mnda
motor neurone disease
association

MND Professionals'
Community
of Practice

An introduction to Kennedy's disease (KD)

For health and social care professionals

Would you like to find out more?

You can contact our helpline MND Connect if you have questions about any aspect of Kennedy's disease, or want more information about anything in this booklet.

How to order publications

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

Download from **www.mndassociation.org/publications** or contact MND Connect to order hard copies.

mndconnect
0808 802 6262
mndconnect@mndassociation.org

We value your feedback

We would greatly appreciate your feedback on this guide. Please visit **www.smartsurvey.co.uk/s/mndprofessionals** or email your comments to **infofeedback@mndassociation.org**

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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 22.

Information for you

We have a number of webinar recordings on KD available on our website at **www.mndassociation.org/webinars**

Information to share

Kennedy's disease - our guide for people with KD

What is Kennedy's disease? animation - available alongside our other animations at **www.mndassociation.org/animations**

See page 2 for details of how to order our publications.

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: This is often significant in KD as it is an inherited genetic disorder. A family history of similar symptoms, or a known family history of the condition, can be a valuable diagnostic clue, but for some patients, they 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 *Management of Kennedy's disease* (page 8-16).

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 (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.


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Management of KD

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, writing etc. 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 12.

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

Information for you

Information sheet P2 – *Wheelchairs for people with MND*

Wheelchair Pathway for MND

Information to share

Information sheet 11C - *Equipment and wheelchairs*

See page 2 for details of how to order our publications.

Fatigue[7]

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

Personal care guide - includes information on managing fatigue.

See page 2 for details of how to order our publications.

Numbness or tingling[8]

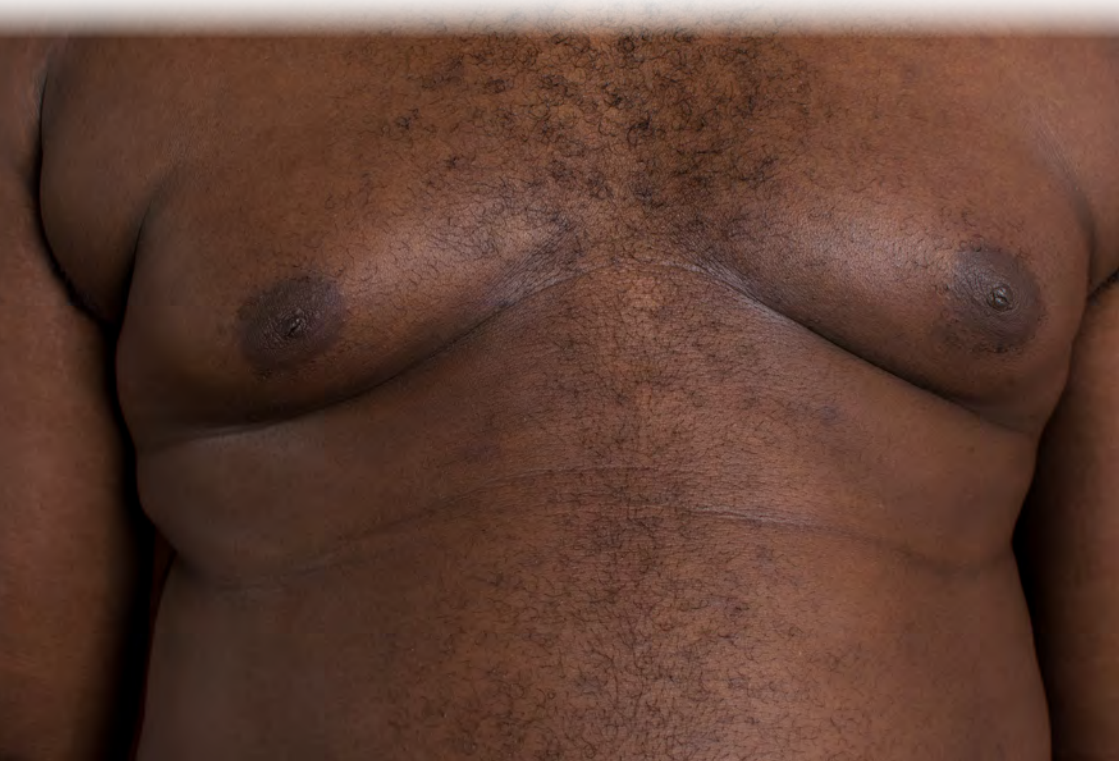
Numbness and tingling can be symptoms of KD, and usually occur in the lower limbs. The symptoms are caused by degeneration of the dorsal root ganglion (part of the spinal nerve roots). It is important that the person ensures good skin care of the affected areas to avoid skin breakdown. Numbness and tingling could also be symptoms of diabetes – see *Metabolic changes* on page 15.

Hormonal changes

Gynaecomastia (excessive growth of breast tissue) is fairly common, affecting 73-78%[5, 7, 9] of men with KD. It usually begins after puberty, and before muscle weakness in 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 other 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.[11]



Urination[9]

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 14). 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 for you

Information sheet P8 – *Dysphagia in MND*

Information sheet P3 – *Managing saliva problems in MND*

Information sheet P9 – *Oral suction*

Information to share

Information sheet 7A – *Swallowing difficulties*

Information sheet 7B – *Tube feeding*

Eating and drinking with MND – information on how to adapt food and drink, as well as easy-swallow recipes.

See page 2 for details of how to order our publications.

Speech problems[6]

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 for you

Communication, speechand language support

Information sheet P10 - *Voice banking*

Information to share

Information sheet 7C - *Speech and communication support*

Information sheet 7D - *Voice banking*

See page 2 for details of how to order our 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 for you

Information sheet P5 - *Managing respiratory symptoms in MND*

Information to share

Information sheet 8A – *Support for breathing problems*

Information sheet 8B – *Ventilation for MND*

See page 2 for details of how to order our publications.

Laryngospasm[3, 12]

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 – taking two consecutive sniffs through the nose followed by a slow exhale through the mouth with pursed lips – helpful. In some cases, Lorazepam medication placed under the tongue is prescribed to help manage laryngospasm.

Metabolic changes[7]

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 impact[7]

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

Making the most of life with MND

Emotional and psychological support

See page 2 for details of how to order our publications.

Genetics of KD[14]

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's no second X to override it.

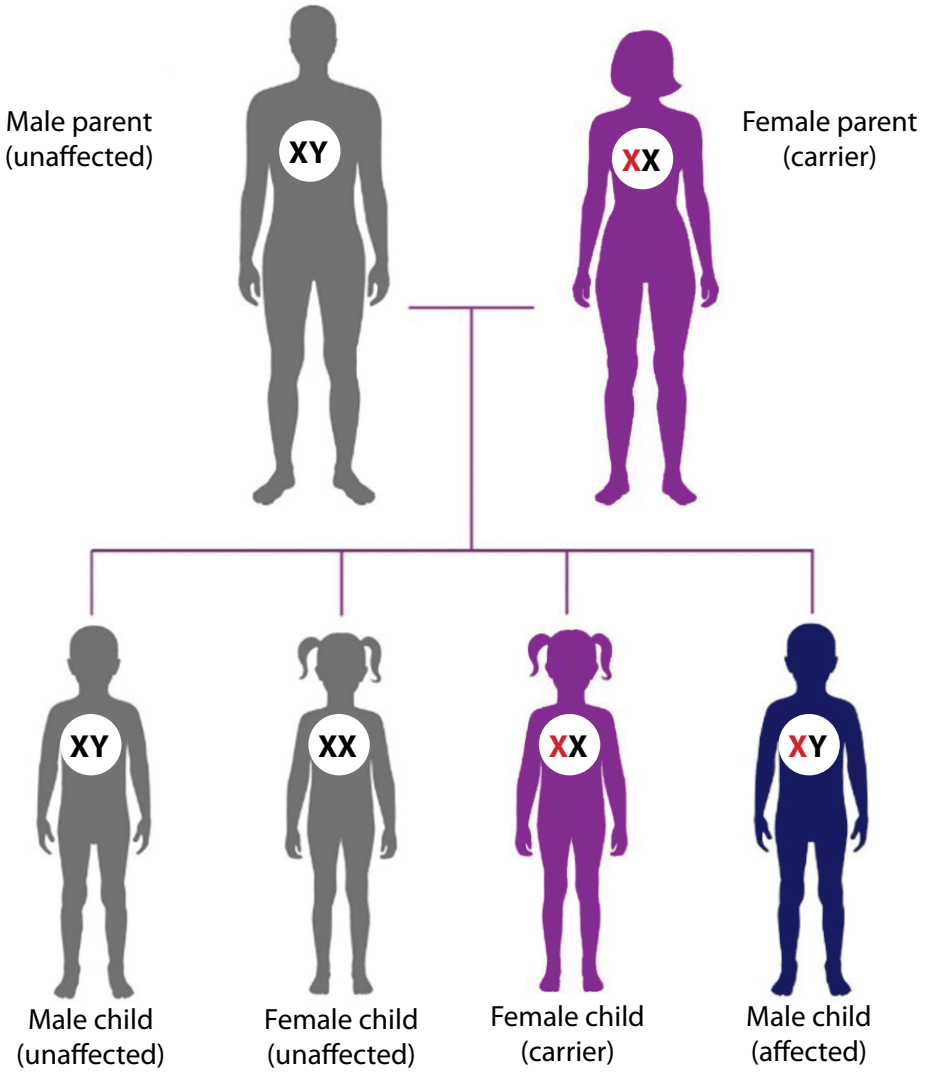
Since the disease is recessive, girls with one normal X chromosome do not show symptoms because the normal gene is largely expressed, masking the mutated one. However, these girls become carriers of the mutated gene. There is a 50% chance of their children inheriting the gene.

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.

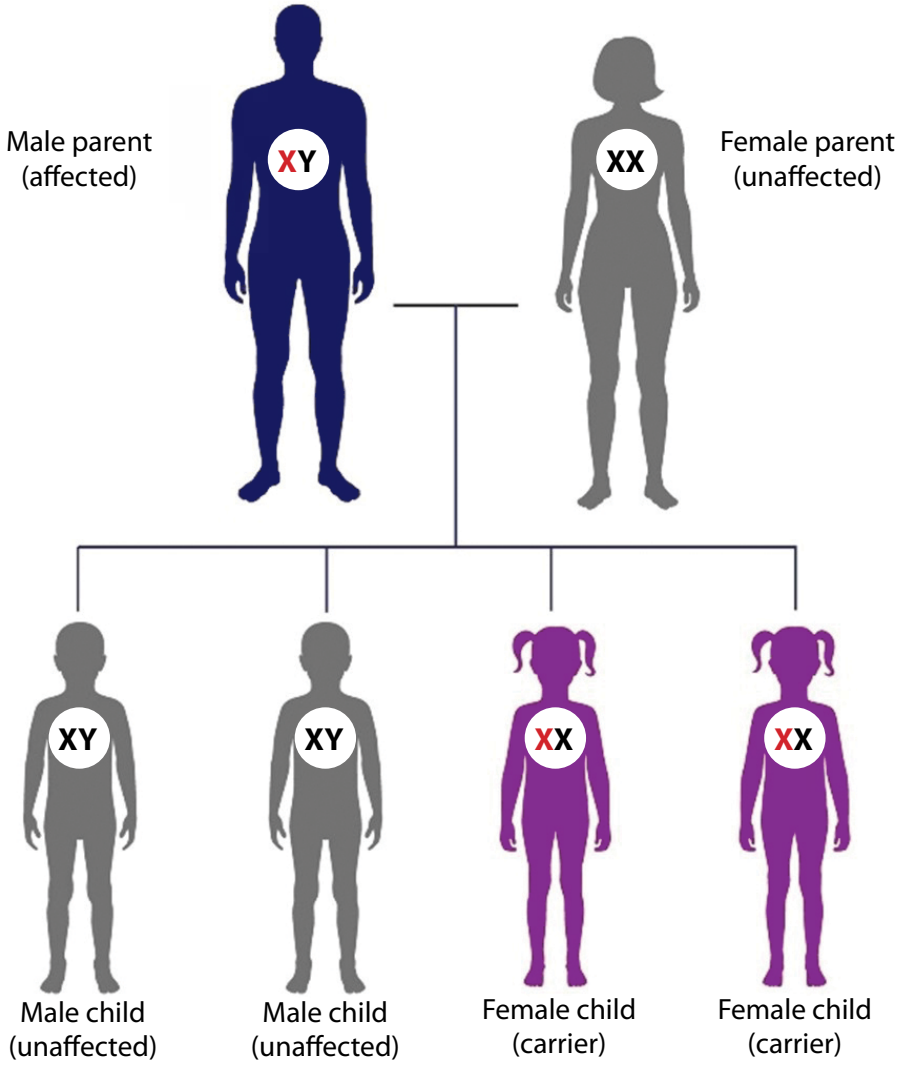
Gene inheritance if a female parent is a carrier

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.



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.



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 21 for details.

Information to share

Kennedy's disease guide

See page 2 for details of how to order our publications.

Support from the National KD 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 3108 7507.

Support from the MND Association

To access any of the services or support listed in this section, please contact our MND Connect helpline. See page 2 for contact details.

MND Connect helpline

Our helpline provides support and information for people living with KD, their carers and families, our volunteers, and health and social care professionals. The team can direct to practical support, including our own services and appropriate external organisations. If someone simply needs to talk, they can listen.

Financial support

The Association is able to offer some financial support to help with:

- funding equipment and services that people with KD have been assessed as needing
- funding for children and young people aged 18 or under living with someone with KD
- non-paid carers supporting someone living with KD (available up to 12 months post-bereavement)
- improving quality of life for someone living with KD.

These are not in place of any statutory funding that should be available, however we can assist with obtaining statutory funding or funding from other charitable organisations.

Visit **www.mndassociation.org/supportgrants** for more information.

Equipment loan

We are able to offer some communication aids on loan. All statutory funding and services should be explored first. However, loaned items can be provided if the person has to wait for health and social care services to arrange equipment or if they are unable to provide an item.

Visit **www.mndassociation.org/equipmentloan** for further details.

MND Association volunteers

The MND Association has trained, experienced volunteers who are able to provide emotional/informal support to people with KD, their carers and close family and friends.

Local branches and support groups

We have a network of more than 85 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide the opportunity to meet others affected by KD. They offer guidance and support, including group meetings specifically for carers. People can share emotional and practical support, and exchange information.

Care information and publications

We provide over 70 items of care information and publications for people with KD, carers and families. These cover a wide range of topics from ventilation and end of life to planning holidays and driving. We provide introductory information in additional languages to English, and a limited translation service for further care publications.

Visit **www.mndassociation.org/careinfo**

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.

Visit **www.mndassociation.org/benefitsadvice** for further details.

MND Wheelchair Support Service

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.

Visit **www.mndassociation.org/wheelchairs** for further information.

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.

Email: through the website contact page
Website: http://kd-uk.com

KD Association (KDA)

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

Email: info@kennedysdisease.org
Website: www.kennedysdisease.org

Remember the Girls

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

Email: info@rememberthegirls.org
Website: https://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 3448 3517 (General Enquiries)
Email: uclh.referrals.mnd.care@nhs.net
Website: www.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: www.facebook.com/groups/kennedysdisease.raisingawareness

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14 Genomics Education programme, Health Education England. **www.genomicseducation.hee.nhs.uk/genotes/knowledge-hub/x-linked-recessive-inheritance**

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Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

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