



## MEDIA RELEASE

### Delayed diagnosis of DCM leaves patients with life changing disabilities

Too many people face life changing disabilities because of failures to recognise the early symptoms of Degenerative Cervical Myelopathy (DCM), according to a new international charity led by top neurosurgeons – Myelopathy.org.

DCM, mainly found in the over 50's but sometimes in significantly younger people, is the result of wear and tear and arthritis in neck vertebrae. The damaged vertebrae can compress and narrow the spinal cord causing difficulties with balancing, walking, hand movements, numbness and, in extreme cases, paralysis from the neck down.

Myelopathy.org is supporting the call by Public Health England for the NHS to recognise and adapt to meet the needs of the health demands of an ageing population – including raising awareness among all health professionals of DCM previously known as CSM (Cervical Spondylotic Myelopathy).

Neurosurgeon and Clinician Scientist at the University of Cambridge Mark Kotter said: “Early diagnosis and appropriate management and treatment of DCM is key to avoiding life changing disabilities. When surgery to relieve pressure on the spinal cord is too late the damage has been done. Patients face life-changing disabilities, unable to pursue their careers and even left totally housebound.

“Currently it is thought up to five in every 100 people over 50 years suffer from DCM. The median age in the UK is 40.7 years and predicted to rise. The number of people with DCM who need to be identified will increase too.”

Myelopathy.org is bringing researchers, clinicians, healthcare professionals and patients together to raise awareness of DCM.

More...

*Myelopathy.org (www.myelopathy.org) is a registered charity (charity no. 1178673)  
Registered office Pioneer House, Vision Park, Histon, Cambridge, CB24 9NL*





Mr Kotter said: “GPs are often at the frontline of recognising the symptoms of DCM but cases are also picked up by physiotherapists, occupational therapists, osteopaths, sports therapists, orthopaedic teams, nurses and others carers. We need to spread the message as widely as possible.”

One cause of delayed diagnosis is that the symptoms experienced by people with DCM can be diverse including pain in the neck or shoulder, numbness in various parts of the body, loss of balance, loss of coordination, spasticity, heavy legs and difficulties walking.

Often patients are referred for a range of therapies which fail to deliver benefits before being referred for an MRI which, alongside other tests, helps identify the condition. “Each referral for a therapy ahead of an MRI delays diagnosis sometimes for several years. Patients with DCM have far better outcomes with early diagnosis. Some need surgery immediately to relieve the pressure and damage being done to their spinal cord. Other patients need careful monitoring so that they can undergo surgery if it is needed. This personalised approach to treating DCM is also proposed in the most recent clinical guidelines,” said Mr Kotter.

The importance of early diagnosis and greater awareness of DCM is emphasised by Dr Ben Davies, Director of Myelopathy.org. He said: “Up to 18 in every 100 people who have a hip fracture also have undiagnosed Myelopathy – a condition that has devastating consequences if left undetected. Myelopathy.org is a unique community bringing patients and professionals together, from all corners of the globe, to develop education and drive progress.”

Ends

*Please contact [info@myelopathy.org](mailto:info@myelopathy.org) for further information and images.*

**Notes to editors:**

Myelopathy.org is a not-for-profit worldwide charity, registered in 2018, promoting collaborative working between researchers, clinicians and healthcare professionals; providing information and support to people diagnosed with DCM; and raising awareness of the condition globally.

It is the only charity and website in the world solely dedicated to DCM and offers a unique portal for professionals and patients to come together.

Charity Trustees include: Dr Mark Kotter, Lady Julia Carter, Weslie Janeway and Dr Johann Graggaber

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