing financial losses and zero interest rates on savings.

Second, about 6% of the social care workforce is from the EU, approximately 80,000 people. They may lose workers' rights protection under EU legislation, which is a concern, but in the meantime also face considerable job uncertainty, a weakening pound, and rises in expressed racism. Without appropriate action we anticipate labour shortages in the care sector, with associated care deficits, and increases in the grey economy and exploitation of workers.

Third, dementia research will suffer from a loss of research funding and collaboration across Europe that may take many years to replace.

Fourth, we need to be vigilant against any threat of erosion to legal protections for human rights, which are needed to protect the dignity and autonomy of people with dementia.

And fifth, what political ideological action might be taken that is either lost in the Brexit noise, or misdescribed as necessitated by Brexit? Political restructuring of services might threaten quality of care in a host of ways, and crucial disability benefits are under political threat.

For all these complex reasons, it is very important to maintain dementia and care as high priority issues on political and funding agendas.

Professor Debora Price is president of the British Society of Gerontology

JDC asks...

The EU referendum result has implications for dementia research, policy, practice and funding. What will the impact of Brexit be on dementia care?

The full effects of the UK's vote to leave the EU will take time to become clear, but we know they will be far-reaching. At Alzheimer's Research UK, our priority is to understand the possible impact on dementia research and to protect our life sciences sector, which is so vital for developing new treatments that are so desperately needed for people with dementia.

Our membership of the EU has brought many positives for UK science. It allows access to funding programmes such as Horizon 2020, enables cross-border collaborations and provides simplified, harmonised regulation that has particularly helped clinical trials. It's not yet clear that leaving the EU will mean losing these benefits, but it will be important to protect the factors that have helped boost life sciences as our newly-formed government negotiates an exit deal. We believe there must be scientific representation at these negotiations; UK-based researchers should not lose out on crucial funding or be cut out of vital international collaborative projects.

The result in June also sent shockwaves through our political landscape, and with a new prime minister and

cabinet now in place, it's crucial that dementia research does not fall from the political agenda.

The Prime Minister's Challenge on Dementia has been a real boost for the fight against dementia, providing focus and leadership that has helped galvanise research efforts.

Research is making progress – but we must keep our foot on the accelerator if we are to deliver new preventions and treatments, and we will be holding our new government to account on this important issue.

Hilary Evans is chief executive of Alzheimer's Research UK

Prior to the Brexit referendum several senior academics voiced their concerns about the impact of Brexit on dementia care and (in particular) research in the UK. This was published in *Lancet Psychiatry* and formed part of a groundswell of opinion that Brexit would cause significant harm to the research environment.

But the political discourse drowned out other expert opinion, which at times was even mocked by certain political voices.

In the immediate aftermath

of Brexit, while we had headline grabbing stories about financial markets collapsing and political leadership imploding, the impact on academia, research and clinical care will not make the front pages. The impact will be much more pernicious and will be felt over months and years.

Already we see evidence of concern about academic leadership for EU funding schemes. Would the EPAD (European Prevention of Alzheimer's Dementia) project be led from the UK if the call went out today rather than in 2014? Will the NHS and dementia strategy directive for research access for patients be achieved if over time less and less high quality dementia research is conducted in the UK? Can we continue to attract the highest calibre researchers, students and academics from Europe when the environment here is tougher to attain prestigious grant awards than elsewhere in Europe and the environment loses status relative to the rest of the world?

Academics and clinicians will endeavour to minimise the damage. But at the point of true breakthrough and leadership being secured by the UK research community,



From left: Debora Price, Hilary Evans, Craig Ritchie, George McNamara and Hilda Hayo

we torpedoed ourselves below the waterline. Now we must do all we can to stop the ship sinking.

Craig Ritchie is professor of the psychiatry of ageing at the University of Edinburgh.

Dementia is a global challenge – with an estimated 47.5 million people living with dementia worldwide and over 10 million in Europe. Our continued relationship with Europe is pivotal in the fight against dementia, enhancing research and development and enabling the sharing of best practice when it comes to ways of improving quality of life and care practices.

But Brexit has put our relationship with the EU into flux. Uncertainty about our future relations with EU countries and the absence of a negotiation strategy from the government will start to have widespread ramifications – and the fight against dementia is not immune.

It would be naive to believe that re-negotiation with the EU will result in the UK receiving the benefits of EU membership without being a member. This period of uncertainty must not put at risk our position as a leader in dementia research. We have been extremely troubled by anecdotal reports that some overseas researchers are now so unsure about their future in the UK they are considering leaving.

Our position as a leader in the dementia field may be weakened. Existing services and support to people living with dementia that are funded through the EU will very likely end, compounding the challenges our public services face at a time of significant financial challenge.

We are fully committed to playing our part in the fight against dementia and as an active member of Alzheimer's Europe. We will be re-doubling our efforts to ensure dementia is a high priority within Europe and indeed globally. Nationally, we will be

working with other lead organisations in the dementia field to ensure dementia is not disadvantaged as a result of Brexit.

George McNamara is head of policy and public affairs at Alzheimer's Society.

Dementia UK focuses solely on dementia care through Admiral Nurses and we work closely with clinical commissioning groups, local authorities, charities and private care providers. Brexit will not impact on our dementia care practice or how we work with these bodies.

Dementia care is still on the government agenda and it continues to be a priority health issue for the UK. We remain committed to working with the organisations that host Admiral Nurses to provide specialist advice and support to families living with the effects of dementia.

Securing funding to commission more Admiral Nurse services was challenging prior to Brexit, so we will remain focused on presenting the cost savings and health benefits that Admiral Nursing delivers to ensure more families are supported.

We do acknowledge, though, that research into dementia care that is funded by the EU will potentially be affected. Dementia UK is not directly dependent on this, although a few individuals within our organisation are working on European research projects. Also, Dementia UK is entirely funded through voluntary donations and the generosity of our supporters, and we recognise that if Brexit impacts on them it could well impact on us.

Hilda Hayo is chief executive of Dementia UK

PERSPECTIVES

Giant strides in dementia care? The credit for any progress must go to care workers, who all deserve medals

■ Mark Ivory is Editor of *JDC*



By Mark Ivory

“Social care is on its knees and the NHS is feeling the pain.” That is what the NHS Confederation said last year and the situation since has shown little sign of improvement. So what are we to make of new health minister David Mowat when he says that this government was elected on the promise to ensure people can grow old in comfort and dignity and that it has made “giant strides” in dementia care and support? Much of the credit for any progress must go to the nurses, OTs and all the other care workers whose own giant strides are worthy of Olympic athlete Usain Bolt and just as deserving of a medal.

But these same practitioners are often overstretched, like sprinters required to run long-distance. The Cameron government came up with an “answer” to the woes of social care and by implication hospitals struggling to discharge patients with dementia and other conditions who frequently have nowhere else to go. That was an optional two per cent increase in council tax to pay for social care. According to the Association of Directors of Adult Social Services it failed even to pay for the new national living wage never mind the remainder of a £940 million gap in funding needed to keep services operating at last year's levels. The NHS, of course, faces a “colossal” funding challenge of its own, as the House of Commons health committee recently reported.

Perhaps we should put our faith in Theresa May, eager to make her mark and give her predecessor's PM's Challenge on dementia a fresh look and more money to achieve its targets? I imagine that few of our readers will pin their hopes on such a revelation. Yet we know that our ageing society will increase not just the prevalence of dementia but the total amount of ill-health and disability in the population. For the same reason ill-health itself is starting to look different: relatively less acute illness and relatively more chronic illness and often more than one condition in the same individual. Families and communities will be expected to play a growing role in meeting this rising care need except that nobody really knows whether all those unpaid carers and responsive communities will be there when they are wanted.

It is hard to see from this distance what the solution will be, beyond the great British tradition of muddling through. Assistive technologies will be an important part of it and there is a fascinating example in this issue, in the form of PARO the robot seal (see page 15). Undoubtedly people with dementia and their family carers will be given a sophisticated armoury of money-saving devices to manage their own health and support needs or have them monitored remotely.

But the new minister had better have something better to offer than a future in which science fiction slowly becomes reality. The Department of Health says he will be “setting the policy direction” over the next few months. Much hangs on the decisions he and his colleagues make.