Jeremy Hunt’s address to the North East

Secretary of State for Health, Jeremy Hunt, gave what everyone in attendance would agree was a speech that didn’t pull any punches in addressing the difficult issues we face as a nation to tackle dementia and “make our country a good country to grow old in”.

He highlighted the fact that a million people in the UK will soon have dementia and that we need to change both the NHS and society to tackle this head on. He added that the challenge is to bang the drum loud enough to get the message through to everyone on the NHS front line and beyond - without this understanding, we won’t transform things.

He also said that everyone seems frightened of dementia, but no one wants to talk about it - it’s rare that people tell you they have dementia and as a country, we need to change attitudes towards it. “We need to recognise that dementia is a horrible condition, that it is not curable, that it destroys relationships and can often open the door for abuse – in short, we need to do a great deal better.”
Jeremy Hunt’s address to the North East continued...

Jeremy went on to say that lots of things have happened to improve things, but that much more needs to be done. He pointed out that progress is being made on improving the low diagnosis rates but also said that drugs companies in particular needed to do more and put their effort into research. “We need to transform the care we offer, in particular tackling issues like understanding and coordinating who is responsible for people when they are discharged from hospital.”

He summarised by reiterating that what we do on dementia is central to our commitment to tackling an ageing population and that everyone needs to talk about dementia as often as they can so that people understand that a diagnosis of dementia is something that can open not close doors.

QUESTION TO THE SECRETARY OF STATE

Q. How is dementia research going to be implemented in light of huge financial cuts?

A. We can and will look for better ways of doing things. At the minute resources are being spent in a way that doesn’t help people with dementia - services are not joined up and we need to break down the barriers between health and social care. Implementing research means we can provide better care for the same money so it must remain a priority.

At the moment there is an regional initiative which has been shortlisted for a £20m bid for funding which would work to translating research into practice.

Gillian Stacey, Dementia Care

Dementia Care is a specialist dementia charity that provides housing, home care, day clubs, respite care, advocacy and training to support people with dementia. It was established 20 years ago in Newcastle upon Tyne and is the third largest dementia charity in country.

The charity is currently looking to expand newly built ‘dementia friendly’ designed specialist housing across the North East and Cumbria as well as developing reablement and respite provision at key locations.

They are also working with other providers to increase their level of knowledge and understanding of dementia through audit, consultancy, training and workforce development including practical work placements.

You can find out more about Dementia Care on their website www.dementiacare.org.uk or by contacting Gillian herself by email at gillian@dementiacare.org.uk or on 0191 217 3319/1323.

Live well north of England dementia portal

Professor Peter Kawalek from Manchester Business School introduced and demonstrated the Live Well website - an information portal and life stories platform with easily accessible and understandable information about dementia and dementia support services for people with dementia, their families and the professionals who care for them. You can access the site at www.livewelldementia.co.uk.
Building networks, Dr Lynne Corner

Lynne is chair of the North East Dementia Alliance and outlined the co-ordinated and combined approach it takes to helping improve dementia care in the North East. The alliance brings together three sectors, research, carers and people with dementia to develop services. It is supported through a very strong research community who work to translate research into action and accelerate innovation.

The alliance is currently funding 80 dementia related projects across the region; many within the NHS, but many also focused on creating dementia friendly communities. To get involved with the alliance contact neda@newcastle.ac.uk

Bernard Gilpin Primary School, Andrew Bainbridge

Based in Coalfields, Sunderland, Bernard Gilpin Primary School is the only primary school in the North of England that is part of the Prime Minister’s Challenge Pioneer Schools Group. The local area has high numbers of people with dementia and the school is heavily involved in inter-generational work to create a community for the future that the children will carry forward.

Children at the school have been working with people with dementia to learn how it affects them, and those around them, and discussing how society should view people with dementia. Some of their many successes so far include the creation of a Dementia Café, inter-generational choir and singing for the brain group and year 5 science-based learning about the brain and dementia resulting in a dementia friendly society debate chaired by local MP Bridget Phillipson.

Future plans include building a community area within the school and embedding dementia learning within the curriculum. To find out more visit www.bernardgilpin.com

Becoming a dementia friendly organisation, Beth Swanson and Anne Sutcliffe

Beth and Anne, from South Tees NHS Trust, outlined the enormous challenge organisations face in becoming dementia friendly hospitals and that acute hospitals are difficult places for people with dementia with 77% of carers unhappy with treatment. At South Tees they have developed a strategy to educate staff and raise dementia awareness. Their aim is to develop a skilled and effective workforce, with recognised competency, able and unafraid to champion compassionate person centred care. They are achieving this through a competency framework, a training directory and organisational training plan and through the appointment of three clinical educators.

Use of Lean methodology to improve Dementia Care, Christine Murphy

Christine, from the North Tees Dementia Collaborative, spoke of how they are using lean methodology to reduce waste and help simplify the complex pathways dementia patients have to negotiate.

The tried and tested ‘lean’ method uses five-day rapid improvement workshops to improve processes. Some of the areas they are concentrating on for people with dementia include: preventing unnecessary admissions from care homes; assessment and discharge planning in acute wards; managing behaviours that staff find challenging in an acute setting; improving access to intermediate care and reablement; assessment and delivery of support plans in the community.
Sporting memories network, Tony Jameson-Allen

Tony introduced the Sporting Memories Network, which aims to tackle dementia through the power of sport, as sport unites communities and holds memories for so many people. The network has many high profile supporters from the sporting world including David Coulthard and Robbie Savage. It runs a number of initiatives including ‘Sporting Memories Games’ held with Premiership and Championship football and rugby league clubs. A BBC 5 Live documentary on the work of the network is due out in Summer 2013 and they are hoping to develop a sporting project across Tyneside in partnership with Newcastle United’s Newcastle upon Tyne Foundation.

They also have a memories website which captures sporting memories and raises awareness of dementia. So far 1700 memories have been shared on the website with open inter-generational conversations happening as a result of these. You can visit the website at www.sportingmemoriesnetwork.com

The dementia research agenda, Professor Ian McKeith

Professor McKeith from Newcastle University’s Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) spoke of the difficulties in engaging people with dementia to take part in research. Last year, only 2.7% of over 32,000 people diagnosed with dementia in the north east took part in research.

Several initiatives are taking place to improve uptake, including adding a note to the bottom of outpatient letters prompting people to ask their clinician about research. Ian asked for help as DeNDRoN needs people to actively come forward with ideas about what research they think is important. He also asked for everyone to support the ‘it’s OK to ask campaign’ and to help get dementia research onto organisational agendas.

You can access the ‘Patients in Research info-kit’ - a platform to share stories, ideas, tips and tools to embed research across the NHS at www.patientsinresearch.org

Carers’ perspectives on research, Anne Lister and David Gambles

Anne cared for her husband Paul who had Lewy Bodies dementia for seven years before he died in 2007. She said: “Paul offered to take part in research because he wanted to stop people going through what he went through. Being part of the studies gave him a sense of purpose as he had lost many of his former skills. Dementia is an isolating illness and because of the research we did not feel as isolated as we were involved in so much. Taking part in the studies also meant we had access to clinical care we might not otherwise have had.”

David’s wife Carol was diagnosed with Alzheimers seven years ago at just 55, and has lived in a home for the past year. David said: “Carol and I got involved with DeNDRoN at a public participation day. Carol was mid way through her illness but was too young at the time to take part in research so I joined the PPI panel and got lots out of it. There is a big hole in life which I want to fill and put something back in repay the help and support I have had from many organisations. To anyone thinking of getting involved in research - go for it! - you get more back than you give. Carol has taken drugs which have helped hold the disease back - drugs that would not have been available without research.”