

## Support and Planning Ahead

Open communication regarding the diagnosis and prognosis will ensure a less stressful journey.

It is essential that the family unit is supported from the time of diagnosis as dealing with the implications of CBD can be far reaching. Having a supportive multidisciplinary team including clinical psychology and a social worker is ideal.

Discussions around options of accessing respite and residential care may be of benefit and guidance through the Aged Care Assessment Team (ACAT) process is recommended.

Conversations regarding medical treatment and arranging Enduring and Medical Power of Attorney and Guardianship and developing Advanced Health Care Plans or Directives are an essential component for future planning.

The information in this brochure is intended as a guide for those diagnosed or affected by a diagnosis of CBD. All symptoms and health issues should be discussed with the treating medical specialist.

For further information about CBD contact your state based Parkinson's office.

A CBD Information Manual is available from Parkinson's Victoria (03) 8809 0400.

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# in brief

## CORTICO BASAL DEGENERATION (CBD)



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Providing support for people with  
Parkinson's and their families and carers

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## What is Cortico Basal Degeneration?

Cortico Basal Degeneration (CBD), also known as Cortico Basal Syndrome (CBS) was first described in the 1960s and is the least common of the group of conditions known as Atypical Parkinsonism or Parkinson's Plus. In the early stages it can be difficult to make a firm diagnosis but with time and progression it becomes clear that this rare condition is something other than idiopathic Parkinson's.

The cause of CBD remains unknown but it is associated with an abnormal or 'misfolding' of the protein tau - for this reason it is referred to as a tauopathy. There is no indication of a genetic link. Both genders may be affected.

The Australian prevalence of CBD is estimated at 150 but this would not include those with a misdiagnosis. Symptoms commonly affect one side of the body and usually become evident around the age of sixty.

CBD runs a progressive course without remissions and one study documents a median survival time of eight years from onset of symptoms, however each person will experience CBD differently.

Clinical features on which diagnosis is based include signs of Parkinsonism (stiffness, rigidity and loss of balance and coordination) which do not respond to Parkinson's treatment.

Intellectual decline with planning impairment and communication changes occur earlier than in Parkinson's.

The tremor in CBD, if present, is usually a postural or action tremor. In addition, alien limb phenomenon or levitation may be seen in later stages. This presents as an inability to use the affected limb or a lack of awareness that it belongs to the person affected.

There are no tests available to confirm diagnosis hence the diagnosis is based on the presentation of symptoms. It is recommended that diagnosis is made or confirmed by a specialist in movement disorders.

## Getting Help

In view of the progressive nature of CBD it is essential that those affected and their families have ongoing support and management to ensure the best quality of life possible. Referral to a multidisciplinary team is essential and this can be generated by the general practitioner.

Parkinson's Nurse Specialists also care for those living with Parkinson's Plus conditions. They offer information and emotional support from time of diagnosis to the palliative stage.

Swallowing and language therapists are invaluable in the management of CBD. Communication is often impaired and alternative means may be of benefit. Swallowing and secretion changes are common and a detailed swallowing assessment will assist with dietary changes to prevent aspiration pneumonia.

Occupational therapists can provide access to equipment necessary for maintenance of independence and safety within the home. They are especially helpful with regard to changes in planning and cognitive impairment.

Physiotherapists provide equipment and information to assist with mobility for as long as possible while maintaining safety. If mobility becomes unsafe the provision of wheelchairs and aids to assist with lifting can be arranged.