

# 2D Progressive muscular atrophy (PMA)

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

If you have been diagnosed with a type of motor neurone disease (MND) called progressive muscular atrophy (PMA), you may want to know more about this condition and how to manage the symptoms. This information sheet includes details about this rare form of MND and how to access support. The content includes:

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



**This content has been evidenced, user tested  
and reviewed by experts. See: [piftick.org.uk](http://piftick.org.uk)**



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.

<b>Atrophy</b>	Where muscles waste and reduce in mass.
<b>Electromyogram (EMG)</b>	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.
<b>Fasciculation</b>	Muscle twitching which can sometimes be seen as a rippling effect under the skin.
<b>Flail arm syndrome</b>	Where the arm muscles waste and become limp and cannot be moved voluntarily.
<b>Magnetic resonance imaging (MRI)</b>	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.
<b>Nerve conduction test</b>	This test uses small patches on the skin to check the speed of electrical signals in the peripheral nerves.
<b>Palliative care</b>	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.
<b>Peripheral nerves</b>	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.

**This information sheet includes details about life expectancy. Read when you feel ready to do so.**

## 2. What is PMA?

PMA is a rare form of MND that affects the nerves known as lower motor neurones. These nerves run from the spinal cord and control muscle movement. PMA results in muscles gradually losing their mass, known as atrophy or wasting. This causes the muscles to become weak. It can also lead to a twitching sensation that ripples under the skin (known as fasciculation).

It usually starts in the arms or legs and may only affect one part of the body for a number of years before spreading to other areas. Like other forms of MND, it typically affects people aged over 50 years, but younger people can also be diagnosed with PMA. It is slightly more common in men.

### What causes PMA?

As with other forms of MND, the causes of PMA are unknown but research is ongoing. With all types of MND, it is thought that a combination of environmental and genetic factors play a part, but it is not currently possible to give the precise causes.

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.

### How is PMA diagnosed?

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

It can take time to be sure that you have PMA. If your doctor thinks you may have a form of MND or another neurological condition, they will usually refer you to a neurologist. After discussing your symptoms and examining you, the neurologist may arrange a series of tests including:

- 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 PMA affect my life expectancy?

PMA usually progresses more slowly than most forms of MND, and many people live for five years or more. It is possible that a PMA diagnosis may be reviewed and changed to another form of MND over time.

### 3. What are the symptoms?

Early symptoms of PMA 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 PMA are:

- weakness and wasting of muscles in the legs, arms, hands, and body
- muscle cramps and pain
- muscles twitching and rippling beneath the skin (known as fasciculations)
- clumsiness
- breathing difficulties
- fatigue
- weight loss.



See section 4: **What help can I get?** for more about managing symptoms.

#### 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 PMA 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 PMA 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 muscle weakness?

Exercise cannot reverse muscle weakness caused by MND, but it may help flexibility and range of movement of your joints. It can also help maintain unaffected muscles, and support posture and balance. Gentle muscle stretching can also relieve cramps.

Ask your GP or health and social care team for a referral to a physiotherapist experienced in MND. They can recommend a suitable exercise programme to meet your needs.



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

Pace your routine, as over-exercise with any form of MND may lead to feeling very tired (fatigue).

## 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 muscle cramps?**

Plenty of rest may help ease painful muscle cramps 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 cramp 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 twitching and rippling sensations?**

Ask your GP, neurologist, MND team or specialist nurse, as medication may help to relieve this symptom.

## **What can be done about falls?**

PMA affects muscle function in arms, legs, or both. This can cause problems with dexterity, grip and balance.

Daily routines may become increasingly difficult, which could lead to risk of injury. Referral to an occupational therapist is important, as you may be able to access advice and helpful equipment.

As PMA progresses, you may need to consider using walking aids or a wheelchair to get around. Your GP, MND team, physiotherapist or occupational therapist can refer you to an appropriate service for support and advice.

Your physiotherapist can also advise you and your carer on how to manage falls if they happen.



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

## What can be done about breathing difficulties?

PMA can weaken the muscles used in breathing. You may notice the following signs or symptoms:

- feeling breathless, even when resting or lying flat
- shallow or rapid breathing
- difficulty clearing mucus or phlegm due to a weak cough
- repeated or lengthy chest infections
- a weak sniff
- disturbed sleep or feeling tired when you wake up
- nightmares or hallucinations
- morning headaches.

If you notice any of these symptoms, contact your health and social care team for advice. This is a good time to ask for referral to your local respiratory team, so you can be assessed and discuss options for treatment and care.



See our range of information sheets 8A - 8D about breathing support.

## What can I do about weight loss?

As your muscles reduce in mass, you may lose weight. This can get worse if you have difficulties swallowing.

Ask your GP for a referral to a speech and language therapist and a dietitian. They can assess your ability to swallow safely and provide guidance on food and drink consistencies, supplements, and ways to maintain a healthy diet.

Some people with MND will choose to have a feeding tube. This is a way of passing fluids, specially prepared liquid feed and medication straight into your stomach through a tube in your abdomen.

Your dietitian and speech and language therapist can advise about your options.



See our resources:

- information sheet **7A Swallowing difficulties**
- information sheet **7B Tube feeding**
- our guide **Eating and drinking**.

## Will PMA affect the way I think?

Up to half of people with MND experience changes in how they think, although this is less likely with PMA.

For many these changes are subtle and have little or no effect on daily life. For some these changes may be more apparent and need more intensive support.

If you, or those close to you, are concerned about changes to your thinking and behaviour, contact your health and social care team for advice. If they are not familiar with links between MND and changes to thinking, share our information with them.



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

## How can I contact other people with PMA?

PMA is a slower progressing form of MND. You may find it beneficial to share experience and knowledge with others in a similar situation.

A regional online support group has been developed for people living with PMA and other slower progressing forms of MND.

If you would like to join the group, contact our MND Connect helpline. Find contact details in section 5, under the heading: Our support.



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

## 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](http://gov.uk) (England and Wales)  
[nidirect.gov.uk](http://nidirect.gov.uk) (Northern Ireland)  
[gov.scot](http://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](mailto:info@mndscotland.org.uk)  
Website: [mndscotland.org.uk](http://mndscotland.org.uk)

#### NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website: [nhs.uk](http://nhs.uk)  
  
Tel: 111 (for urgent medical advice in England, available 24/7)  
Website: [111.nhs.uk](http://111.nhs.uk) (For England)  
  
Tel: 111 (for urgent medical advice in Wales, available 24/7)  
Website: [111.wales.nhs.uk](http://111.wales.nhs.uk) (For Wales)  
  
Tel: Find individual trusts in Northern Ireland on website contact page  
Website: [hscni.net](http://hscni.net) (For Northern Ireland)  
  
Tel: 111 (for urgent medical advice, available 24/7)  
Website: [nhs24.scot](http://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](http://nidirect.gov.uk)

#### National Institute for Health and Care Excellence (NICE)

National guidelines to improve health and social care, including a guideline on MND.

Tel: 0845 003 7780  
Email: [nice@nice.org.uk](mailto:nice@nice.org.uk)  
Website: [nice.org.uk/guidance/ng42](http://nice.org.uk/guidance/ng42)

## Acknowledgements

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**Dr Tim Williams** Consultant Neurologist & Associate Clinical Lecturer in Neurology, Royal Victoria Infirmary

**Gitana Zvikaite** MND Care Centre Coordinator, Barts and The National MND Care Centre

## References

References used to support this resource are available on request:

Email: [infofeedback@mndassociation.org](mailto: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**

- 6A Physiotherapy
- 6B Complementary therapies
- 7A Swallowing difficulties
- 8A Support for breathing problems

### **Booklets**

- Caring and MND - quick guide
- Changes to thinking and behaviour with MND
- Getting Around
- Emotional and psychological support
- Personal Care
- Types of care
- Telling other people about MND
- Inherited MND and genetic testing

### **Large guides**

- Living with MND
- Eating and drinking with MND
- Caring and MND - support for you

Search for information by need at: [mndassociation.org/careinfofinder](http://mndassociation.org/careinfofinder)

Find information for professionals at: [mndassociation.org/professionals](http://mndassociation.org/professionals)

Download our information at: [mndassociation.org/publications](http://mndassociation.org/publications)

Find information in other languages at: [mndassociation.org/languages](http://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](http://mndassociation.org/mndconnect)

Tel: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### **Support services**

Find out about our support services at: [mndassociation.org/our-services](http://mndassociation.org/our-services)

### **Local and regional support**

Find out about our branches and groups, at: [mndassociation.org/local-support](http://mndassociation.org/local-support)

### **MND Association Benefits Advice Service**

For help to identify claims and how to apply. Find current contact details for England, Wales and Northern Ireland at [mndassociation.org/benefitsadvice](http://mndassociation.org/benefitsadvice) or contact our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: [mndassociation.org](http://mndassociation.org)

Online forum: [forum.mndassociation.org](http://forum.mndassociation.org)

or through the website

## 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](https://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](mailto: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](mailto:infofeedback@mndassociation.org)**

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