IWMD Service patient information leaflet

Ten top tips for people who have been referred to the NHS Inherited White Matter Disorders (IWMDs) Diagnostic and Management Service, and their family or carers

1. What is an IWMD?

Inherited white matter disorders (IWMDs), also known as leukodystrophies, are rare genetic disorders that mostly affect the nervous system including the brain.

Many, but not all, IWMDs are progressive diseases that lead to increasing damage to nerves, affecting a person’s mobility, speech, feeding, vision, hearing and thinking.

There are many different IWMDs; how someone is affected depends on the type of IWMD they have. IWMDs affect people of all ages and ethnic backgrounds.

For information on what an IWMD is and the different IWMDs, please visit: https://www.alextlc.org/what-is-a-leukodystrophy/the-different-leukodystrophies/

2. Why have I, or the person I am responsible for, been referred to the IWMD service?

You, or the person you are responsible for, have been referred to the IWMD service for one of the following reasons:

- You or they have a suspected IWMD based on neurological observations made by a local or regional clinician.
- You or they have a sibling or near relative who has been diagnosed with, or who is suspected of having an IWMD.
- You or they have already been diagnosed with an IWMD and the local clinician managing your/their care has asked the IWMD service to review the treatment or management plan.
• You or they are participating in or are considering taking part in the trial of a potential new IWMD treatment.
• You or they are expecting a baby who has a suspected IWMD, and concerns have been raised about the baby following an antenatal screening or scan.

3. Who can refer me or the person I am responsible for to the service?

The referral to the IWMD centre team must be made by a local specialist clinician, such as a:

• consultant neurologist
• paediatric neurologist
• paediatrician
• physician
• geneticist or consultant in metabolic diseases.

If you, or the person you are responsible for, have already been diagnosed with an IWMD, but are not currently being seen by one of the above specialist clinicians in your local area, your GP can make a referral to a regional neurologist who will see you and then refer your case to the IWMD service.

4. What does the IWMD service do?

The NHS IWMD Diagnostic and Management Service is made up of NHS trusts known as IWMD centres which have been selected by NHS England. These work together to:

• improve opportunities for an early diagnosis
• support local and regional referrers to better manage the care of their patients
• establish a standard of care for people with an IWMD
• improve access to clinical trials and research studies.

They will do this by:

• reviewing the results of investigations already carried out and giving advice to referrers on the future management and treatment plan to be followed
  – this may include recommendations for additional investigations to be carried out to give more information on the patient’s case and how to manage it
  – the referrer and the IWMD centre team may have multiple discussions about the patient’s progress which will be influenced by the results of any new tests and assessments carried out.
• inviting local and regional clinicians to attend multi-disciplinary team (MDT) discussions about the patient’s case
• providing education and training on IWMDs for those involved in the patient’s clinical management.

5. What can I/the person I represent expect from the IWMD service?

This service is set up differently to other services as it is primarily to provide management advice to local or regional referring clinicians.

Most of the work of the IWMD service can be done without the patient needing to travel away from their home area. This means that most patients with an IWMD will continue to receive all of their healthcare from their local or regional specialist team.

In-person clinic appointments at an IWMD centre will only be offered to those people whose IWMD requires a complex management approach or to those people who do not yet have a definite diagnosis.

A combination of in-person and virtual (video or telephone) appointments may be offered. During these appointments you will be able to discuss ongoing clinical issues.

If you or the person you are responsible for have been given a diagnosis of an IWMD, you will be given regular opportunities to share your experiences of the IWMD service to help the IWMD centres to continuously improve the quality of care.

6. Who is in the IWMD MDT?

The core multidisciplinary team (MDT) at each IWMD centre includes the following specialists:

**Consultant neurologist (adult and/or paediatric)**
A doctor who specialises in the diagnosis and management of conditions which affect the brain and spinal cord and the nerves that transmit signals between the body and the brain.

**Consultant neuroradiologist**
A highly specialised healthcare professional who performs imaging to assist in the diagnosis and management of neurological conditions.

**Consultant in metabolic diseases**
A doctor who specialises in the diagnosis and management of inherited metabolic disorders which are rare, genetic disorders affecting the body’s metabolism.
Consultant in clinical genetics
A doctor who specialises in the diagnosis and management of genetic disorders.

Molecular genetic laboratory scientist
A scientist who examines a person’s DNA to identify and understand genetic changes which help in the diagnosis and treatment of genetic conditions.

Neuropsychologist
A clinician who will understand a person’s cognition and do an assessment.

Neurology nurse specialist
A specialist nurse who works closely with those diagnosed with a neurological condition and their families to evaluate their individual needs and ensure people understand their condition and how it can be managed.

They will be able to offer support if you are waiting for a diagnosis or if you have any queries and can signpost to local services.

MDT co-ordinator
A person who facilitates the smooth running of services provided by multidisciplinary teams (a united team of healthcare professionals in different specialities).

Data manager
Data managers collate, analyse, and provide reports on data linked to the diagnosis, treatment and outcomes of patients who attend the service.

Patient support groups
Patient advocacy and support will be offered during face-to-face clinic appointments by the patient organisation Alex TLC. You can also contact Alex TLC direct to access a range of support and resources.

You are most likely to meet different team members in different consultations, although your neurologist will be there in most of your consultations.

7. What happens after a person’s test and other details of their case has been reviewed?

Following the clinical review of the information about the person, the IWMD centre team will send a report on the outcome of the clinical review to the referrer. A copy of this letter will be sent to you and to your GP. The report may include the recommendation for an additional referral to be made for the patient if appropriate to other local specialist MDTs.
The review will include the IWMD centre team, and they will invite the referrer to join the initial IWMD centre MDT meetings. The IWMD team will be in contact with the referrers to provide any updated information on your condition.

The local and regional teams will continue to be responsible for co-ordinating your ongoing care. You or the person you are responsible for will be given a contact number for the IWMD centre in case you or they need any further help or information.

The IWMD centre team will also advise about current and proposed treatment trials that might be relevant to the patient so that they can register interest to seek further information on whether they would be suitable.

8. Where are the IWMD centres located?

**IWMD centres for adults**
The National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust (Lead Unit), is the lead adult unit and works in association with:

- University Hospitals Birmingham NHS Foundation Trust
- Northern Care Alliance NHS Foundation Trust (Salford Royal)
- Leeds Teaching Hospitals NHS Trust

**IWMD centres for children**
- Manchester University NHS Foundation Trust in association with Leeds Teaching Hospital NHS Trust
- Birmingham Women’s and Children’s NHS Foundation Trust
- Guy’s and St Thomas’ NHS Foundation Trust in association with Great Ormond Street Hospital, for Children NHS Foundation Trust, London

9. What other support is there?

Alex TLC is a trusted and experienced organisation offering support and information for all those affected by a leukodystrophy (IWMD) in the UK and worldwide.
They deliver tailored packages of support, alongside quality information and updates, providing an empathic and proactive community of care.

Website: www.alextlc.org / Email: info@alextlc.org / Phone: 020 7701 4388

Metabolic Support UK are a leading umbrella patient organisation for all Inherited Metabolic Disorders (IMDs) supporting patients of all ages and their families, worldwide.

The organisation offers practical information and advice, emotional support, and focuses on advocacy and empowerment for those living with IMDs.

Website: www.metabolicsupportuk.org / Email: contact@metabolicsupportuk.org / Phone: 0800 652 3181

10. IWMD Patient Registry

Guy’s and St Thomas’ NHS Foundation Trust manages the IWMD patient registry on behalf of NHS England as well as being one of the NHS Trusts which has been selected to provide the IWMD service. The registry is a national database which:

- provides valuable information to support clinical diagnosis, direct care management and clinical decision-making
- helps IWMD teams to understand the incidence and prevalence of these conditions in the UK, how they are inherited and their impact on patients and carers
- measures the quality and uptake of care and treatments to improve patient outcomes
- provides comprehensive data for future research.

Patients accessing the IWMD service will be enrolled in the registry.

Please note that putting information into the registry is not a substitute of your clinical care and the registry should not be used for telling the NHS about any clinical emergencies.

If you are unsure if you or the person you are responsible for has been added to the registry, you can:

- Ask your local clinician whether a referral has been made to the registry or:
• Contact the registry co-ordinator and ask to self-enrol to be added to the registry by clicking here gst-tr.IWMDR@nhs.net

or:

• Contact the Alex TLC team who can provide advice with any enquiries and assist with self-enrolment. Email: info@alextlc.org or phone: 020 7701 4388.