

Myelopathy.org Media Fact Sheet

Myelopathy.org is the first global scientific and clinical charity dedicated to positively transforming patient outcomes in Degenerative Cervical Myelopathy (DCM) through patient support, patient and professional education, global awareness, and worldwide research. Together we will create a world where people live their lives free of the pain, terror, and isolation of DCM with immediate diagnosis, timely treatment, and wrap-around patient-centred support.

DCM is a life lived in fear of instant paralysis and the knowledge that the tremors, shooting pains, imbalance, and incontinence can only get worse, at best be stopped but never reversed. This community is shrouded in an endemic lack of knowledge¹ that prevents its diagnosis and has starved patients and researchers alike of support.

Described by The Lancet as “ambitious, but long overdue,” Myelopathy.org is leading the fight for this previously unseen community to build a world where people can live their lives free of the life-limiting impact of DCM and have a healthy, active, and independent future.

Vision

Working together to create a world where people live their lives free of the debilitating impact of Degenerative Cervical Myelopathy (DCM) with immediate diagnosis, timely and effective treatment, and wrap-around patient-centred support.

Mission

Our mission is to be the catalyst that positively transforms patient outcomes in Degenerative Cervical Myelopathy (DCM) through patient support, patient and professional education, global awareness, and worldwide research.

About Myelopathy.org

Myelopathy.org was founded in 2017 as a collaborative information and support initiative bringing together the work of Dr Mark Kotter, academic neurosurgeon and specialist in complex spinal surgery, and Dr Benjamin Davies, trainee academic neurosurgeon and Research Fellow, with the prolific Myelopathy.org Support Group on Facebook founded by Iwan Sandler who has been living with Degenerative Cervical Myelopathy (DCM) since 2014.

Mark and Ben initially set up Myelopathy.org to better engage with people who have DCM as they had both become interested in DCM through their research into regenerative medicine and development of NHS care pathways. Iwan Sandler was diagnosed with DCM in 2014 and feeling increasingly alone and frustrated by the lack of information and support he developed his own awareness campaign and one of the first Facebook community pages for DCM. It was inevitable the three should meet and their combined goals to raise awareness, increase support and improve diagnosis and treatment pathways led to the creation of Myelopathy.org. Registered as a charity (No. 1178673) in June 2018 our charitable objectives are to advance health and education in all aspects of DCM in particular by:

¹ Wager, M., et al., Quantitative analysis of medical students' and physicians' knowledge of degenerative cervical myelopathy. BMJ Open, 2020

- Immediate Diagnosis: Helping people and health professionals recognise the symptoms.
- Timely Treatments: Driving research into new & innovative treatments that are timely & effective.
- Patient Support: Building an international support community for people living with DCM.

The work of all three co-founders has been recognised by the Prime Minister through the Points of Light Award in February 2020 for outstanding volunteers who are making a change within their community.

What Is Myelopathy?

Myelopathy is a medical term used to describe damage to the spinal cord. Although myelopathy can be caused by a range of diseases, Degenerative Cervical Myelopathy (DCM) is by far the most common cause, estimated to affect of up to 5% of people over 40 years old, and incidence is expected to rise in ageing populations². DCM, formerly known as Cervical Spondylotic Myelopathy, is a common and disabling condition that arises when degenerative conditions of the cervical spine (the neck) compress the spinal cord, leading to an evolving spinal cord injury. It is a progressive condition that can cause irreversible spinal cord damage and surgery to alleviate DCM is currently the only treatment available to create space for the spinal cord and stop further spinal cord injury.

DCM can affect almost any of the body's functions. Symptoms are varied and often differ from one person to the next. The spinal cord connects the brain to the rest of the body. Damage to the spinal cord in the neck can interrupt the control systems and information running through the cord and linking the brain to the rest of the body.

People with DCM can therefore experience a range of symptoms including:

- difficulty using their hands – dropping things, struggling to do up buttons etc.
- difficulty using their legs – stiffness, unbalanced, changes in walking, falls etc.
- changes in feelings and sensation – numbness, pins, and needles etc.
- difficulty passing urine and/or incontinence
- pain
- problems with mood and sleep

Diagnosing DCM, especially early, is not straightforward. It requires medical practitioners being aware of DCM and then pulling three key sources of information together. The three key sources of information required to diagnose DCM are:

- a person's symptoms
- a physical examination and
- MRI (Magnetic Resonance Imaging) of the cervical spine

Early diagnosis, and appropriate monitoring and treatment, are the only way of improving outcomes. However, many early symptoms of DCM can be very subtle or only occur now and then meaning it is often mis-diagnosed, missed, or ignored as part of "growing older". Yet without diagnosis and timely treatment this condition progressively gets worse, and people have a far higher risk of acute spinal cord injury following minor injuries, such as a fall at home, the result of which can be instant paralysis.

Owing to the potential risks of surgery, and the potential for DCM symptoms to remain mild for extended periods, surgery is currently only offered to those with moderate to severe, or progressive symptoms.

² A Focus on Patient Outcomes in Cervical Myelopathy, The Lancet, Vol 18, July 2019

Why Are We Needed?

Too often written off as infirm, clumsy, or ageing badly, people with Degenerative Cervical Myelopathy (DCM) fight a daily battle with this debilitating spine condition to be heard, diagnosed, treated, and informed. Conservative estimates predict that up to 5% of people over the age of 40 are living with DCM, nearly 6 million people in the UK and USA alone. Most will never get a diagnosis and it is estimated that fewer than 20% of cases are diagnosed in the UK meaning over 1 million people are living with the uncertainty and physical challenges of no diagnosis. Sufferers that are diagnosed wait on average two to five years for diagnosis. Sadly, treatment is not guaranteed upon that diagnosis and patients wait on average three to five years before getting appropriate treatment, even though treatment within four months is recommended. Furthermore, due to a lack of research the only treatment available today is surgery which cannot undo the damage that has already been done.

Even though DCM is one of the most common neurological conditions, it is probably one of the least studied. In the last 25 years DCM has received less than £35million in research funding, less than 2% of the research funding for conditions such as ALS, MS or Traumatic Spinal Cord Injury. It is also a sad indictment that DCM rarely features in the UK Medical School curriculum or textbooks. This overwhelming knowledge deficit is one of the primary reasons the condition is under-diagnosed, and diagnosis is usually delayed. Alongside the lack of education and research reasons include the absence of a diagnostic algorithm, poor awareness of the disease, and the often subtle and nonspecific symptoms that are commonly mistakenly attributed to ageing or to other conditions (e.g., carpal tunnel syndrome, multiple sclerosis).

The lack of immediate diagnosis and timely treatment leads to unnecessary suffering, and increases the burden on carers, families, and health care systems. Without diagnosis and treatment people have a far higher risk of acute spinal cord injury following minor injuries, such as a fall at home, the result of which can be instant paralysis. As a result:

- 40% of people with DCM reported they were reliant on others for support with their day-to-day activities
- 35% reported they were unable to work because of the disease
- more than 50% of people with DCM are left with lifelong disability and unable to work³

As the only treatment, surgery is able to offer the most meaningful benefit but fewer than 5% of patients make a full recovery and are instead left with lifelong disabilities. This has been associated with high levels of long-term dependence, consequent unemployment and low quality of life, and the cost to UK society has been conservatively estimated at £74.1m⁴.

The global lack of awareness of DCM means that people with DCM are confused, isolated and have some of the lowest quality of life scores of all chronic diseases, worse than forms of cancer, heart, and lung disease. Prior to the creation of Myelopathy.org patients literally had nowhere to turn – a Google search for the condition would only return information on canine myelopathy (an equivalent disease prevalent in dogs).

³ Pope, D.H., et al, Diagnostic Delays Lead to Greater Disability in Degenerative Cervical Myelopathy and Represent A Health Inequality. *Spine (Phil Pa 1976)*, 2019

⁴ Cost of Myelopathy to Society by Dr Richard Phillips & Ellen Sarewitz, Goffin Consultancy commissioned by Myelopathy.org

The deadly conundrum of DCM is a combination of unseen prevalence and unmet needs. Together we have a responsibility to change today's reality of a life of pain with DCM - from immediate diagnosis to effective intervention - and transform the outcomes for a pain-free tomorrow.

What Is Our Impact?

Our goal is for all people with Degenerative Cervical Myelopathy (DCM) to be immediately diagnosed and have access to timely and effective treatment and wrap-around patient-centred support. To achieve these goals, we are investing in research and awareness raising campaigns across the three outcome areas of: diagnosis, treatment, and support. We are committed to pioneering and pursuing patient-directed research for public benefit and have founded the SMART Research Group (Sufferers with Myelopathy Approved Researchers to Research) to ensure all external proposals are peer reviewed and approved prior to funding. Projects we are currently funding include:

DIAGNOSIS

Sufferers wait on average 2-5 years for diagnosis. However, treatment within 4 months is associated with the best chance of a full recovery. Delays lead to greater dependence and disability with over half of sufferers unable to return to work. For this reason, as well as others, DCM sufferers have amongst the worst quality of life scores of all chronic diseases. The primary barrier to accurate and timely diagnosis is awareness and accurate diagnostic pathways amongst healthcare practitioners so they can identify a person's symptoms and undertake a physical examination and MRI to confirm the diagnosis.

- **Assessment Tool Development**

In collaboration with the University of Cambridge we are working to develop new methods for modelling diagnostic and assessment pathways. By identifying the key drivers and barriers to assessment flow, we will be able to identify an optimum pathway and create an assessment tool that utilises this for practitioners.

- **Professional Awareness**

To raise awareness of this condition amongst professionals we are attending and presenting at a variety of professional conferences including the Society of British Neurological Surgeons and the British Association of Spine Surgeons.

Currently, surgery is the only evidence-based treatment for DCM. It is able to stop further damage to the spinal cord, but recovery is dependent on the amount of spinal cord damage that has already occurred at the time of surgery. Strategies such as rehabilitation, or novel medicines that support neural plasticity, are needed to allow more considerable recovery.

- **Medicinal Treatment: RECEDE Myelopathy**

Regeneration in Cervical Degenerative Myelopathy (RECEDE) led by the University of Cambridge and National Institute for Health Research is a Phase III, double blind, placebo randomised controlled efficacy study of Ibudilast (a medicine) as an additional therapy to decompressive surgery (the gold standard treatment) for DCM. Ibudilast is a medicine currently under investigation for treatment of Multiple Sclerosis, Motoneuron Disease (ALS) and Brain Tumours.

- **Optimal Surgical Management: NIHR POLYFIX DCM**
There are currently two surgical options for DCM (when at the back the neck): a Laminectomy (just removal of bone behind the spinal cord) or a Laminectomy and Fusion (the removal of the bone and stiffening of the neck using metal implants). There is currently no evidence as to which approach is superior and surgeons advocating for one or other approach are split 50/50. This study with the National Institute for Health Research aims to determine the superior approach with pre- and post-surgery analysis of 394 patients across 30 UK sites.
- **Pre-Surgical Myelopathy Management**
This small research study at the University of Cambridge is analysing the best management pathways at the point of pre-surgical diagnosis of DCM and aims to inform and enable patients to manage their condition to the best possible level prior to surgery.
- **Surgical Aftercare & Recovery**
In a qualitative study led by the University of Nottingham we are investigating the impact of DCM surgery on your ability to exercise. Initial research is through a qualitative study that aims to produce a consensus initiative to produce recommendations on surgical aftercare.
- **Professional Collaboration & Debate: UK Academic Spine Symposium**
Myelopathy.org established the first annual UK Academic Spine Symposium at the Royal Society of Medicine in 2019. This meeting brought together the leaders in the field of academic spine surgery to talk about the clinical research studies they are involved in, for example the FORVAD trial, the NERVES trial and the GIRFT National Report.

SUPPORT

A lack of awareness across both professionals and patients has led to patients feeling isolated, scared and alone. Peer-to-peer support alongside centralised, peer-reviewed information is vital to empowering people living with DCM to take ownership of their condition and care. To facilitate this, we are investing in a number of initiatives.

- **Website: Patient Access to Information**
We have redesigned and launched our website with improved search engine optimisation to ensure it reaches more people affected by the condition. We updated and added to the content and signposting including videos, patient stories and access to research papers.
- **Myelopathy.org Support Group on Facebook**
Run by volunteers the private Myelopathy.org Support Group on Facebook is a unique space for our community to interact and engage on a one-to-one basis with people in similar circumstances. Moderated by our team of volunteers it has over 1,800 members each of whom requests permission to join by answering three questions. An incredibly active group that is growing by over 30 members a month we see over 200 posts, 3,000 comments and 5,000 reactions each month. The group provides emotional support for its members, social companionship, and acts as a trusted information source via the large number of guides and files available. We also provide a mentorship pairing service and run regular online events.

- **DCM Core Information Set (COINS)**
A review of existing educational content alongside undertaking qualitative interviews and a multi-stakeholder (professional and patient) DELPHI process to define the key points at which information is required by patients and the content of that information. This will then be piloted at Cambridge University Hospital to evaluate its impact on knowledge and experience using pre-validated measures. Once validated we aim to distribute the COINS nationally and internationally.
- **Myelopathy Matters Podcast**
Myelopathy Matters is the official podcast of Myelopathy.org, it aims to bring the latest information on living with, managing and understanding the condition, through expert guests from around the world. The show is hosted by Dr Benjamin Davies (Neurosurgeon, Scientist and Co-Founder of Myelopathy.org) and Iwan Sadler (Person with DCM and Co-Founder of Myelopathy.org). The show is produced by Carl Homer from Cambridge TV. In 2020 our 16 30-45 minute podcasts were listened to over 10,000 times.

Governance & Leadership

Myelopathy.org is led by a volunteer board of four men and three women from a range of professional backgrounds including researchers, physicians, medical philanthropists, neurosurgeons, management consultants, finance professionals and a solicitor. The Board is supported by our volunteer leadership team consisting of four members including a neurosurgeon, PR consultant and spinal research associate, two of whom have Degenerative Cervical Myelopathy (DCM).

Our Board of Trustees is made up of:

- **Lady Carter of Coles** was an academic researcher and lecturer and was diagnosed with DCM in 2016. She was a Magistrate in Central London for 20 years and has served on the board of both HMP Wandsworth and School-Home Support.
- **Dr Johann Graggaber** is a consultant physician specialising in acute internal medicine at Addenbrooke's Hospital, Cambridge.
- **Weslie Janeway** is an investor, author, philanthropist, financial analyst, and scientist based between New York and Cambridge, UK. She has served in a variety of non-executive roles and currently sits on the Board of The Rockefeller University and the New York Genome Centre.
- Co-Founder **Dr Mark Kotter** is an academic Spine and Neurosurgeon at the University of Cambridge whose translational research investigates the cellular and molecular mechanisms underlying DCM.
- Co-Founder **Iwan Sadler** has a career in print and design and was diagnosed with DCM in 2014 which led him to create the first Myelopathy Support Group on Facebook for DCM and thus met Dr Benjamin Davies and Dr Mark Kotter and founded Myelopathy.org. He plays an active role in the day-to-day activities of the charity.
- **Carol Sun-Schuster** is an independent management consultant who has worked with Chelsea Football Club, Disney, NBCUniversal and Warner Bros and supports the development of Myelopathy.org's branding, communications, and marketing.
- **David Townshend** is a retired Goldman Sachs Managing Director who brings his financial expertise to the Board.
- **Helen Wood (Chair)** is a former experienced solicitor with a Masters in Medical Ethics and Law and a wealth of experience working with human rights and medical charities. She is also a trained mediator and sits on a Research Ethics Committee.

Our Leadership Team is made up of:

- Co-Founder **Dr Benjamin Davies** is an academic neurosurgeon and Research Fellow at the University of Cambridge where he met Dr Mark Kotter and then Iwan Sadler. He plays an active role in the Research development for the charity.
- **Zahabiya Karimi** has over 9 years experience working in the charity sector in Programme Management, Volunteer Management and Fundraising. She has worked in Pakistan with underprivileged children and the WWF, the UNCHR in Malaysia and YCare and SOS Children's Villages in the UK. She is the Director of Myelopathy.org, oversees the day-to-day operations and works with a team of volunteers.

Our Scientific Advisory Board is currently being formed under the leadership of **Professor Michael Fehlings** who is currently Professor of Neurosurgery and Vice-Chair of Research for the Department of Surgery at the University of Toronto alongside, amongst other positions, being Co-Director of the University of Toronto Spine Program, Staff Neurosurgeon at Toronto Western Hospital, and Senior Scientist at the Krembil Brain Institute, University Health Network.

For further information, email info@myelopathy.org or visit our website at www.myelopathy.org.

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