New care framework for Huntington’s disease

Local staff and families at forefront of work to help people with complex neurodegenerative condition

One of the world’s first local Care Frameworks for Huntington’s Disease (HD) has been launched in Lothian.

Families affected by HD joined health and social care partnership staff at the launch at University of Edinburgh’s Chancellor’s Building, within the campus of the Royal Infirmary of Edinburgh. Lothian is rolling out its own localised version of the Scottish National Care Framework for HD.

The Framework seeks to help families affected by the complex neurological condition to receive the best possible care, information and support regardless of where they live. Families and staff from Edinburgh City, East Lothian, West Lothian and Midlothian were present at the launch.

Dr John Harden, National Clinical Lead for Quality and Safety at the Scottish Government, said:“It was a pleasure to have been involved in the launch of the Lothian Care Framework for Huntington’s Disease. The Scottish Government funded Scottish Huntington’s Association to develop a National Care Framework for HD, and has been hugely encouraged by this and the localised versions now being rolled out across Scotland.

“We are fully committed to backing this project until its completion. Not only does it stand to benefit families impacted by Huntington’s disease but we are hopeful it could in due course be used as a model to help people affected by other neurological and long term conditions. This is a really exciting prospect.”

Dr Alasdair FitzGerald, Clinical Lead Consultant in Neurorehabilitation at NHS Lothian, was a key member of the advisory group that developed the Lothian Framework.

He said: “Huntington’s disease is a rare neurodegenerative condition with symptoms that vary widely from person to person. The Framework is designed to help by guiding health and social care staff and empowering families impacted by the disease.

“Developing it has been an enormous task, but the result is an extremely comprehensive and easy to use tool that has the ability to transform care and support for families. I would encourage anyone with an interest in the condition to make use of the Framework to drive up standards of care and support throughout Lothian.”

Dina De Sousa, Chair of the Lothian Huntington’s Disease Support Group, said:“Having the Care Framework in place allows families to access information and help all in one place. I remember an advert for Yellow Pages that said ‘let your fingers do the walking.’ This is one of the things the Framework is about.

“It’s an easy to use guide all at your fingertips. Information from genetic testing, planning a family, care support, financial support, dealing with symptoms and much more. The behind the scenes labour has been going on for a few years and there have been so many people involved. A big congratulations to all. But the work is not finished, far from it. There is still a lot to do. This actually will be an ever evolving project. The foundation has been set and now we can build upon it.”

Susan Dalgliesh, Strategic Planning & Commissioning Officer for Physical Disabilities at Edinburgh City HSCP, said:“The

Framework has had numerous challenges and a diverse range of participants. However it has had one constant: committed and compassionate people, determined to drive the focus and energy to create a personalised and humanistic approach to supporting people with HD and their families and carers.

“I think it has been an outstanding process with a unique diligence to detail and great credit is due to all involved. If shared and used this Framework will make a real difference.”

John Eden, Chief Executive of Scottish Huntington’s Association, said:“Family members and a full range of health and social care staff from across Lothian have been instrumental in developing this tool. We owe so much to them all for their guidance and support.

“Not only is the Framework making waves throughout Scotland but is capturing attention internationally. It’s a hugely significant piece of work that, if widely shared and used, has the potential to make a real difference to people’s lives.”

The HD Care Framework has been supported by the Scottish Government, all parties in the Scottish Parliament, the National Advisory Committee for Neurological Conditions, NHS Boards, Health & Social Care Partnerships, health & social care staff, professional bodies, HD family members, academics and national and international third sector partners. The National Framework can be viewed at care.hdscotland.org . The Lothian version can be viewed within the “Regional Frameworks” section of the site.

Back row, L-R: Dr Alasdair FitzGerald, Clinical Lead Consultant in Neurorehabilitation at NHS Lothian; Pete Carruthers, Specialist Youth Advisor, Scottish Huntington's Association; John Eden, CEO, Scottish Huntington's Association; Dr John Harden, National Clinical Lead for Quality and Safety, Scottish Government; Trevor Law, HD Specialist for Lothian, Scottish Huntington's Association; Annette Brown, Senior HD Specialist for Lothian, Scottish Huntington's Association.

Front row, L-R: Jo Baldock, Senior Financial Wellbeing Advisor, Scottish Huntington's Association; Shona Cumming, Admin/Resource Worker, Scottish Huntington's Association; Dina De Sousa, Chair of Lothian HD Support Group; Susan Dalgliesh, Strategic Planning & Commissioning Officer for Physical Disabilities at Edinburgh City HSCP.

Around 1 in 5,000 people in Scotland have HD. 1,100 people have been diagnosed with the disease with an estimated 4,000 – 6,000 at risk of inheriting it from their parents.

The National Care Framework seeks to help ensure families affected by the condition are given the best possible care, information and support regardless of where they live in Scotland. It has been endorsed by NHS Boards, HSCPs, health &

social care staff, professional bodies, HD family members, academics and national and international third sector partners (http://care.hdscotland.org/endorsements/)

The Framework – the first of its kind in the world – was developed by a multi-disciplinary expert group lead by the Scottish Huntington's Association, with funding and support provided by the Scottish Government. The National Framework can be viewed at care.hdscotland.org The Lothian Framework can be viewed within the "Regional Frameworks" section of the site.

About the Scottish Huntington's Association (SHA)

Scottish Huntington's Association is the only charity in the country exclusively dedicated to supporting families impacted by HD.

SHA does this through a team of HD Specialists, a world leading team of Specialist Youth Advisors and a Financial Wellbeing Service. The lifeline services SHA provides make the difference between families coping and not coping.

You can support our SHA's work by visiting: hdscotland.org

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For enquiries relating to the Scottish Huntington's Association and/or the Care Framework for HD please contact Alistair Haw on 07736 457247 or alistair.haw@hdscotland.org