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Time matters: a call to prioritise brain health

This article summarises the content of a policy report recommending a proactive approach to neurodegenerative disease management. Nurses are reminded of the importance of the contribution of nurses to policy making and implementation of policy.

Key words: Neurodegenerative disease, Alzheimers' Disease, Parkinsons' Disease, Policy

It is well recognised that neurological conditions need to become more of a priority at Government or commissioning levels in the UK (Thomas, 2016) and that, often, there are variations in the quality of services provided to patients with neurological conditions (Fuller et al, 2018). For some conditions, campaigns for early disease detection, the timely provision of interventions and the communication of important-public health messages have shown great success (Hughes-Hallett et al, 2016). However, the same is not true for most conditions of the brain (Giovannoni et al, 2019). Brain health is slowly becoming better understood, but much still needs to be done to manage the projected increase in the numbers of people affected by progressive neurodegenerative diseases. Greater education is also needed, both for the patients with these conditions and the health professionals caring for them.

Nurses' contribution to policy-making

Nurses have a key role to play in both the design and implementation of national policy documents and guidelines. Owing to the close relationships nurses share with their patients, their perspective is unique, particularly with regard to insight into the problems faced daily by people with long-term neurological conditions. Nurses have an understanding of inter-family dynamics, practical issues, psycho-social concerns and financial stresses and, therefore, should be involved in policy development to add that 'realworld' aspect.

Strong, co-ordinated nurse leadership is essential, not only in the development of national policy but in the subsequent planning for the delivery of recommendations for service improvements. Health promotion messages will be delivered and implemented by nurses; resources are often administered by nursing teams; and nursing records are often used for research purposes and data collection.

2020 marked the bi-centennial celebration of Florence Nightingale's birth, and many tributes have been paid to the 'philosophical founder of modern nursing' (Peate, 2019). It is interesting to reflect that records show all of the roles listed above—health promotion, administration of resources and data collection—were all regularly performed and championed by Florence Nightingale. Therefore, if offered the opportunity, nurses should be prepared to contribute to the development of national and international policy documents and to engage fully in their implementation and audit.

Time matters: the *Think Brain Health* report

In 2018, I was invited to join a working party, made up of an independent group of international scientists, clinicians and health provision professionals, to develop a policy report calling for a more proactive approach to the detection and management of neurodegenerative disease. The intention was to develop a set of recommendations,

targeting the general public, health professionals, policymakers and regulators, to propose a preventive approach to neurodegenerative disease. Alzheimer's disease (AD) and Parkinson's disease (PD) are the focus of the report, because they are the two most common neurodegenerative diseases: PD affects more than 6 million people worldwide (Dorsey *et al.*, 2018); AD is the most common cause of dementia, which affects approximately 50 million people (World Health Organization (WHO), 2020). However, the principles underlying the recommendations can be applied to the majority of long-term neurodegenerative conditions.

What follows is a summary of the published report and the resulting policy recommendations. *Time matters: a call to prioritize brain health* summarises published evidence and the consensus findings of the international multidisciplinary expert group, including clinicians, researchers and representatives from patient advocacy and professional groups. It presents an expert, evidence-based position for policy recommendations that encourage individuals to participate actively in prioritising their own brain health. It challenges policymakers, researchers, funding bodies and health professionals to collaborate in planning for the healthcare structures of the future—and it is important that nurses are part of this.

The report is supported by a campaign website—<https://www.thinkbrainhealth.org/>—and a successful conference series in November 2020, entitled **Think Brain Health—a policy, clinical and research challenge**, covered some of the issues raised within the report. All the conference presentations can be viewed online: <https://www.thinkbrainhealth.org/events/>

The six chapters cover the wide-ranging issues to be considered by health professionals, policymakers and patients alike. The detail and high-quality deliberation of evidence, combined with expert opinion, allows the reader a useful insight into the breadth of clinical topics linked to PD and AD and makes the document a useful resource for neuroscience practitioners. The chapters are as follows:

- Chapter 1: The impact of neurodegenerative diseases
- Chapter 2: The course of neurodegeneration
- Chapter 3: Risk factors for neurodegeneration
- Chapter 4: Strategies to identify people at risk of the disease
- Chapter 5: Management following neurodegenerative disease diagnosis
- Chapter 6: Actions to avert a future crisis.

The detail of the report can be condensed into the following conclusion and policy recommendations:

- The key risk factors for AD and PD, both modifiable and non-modifiable, should be understood by health practitioners and the general public. By implementing beneficial behaviours and potential lifestyle changes, brain health can be improved, just as these behaviours have been shown to improve health in other conditions, such as cardiovascular disease
- What is good for the heart is generally good for the brain is an important public health message that should be shared

- Primary prevention strategies that encourage modification of behaviour are not the only potential interventions. Population screening or health-check programmes that aim to detect disease early have been successful in some areas of medicine (e.g. cancer and heart disease) and should be considered in neurological disease
- To prepare for future advances, the authors recommend some specific areas for research, including continuing the search for effective diagnostic tools, biomarkers, drug targets and treatments. If associations between brain diseases and some of their causative factors could be identified, this could speed up the identification of drug targets
- Wearable technology may be useful in tracking an individual's disease course and enabling personalised healthcare
- The recommendations should help those tasked with organising health services to decide how best to prepare for the advent of national programmes that facilitate earlier detection and intervention of neurodegenerative diseases, such as AD and PD
- All interested stakeholders need to work together for the common goal of improved healthcare for neurodegenerative diseases. This can be achieved far more effectively together than separately.

Policy recommendations

Health promotion recommendations

The message 'what is good for your heart is generally good for your brain' needs to be widely communicated and understood. Therefore, policymakers and public health bodies that provide health information to the general public should act on the recommendations below which are listed in the report and on the Think Brain Health website ([Alzheimer's Research UK, 2020](#)):

- Protect and provide the public health budgets to improve public understanding of how to promote brain health and promote a positive approach that helps to prevent neurodegenerative diseases
- Encourage behaviours at all ages that help to improve brain health, such as healthy eating and taking adequate exercise
- Provide a supportive environment, including national guidance and legislation when appropriate, that empowers individuals to make important lifestyle changes
- Prepare for the likely growth in the demand for genetic testing by people who want to understand their risk of a neurodegenerative disease. This should involve establishing rigorous support systems and processes, including training health professionals to counsel individuals who have undergone testing and to share their test result in an ethical and regulated way
- Provide access to available and effective treatments in a timely manner.

Clinical recommendations

Health professionals and administrators will continue to play a key role in the management of people with, or at risk of, a neurodegenerative disease and should act on the recommendations below:

- Refer anyone with a suspected neurodegenerative disease to specialist, multidisciplinary services, if they are available
- Provide follow-up to individuals in the form of multidisciplinary services to provide ongoing, widely accessible holistic care, including prevention information, treatment options and support.

Research recommendations

Researchers and organisations that fund scientific research need to help health professionals and society to avert a future health crisis. Further work is needed to develop treatments for neurodegenerative diseases and validate diagnostic tools to identify people at risk. Meanwhile, healthcare decision-makers should start to pave the way for the advent of national programmes that facilitate earlier disease detection and intervention, with appropriate consideration of the ethical implications this would entail. To this end, the authors recommend that additional funding for research is provided in order to meet the goals listed below:

- Improve our understanding of the underlying molecular mechanisms of the at-risk and pre-symptomatic phases of neurodegenerative disease
- Increase our understanding of diagnostic and progression markers, particularly during the pre-symptomatic and prodromal phases, to help to track the disease course and severity
- Identify the effectiveness and cost-effectiveness of interventions to promote brain health
- Identify which tests for disease detection and diagnosis have optimal accuracy, availability and affordability
- Assess the relative weight of different risk factors (e.g. lifestyle, genetic and molecular factors) and the interactions between them, so that decision-makers can decide how to prioritize them and address them
- Understand the extent to which an individual's awareness that he or she has strong risk factors for a neurodegenerative disease may motivate them to change their behaviour, and how best to support that behaviour change
- Agree on policy and recommendations about the appropriate support required for a tested individual before and after a health check
- Investigate the risk and protective factors involved in specific neurodegenerative diseases and neurodegeneration in general, at both the individual and societal level (e.g. by improving infrastructure and social capital)
- Develop, validate and approve tests, tools and apps for monitoring brain health at an individual level by working in collaboration with regulatory authorities and stakeholder groups, including researchers, clinicians and funding bodies
- Ensure that data from research are made publicly available and pooled to maximise their usefulness in developing the best diagnostic tools and treatments
- Ensure that research results are provided, in a sensitive manner, to study participants, and that appropriate support is given.

Actions to avert a future crisis

Neurodegenerative diseases pose an enormous socioeconomic and individual burden, and this will continue to grow. To avert a crisis, the following recommendations are made:

- Individuals should start to look after their brain health now and to change their behaviour to improve their chances of healthy ageing
- Health professionals should educate the public about safeguarding their brain health
- Public authorities should provide general health recommendations that include the benefits for brain health
- Administrators of healthcare systems should ensure timely access to available interventions and services
- Budget holders in relevant organisations should plan now to conduct research that will inform healthcare service design and delivery, so as to optimise disease diagnosis and management of people with or at risk of neurodegenerative diseases

- Researchers should investigate the best ways for health professionals to tell people the results of risk assessments or diagnoses in a timely and sensitive manner
- Researchers should investigate further the most appropriate and effective biomarkers and treatments.

Implications for clinical practice

The knowledge and recommendations contained within this publication will help to facilitate the ongoing collaborative planning and management of health and social care systems favoured by policy documents such as NHS England's *Five Year Forward View* (NHS England, 2014). In the subsequent document, *Delivering the Forward View: NHS Planning Guidance 2016/17—2020/21*, health services are required to design a 'Sustainability and Transformation Plan' that includes considering primary care services, social care and prevention of disease (NHS England, 2015). Dementia is mentioned specifically: at a minimum, two-thirds of people with dementia should have a diagnosis (NHS England, 2015) and, by implication, access to appropriate services. While these documents reflect plans for NHS England, the Think Brain Health Report makes recommendations that can be applied to healthcare systems across the world.

There is a clear role for nurses in delivery of many of the policy recommendations detailed in *Time matters: a call to prioritize brain health*. The first step towards succeeding in this is to **be aware of the recommendations and share them with colleagues**. Following this, nurses should be prepared to **take the lead in pushing for implementation of new ideas**. Many policy documents are published every year, with resources of time and money poured into their development—but how many actually make a significant difference to patient outcomes?

This is where strong nurse leadership is needed to embrace forward-thinking and innovative ideas that will positively affect services and patients, and to be prepared to fight for them at local and national levels, with the same passion with which we care for our patients every day. To follow in Florence's footsteps.

The report is

Key points: 3-4 bullet points summarising the article

This article has summarised and presented the contents of 'Time matters: a call to prioritize brain health' report. This document written by leading figures linked to neurodegenerative disease. The report call for individuals, health practitioners and policy makers to promote brain health, consider the judicious use of risk assessment and conduct research that will inform healthcare service design and delivery, all in order to optimize diagnosis and management of people with, or at risk of, neurodegenerative diseases.

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