MND Association

PLS

2C
Primary lateral sclerosis (PLS)

Information for people with or affected by Motor Neurone Disease (MND)

Primary lateral sclerosis (PLS) is a very rare form of motor neurone disease (MND) that progresses slowly. If you have been diagnosed with PLS, your needs may be different to those with other types of MND. This information sheet looks at ways to manage the symptoms and how to access further support. The content includes:

1. **What do the words mean?**
2. **What is PLS?**
3. **What are the symptoms?**
4. **What help can I get?**
5. **How do I find out more?**

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This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5 **How do I find out more?**

1. What do the words mean?

You may hear these terms used at appointments.

Bulbar	Used to describe symptoms relating to swallowing and speech, as the bulb-shaped part of the brainstem contains the motor neurones for swallowing, speaking and chewing.
Dysarthria	Slurring of speech.
Dysphagia	Difficulties with swallowing of liquids, solids or both.
Electromyogram (EMG)	A test that uses thin needles to measure activity in muscles. When muscles start to lose their peripheral nerve supply, they show abnormal electrical activity.
Emotional lability	Also known as pseudo-bulbar affect, emotionality or emotional reflex hypersensitivity. This refers to a response where you laugh or cry in situations that feel inappropriate to you.
Magnetic resonance imaging (MRI)	A scan which involves lying inside a large tube-shaped scanner that produces detailed images of the inside of the body. It is used to rule out anything abnormal in the brain and spinal cord, that might produce similar symptoms to PLS.
Nerve conduction test	This test uses small patches on the skin to check the speed of electrical signals in the peripheral nerves.
Palliative care	Specialist care for people with a life-shortening condition. This includes symptom control, but looks to improve quality of life with support for practical, psychological, social, spiritual, religious and other needs.
Peripheral nerves	Nerves in your body beyond the brain and spinal cord. With all forms of MND, focus is on the motor nerves that help you move.
Urinary urgency	An urgent sense of need to use the toilet (urinate) when your bladder feels full.

2. What is PLS?

PLS is a neurological disease. This rare form of MND has symptoms that progress slowly over many years. It represents 3 in 100 cases of MND.

The symptoms of PLS typically start when people are aged over 40, but younger adults can be affected.

“Like myself at age 38, many people in my PLS community were diagnosed in their late 30s.”

As with all types of MND, there is no cure or specific treatment for PLS, but symptoms can be managed to improve your quality of life. With PLS, you are likely to remain more independent than with other forms of MND. You may still require some care support depending on the way your symptoms progress. Each individual with PLS may have different needs.

“Including more than 13 years of volunteering service, I’m still relatively able with PLS. I can manage for several nights at home by myself.”

PLS most commonly begins with symptoms affecting the legs and overall balance, but some people develop problems with the muscles used for speech and swallowing. Over time, it affects the arms and hands.

See our guide: **Living with Motor Neurone Disease** to help manage possible symptoms with all forms of MND.

Not all symptoms happen to everyone with PLS and they usually don’t develop at the same time.

Living with PLS can be challenging, due to the ongoing impact on your communication, mobility and independence. Ensuring that your needs are well met can help reduce frustration. Equipment, advice and support are available to assist with many aspects of daily living.

See section 4: **What help can I get?**

What causes PLS?

It is not known what causes PLS, and research is ongoing. Like most diseases, it is thought that a combination of both environmental factors and genetics play a part.

Environmental factors are things that we experience in life that may have an effect. These could be different for each person and in combination. This makes it very difficult to know what could have triggered the disease.

Our genes to carry information in our cells to instruct how our bodies grow and develop over time. Genes may have some impact with PLS, but it has not been shown to be an inherited disorder beyond a very few families reported worldwide.

How is PLS diagnosed?

Like all forms of MND, there is no single test to diagnose PLS, but an experienced neurologist can identify the possibility based on symptoms and physical examination.

It can take time to be sure that you have PLS, rather than another form of MND or a different condition. You may have symptoms for up to four years before a diagnosis can be confirmed.

If your GP thinks you may have MND or another neurological condition, you will be referred to a neurologist, who may arrange for:

— a full assessment of your symptoms and family medical history

— a physical examination

— scans to check for any problems in the brain and spinal cord

— tests on your nerves and muscles

— blood tests to exclude other causes or conditions

— tests on the fluid from around your spine (cerebrospinal fluid or ‘CSF’), known as a lumbar puncture.

How will PLS affect my life expectancy?

PLS is disabling, but the slow progress of symptoms means that it is not necessarily life-shortening. Most people live a typical lifespan following diagnosis, but this depends on age and any other medical conditions.

Symptoms and the individual speed of progress become clearer over time. This means a PLS diagnosis imay be reviewed and changed to amyotrophic lateral sclerosis (ALS). ALS is the most common form of MND. It progresses more quickly than PLS and is usually life-shortening.

3. What are the symptoms?

PLS usually begins in the lower limbs, such as stiffness in the way you walk. If you run, your movement may not feel as fluid as before. Other symptoms may impact speech, which may feel as though it takes more effort or sound slurred.

"At first, most people in my PLS group noticed it in their legs, due to problems with walking and balance. However, over time most of us had problems with arms and hands to varying degrees."

Early symptoms of PLS are very similar to other forms of MND, so it can be difficult to identify at first. Not everyone will experience all of the following symptoms or in any particular order. You may even have additional symptoms, not listed here. Ask your GP about any concerns in case you have an unrelated problem that needs medical help. Some of the symptoms you may experience with PLS are:

- problems with balance, stiffness, spasm and weak muscles (especially in the legs)
- being easily startled (known as hyperekplexia)
- slurring of your speech
- emotional lability
- bladder urgency
- fatigue.

Your symptoms may cause:

- a higher number of trips and falls, and difficulties walking
- pain in your neck, back, legs and other muscles
- problems with speaking clearly
- sudden crying or laughing that feels out of place
- difficulties with daily tasks, such as washing, toilet access, dressing and cooking.

Can I still drive?

Legally, you must inform the DVLA and your insurance company if you are diagnosed with PLS. It may eventually affect your ability to drive but it's still possible to drive when disability is mild. Ask your GP, consultant or MND care co-ordinator for advice.

See our booklet: **Getting around** for guidance.

4. What help can I get?

Although PLS affects everyone differently, its impact can be frustrating. Equipment and therapies can help you stay independent for as long as possible and improve quality of life.

Over time you may develop your own solutions, but ask an occupational therapist (OT) for advice on safety and how to adapt to make activities easier. Your GP can refer you to an OT for assessment of your needs, advice on equipment and ways to help you continue daily routines.

With PLS you have time to plan your future needs, but it is worth thinking ahead in case you need to go on a waiting list. Before buying any equipment and aids, an independent assessment of your needs by an OT is recommended. Private purchases can be costly and may not suit your needs or your home.

See the following information sheets:
- **3D Hospice and palliative care**
- **6A Physiotherapy**
- **6C Managing pain**

We also have information about equipment, wheelchairs and environmental controls.

What can be done about stiff, tight muscles or spasms?

Plenty of rest may help ease painful muscle spasms and help recovery after a fall or injury. Ask your health and social care team for advice.

Your GP, consultant, specialist nurse or MND care co-ordinator may offer medication to relax your muscles and relieve spasms.

If your pain is persistent, ask for referral to a pain clinic or palliative care team. Physiotherapy can also provide some relief.

Some people find massage helpful to ease stiff or painful muscles. Get advice from your GP or consultant to ensure this is suitable for you.

See information sheet: **6B Complementary therapies** for more about massage and other therapies.

Massage should be provided by an experienced, registered therapist.

What can be done about muscle weakness?

Muscles already weakened by PLS cannot recover, but gentle regular exercise can:

- assist with flexibility and range of movement in your joints
- help strengthen unaffected muscles
- support posture and balance.

“Regular physio is of great benefit with PLS. After no exercise for 20 years, I gradually improved my distance and speed by treadmill sessions.”

Ask your GP or health and social care team for a referral to a relevant physiotherapist, experienced in MND. They can recommend a suitable exercise programme to meet your needs and help you avoid unnecessary fatigue.

See information sheet: **6A Physiotherapy.**

What can be done about my foot dragging?

If you experience ‘foot drop’ where your foot drags, ask your physiotherapist or OT for guidance. This may include a referral to an orthotics department who can provide appropriate splints and footwear to help support your foot and ankle. As PLS progresses, you may need walking aids or a wheelchair to get around. Your GP, physiotherapist or OT can refer you to an appropriate service for support and advice.

What can be done about speech difficulties?

PLS may affect how fast the muscles in your tongue, face and throat, making it difficult to speak. Your speech may slur and become unclear.

“I noticed difficulties with speech just over a year from diagnosis. Within five years of diagnosis, only my family could interpret my speech. I still try to speak short sentences with my wife and she can sometimes figure out what I’m saying if it’s in context.”

A range of support is available if you do have problems with your speech, including learning techniques or using communication aids. These aids can be simple, manual solutions or high tech, for use on devices.

Ask your GP or wider health and social care team for a referral to a speech and language therapist (SLT) for an assessment. They can advise you about techniques and equipment to help with speech problems.

See information sheets: **7C Speech and communication support** and **7D Voice banking and message banking**

What can be done about swallowing difficulties?

With PLS, weakening muscles can affect swallowing. You may experience occasional coughing or a choking sensation, but this usually passes without the need for support. However, this slightly increases the risk of inhaling small pieces of food into your lungs (known as aspiration), which may lead to chest infections.

Ask your GP or other healthcare professional for referral to a speech and language therapist (SLT). Your SLT can assess your ability to swallow safely and advise on consistencies of food and drink.

“I have not been able to drink normally for over 20 years, but I still eat normally, albeit slowly.”

Also ask for referral to a dietitian, for guidance about diet and supplements. This may be helpful if swallowing difficulties lead to weight loss or dehydration.

With PLS, you are likely to maintain your eating and drinking needs without having to top up with tube feeding. This is where liquid feeds are passed through a tube inserted through the outer wall of your stomach. However, if you feel tube feeding could help, ask your SLT and dietitian for guidance.

If your swallowing is affected by PLS, saliva can gather in the mouth and throat and lead to drooling, which may be embarrassing. However, drooling is much less common for people with PLS than other forms of MND.

Ask your health and social care team for support with drooling. They may be able to offer medication to help dry up saliva or suction machines to help clear your mouth.

See the following resources about swallowing, saliva, eating and drinking:
— **7A Swallowing difficulties**
— **7B Tube feeding**
— **Eating and drinking with motor neurone disease**

Will I be affected by emotional lability with PLS?

Emotional lability (also known as pseudo-bulbar affect, emotionality or emotional reflex hypersensitivity) is a symptom more commonly seen in PLS than other forms of MND.

If this happens, you may suddenly start to cry or laugh in a way that feels inappropriate for the situation.

“It is so difficult to explain that my crying does not mean I am depressed, in fact I more often cry about happy things”

This can be difficult to prevent and you may feel out of control, but it often eases or stops quickly.

This symptom can be distressing for you and those close to you, who may not understand and assume that crying means you are depressed.

Usually, this symptom eases over time. If the responses are persistent and causing distress, talk to your GP as medication may help.

See our booklet: **Emotional and psychological support** for more about emotional liability.

If your GP is not familiar with emotional lability, ask a member of your health and social care team with experience of neurological conditions.

“The more people that know this problem is due to my disease, the less of a problem it feels to me.”

Will PLS affect the way I think?

You are less likely to be affected by significant changes to thinking and behaviour with PLS than with other forms of MND.

For most, the changes are subtle and have little or no effect on daily life or the ability to make decisions.

If you experience changes to the way you think and learn, you may find it becomes more difficult to:

- make and carry out plans, or finish tasks
- think about what you need or want to do
- do activities in the right order
- do more than one thing at a time
- process information and solve problems
- consider choices and consequences carefully
- concentrate and take in new information
- recognise other people's feelings.

See our booklet: **Changes to thinking and behaviour with MND.**

What can be done about fatigue?

It might be helpful to take on board the idea that your energy is like a battery. If you use a lot of energy one day, you may need to rest and 'recharge' the next day.

Do essential tasks first and get support for other tasks as needed.

See our booklet: **Personal care** for more information.

Try to:

- listen to your body and pace yourself
- prioritise tasks, manage your time and be flexible with routines
- use equipment to help you do things more easily
- ask your physiotherapist or occupational therapist about ways to manage your fatigue
- plan a rest day before and after a particularly busy time, such as a family event
- avoid excessive exercise routines.

What can be done about bladder urgency?

Some people with PLS experience a strong, sudden urge to urinate (known as urinary urgency) caused by over-activity of the muscles that control the bladder. Medication may help with this symptom, so ask your GP or neurologist for advice. They can also rule out other causes such as bladder infections.

"Frustratingly, urinary urgency issues are very common for those of us with PLS, although bowel issues seem to be rare."

What can be done about falls?

PLS often affects balance early on and, with additional weakness of the leg muscles, you may be more likely to have falls. This can make daily tasks difficult, and you could injure yourself.

Ask your GP to refer you to an OT who may be able to provide you with equipment and advice to reduce the risk of falls. Your physiotherapist can also advise you and your carer on how to manage falls if they happen.

As PLS progresses, you may need to use walking aids or a wheelchair to get around. Your GP, physiotherapist or OT can refer you to an appropriate service for advice.

How can I contact other people with PLS?

Find our MND Connect helpline details in section 5, under the heading: Our support. They can guide you to our local branches and groups, where you can meet others with forms of MND.

As PLS is a slower progressing form of MND, you may find it beneficial to share experience and knowledge with others in a similar situation. An online support group is available for people living with PLS and progressive muscular atrophy (PMA) – another slower form of MND. Contact MND Connect to find out how to join.

Find our online forum at: **forum.mndassociation.org** which provides a safe space for people with or affected by MND to share experiences and support. This will include posts from people affected by all forms of MND.

You can also find a variety of MND and specific PLS groups on social media. They may have a local, national or global presence, allowing for wider peer support. Search for PLS or primary lateral sclerosis to see what's available. However, these groups may not be moderated.

5. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Government information
Online government information about benefits and support.
Website **gov.uk (**England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

MND Scotland
Care, information and research funding for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

NHS and UK healthcare
Information about NHS services and healthcare across the UK.
Website: **nhs.uk**

Tel: 111 (for urgent medical advice in England, available 24/7)
Website: **111.nhs.uk** (For England)

Tel: 111 (for urgent medical advice in Wales, available 24/7)
Website: **111.wales.nhs.uk** (For Wales)

Tel: Find individual trusts in Northern Ireland on website contact page
Website: **hscni.net** (For Northern Ireland)

Tel: 111 (for urgent medical advice, available 24/7)
Website **nhs24.scot** (For Scotland)

NI Direct
Provides government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.
Email through the website contact page
Website **nidirect.gov.uk**

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Helen Madden	Care Centre Co-ordinator, Bristol MND Care Centre
Prof Martin R. Turner	Consultant Neurologist, University of Oxford

References

References used to support this resource are available on request:
Email: **infofeedback@mndassociation.org**

Or write to:
Information feedback,
Motor Neurone Disease Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton, NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

3D Hospice and palliative care
6A Physiotherapy
6B Complementary therapies
6C Managing pain
7A Swallowing difficulties
7C Speech and communication support
7D Voice banking

Booklets

Caring and MND - quick guide
Emotional and psychological support
Changes to thinking and behaviour with MND
Getting Around
Making the most of life with MND
Personal Care
Types of care
Inherited MND and genetic testing

Large guides

Living with Motor Neurone Disease (MND)
Eating and drinking with MND
Caring and MND - support for you

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on any of our information sheets, access our online form at:
smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton, NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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