

MN
Association



For
professionals

An introduction to Kennedy's disease (KD)



Contents

Introduction	3
Section 1: Introducing Kennedy's Disease	
Diagnosis of KD	5
Symptoms of KD	6
Section 2: Management of symptoms	
Muscle problems	9
Fatigue	11
Numbness or tingling	12
Hormonal changes	12
Urination	13
Eating and drinking	14
Speech problems	15
Breathing difficulties	16
Laryngospasm	17
Metabolic changes	18
Psychological impact	19
Section 3: The genetics of Kennedy's disease	
Genetics of KD	21
Genetic counselling	24
Section 4: Further support	
Support from the National Kennedy's Disease Clinic	26
Useful organisations	27
How we can support you	28

Introduction

Kennedy's disease (KD), also known as spinal bulbar muscular atrophy (SBMA), is a gradually progressive neuromuscular disorder caused by degeneration of the lower motor neurones. It is caused by a genetic mutation which is passed on from parent to child. This mutation is X-linked (the abnormal mutation is found on the X chromosome), which means that it principally affects men. In rare circumstances, women carrying the gene also develop symptoms.

It is a rare disease, affecting around 1 in 40,000 people.¹ Most people with KD start to show symptoms after the age of 40, but it can appear in older or younger people.^{2,3,4} People with KD may live a normal lifespan, with progressive disability as they age.⁵

Although KD is not a form of motor neurone disease (MND), the similarity in some symptoms and the rarity of the disease may lead to misdiagnosis. This publication has been created to increase awareness and understanding of this rare disease among health and social care professionals, and highlight support and treatment options.

The MND Association provides a wide range of support to people with KD, as well as people with MND. See page 28 to learn more.



Information to share:

Booklet – Kennedy's disease
Animation – What is Kennedy's disease?

Information for professionals:

We have a number of webinar recordings on KD, available on mndassociation.org/webinars

See page 35 to order publications.

1

Introducing Kennedy's disease



Diagnosis of KD

KD is a clinical diagnosis that is confirmed by genetic testing. It is typically diagnosed through a combination of diagnostic procedures, including:

Clinical evaluation: A neurologist will conduct a thorough clinical evaluation. This includes taking a detailed medical and family history, and a physical examination to assess the person's symptoms. Neurological tests may be performed to evaluate muscle strength, reflexes, and coordination.

Nerve conduction studies (NCS) and electromyography (EMG): These tests may be conducted to assess the electrical activity and function of nerves and muscles.

Family history: A family history of similar symptoms, or a known family history of the condition, can be a valuable diagnostic clue, but some patients will be the first person in their family to have KD.

Blood tests: Blood tests may be performed. Around 90% of people with KD have a raised creatine kinase (CK), an enzyme found in the heart, brain and muscles which may leak into the bloodstream due to injuries or disease.

Genetic testing: A definitive diagnosis of KD is made through genetic testing. A blood sample is taken from the patient, and DNA analysis is conducted to identify the presence of the gene mutation.

Muscle biopsy: In some cases, a muscle biopsy may have been performed when considering other diagnoses, however this is not required to make a diagnosis of KD.

Once a diagnosis of KD is confirmed, treatment options and support can be explored with the person and their family. Although there is currently no cure for KD, management strategies can help improve quality of life and manage symptoms. See section 2 on page 8.

Symptoms of KD

The severity and progression of symptoms varies from person to person. People living with KD may experience:

- muscle problems such as weakness, wasting, cramps, hand tremors and fasciculations (muscle twitching)
- issues with balance and an increased incidence of falls
- fatigue
- sensory changes such as numbness or tingling
- hormonal changes, leading to gynecomastia (enlargement of the breast tissue), testicular atrophy reduced fertility, erectile dysfunction and reduced libido
- frequent urination
- facial weakness, speech disturbance (dysarthria) and difficulties with swallowing and chewing (dysphagia)
- laryngospasm (spasms in the voice box, or larynx, which can be uncomfortable and frightening)
- metabolic changes which may lead to insulin resistance, high cholesterol, fatty liver disease or diabetes
- rarely, respiratory muscle weakness (including weakness of the diaphragm) and aspiration (food, drink or saliva entering the airway) due to swallowing and/or breathing difficulties.

Little is known about KD in females and research is ongoing. Most females who inherit the affected gene will not develop any symptoms, but will be carriers of it and may pass it on to their sons or daughters.

In rare cases, females may develop symptoms – usually cramps and fatigue, which are generally milder than symptoms experienced by males living with KD.



2

Management of symptoms



Although there is currently no cure for KD, much can be done to help manage the person's symptoms. Co-ordinated care from a multidisciplinary team is recommended to ensure effective interventions and effective communication between professionals. It also reduces duplication of discussions for the person with KD.

Muscle problems

KD causes weakness and wasting of the muscles, resulting in reduced strength and endurance, and increased fatigue. These symptoms can cause significant disability, making activities of daily living more challenging.

Although physical activity cannot reverse the effects of KD, it is crucial to keep as active as possible. Inactivity leads to deconditioning, which can increase weakness, stiffness, and fatigue.

A well-balanced programme of physical activity can help to slow down the speed of muscle wasting, maintain flexibility, improve balance, and boost energy levels, helping people to live well with KD. Discussion with a physiotherapist with experience of progressive neurological diseases is recommended prior to starting any new programme of physical activity.

Individual experiences with KD vary widely. While some people can maintain mobility without assistance, others may find walking aids or wheelchairs beneficial. Referrals for assessment from an occupational therapist, physiotherapist and wheelchair services should be considered based on each person's unique circumstances and needs.

By law, people with KD must inform the DVLA and where relevant, their car insurance company. In some instances, if mobility and movement has been affected, this may involve a driving assessment to establish if there are any required modifications to manage this.

Some people with Kennedy’s experience hand tremors, which may present many years before any other symptoms. These tremors may cause difficulty with daily tasks such as cutting up food, accessing a computer or writing. An occupational therapist can advise on strategies and equipment to help manage the impact of hand tremors.

Some people experience twitching of the muscles, known as fasciculations, which mostly affect the tongue and face, particularly around the mouth and chin.⁶ Fasciculations may be accompanied by weakness and wasting in the tongue and face. See “Eating and drinking” on page 14.

The person’s GP, neurologist or specialist nurse can offer medication to help with fasciculations, cramps and muscle spasms.



Information to share:

Information sheet 11C – Equipment and wheelchairs

Information for professionals:

Information sheet P2 – Wheelchairs for MND
Care pathway – Wheelchair pathway for MND

See page 35 to order publications.

Fatigue⁷

People with KD often experience muscular fatigue after performing exercise or repetitive tasks due to underlying muscle weakness. However, fatigue is complex and can also be influenced by many other factors such as diet, sleep, mood, inactivity, and hormonal changes.

Fatigue can affect people in different ways, including overwhelming tiredness, often not in proportion to activities being undertaken. Fatigue, and the anticipation of fatigue, may affect a person's motivation to continue with some of the activities of daily living, affecting quality of life. Referral to an occupational therapist and physiotherapist can support the person to develop strategies to manage their fatigue. The occupational therapist will explore options such as:

- energy conservation and pacing of activities, (breaking tasks down into smaller steps and taking frequent breaks)
- prioritising tasks
- adaptations to the home environment
- assistive equipment
- accepting help with tiring tasks.



Information to share:

Booklet – Personal care

See page 35 to order publications.

Numbness or tingling⁸

Numbness and tingling can be symptoms of KD, and usually occur in the lower limbs. The symptoms are caused by degeneration of the dorsal root ganglion (part of the spinal nerve roots). It is important that the person ensures good skin care of the affected areas to avoid skin breakdown. Numbness and tingling could also be symptoms of diabetes – see “Metabolic changes” on page 18.

Hormonal changes

Gynaecomastia (excessive growth of breast tissue) is fairly common, affecting 73-78% of men with KD.^{5,7,9} It usually begins after puberty, and before muscle weakness is noticed.⁵ This can be corrected with surgery. Alternatively, the person may wish to try to disguise this by using compression chest binders or wearing loose, dark patterned tops.

Erectile dysfunction and decreased libido affect 40-50% of men with KD.^{5,10} They may also experience testicular atrophy and reduced fertility. The person’s GP can explore medications which may help with erectile dysfunction and reduced libido. They will also be able to advise the person about their options if they have reduced fertility and are planning a family. Genetic counselling, prenatal and pre-implantation testing of embryos (to select embryos not carrying the genetic abnormality) are available.

Research on medications that replace hormones currently indicates that they are not effective in managing hormonal changes in KD.²

Urination⁹

Around 30-40% of men living with KD may experience lower urinary tract symptoms, such as urinary urgency or discomfort during urination. Research has shown bladder outlet blockages in some people with Kennedy's, and a small proportion may need to use a catheter. The exact cause of this issue is unknown.

If mobility is affecting the person's ability to get to the toilet in time, clothes that are quick and easy to unfasten can be helpful, along with aids such as grab rails or a raised toilet seat to make getting on and off the toilet easier. An occupational therapist can advise. The person may also wish to explore urinary sheaths or bottles for convenience.



Eating and drinking

Weakness in the muscles of the mouth and throat can cause difficulty with chewing and swallowing (dysphagia). This symptom usually appears 10 years or more after the person starts experiencing muscle weakness. If left unmanaged, the person may aspirate food, drink or medications into their lungs, which can cause aspiration pneumonia (see “Breathing difficulties” on page 16). It is important that this is well managed, as aspiration pneumonia is a common cause of premature death in men with KD.²

People living with KD should be referred to a speech and language therapist for an assessment of their chewing and swallowing ability, and to a dietitian for advice regarding nutrition. Advice may include recommending changes to the consistency or texture of food and drink, as well as exercises and techniques to assist with swallowing. Nutritional supplements may help the person maintain a healthy weight and stay nourished when living with dysphagia. Enteral nutrition through gastrostomy may be indicated in rare cases.⁶



Information to share:

Information sheet 7A – Swallowing difficulties
Information sheet 7B – Tube feeding
Booklet – Eating and drinking with MND

Information for professionals:

Information sheet P3 – Managing saliva problems in MND
Information sheet P8 – Managing dysphagia in MND
Information sheet P9 – Oral suction for MND

See page 35 to order publications.

Speech problems⁶

Weakness in the face, tongue, soft palate and throat muscles of people with KD can lead to speech changes (dysarthria). This usually happens later in the disease course and can affect a person's ability to be understood, particularly in noisy or social environments.

A speech and language therapist can assess the person's speech, and offer techniques, exercises and equipment to maintain effective communication. It is rare for these symptoms to escalate to the point of a person completely losing their speech or relying on communication aids.



Information to share:

Information sheet 7C – Speech and communication support

Information sheet 7D – Voice banking

Information for professionals:

Information sheet P10 – Voice banking for MND

Booklet – Communication, speech and language support

See page 35 to order publications.

Breathing difficulties^{3,7}

Respiratory muscle weakness, including weakness of the diaphragm, can occur in KD. Whilst this can lead to breathlessness (particularly when lying down) it is uncommon to develop respiratory failure requiring breathing muscle support with a ventilator. However, respiratory symptoms should be monitored regularly and referral for breathing tests made if concerns arise.

Respiratory care primarily focuses on maintaining respiratory health via a range of interventions such as optimising posture and positioning and chest physiotherapy techniques such as breath stacking and support to cough effectively. Antibiotic treatment may be prescribed where necessary. In a few cases, the use of non-invasive ventilation may be recommended.

Pneumonia, usually due to aspiration, can lead to serious, life threatening, health issues in people with KD. A respiratory physiotherapist can support the person to cough effectively using breath stacking techniques or a mechanical insufflation:exsufflation machine (MI:E – often known by the brand name CoughAssist). Involvement of a speech and language therapist and dietitian is essential to help avoid aspiration and maintain adequate nutrition in those with swallowing difficulties.



Information to share:

Information sheet 8A – Support for breathing problems

Information sheet 8B – Ventilation for MND

Information for professionals:

Information sheet P8 – Managing respiratory symptoms

See page 35 to order publications.

Laryngospasm^{3,11}

Up to half of people with Kennedy's experience uncomfortable spasms in the voice box (larynx), known as laryngospasm. The person may feel unable to breathe, as though they are choking. Although these spasms are not life threatening, they can be very distressing both for the person with KD and those around them.

In some cases, laryngospasm may be caused (or exacerbated) by gastroesophageal reflux, so the potential for this should be investigated. If reflux is identified as a contributing factor, antacid and anti-reflux medications can help. For other people, laryngospasm may be triggered by upper airway infection, swallowing difficulties (particularly with saliva), and following extubation in general anaesthetic.

Breathing techniques such as pursed-lip breathing (also known as straw breathing) can be helpful. People have also found drinking small sips of water and/or the sniff-blow technique helpful. This consists in taking two consecutive sniffs through the nose followed by a slow exhale through the mouth with pursed lips. In some cases, Lorazepam medication placed under the tongue is prescribed to help manage laryngospasm.

Metabolic changes⁷

People with KD may experience metabolic changes such as:

- high cholesterol
- non-alcoholic fatty liver disease
- increased triglycerides in the blood
- glucose intolerance or diabetes
- insulin resistance
- abdominal obesity.

The person's GP should monitor their glucose, cholesterol and triglyceride levels. If the person shows signs of diabetes or high cholesterol or triglycerides, they should be referred to a dietitian and/or be prescribed medication to help with this.



Psychological impact⁷

People with KD may experience anxiety or depression due to the progressive nature of the disease, increasing disability and uncertainty about the future. The symptoms of KD and environmental barriers can impact on someone's social participation and ability to take part in activities that are important to them. This can cause psychological distress.

An occupational therapist can explore equipment, adaptations and adjustments to help a person continue doing the things that matter most. Social prescribers, available via the person's GP, connect people to activities, groups, and services in their area. They may be able to help a person to identify and access local opportunities such as community groups and charities to maintain active involvement with local communities.

Psychological support and/or medications should be offered to people with KD who need them.



Information to share:

Booklet – Making the most of life with MND

Booklet – Emotional and psychological support

See page 35 to order publications.

3

The genetics of Kennedy's disease



Genetics of KD¹³

KD is an X-linked recessive genetic condition. In humans, the 46 chromosomes come in pairs, including two sex chromosomes that determine gender. The mother's egg always contributes an 'X' sex chromosome, while the father's sperm can provide either an 'X' (female) or 'Y' (male) chromosome. A combination of 'XX' results in a girl, and 'XY' results in a boy. KD is caused by a mutation in the androgen receptor gene on the X chromosome.

A recessive condition means that two copies of the mutated gene are needed for the condition to present. Since males only have one X chromosome, if they inherit the mutated gene on that X chromosome, they will have the condition because there is no second X to override it.

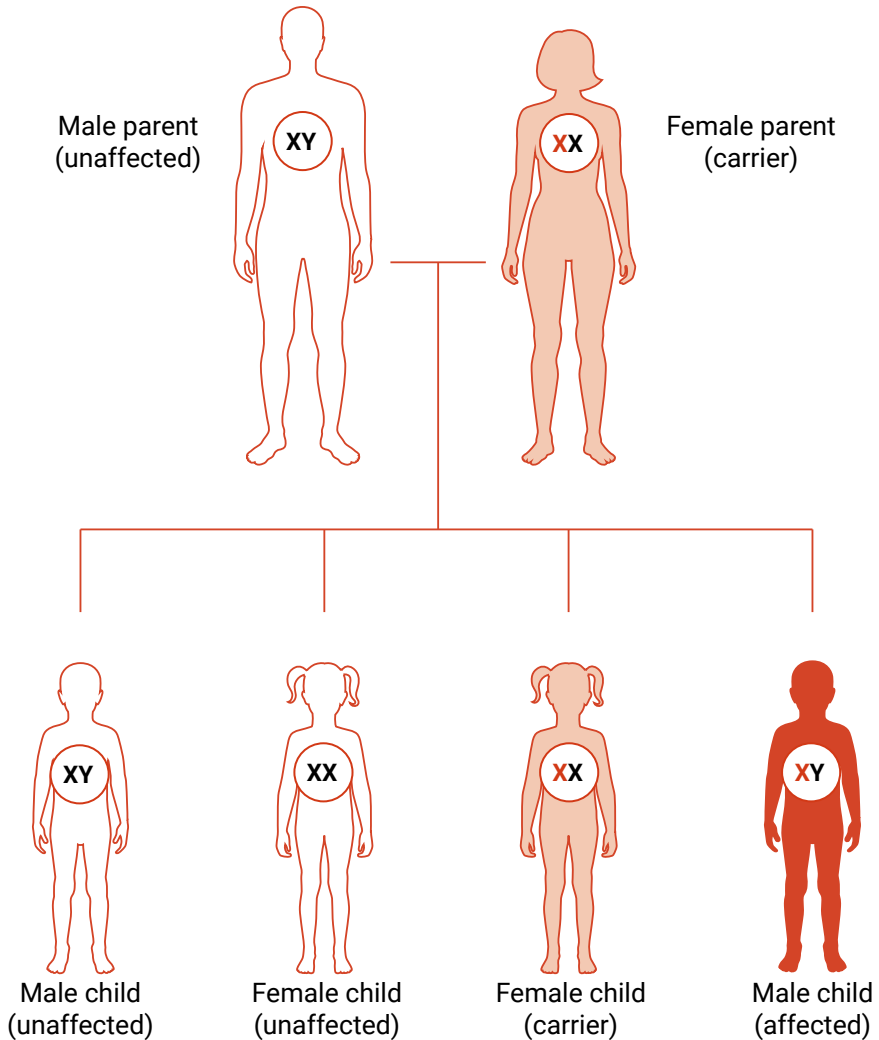
Since the disease is recessive, girls with one normal X chromosome do not show symptoms because the normal gene is largely expressed, masking the mutated one. However, these girls become carriers of the mutated gene. There is a 50% chance of their children inheriting the gene.

If a male child inherits the gene, they will have KD. If a female child inherits the gene, they will become a carrier. Males inherit only one X chromosome, and if the X chromosome carries the mutated gene, they will eventually exhibit the symptoms of the disease. Males with KD will pass on the mutated gene to all of their daughters, who will become carriers of the gene. Their male children will be unaffected.

The diagrams on the following pages explain what this means in simple terms, if a female parent is a carrier, or a male parent is affected by KD. The parents are shown with four children (two male and two female) in these examples to show the overall likelihood of inheriting the gene. The mutated X chromosome is shown in red.

Gene inheritance if a female parent is a carrier

There is a 50% chance of children inheriting the gene. If a male child inherits the gene, they will have KD. If a female child inherits the gene, they will become a carrier.



Key

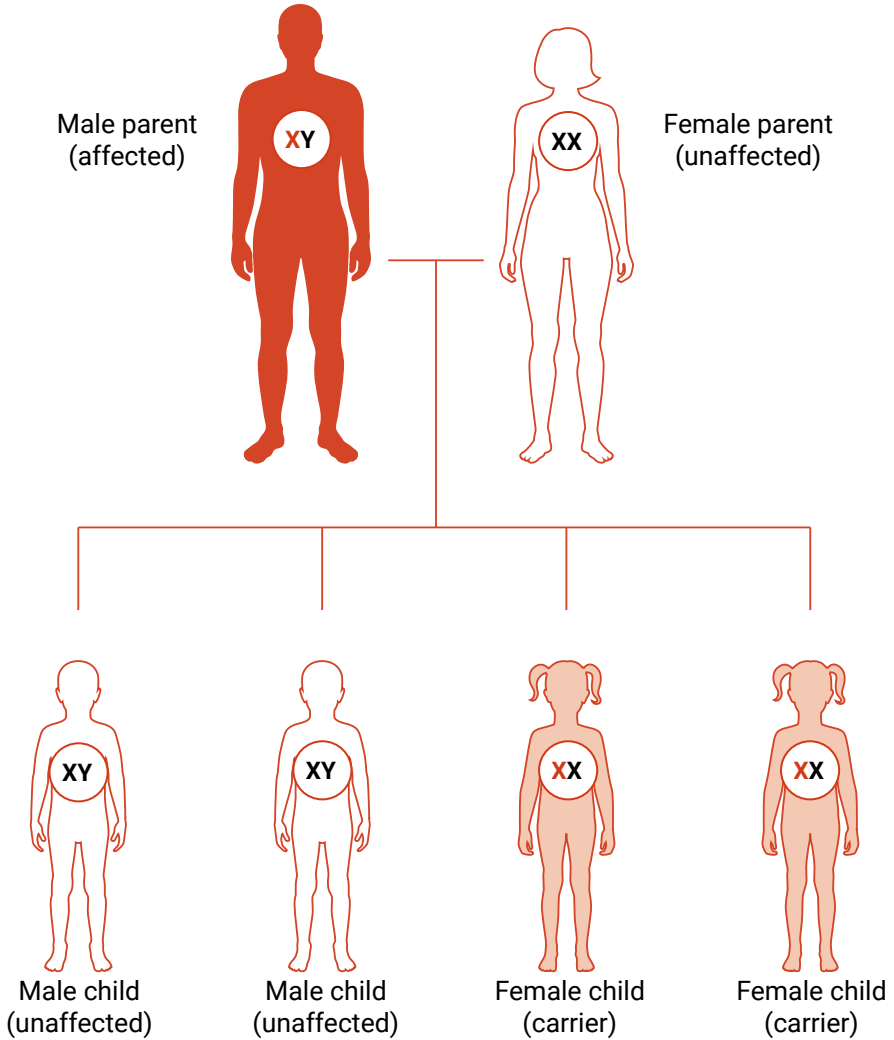
□ Unaffected

■ Affected

◻ Carrier

Gene inheritance if a male parent has KD

Males with KD will pass on the mutated gene to all of their daughters, who will become carriers of the gene. Their male children will be unaffected.



Key

□ Unaffected

■ Affected

◻ Carrier

Genetic counselling

People living with KD may wish to explore genetic counselling. A genetic counsellor will specifically discuss the risk of family members developing KD and explain how the X-linked recessive mode of transmission works. Genetic counselling will also discuss the probability of passing on this genetic mutation to their children.

For those planning families, options including prenatal or pre-implantation diagnosis will also be explained. The person may also wish to explore options such as using donor eggs or sperm, or adoption. Following genetic counselling, genetic testing may take place if the person chooses to proceed.

Genetic counselling for people with KD or carriers is available from the Kennedy's National Clinic – see page 26 for details.



Information to share:

Booklet – Kennedy's disease

See page 35 to order publications.



4

Further support



Support from the National Kennedy's Disease Clinic

The National KD Clinic is based at the National Hospital for Neurology and Neurosurgery in London. It is the only KD specialist clinic in the UK. Approval from local authorities might be needed for people with KD living in Wales, Scotland, and Northern Ireland.

This clinic is linked to the National Register for KD and provides:

- a central referring point for all patients in the UK
- multidisciplinary care
- access to research
- genetic counselling and testing
- screening for a number of non-neurological conditions that may be associated with KD
- referral to, and liaison with local support services.

People with Kennedy's can be referred, or self-refer, to the clinic by emailing uclh.kdregister@nhs.net or call the team on 020 31087507.



Useful organisations

The following listings may be useful to your patients with KD.

KD UK

UK based charity run by volunteers and people with KD. Working to raise awareness of the disease.

Website: **kd-uk.com**

KD Association (KDA)

American organisation supporting people with KD. Their website includes a forum.

Website: **kennedysdisease.org**

Remember the Girls

American organisation raising awareness and support for women and girls who carry X linked recessive disorders.

Website: **rememberthegirls.org**

Kennedy's disease clinic (based in London)

The only Kennedy's disease specialist clinic in the UK, providing multidisciplinary care and support.

Telephone: 020 34483517 (General enquiries)

Email: **uclh.referrals.mnd.care@nhs.net**

Website: **uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/motor-neuron-diseases**

Kennedy's disease raising awareness (Facebook)

It can help to share experiences with others affected by Kennedy's disease. The MND Association is not responsible for this group.

Website: **facebook.com/groups/kennedysdisease.raisingawareness**

How we can support you

Our MND Connect helpline offers practical and emotional support, information and signposting to people with KD, carers, family and professionals. They can also provide information about our services mentioned below.

Email: mndconnect@mndassociation.org

Tel: 0808 802 6262

MND Association website

Our website offers supporting information on KD, our work, services, and how to get involved.

mndassociation.org/professionals

Stay updated on events, publications and opportunities for health and social care professionals.

mndassociation.org/educationupdate

X: **[mndeducation](#)**

Bluesky: **[mndeducation.bsky.social](#)**

Information resources

We produce high quality information for people with MND and KD, carers, families and professionals, available in multiple formats and languages.

mndassociation.org/pro-info-finder

mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.

mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.

mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.

mndassociation.org/local-support

Financial support

We offer a range of support funds for people living with KD or MND, their families and unpaid carers. Our support funds can help to buy equipment and assisted technology, and contribute to costs of living and wellbeing activities. They are not in place of any statutory funding that should be available.

mndassociation.org/getting-support

MND Association Benefits Advice Service

Our trained advisers can help identify benefits a person may be able to claim if living with KD or a carer. The service is available by telephone or email for people living in England, Wales or Northern Ireland, and there is also a web chat facility for those living in England or Wales.

mndassociation.org/benefitsadvice

Wheelchair support

Can offer advice and support for a wheelchair or mobility enquiries you may have and talk you through what is available through statutory services and privately.

mndassociation.org/wheelchairs



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We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit smartsurvey.co.uk/s/mndprofessionals or email your comments to education@mndassociation.org.

If you would like to help us by reviewing future versions of our information resources, please email us at education@mndassociation.org.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from mndassociation.org/publications or contact MND Connect to order hard copies. Call **0808 802 6262** or email mndconnect@mndassociation.org.

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**Every day we support people affected
by Motor Neurone Disease.
Because with MND, every day matters.**