

job so you may sometimes need a respite break to relax and recharge your batteries. If you are a main carer, a number of options are available such as a few days residential care for the person you look after, day- and/or night-sitting services, day care centres and support with holidays. For more information go to www.nhs.uk/CarersDirect.

8. Eat well. Caring can be time-consuming and you may get into the habit of not eating properly. It is important you look after yourself - not least because you need your strength and health in order to keep caring.

9. Try to get adequate sleep. Sleep is vital for health and if you are not getting enough then you can quickly start to feel the effects. If the sleep pattern of the person you care for is too disturbed to allow you to get enough sleep then you may need to request nighttime cover as part of your carer's assessment.

10. Get a hobby. It is not possible for anyone to spend 100% of their time caring so you need other activities to maintain balance in your life. If necessary, you can ask for respite support to enable you to do this.

11. Give yourself credit. You are performing a vital service both to the person you care for and the wider community. So you should be proud of what you do.

12. Make time for YOU!

Useful Resources

- // www.nhs.uk/CarersDirect NHS Carers Direct
- // www.carers.org Princess Royal Trust for Carers
- // www.carersuk.org Carers UK
- // www.youngcarers.net Information for young carers
- // www.carerscentre.com General information for carers
- // www.gov.uk/dwp Benefits and employment issues
- // www.direct.gov.uk National government services site

What the Society offers

The **Dystonia Society** is dedicated to providing information and support to everyone affected by dystonia in the UK. Our services include a helpline, advocacy, regional support groups and events about dystonia across the UK.

Helpline

0845 458 6322

Website

www.dystonia.org.uk

2nd Floor, 89 Albert Embankment, London SE1 7TP
 Office no: 0845 458 6211
 email: info@dystonia.org.uk
www.dystonia.org.uk
 Registered Charity No: 1062595 and SC042127

Carers and dystonia

The
dystonia
 society

Carers & dystonia

What is dystonia?

Dystonia is uncontrollable and sometimes painful muscle spasms caused by incorrect signals from the brain. It affects at least 70,000 in the UK. Dystonia is a neurological movement disorder that results in abnormal postures or movements, with or without tremor.

What kind of care might people with dystonia require?

The care required will vary widely from person to person. It will depend on the type of dystonia they have and the needs of the individual. For instance, some dystonias may cause difficulty driving while others may cause problems speaking face-to-face or on the phone. Some dystonias can cause difficulty eating so diet will be important. Many adults with focal dystonias may require very little care while a child with generalised dystonia may need a significant level of care.

Many people with dystonia report feeling embarrassed or self-conscious and the experience of dystonia can cause anxiety and/or depression. A key role for carers is therefore to provide emotional support and encouragement.

How do I cope with being a carer?

Looking after someone with dystonia can be a strain both physically and emotionally. It is vital you look after yourself as well. Following these golden rules will help:

1. Identify yourself as a carer. A carer is anyone who provides unpaid care for someone who is ill, frail or disabled. People caring for a family member do not always define themselves as carers. But the fact is you are also a CARER !

2. Know your rights. The person you care for may be entitled to a number of different benefits:

// Personal Independence Payment (PIP) for disabled people who need assistance with personal care and/or mobility (new applicants must be under the age of 65).

// Attendance Allowance for disabled people aged 65 or over who have difficulties looking after themselves.

// Employment and Support Allowance for people who are not able to work due to illness or disability.

As a carer, the main benefit you may be entitled to is Carer's Allowance. You may also be entitled to Child Tax Credit if you look after a child under 16 (or under 19 and in education). In addition, you might be able to get Council Tax Benefit which

would reduce your council tax bill.

3. If you feel you need help then ask. Caring can be hard work, stressful and isolating so many carers need their own support. This can be from a friend or relative but also from a fellow carer, support group, internet forum or professional. Carers UK organises support for carers through the UK (www.carersuk.org) or you can use the Dystonia Society internet forum and find out about our support groups at www.dystonia.org.uk.

4. Get an assessment. All carers are entitled to a Carers Assessment from local social services. This will assess your needs and how you can be supported. Social Services may be able to provide respite care to give you a break, help with aids and adaptations or they can be a back-up in an emergency. For details, go to www.carersuk.org or call us on **0845 458 6322**.

5. Tell your GP. Your GP should offer carers regular healthchecks and flu jabs and may be more flexible on appointments. They may also refer carers to additional support where necessary such as counselling.

6. Get a healthcheck. Caring may affect your health so it is important that your GP checks this regularly.

7. Take a break. Caring can be a full-time