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**Access to Kennedy’s Disease Care**

As Kennedy’s Disease (KD) is a rare disease it can be difficult for people living with the illness, be they patients, carers or carriers, to access support. There is no dedicated NHS protocol for the management of the illness and the support can vary significantly depending on where you live.

Some neurologists, and almost all GPs, have little or no knowledge of Kennedy’s Disease which can make the access to care all the more challenging.

Once your Kennedy’s Disease has been diagnosed, the main routes to support are:

**The Kennedy’s Disease Clinic at the National Hospital for Neurology and Neurosurgery in London**

The Gold standard.

There is a dedicated Kennedy’s Clinic at the National Hospital for Neurology and Neurosurgery in London that is run by highly experienced consultants, a Kennedy’s Disease clinical research nurse, and a specialist clinical research physio.

The clinic aims to see registered Kennedy’s Disease patients at least once a year and can provide telephone/E-Mail support between visits. The clinic can refer patients to specialists within the University College London Hospital Group. These specialists include gastroenterologists, urologists, respiratory doctors, speech and language therapists, occupational therapists and genetic counsellors. The clinic can also see patients remotely using video teleconferencing.

Apart from being a centre of excellence the clinic collects, from patient visits, very valuable patient information to help the research into finding a cure or effective treatment. All UK based Kennedy’s Disease drug trials are also managed through the clinic.

You can be referred to the clinic by your GP. The referral contact details are:

Tel: 0203 448 030 E- Mail: uclh.enquiry.neuromuscular@nhs.net

**Regional MND Centres**

If, as the disease progresses, you find the trek to London too challenging, you can be referred by your GP to one of the 23 Regional MND Care Centres in the UK (England, Wales and Northern Ireland). These centres are based within Regional Neuroscience Centres, and they will have an in depth understanding of motor neurone diseases, including Kennedy’s Disease

The centres should be able to provide you with the right level of support depending on how advanced your illness is. They should also be able to refer you to specialist neuro therapists who are based close to where you live.

The system is slightly different in Scotland. Your GP should, however, be able to refer you to a Neurocentre in either Aberdeen, Dundee, Glasgow or Edinburgh.

The level of support can vary quite significantly from region to region, but work is ongoing to try and ensure that it is as consistent as possible throughout the UK. Do not be afraid to ‘fight your corner’ if you feel you are not getting the level of support you need.

[Click Here](https://www.mndassociation.org/support-and-information/our-services/care-centres-and-networks?gad_source=1&gbraid=0AAAAAD2ZVejA_FlbCXwavEkkx6G0pA-IN&gclid=EAIaIQobChMI98bBzcmCjAMVG41QBh002DC8EAAYAiAAEgKpe_D_BwE) for a list of MND Care Centres.

**Local Neurologists**

Your GP will be able to refer you to a neurologist at your closest hospital that offers a neurology service.

Although all neurologists should have some knowledge of Kennedy’s Disease it is quite possible that your local neurologist may never have seen a Kennedy’s Disease patient.

Should you be referred to a local neurologist then KD-UK would recommend that you take along a copy of the French Protocol for the Management of Kennedy’s Disease. [Click Here](https://kd-uk.com/wp-content/uploads/2023/08/Protocol-and-Highlights_V5.pdf)  to download it. This is an internationally recognised document that gives excellent guidance to doctors on disease management.

**GP Direct Referrals**

Depending on your regional health authority your GP may also be able to refer you directly to specialist respiratory specialists, physiotherapists, speech and language therapists, occupational therapists and wheel chair services within your local area.

This can be helpful if there is long wait to see a neurologist, or to be seen at your regional MND centre.

**Private Care**

You can, of course, access private health care to help manage your disease but please do be aware that very few private neurologists will be experts on Kennedy’s Disease. Do your research first before you spend your hard-earned money on a consultation.

Please also be aware that because Kennedy’s Disease is a chronic progressive condition it is unlikely that, following a diagnosis, private health insurance will cover ongoing treatment.

As there is no NHS protocol for Kennedy’s Disease you may find that the NHS will only give you a set number of Physiotherapy appointments and will then sign you off. There are, however, private neuro physios throughout the UK who can support you if you are unable to get the support you need through the NHS.

Hydrotherapy can be a very good way of improving balance, thereby reducing the risk of falls. If you don’t have a local NHS hydrotherapy pool, or if the NHS pool is heavily oversubscribed, you might like to consider going to a private pool. Before starting Hydrotherapy do refer first to a qualified neuro physiotherapist for a list of exercises.

**Kennedy’s Disease Charities and Advocacy Groups**

Although patient advocacy groups are not staffed to give medical advice, they are a highly valuable source of information.

Kennedy’s Disease UK ([www.kd-uk.com](http://www.kd-uk.com/)) has lots of information on its website and publishes quarterly newsletters with all the latest updates. If you register with the charity, then the newsletters will be automatically sent to you by E-Mail along with any key updates.

The American charity, the Kennedy’s Disease Association, is also another excellent source of quality information. ([www.kennedysdisease.org](http://www.kennedysdisease.org)).

The more informal UK Facebook page, Kennedy’s Disease Raising Awareness, is an excellent platform for directly engaging with other people who are living with the illness. [Click here](https://www.facebook.com/kennedysdiseaseuk/?locale=en_GB) to access it.

**Support Groups**

The Motor Neurone Disease Association (MNDA) has a very well-established volunteer run regional support network that welcomes people living with Kennedy’s Disease; be they patients, carers, carriers, or partners.

There will be a group close to where you live, and they typically meet every couple of months.

It is well worth participating in these groups as, apart from being very sociable, they are an excellent place to garner intelligence on how to best access local care and support.

[Click here](https://www.mndassociation.org/support-and-information/local-support/branches?gad_source=1&gbraid=0AAAAAD2ZVejA_FlbCXwavEkkx6G0pA-IN&gclid=EAIaIQobChMIyseN-saCjAMVm4NQBh1ukSrjEAAYASAAEgJ0N_D_BwE) for details of the groups.