



www.dystonia.org.au

Fact Sheet 1 – Information for the Carer in Dystonia

What is Dystonia?

Dystonia is a neurological movement disorder that makes it difficult for people to control their muscles. It can cause abnormal twisting or positions in part(s) of the body along with spasms or tremors. In some people, the postures may be fixed or locked in position and in others pain can be the main symptom. Dystonia can affect almost any part of the body. There is no known cure. For more information refer to the brochure **What is Dystonia?** which can be found on the Dystonia Network of Australia Inc. website at <https://www.dystonia.org.au/what-is-dystonia/> or contact us at info@dystonia.org.au

What is a carer?

A carer is someone who is involved in the physical or emotional care of someone with dystonia and can be a partner, family member or a close friend.

How can a carer help?

There are many different types of dystonia and no two people will have exactly the same symptoms, so the care required will vary. Some people with dystonia do not require physical care but will need consideration and adjustments in the home and work environment and most importantly your understanding of the challenges living with a movement disorder brings on a day to day basis. Others, however, may be completely dependent for all aspects of their activities of daily living.

Knowledge of the symptoms of the type of dystonia the person has is crucial. Knowing some of the important general facts, reading the appropriate dystonia brochures (see web site URL) and actively listening to the person will assist you in a better understanding of this extraordinarily complex condition.

You can also be an advocate for a person with dystonia, helping others to understand the condition and speaking on their behalf when needed. There are advocacy networks that can assist you to explore the benefits, payments and outside care that is available which can be beneficial for both of you. The National Disability Insurance Scheme (NDIS) is also available to provide equipment and support for people with a disability and familiarising yourself with the role of the agency and the support it can provide is also helpful.

Important general information on dystonia

People with dystonia have little or no control over their abnormal movements, positions and postures which may change day to day and often worsen when people are anxious or under stress or when they perform certain other movements.

- Treatment results differ in people who have the same dystonia diagnosis, so just like the different types of dystonia, one size does not fit all.
- Do not attempt to stop spasms or tell the person to relax as this can worsen the situation.
- As discussed, fluctuations in function are common: some days the person will require more assistance than others.
- Mood disorders, such as anxiety and depression, are common in all forms of dystonia. These issues can be as disabling as the dystonia symptoms. Support the person and encourage them to seek professional help.
- Pain is a feature in dystonia and can be severe. It can be due to the abnormal positions, cramp-like spasms or be secondary to the dystonia. For instance, neck dystonia may cause severe headaches. Pain in dystonia is extremely difficult to control as mainstream pain relief is rarely successful. Pain must be addressed and reported to the movement disorder specialist for advice or treatment options.
- Other symptoms that cause distress, include difficulty in seeing (blepharospasm), difficulty in eating (generalized dystonia, neck dystonia and dystonia of the face and jaw), problems with speaking or being understood when speaking (spasmodic dysphonia) and issues with writing (writer's cramp). For those people who are non-verbal assistive technology may be required to allow them to communicate.

Looking after Yourself

It is important that carers, who are often family members, look after themselves too. That means eating well, sleeping well, and taking care of **your** health. It is important to keep active yourself and this might mean taking part in activities outside the home or being involved in a hobby. Time out helps to prevent carer 'burn out' and talking with friends and family / joining a carer's group may help feelings of stress and isolation. Becoming a member of a support group or other network can be of assistance. Carers Australia can be contacted for support at www.carersaustralia.com.au

If you need to take a break from time to time, there are support networks that can help you with respite care. For more information <https://www.carergateway.gov.au/what-is-respite-care> You can also speak to a Counsellor if you are feeling stressed or for tips with coping. You can contact the National Carer Counselling Program on 1800 242 636 for access to short-term counselling services.

Information on support for parents of children with a disability - <https://www.mytime.net.au/>

Are you aware you have rights as a carer?

The Australian Government has created the Carer Recognition Act to recognise and support unpaid carers. Most states and territories also have legislation that sets out your rights as a carer. For further information visit the Carer Gateway [Legal rights for carers](#) page. You may need to make decisions relating to medical care and if needed, you may need to be aware of [power of attorney](#) options and the rights of the person you are caring for.

This fact sheet was endorsed by the Advisory Board of Dystonia Network of Australia Inc.