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Tallaght University Hospital  
Ospidéal Ollscoile Thamhlachta  
An Academic Partner of Trinity College Dublin

Institute of Memory and Cognition



# Neurocognitive Clinic

An ERN Expert Centre  
for PSP, CBS & MSA

# TUH Neuro-Cognitive Clinic

This clinic is part of the TUH Neurology Dept and takes place in the SIMMS building, Tallaght Cross, beside the Hospital. It is led by Dr Seán O Dowd, Consultant Neurologist.

It is a multi-disciplinary clinic with a team of doctors, nurses, physiotherapist, speech therapist and social work, supported by clerical staff.

The team assess and manage many neurodegenerative conditions and take referrals for all ages from across the country.

We are an expert clinical site for Atypical Parkinsonian Syndromes(APS) such as Progressive supranuclear palsy (PSP), Corticobasal Syndrome (CBS) and Multiple System Atrophy (MSA). We are part of a network of specialist Europe wide clinics under the European Reference Network- Rare Neurological Diseases (ERN-RND).





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## Neurological Diseases (ERN-RND)

### What is the ERN

The ERN-RND is established by the EU to support patients and families affected by rare neurological diseases which require specialised knowledge, treatment and resources.

Some diseases are so rare that the necessary knowledge might not be available in the patient's nearest health centre or country. The patient does not travel but knowledge does.

After a detailed assessment process conducted by the ERN our clinic was granted membership in 2022. Being a member means our patients have access to research.

Together we are stronger !!  
Specific information about the diseases ERN-RND covers can be found on their website [ERN-RND | European Reference Network on Rare Neurological Diseases – for rare or low prevalence complex diseases](#)

## ERN Registry for PSP, CBS and MSA

As an ERN member we maintain a **registry** of all patients with APS. This is important for research but also for service planning and resource allocation. It is voluntary and consent is required. All data is anonymised so no personal identifiable information is put on the database.



## ERN-RND Bulletin European Reference Network for Rare Neurological Diseases

## Part of the National Dementia Network

A key strength of our clinic is our collaboration with the gerontology-led memory service Prof Seán Kennelly in TUH.

This collaboration resulted in the formation of the TUH Institute of Memory & Cognition. Together both clinics combine to form a Regional Specialist Memory Centre (RSMC) which receives referrals from GP, other smaller memory centres and from within the Hospital.

The RSMC means all patients have access to important services, as deemed necessary, such as neuro-psychology, speech & language therapy, social work, dietetics, occupational therapy and brain health supports. We also have strong links with local integrated care services.

The Centre is fully staffed and hold interdisciplinary meetings on a weekly basis.

# Why come to our clinic?

**Rare conditions such as PSP, CBS, MSA require a coordinated expert approach. Our clinic is staffed by a consultant, specialist registrar, nurse specialist and a clinical specialist physiotherapist with experience and knowledge of these conditions. We work closely together.**

## **Diagnosis is the first step.**

We support patients and families through this process. We know it is both confusing and difficult.

## **After Diagnosis**

Our Advanced Nurse Practitioner (candidate) in Rare Neurodegenerative Disease, Emmet Kelly, runs a nurse led service. This means people can be reviewed, as needed, in the period between consultant reviews. He also runs a telephone line to address issues that may arise.



Our Clinical Specialist Physiotherapist, Evelyn Kimmage, sees any patients with a new diagnosis or a recent functional decline. Patients receive an individual assessment and recommendations for treatment; this may include 1:1 rehab either at home or in a gym-based setting depending on need. She will work with patients and families in developing a plan to help mobility, address falls risk and other symptoms which may affect activities of daily living.

## **Specialised treatment**

Some people with PSP/CBS require specialised treatments for severe problems with stiffness/ spasticity of legs or issues relating to eyelid opening. These may require botox treatments which we can provide.

## **Access to research**

Through the ERN our patients are part of a wider community of patients and neurologists. Some have taken part in contributing to care guidelines from a patient perspective. We also have run our own study called **Leinster Tauopathy Study**.

A palliative care doctor who worked in our clinic has conducted a study on **unmet palliative care needs in APS in 2023**. A Speech & Language therapist in TUH has also published research this year on **dysphagia (swallowing difficulties) in PSP**.



## **Our clinic is growing**

We are actively recruiting for a Clinical Specialist Occupational Therapist.

Patients in our clinic can also be referred to the wider RSMC team in TUH.

## **Links with other services**

We have developed links with palliative care services in TUH and the wider community. We work with our colleagues in psychiatry also. We hope to develop further links with other specialities (e.g. Urology) to provide a smoother and more rapid access for our patients.

## **Tell us what we can do better**

We see our patients as equal partners in everything we do. We also value the input of their relatives and patient organisations. We actively welcome feedback on how we can do better. We routinely conduct patient feedback surveys.

## **Is this clinic for You?**

If you already have a diagnosis of PSP, CBS, MSA and wish to be part of the ERN Registry, then ask your **GP to refer to Dr Seán O Dowd, TUH Neurology.** The clinic can only accept referrals from GPs.

For those with parkinsonism there are certain **RED FLAGS** that may indicate they have a more complex condition like PSP, CBS,MSA. These include:

- **Early Falls**
- **Poor or no treatment response e.g Sinemet**
- **Early bowel, bladder, light headedness**
- **Speech difficulties**
- **Eyelid or sight problems**
- **Early memory or other cognitive/ behavioural problems**

