

**Consider requesting flexible working**

In some circumstances flexible working arrangements may help you cope better. The law gives you a right to make one application a year for flexible working hours. Such a request does not give your employer the right to treat you badly or less favourably than your colleagues, or for them to dismiss you.

**When the going gets tough...**

If you or your family are concerned about your mood being low, get help as soon as you can. Visit your GP and seek a referral to a counselling service and local support groups.

If your caring responsibilities are substantial and you need an extended break, there are organisations that may be able to help take over your role and support the person you look after.

Remember you are not alone. Immunology nurse specialists are there to help support carers as well as people with a PID.

**Carer's Allowance**

You may be eligible for Carer's Allowance if you look after someone with considerable caring needs and are receiving certain other types of benefits. For an overview of Carer's Allowance, visit the PID UK website at [www.piduk.org/livingwithpids/forcarers/carersallowance](http://www.piduk.org/livingwithpids/forcarers/carersallowance).

**Other support organisations and links**

- Carers UK ([www.carersuk.org](http://www.carersuk.org)). Call 0808 808 7777 or email [advice@carersuk.org](mailto:advice@carersuk.org)
- Carers Trust ([www.carers.org](http://www.carers.org))
- PID Facebook support group for carers: [www.facebook.com/groups/ukpidcarers](https://www.facebook.com/groups/ukpidcarers)

**About Primary Immunodeficiency UK**

Primary Immunodeficiency UK (PID UK) is a national organisation supporting individuals and families affected by primary immunodeficiencies (PIDs).

We are the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for PID patients worldwide.

Our website at [www.piduk.org](http://www.piduk.org) provides useful information on a range of conditions and topics, and explains the work we do to ensure the voice of PID patients is heard.

If we can be of any help, please contact us at [hello@piduk.org](mailto:hello@piduk.org) or on **0800 987 8986**, where you can leave a message. Visit [www.piduk.org](http://www.piduk.org) for further information.

Support us by becoming a member of PID UK. It's free and easy to do via our website at [www.piduk.org/register](http://www.piduk.org/register) or just get in touch with us. Members get monthly newsletters.

PID UK is reliant on voluntary donations. To make a donation, please go to [www.piduk.org/donate](http://www.piduk.org/donate)



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**Being a carer for someone with a PID**

[hello@piduk.org](mailto:hello@piduk.org)  
**0800 987 8986**  
[www.piduk.org](http://www.piduk.org)

This leaflet provides information for adult carers of people affected by a primary immunodeficiency (PID).

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## Being a carer for someone with a PID

Being a carer, whether for an adult or a child, can be very rewarding but for some people occasionally it can also be hard work and stressful. This leaflet examines some of the feelings that you, as a carer, may experience and aims to give practical advice that might help.

### Caring

It is such a natural instinct to help and support someone you love that people often do not identify their role as that of carer. Carer is the most widely used term to describe someone who gives unpaid support to a family member or friend who could not manage his or her condition without help. Everyone's situation is different, but looking after a child with a PID, giving emotional support at diagnosis, helping with immunoglobulin infusions and accompanying a person to hospital appointments, are just a few examples of what being a carer can entail.

### Taking on a new role

Caring may be a new role and one you never expected to take on. It's a role that may take time to adjust to and may require you to educate yourself about the condition affecting your family member or friends, e.g. learning new medical terms and procedures. There will be times when you feel confident and times when you may feel you are not managing well or feel that you are not doing or saying the right things. Please be reassured that this is absolutely normal.

### Recognising and accepting your feelings

Caring for someone you love and cherish can be really fulfilling but sometimes carers may feel tired, have negative thoughts and experience feelings of anxiety.

Caring can sometimes change the dynamics of relationships. Owing to their caring role, some

people report 'losing' certain aspects of their relationship with the person they are caring for. Feelings associated with a loss of freedom and flexibility in their lives, alongside occasional feelings of resentment and guilt, may also be experienced. All these feelings are perfectly understandable and quite typical.

### Stress and being a carer

Some carers feel they are the only person having to deal with everything and that they are entirely responsible for that care. This sense of responsibility and isolation can cause stress, making it harder to cope and it can put a strain on other relationships as the carer becomes exhausted and irritable.

In the long term stress can affect the carer's health and their physical ability to care, so it's good to learn how to recognise any signs of stress and how they affect you. Symptoms of stress can include insomnia, fatigue, low mood and not getting pleasure from doing things you usually enjoy. Seek help if you recognise any of these symptoms.

### Looking after yourself

Often when you are caring for someone close, you can be so preoccupied with their needs that your own needs take a back seat. But it's really important that you look after yourself, too. While you may find that a really difficult thing to do, if you are unwell you may be unable to carry on providing the support you want to give.

The 'Being a carer' section of our website [www.piduk.org/livingwithpids/forcarers](http://www.piduk.org/livingwithpids/forcarers) explores in more depth some of the experiences of being a carer, and provides information on eligibility for the benefit Carer's Allowance.

### Practical things to keep yourself well

#### Sleep

Getting enough sleep is vital to staying physically and mentally healthy. Being a carer may result in you not always getting a good night's sleep. Visit the

NHS Choices website [www.nhs.uk/Livewell/sleep/Pages/sleep-home.aspx](http://www.nhs.uk/Livewell/sleep/Pages/sleep-home.aspx) for advice. If the problem persists, then contact your GP.

#### Eat well

Eating a healthy diet will keep you well and your energy levels up. Make sure your meals contain a good balance of fruit and vegetables, carbohydrates, protein and dairy foods.

#### Be kind to yourself

Don't be too hard on yourself. Everyone has bad days.

#### Use supportive networks

Sometimes caring for someone can be physically and emotionally demanding. Consider confiding in a good friend; they may provide a helpful, listening ear. Don't be afraid to admit that you need some help. Think about family members, friends and any others who might be happy to help if you are going through a difficult time.

If you find you are not coping well and don't want to tell anyone in your family, then do speak to your GP. Tell them you are a carer and how it is affecting you so they can offer you, in confidence, the support and advice you need. Speak to people who make you feel positive.

#### Explore ways of coping with any stress you may feel

It's important that you take breaks from your caring responsibilities to maintain your own well-being and quality of life. Take time out to do something you enjoy and get pleasure from.

Some people find exercise can help relieve feelings of stress. Try and find time to do any form of activity to help lift your mood – walking, swimming, gardening, singing along to music in the car, whatever works for you!

Simple relaxation exercises can also work. Visit the NHS Choices website for tips for relieving stress: [www.nhs.uk/conditions/stress-anxiety-depression/pages/ways-relieve-stress.aspx](http://www.nhs.uk/conditions/stress-anxiety-depression/pages/ways-relieve-stress.aspx)