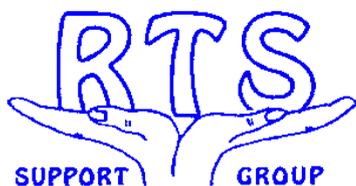


**CLAIMING DISABILITY LIVING ALLOWANCE  
FOR A CHILD UNDER 16  
WITH  
RUBINSTEIN-TAYBI SYNDROME**



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This guide has been produced by the Rubinstein-Taybi Syndrome (RTS) Support Group, a UK registered charity whose main objective is to support families and carers of those affected by RTS. For further information on either RTS or the Support Group, please visit our website at [www.rtsuk.org](http://www.rtsuk.org), or contact us at [mail@rtsuk.org](mailto:mail@rtsuk.org).

## 1. Introduction

Most parents/carers looking after a child with Rubinstein-Taybi Syndrome (RTS) will be eligible to claim Disability Living Allowance (DLA) on behalf of their child. DLA is a tax-free social security benefit for people with an illness or disability, who need help with getting around, or help with personal care, or both. Its purpose is to provide assistance with the additional expenses which are frequently incurred as a result of someone having a disability, such as additional laundry, higher heating bills, or needing to buy special equipment. It is not affected by the amount of the child's or parents' income or savings.

The RTS Support Group recommends that all parents /carers of children with RTS consider submitting a claim for DLA, as there is a good chance that they will be successful. However, your son or daughter won't get it simply by virtue of the fact that they have RTS; it is awarded according to how each individual is affected by their disability. So if you do decide to apply, because each case is considered individually by the Department for Work and Pensions (DWP), you will have to fill in a rather lengthy claim form (currently 41 pages long!).

We know from talking to people, and from our own experience, that completing the form can be hard work, both mentally and emotionally, so we have put together this guidance with the aim of directing you to sources that can help you with the job. It will probably be of most use to those making a claim for the first time, but may also be helpful if you are making a renewed claim.

Note to our readers in N Ireland: Where we use the term "Department for Work and Pensions (DWP)" (which applies in England, Scotland and Wales), **this means also** the "Department for Social Development (DSDNI)" in N Ireland.

## 2. Obtaining more information about DLA

The DWP provides comprehensive notes and assistance, including up-to-date rates for benefits, through the following means:

- Benefit Enquiry Lines
  - For England, Scotland, Wales : 0800 88 22 00
  - For N Ireland : 0800 22 06 74
- a range of booklets and leaflets which can be obtained either from your local Jobcentre Plus or social security office, or ordered via the Benefit Enquiry Lines or in some cases ordered on-line.
- on-line at [www.gov.uk](http://www.gov.uk) (follow links to benefits or disability); and at [www.nidirect.gov.uk](http://www.nidirect.gov.uk) (look under "People with Disabilities")

### 3. How DLA is made up

It may be useful to explain here that DLA is split into 2 parts, called "components" - a care component and a mobility component. Either or both may be awarded. With many RTS children it is likely to be both - but it will depend in the end on how the individual is affected by their disability, so this cannot be guaranteed. Different rates can be awarded for each component:

Care component - composed of lower, middle and higher rate

Mobility component - composed of lower and higher rate

Please note that the care component is not payable before a child reaches 3 months old, the higher-rate mobility component is not payable to children under 3 years old, and the lower-rate mobility is not payable to children under 5 years old.

### 4. Obtaining a claim form

To submit a claim for DLA, you need to fill in a claim form. There are various ways in which you can do this:

- request a claim pack by phone from one of the Benefit Enquiry Lines (see para 2 for details)
- complete one on-line at [www.gov.uk](http://www.gov.uk) for England, Scotland and Wales, or [www.nidirect.gov.uk](http://www.nidirect.gov.uk) for N Ireland
- download a form (with notes) from the web sites quoted above, print it off and complete it manually.

### 5. Help with filling in the claim form

Some people, particularly those still coming to terms with the fact that they have a child with a disability, can find completing the claim form a distressing experience. The claim process may have the effect of making you focus on many of the negative aspects of the child's disability - what they can't do, rather than what they can do - and this is understandably upsetting.

In coping with this it is common to minimise some of the negative aspects of the child's disability, and to unwittingly give a rosier picture than is realistic of what the child is capable of. Try to be aware of this and, whilst you must of course be honest, don't only think of your child's behaviour and capabilities when they are at their best.

If their behaviour and capabilities fluctuate a lot from day to day however, you will need to decide how they are on **most** days.

You can get more detailed help and advice from the following:

- The Benefit Enquiry Lines (see para 2 for telephone numbers).
- Your local Jobcentre Plus
- Your local Citizens' Advice Bureau
- DIAL UK - a network of approximately 130 Disability Information and Advice Line services across the country. They provide information and advice to disabled people and others on all aspects of living with a disability. Tel 01302 310123, or visit [www.dialuk.info](http://www.dialuk.info).

The list is by no means exhaustive, and there may be other advice or disability organisations in your own locality which can help.

## **6. Keeping track of your claim**

It is important to keep a photocopy of everything you send to the DWP in case it gets lost. You will also find a copy of the completed claim form useful if you need to challenge the decision you are given, and when you come to renew the claim later on. Also keep all letters you receive from the DWP, a note of the date of all phone calls and the name of the person to whom you spoke.

## **7. Disclaimer**

This guide has been compiled by the trustees of the RTS Support Group. However, we are not experts in law or in claiming benefits, but simply parents and relatives of people affected by RTS.

We offer the information here in good faith, to be used or not as you choose. Every care has been taken to include in this guide as up-to-date information as possible, and we will review it periodically, but we cannot guarantee that changes will not have occurred by the time you use it.

We cannot accept responsibility for any inaccuracies, or for any loss incurred by anyone as a result of acting or not acting as a result of any statement in this guide.