

Myelopathy FAQs

Dr Mark Kotter and Dr Benjamin Davies, world-leading researchers into the causes and treatments of Degenerative Cervical Myelopathy (DCM), answer frequently asked questions from people affected by myelopathy

What is Myelopathy?

Myelopathy is a medical word to describe damage to the spinal cord. Although myelopathy can be caused by a range of diseases, DCM is by far the most common cause. In DCM, arthritic wear and tear changes in the neck stress and injures the spinal cord. Some healthcare professionals use other terms such as CSM – Cervical Spondylotic Myelopathy – to describe the same condition.

Who gets DCM?

Myelopathy can affect people at any age, but DCM is most commonly seen as a problem of middle to later life when wear and tear changes that can stress the spinal cord are more frequent. Current data indicates men are more often affected than women, but this difference is only small.

It is not known exactly how many people experience myelopathy because most people never get a diagnosis! Research often quotes 'operative incidence'. This is the number of times an operation is carried out. For DCM across the world this is about 60 operations for every 100,000 people each year. However, in addition to widespread under-diagnosis, not all identified DCM patients need an operation! So, this is definitely an under-estimation.

A more likely estimation therefore comes from imaging studies of healthy volunteers. These studies indicate that for every 100 healthy adults over the age of 40, up to 60 people will show MRI features of myelopathy. However, at that time, only two people could have a new diagnosis of myelopathy (i.e., symptoms of myelopathy). If you then follow the 60 people whose MRIs indicated myelopathy, up to 12 will go on to develop the disease over time.

If correct, these studies suggest as many as five in every 100 people aged over 40 years will develop myelopathy – 5%. Or 1 in 50 adults.

What are the symptoms of Myelopathy?

Myelopathy can affect almost any of the body's functions. Symptoms are varied and often differ from one person to the next.

The cervical 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 myelopathy experience a range of symptoms. Most commonly this includes:

- 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

Myelopathy is a progressive condition, so these difficulties can get worse over time.

How is Myelopathy diagnosed?

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

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

Early diagnosis, and appropriate monitoring/treatment, improves outcomes. However, many early symptoms of myelopathy can be very subtle or only occur now and then. Other symptoms may be missed or ignored as part of "growing older".

As outlined, an additional challenge is that the MRI is not a specific test (as would be the case for example of a blood test for diabetes). So there can be MRI features of myelopathy but no symptoms or physical findings at the time of the scan.

What treatments are available for Myelopathy?

Surgery aims to relieve the stress placed on the spinal cord. The type of operation selected is based on the cause and location of this.

International guidelines recommend surgery for people with progressive symptoms, or moderate to severe myelopathy.

The timing of surgery is important as the spinal cord has a limited natural ability to repair itself. The amount of recovery after surgery depends on the extent of the spinal cord injury at that time – which can be difficult to assess.

Surgery can be offered for mild myelopathy, but close observation is an alternative. People with mild myelopathy, whose symptoms are being monitored, may benefit from specialist physiotherapy to improve function and symptoms.

What do operations for Myelopathy involve?

There are many different types of operation for myelopathy. They all aim to remove the stress on the spinal cord safely. The different types of operation are often talked about as either Anterior (from the front of the neck) or Posterior (from the back of the neck). A common Anterior operation is an ACDF or Anterior Cervical Discectomy and Fusion. A common Posterior operation is a laminectomy.

Sometimes surgeons choose to bolster these procedures by placing metal implants to connect different levels of the spine together, to ensure it remains stable. It has been speculated that this may act like a "cast" and help the spinal cord to recover, and or may help prevent neck pain related to poor posture. However, this is unproven and the subject of a number of ongoing trials.

All the operations require a general anesthetic and, typically, a few days in hospital to recover. The recovery period depends on the individual and the type of operation. Most people, especially those that have undergone posterior surgeries, will experience additional neck pain (due to the trauma of the operation). This should gradually improve during the weeks of recovery.

This short summary shows that once the decision to undergo surgery has been reached, there are still many more decisions to be made. Two surgeons may treat the same scenario very differently. At present there is no good evidence to suggest one technique is better than the other, although key trials are ongoing. It is important therefore to be part of this process and don't be afraid to seek a second opinion.

What risks are associated with surgery for Myelopathy?

Unfortunately, all surgical procedures have some risks associated with them. The risks will vary depending on the type and location of surgery but in general affect up to 15 in every 100 procedures. Mostly the problems are minor and temporary (such as increased neck pain) but include severe and permanent risks (such as a spinal cord injury).

A recent study has looked at all the risks ever reported for myelopathy surgery, and generated the following data:

- Post Operative Neck Pain (15%) – generally improves over three to four weeks
- Post Operative Swallowing Difficulties (Dysphagia) (15%) – generally improves over one to two weeks
- C5 Palsy (5%)
- Cerebrospinal Fluid Leak (2%) – the spinal cord sits within a sac of spinal fluid called cerebrospinal fluid. Unfortunately, it is possible to damage this sac when releasing the compression. A leak carries a higher risk of infection after surgery.
- Infection (3%)
- Hoarseness (4%)
- Epidural Hematoma (1%) – a collection of blood forming within the spinal canal after surgery and causing further spinal cord compression
- Spinal Cord Injury (<1%) – this is a very uncommon complication and therefore it is not possible to provide an exact number

What is the risk of becoming paralysed as a result of Myelopathy?

The greatest risk of a sudden and abrupt deterioration in myelopathy is associated with falls. Due to the spinal cord canal stenosis, there is less room for the spinal cord to move in response to a sudden jolt. Even minor falls can have significant consequences for people with myelopathy.

A study using the population of Taiwan, identified that two in every 1,000 people with myelopathy would suffer a spinal cord injury each year. This risk is doubled if a person has not previously had surgery for their myelopathy.

Will all my Myelopathy symptoms go away after an operation?

It is very unlikely all your symptoms will go away after surgery. However, almost all patients get some meaningful benefit from surgery which aims to prevent symptoms getting worse.

People with myelopathy 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 by Myelopathy.org of more than 1,000 patients, 40% reported they were reliant on others for support with their day-to-day activities. In the largest study of myelopathy so far, less than 5% of people achieved normal functional scores after their operations.

People who had milder symptoms, experienced a shorter time to diagnosis – less than six months, who did not smoke and/or whose legs were unaffected before surgery, were more likely to make a better recovery from surgery.

What can I expect six weeks after surgery?

Six weeks after surgery the pain of the operation should be getting better, and you may already notice a difference in your symptoms. Doctors will be keen to look at how things are going over time and expect gradual improvement or, at the least, no change. Further investigation will be needed if your condition is getting worse.

What can I expect three months, six months and one year after surgery?

Three months after surgery many people can increase their physical activities, if their surgeon agrees.

For most people, maximum recovery occurs between six months and one year. Most people will be starting to return to more normal activities such as work or driving. It is unlikely any on-going symptoms will improve after one year. Additional therapies should be considered to help manage them.

Who is responsible for my post-operative care?

Your surgical team will be responsible for your post-operative care after you leave the hospital. There is no standard practice in the longer term.

Some surgeons may continue to see patients periodically. Most surgeons in the UK will discharge patients back to the care of their GP. It is then the responsibility of the person with myelopathy, and their GP, to be alert to any new symptoms or difficulties. If these arise, you should be re-referred to a spinal surgeon.

Your GP is also the access point for additional symptom therapies, such as pain medicines, and enabling your access to additional services to manage your symptoms such as physiotherapy or pain medicine specialists.

What therapies will best support my recovery?

There are currently no additional therapies to support recovery after surgery, but this is a research priority in a bid to overcome the significant disabilities of myelopathy.

Will chiropractors and massage therapists be able to help with pain reduction and muscle relaxation?

A. This is not currently known. Some patients report a benefit and others do not. One concern about the use of physiotherapy, and other therapists, is that manipulation of the neck could cause further damage to the spinal cord. This risk is thought to go away, once an individual has had surgical treatment.

Is it best to seek therapy through a neuro-physiotherapist or a general physiotherapist and what are the differences?

Physiotherapists undergo general training and then can choose a specialism. Neuro-physiotherapists will have specialist experience in looking after neurological conditions, such as myelopathy. They are more likely to be aware of the concerns around neck manipulation. They will also have experience in supporting people with myelopathy and the specific problems they can face.

What medications are available to relieve Myelopathy symptoms?

There are two major areas which medication can address: 1) pain and 2) spasticity (stiffness). There are many different types of medications which can be used to alleviate these problems. You can discuss these with your consultant and your GP.

Will I be able to continue working?

This will depend on your level of disability and the type of job you do. In our experience, most people with myelopathy continue to work but often make some changes in their type of work or role, or the hours worked.

In a survey by Myelopathy.org of more than 1,000 people with myelopathy, 35% reported they were unable to work because of the disease.

If I cannot work, will I be entitled to benefits?

This will depend on individual circumstances but generally support should be available. Unfortunately, it is the experience of Myelopathy.org that access to benefits in the UK to date has been difficult for people with myelopathy. This seems to be due to the limited awareness in government and local authority departments of the disease and its impact. It is also magnified by the long time it currently takes to get a diagnosis, as many people seek support without a formal medical label.

Will I be able to do routine housework and childcare?

This will depend on your level of disability but, after a period of recovery, most people can continue to do this.

Will I be able to drive?

This will depend on your level of disability but, after a period of recovery, most people can continue to do this. If you are unsure because of your ongoing symptoms or any medications you are taking, you may need to check with the DVLA in the UK.

Will I need to buy special equipment for my home or move to different accommodation?

This will depend on your level of disability. Some people with myelopathy do need to adapt their homes to support themselves. In the UK grants are available to assist with changes needed to a home.

Will I be able to exercise and play sports?

This is a difficult question, as the impact of sport and exercise is not specifically known. It is probably why advice from doctors can be mixed. Most likely it will depend on your individual circumstances including the severity of your myelopathy, the type of operation you have had, and the type of exercise or sport proposed.

There will need to be a period of recovery after an operation for the wounds to heal and/or components of the operation to fuse. This will depend on the type of operation but typically it takes a few months. Following this, if your surgeon agrees, a gentle return to exercise is recommended. It may be necessary to choose appropriate exercise to suit your individual circumstances. Overall exercise is good for health and well-being after all.

Will I need to take special care of my neck forever and, if so, how?

There is no special advice for neck care long-term.

Why do some patients experience a return of symptoms, or worsening symptoms, after surgery?

Unfortunately, myelopathy can reoccur. The return or worsening of symptoms must be investigated promptly.

In some cases, a worsening or return of symptoms can occur even with no recurrence of spinal cord compression. It is unclear why this happens, although there are some theories. For example, it is emerging that in people who experience pain constantly the stimulation changes how the brain and spinal cord processes pain. As a result, it increases the feeling of pain.

What should I do if my Myelopathy symptoms gradually get worse or new ones develop?

You will require further investigation, typically in the form of repeat MRI imaging. In the UK, the best access is via your GP for a referral back to your spinal surgeon.

Is there any research explaining why some people with Myelopathy get very fatigued physically and mentally – often described as brain fog? Is there anything to relieve these problems?

Although not reported in the medical literature, this is a symptom that we often encounter in our clinical practice. For example, the Myelopathy.org community often describes an experience whereby an exertional day can have a hangover for many days to come, as though they had run a marathon. Unfortunately, there is no specific research on this at this time and therefore the cause of the fatigue is not known.

It is possible that it is the consequence of a specific kind of injury in the spinal cord. Equally, it could be the result of the various symptoms and obstacles that many people with myelopathy face every day.

What can be done if I experience regular bladder and bowel problems because of my Myelopathy?

Urinary symptoms can occur as myelopathy develops and they may persist after treatment. Stable urinary symptoms should be discussed and addressed with your family doctor, who may refer you to a urologist for specialist advice.

For simple problems, there are some medications which may help. Alternatively, you may be able to seek specialist input. In some areas there are specialist clinics available for assessment and management of continence.

If urinary symptoms increase, they need to be investigated promptly as they could indicate worsening myelopathy.

Will I still be able to enjoy intimate relationships with my partner?

Once you have recovered from your operation, this should not be a problem. However, there may be factors which make this difficult. For example, poorly controlled pain or low mood can reduce your libido. Some men with myelopathy experience erectile dysfunction. Some antidepressants used for neuropathic pain, but not all, can also cause erectile dysfunction in men while women can find their libido and their sexual sensation and sensitivity reduced. People with myelopathy experiencing these problems would be eligible for medication from their GP.

How can I cope with my own frustration and low moods?

This is a difficult question and is probably best discussed with your GP. It will be important to try and identify the factors that are driving these issues, such as pain, to see if these can be improved.

Your GP should also be able to direct you to support services such as Behavioral Therapies including Mindfulness. Myelopathy.org also has information about useful strategies to help you cope with the psychological problems of a chronic and often debilitating condition.

Depression is likely to be common among people with myelopathy and medical treatment with antidepressants may be indicated. These treatments may have additional benefits such as reducing pain.

How can I help my friends, family members and carers understand my problems?

Education and sharing as much information as possible is clearly important. We hope that the information available from Myelopathy.org will be useful and informative to people with myelopathy and everyone providing them with care and support.

It is our perception that, on the surface, many people with myelopathy tend to look well. As a result, they do not always receive due care and consideration. Someone with myelopathy cannot be gauged or assessed by a simple look!

Where can I find more information, support and advice?

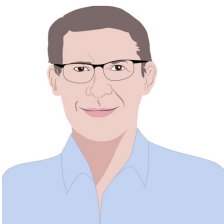
There is a general lack of information about myelopathy and the support available for its many problems.

Myelopathy.org is aiming to fill this void. The website contains a lot of information about the condition, practical tips/suggestions, and details of the latest research and numerous references to other websites of interest.

[Myelopathy.org Support Group](#), a peer-to-peer support group hosted on Facebook, is a rich forum where people with myelopathy can share problems and ask questions. Myelopathy.org Support Group can also be accessed via Myelopathy.org.

Myelopathy is an under-recognised but relatively common condition. At Myelopathy.org our aim is to encourage any initiatives that bring people with myelopathy together.

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.



Dr Mark Kotter

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Mark (MD, MPhil, PhD) is a National Institute for Health Research (NIHR) clinical scientist. He is an academic Spine and Neurosurgeon at the University of Cambridge. His ambition is to advance the way DCM is treated based on a better understanding of the course of the disease, and by identifying the best care for patients. His translational research investigates the cellular and molecular mechanisms underlying DCM in a bid to develop novel therapies.



Dr Benjamin Davies

Co-Founder and Research Director
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Ben (MBChB, Hons BSc MRCS) is also an academic neurosurgeon at the University of Cambridge, although still in training to become an independent spine surgeon. He has a research interest in myelopathy, particularly around improving clinical assessment and improving the healthcare pathway. His ambition is to create a system, where people with DCM receive a prompt diagnosis, can access timely surgery or other necessary treatments, and are better empowered to take charge of their care.

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