

Media Fact File

Myelopathy.org

Myelopathy.org is the first charity in the world dedicated to Cervical Spondylotic Myelopathy (CSM) – also known as Degenerative Cervical Myelopathy (DCM).

The charity is raising awareness of this common neurological condition which can lead to serious disabilities; driving forward scientific research into innovative approaches and treatments; and providing information and support to people with CSM across the world.

Myelopathy.org, which gained its charity registration in 2018, was founded by Dr Mark Kotter, National Institute for Health Research (NIHR) Clinician and Honorary Consultant in Neurosurgery at the University of Cambridge, and Dr Benjamin Davies, researcher and NIHR trainee neurosurgeon at the University of Cambridge.

Dr Kotter's ambition is to advance the way CSM is treated based on a better understanding of the course of CSM, and by identifying the best care for patients. His translational research investigates the cellular and molecular mechanisms underlying CSM in a bid to develop novel therapies. [@KotterLab](#)

Dr Davies is determined to accelerate the diagnosis of CSM and improve patient outcomes by improving our understanding of the disease.

They also believe that bringing together CSM researchers from across the world to share their knowledge and expertise will transform the treatment of CSM and eliminate many of the disabilities associated with the condition.

The Lord Carter of Coles generously offered to host the official launch of Myelopathy.org at the House of Lords, Westminster, London, on 7 May, 2019.

The Director of Myelopathy.org is Dr Benjamin Davies MBChB Hons BSc MRCS.

The Trustees include Lady Julia Carter, Weslie Janeway, Dr Johann Graggaber and Dr Mark Kotter.

Dr Michelle Starkey is the charity Administrator and works with a team of volunteers. Iwan Sadler founded the charity's international community support group for people with CSM on Facebook, Myelopathy Support, and is assisted by a team of volunteer moderators.

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For further information, email: info@myelopathy.org or call XXXXXXXXXX

11 April 2019

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Cervical Myelopathy

For the best clinical outcome, people with CSM need to be recognised, diagnosed and treated within six months.

Cervical Spondylotic Myelopathy (CSM) – also known as Degenerative Cervical Myelopathy (DCM) – is thought to affect at least five per cent of people over 40 years. However, some people develop the condition in their 20s and 30s.

CSM is primarily caused by wear and tear on the vertebrae in the neck which can compress the spinal cord causing irreversible nerve damage and potentially leading to paralysis from the neck down.

Diagnosis is confirmed by a spine surgeon, a neurosurgeon or an orthopaedic surgeon following a physical assessment and an MRI (Magnetic Resonance Imaging) of the cervical spine.

Many patients will be recommended to have surgery on one or more cervical vertebrae to relieve the pressure on their spinal cord and prevent further nerve damage. Others will require monitoring for any worsening of their condition.

Many people mistake or dismiss the early signs of CSM as a natural part of ageing. Symptoms may include some of the following:

- Clumsy hands – difficulty doing up buttons, handling small items, dropping things even when being particularly careful
- Changes in feeling and sensations – tingling, pins and needles, numbness
- Awkward legs – stiffness, difficulties walking, change in gait, lack of balance, trips and falls
- Aches and pains
- Difficulties passing urine and/or incontinence
- Problems with mood and sleep

Myelopathy is a progressive condition and any symptoms caused by CSM, if ignored, will worsen over time.

Currently, not all GPs are fully aware of the range of symptoms caused by CSM. Reports from people in the Myelopathy.org support group show that initially patients are frequently referred for investigations and treatments for other possible conditions, for example, carpal tunnel syndrome, MS and physiotherapy for neck pain or walking difficulties.

The waiting times for these investigations and treatments cause significant delays – many months and in some cases years – during which the condition of the patient continues to deteriorate.

For the best clinical outcome, people with CSM need to be recognized, diagnosed and treated within six months.

The spinal cord, and its nerves, is very limited in its ability to recover from any damage so people receiving a late diagnosis and treatment are most likely to suffer from life changing disabilities – many unable to continue their careers and in need of support to live independently.

People with CSM have some of the lowest quality of life scores of all chronic diseases, worse than forms of cancer, heart and lung disease.

In a survey of more than 1,000 patients by Myelopathy.org, 40 per cent reported that they were reliant on others for support with their day-to-day activities.

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