



Understanding Chromosome & Gene Disorders

# Carers Wellbeing



[rarechromo.org](http://rarechromo.org)

## Carers Wellbeing

Being the parent carer of a child or adult with a chromosome or gene disorder can be overwhelming. Whilst we love our child we care for unconditionally, at times we can be so busy that we forget to take care of ourselves. It is really important that we look after ourselves and keep healthy, so that we can cope with the everyday challenges of raising a child with a disability.

### Emotions

Many Unique parents feel guilty for even thinking about themselves. It is normal to want to be like any typical parent and enjoy some 'me' time. It is perfectly natural to have feelings of guilt, frustration and anger. But you should never feel guilty about wanting some time to yourself. If you look after yourself, it will help you and make you a stronger person. Many of our parents on finding out that their child has a chromosome or gene disorder react with shock, anger or sorrow. It can be difficult to cope with these emotions, many of us learn to do so, but for some it is a much bigger challenge, especially if you have little or no support. As well as caring for your child with a chromosome or gene disorder and their siblings, you might also be caring for an elderly parent(s). You might also be trying to hold down a job at the same time. So it is really important that we stop and take the time to think about ourselves from time to time. Try to get a break if possible, even if it is a quiet ten minutes in the garden, or a quiet room in your home. If you are able to access respite/short break services, then you should try to use them without feeling any guilt about taking a break from caring for your loved ones. Often taking a short break is just what we need to recharge our batteries. Talking about our situation with others that understand, can strengthen us and our relationships with all of our family members. Many of our parents and grandparents find support from joining our Unique Network Cafe on Facebook, there they can talk to other parents that understand; those that know what it is like to care for a child or adult with a chromosome or gene disorder. Some of our parents have very little, or no support from their family and friends, so getting help from outside sources is really important. Make sure that you are getting all the benefits and services that you are entitled to. The purpose of this guide is to offer general information about what you are entitled to as a carer; to discover how you can look after yourself and how to get more support. It is aimed at parents or grandparents, guardians and siblings who are caring for a child with a chromosome or gene disorder. Find the courage and strength to have a little 'me' time. You may say that you don't have time to think about yourself, but if you practice the art of mindfulness, you can do it wherever you are. If you can't find a quiet spot, just try to tune into your own mind and block out other noises around you. We all have to go to the bathroom, so often that is a good time to try and relax without any distractions.



**Look after yourselves.....**



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## What is a carer?

A carer is a person who cares for a family member who has an illness or a disability and cannot look after themselves, or needs support with some aspects of daily living. Many carers of children with a chromosome or gene disorder do not see themselves as carers because they see themselves as a parent first and foremost, and as a result they often miss out on services, support, advice and benefits which may be available. This guide is designed to give parent carers information and to encourage wellbeing. Many local councils offer courses on wellbeing.

### **Facts and Figures** – (Source, Carers UK 2023)

- The most recent Census 2021 puts the estimated number of unpaid carers at 5 million in England and Wales. This, together with ONS Census data for Scotland and Northern Ireland, suggests that the number of unpaid carers across the UK is 5.7 million.
- This means that around 9% of people are providing unpaid care. However, Carers UK research in 2022 estimates the number of unpaid carers could be as high as 10.6 million (Carers UK, Carers Week 2022 research report).
- 4.7% of the population in England and Wales are providing 20 hours or more of care a week.
- Every year, 4.3 million people became unpaid carers – 12,000 people a day (Petrillo and Bennett, 2022).
- 59% of unpaid carers are women (Census 2021). Women are more likely to become carers and to provide more hours of unpaid care than men. More women than men provide high intensity care at ages when they would expect to be in paid work (Petrillo and Bennett, 2022)
- One in seven carers in the UK are juggling work and care (Carers UK, Juggling Work and Care, 2019).
- Between 2010-2020, people aged 46-65 were the largest age group to become unpaid carers. 41% of people who became unpaid carers were in this age group (Petrillo and Bennett, 2022).



## Caring with Confidence

Caring with Confidence is a set of seven short, free online courses for carers. It helps you develop skills and knowledge for your caring role. You can:

- Learn simple techniques to help you care.
- Work at your own pace and at a convenient time.
- Do as much or as little at a time as you want.
- Find details of organisations that can give you further information and advice.
- Build up a collection of useful resources and notes.

Each course has several parts, which you can complete in order or dip into whenever you have time. For more information visit:

<https://carers.org/article/free-online-courses-carers>

Your **local carers support centre** may also run free sessions or groups that can build your confidence and help you cope with your caring role.

## Guilt and Anger

Many Unique parents feel guilty for even thinking about themselves. It is normal to want to be like any typical parent and enjoy some 'me' time. It is perfectly natural to have feelings of guilt. But you shouldn't feel guilty about wanting some time to yourself. If you look after yourself, it will help you to deal with the challenges of raising a child with a chromosome or gene disorder and make you a stronger person. Many of our parents on finding out that their child has a chromosome or gene disorder react with shock, anger or sorrow. It can be difficult to cope with these emotions, many of us learn to do so, but for some it is a bigger challenge, especially if they have little or no support.

## Counselling and Relationship Support

Having a child with a chromosome or gene disorder or any disability can put a huge strain on your relationships, not only with your child - but with your spouse or partner. It is very important to talk to each other about your family situation as much as possible and work on supporting each other. Having a supportive partner than can help you with some of the caring can be a lifeline to so many of our families, particularly as your child gets older, bigger and stronger. Just coming to terms with having a child with a chromosome or gene disorder can be so difficult for parents and also grandparents too. Initially it can come as a sense of loss. For the parents the loss of their longed for 'typically functioning child' and for the grandparents the loss of their longed for 'typically functioning grandchild' - but also their grief at seeing their own child having to go through that loss. It is not meant to sound like a bad thing, because for so many parents it isn't, it is just different, it takes some getting used to. It is important to not look at what you have lost, but to appreciate what you have in your child.

If it's possible to do so, it is important for everyone in the family to sit down and talk to each other to discuss things and not bottle things up or end up shouting at each other. Your child won't necessarily know they are different whilst young, and it isn't theirs or your fault. Just try to live and enjoy life the way you would have been doing, as much as possible.

Some professionals like doctors, nurses, and therapists can be very helpful and supportive, but some aren't always as helpful as we'd like and can end up making you feel more stressed. There are organisations that can help with support, some just offer a listening ear, whilst others offer more support. Listed below are some of the organisations that can help. Talking to other families whose child has a chromosome or gene disorder will also help.



#### ■ **Affinity Hub**

Website: <https://www.affinityhub.uk/1/>

This website signposts to emotional support for parents and carers of children with special needs. Many parents of disabled children or children with special needs face additional associated challenges in practical, physical and emotional terms.

#### ■ **Care for the family**

Website: <https://www.careforthefamily.org.uk/>

Telephone: 029 2081 0800 Email: [mail@cff.org.uk](mailto:mail@cff.org.uk)

Care for the Family is a national charity which aims to promote strong family life and to help those who face family difficulties.

#### ■ **Contact**

Website: [https://contact.org.uk/wp-content/uploads/2021/03/forgotten\\_isolation\\_report.pdf](https://contact.org.uk/wp-content/uploads/2021/03/forgotten_isolation_report.pdf)

A guide on the impact of relationships and caring for a disabled child

#### ■ **College of mediators**

Website: <https://collegeofmediators.co.uk/>

Telephone: 0845 65 85 258

Offering information on local mediation services. Mediation is the involvement of an impartial person who is trained to help resolve disputes. They can help you identify and discuss issues that need resolving, consider possible ways forward and reach a decision that feels fair to everyone involved.

### ■ **Counselling directory**

Website: <https://www.counselling-directory.org.uk/>

Counselling falls under the umbrella term 'talking therapies' and allows people to discuss their problems and any difficult feelings they encounter in a safe, confidential environment. The term can mean different things to different people, but in general it is a process people seek when they want to change something in their lives or simply explore their thoughts and feelings in more depth.

### ■ **The British Association for Counselling and Psychotherapy (BACP)**

Website: <https://www.bacp.co.uk/>

Telephone: 01455 883300 Email: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

BACP can provide a list of accredited counsellors in your area.

### ■ **Relate**

Website: <https://www.relate.org.uk/>

Telephone: 0300 100 1234

The UK's largest provider of relationship support. Services include:

- ◇ Relationship counselling for individuals and couples
- ◇ Family counselling
- ◇ Mediation
- ◇ Children and young people's counselling.

They also provide informal workshops for people at important stages in their relationships

### ■ **One plus one**

Website: <https://www.oneplusone.org.uk/>

Over the last 40 years One Plus One has been investigating what makes relationships work (or fall apart). They also work in partnership with the charity Contact.

### ■ **Samaritans**

Website: <https://www.samaritans.org/>

Telephone free: 116 123 24 hours a day, 365 days a year.

If you need a response immediately, it's best to telephone.

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Samaritans is a well known organisation that provides a listening ear to people going through relationship and family problems, loss and bereavement, financial worries, stress, loneliness, depression and pain, etc.

### ■ **Mind**

Website: <https://www.mind.org.uk/>

InfoLine: 0300 123 3393 Email: [info@mind.org.uk](mailto:info@mind.org.uk)

The Mental health charity in England and Wales.

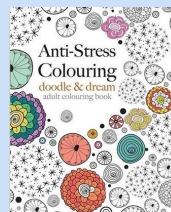
We have a separate guide on **mental health** on our website: <https://rarechromo.org/practical-guides-for-families/>

## Therapies

Being the parent of a child with additional needs, when you think of therapies you probably think of things like Physiotherapy, Occupational therapy and Speech therapy. Being a parent will always come first - it is natural and normal to think about our children before ourselves. However there are so many other therapies that can help us as carers. Listed below are some of the therapies that can help carers to de-stress and relax.

### Colouring books for Adults

There are some fantastic colouring books on the market. They are similar to children's colouring books but the patterns and pictures are more grown up, the pictures often look amazing when they are coloured in and it can be very relaxing and therapeutic. They are great if you have always liked art but never felt confident with drawing; the drawing has already been done, you just colour in. You can get them in many shops, garden centres or online.



*“ My niece gave me my first grown up colouring book. I found it so therapeutic that often of an evening I can be found curled up on the sofa with a book and colouring pens. It stops me from feeling overwhelmed and helps to calm my mind. ”*

## Complimentary therapies

There are so many of these now, everyday a new one seems to surface that I have not heard of. Here are just a few of the most popular ones.....

**ACUPUNCTURE** is a form of therapy that has been used for thousands of years. It involves the careful placement of fine needles into particular points on the body called acupuncture points. The needles are left in position for as little as a few seconds or up to twenty minutes.

**AROMATHERAPY** is the systematic use of essential oils in treatments to improve physical and emotional well-being. Aromatherapists in the UK are trained to use essential oils topically and through inhalation. Essential oils are applied in a variety of ways, which include massage, vapourisers, baths, creams and lotions.

**CRANIO-SACRAL THERAPY** is a gentle, non invasive form of treatment which can promote feelings of relaxation, bring calmness & peace of mind, improve energy levels and contribute to a sense of wellbeing.

**EAR ACUPUNCTURE** this is a particular type of acupuncture using very small, fine needles inserted into acupuncture points on the surface of the outer ear.



**EFT (Tapping)** EFT is a simple and effective therapeutic tool, sometimes known as "emotional acupuncture". EFT is like acupuncture without needles. It involves focusing on the memory while tapping on specific points on the meridians.

**HYPNOTHERAPY** is a therapy delivered through the medium of hypnotic trance. Hypnosis is a natural phenomenon which combines strong focus with guided imagery and relaxation.

**INDIAN HEAD MASSAGE** Although an ancient craft, it is well suited to alleviate some of today's stress related conditions. The techniques are applied to the upper body (shoulders, upper arms, neck and head) collectively they represent a de-stressing therapy for the whole body. It involves the therapist using their hands to knead, rub and squeeze soft body tissues such as the muscles.

**KINESIOLOGY** is a way of identifying any imbalances a person has by monitoring their ability to hold their muscles against light pressure. Kinesiology helps to uncover the root of your health issue by looking at physical, nutritional, emotional and energetic imbalances.

**MASSAGE** benefits people both physically and mentally. Massage is a general term for a variety of techniques that involve manipulation of the soft tissues of the body through gentle pressing, kneading and smoothing movements, for therapeutic purposes. There are several different types of massage practised.

**REFLEXOLOGY** First practised thousands of years ago by the Chinese, Indian and Egyptian peoples, reflexology is a natural touch therapy, practised on the feet and hands. It is based on the principle that there are reflex areas in the hands and feet that correspond to all of the glands, organs and parts of the body. The purpose of the systematic application of pressure, using the thumb and fingers, to specific reflex points on the feet or hands is to release congestion, promote the flow of energy and promote balance.

**REIKI** is a method of healing that was rediscovered in Japan in the 1800's. The basis of this system of healing, is the concept that an energy flow exists in living beings which supports life, by helping to maintain balance. This energy is known as Qi.

### **THERAPEUTIC ART**

Art therapy has been in development for over 50 years. In the UK Adrian Hill and Edward Adamson pioneered this work in hospitals with soldiers recovering from experiences received during the Second World War. Since then Art therapy has been used clinically in many areas with adults and children. Art therapy allows the communication of internal emotional feelings, which are sometimes difficult to speak about, in a non verbal way.

## CRAFTING

Many of our parents like to craft and this has become huge all over the world. Crafting can involve anything from sewing to woodwork and making greetings cards to baking cakes. There are large craft shops and many shops and supermarkets selling a huge variety of different craft items.

## LAUGHTER YOGA THERAPY

Laughter yoga is used to promote health and wellness. It aims to use the natural physiological process of laughter to help relieve physical or emotional stresses or discomfort. It is a therapy that not only increases happiness, but it also strengthens the immune system, and helps to lower stress. Laughter relaxes the whole body. There are many Laughter clubs, or Laughter Yoga clubs popping up all over the country. Type into a search engine online and you will get lots come up Or visit these links for some more information:

### ■ Laughter Therapy

Website: <https://laughtertherapy.org.uk/>

Telephone: 0115 772 2062 Mobile: 07545 347 462

### ■ Laughter Yoga

Website: [www.laughteryoga.co.uk/](http://www.laughteryoga.co.uk/)

Telephone: 07736 341 717

Email: [info@laughteryoga.co.uk](mailto:info@laughteryoga.co.uk)



## Meditation and Mindfulness

What is the difference?

Mindfulness and meditation are very similar but they are not exactly the same. Meditation usually refers to formal, seated meditation practice. There are many types of meditation that focus on opening your heart, expanding your awareness, calming your mind, experiencing inner peace, etc. Often meditation can be practiced for anything up to an hour.

Mindfulness exercises are ways of paying attention to the present moment, using techniques like meditation and breathing. It helps people to relax and achieve self-calmness. It helps people to become more aware of their thoughts, feelings, and body sensations, so that instead of being overwhelmed by them, they are better able to manage them. It is also a way of letting go. We frequently energise our body through exercise and rest, but to energise our mind is to do the reverse. We all need to take time to sit in a quiet relaxing space and stop or slow down our mental activity. Many of us get little sleep or poor quality sleep because of insomnia or being woken up by our child, children or pets (or even snoring partners!). Sleep is a good time to energise your mind, but if you are not getting enough sleep, meditation or mindfulness can help to energise your mind.

## Find a breathing space for yourself

A little and often is good, 10-20 minutes each day.

- Sit upright in a comfortable chair, use a cushion to support your back if you need to and have your feet touching the ground.
  - If you are feeling tense, use gentle body movements and deep breathing to settle your body's energy and bring your attention back to how your body felt before you sat.
  - Focus your attention and move it down your body, noticing places to investigate sensations. If you have tension in your body, think about letting go to the place or places where you are feeling that tension and imagine the tension melting away, sometimes just thinking about this deeply is enough is all that you need. Be aware of how you're feeling and if you don't feel peace straight away, know that you are at the beginning and sometimes it can take a little time to let go and be aware of it. You might find it helpful to start by thinking about your toes and then telling yourself (in your mind, not out loud) to relax, work your way slowly up your body mentioning each part of the body until you reach your head.
  - Be aware of your breathing, it is normal to breath in deeply through your mouth and out through your nose. Try this in reverse by pushing your abdomen forward whilst breathing in through your nose and letting go whilst breathing through your mouth.
- There are many courses available now to practice mindfulness and meditation, some of these can be expensive, so it is worth shopping around. Or contact your local carers support service, as they often organise Mindfulness taster sessions or day retreats for carers. There are also mindfulness and meditation videos available to view on websites like YouTube. Mindfulness is recommended by the National Institute for Health and Care Excellence (NICE) as a way to prevent depression in people who have had 3 or more bouts of depression in the past.

- **NHS website:**

<https://www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/>

- **Be Mindful**

website: <https://bemindful.co.uk/>

- **Be Mindful online**

website: <https://www.bemindfulonline.com/>

- **Mindful**

website: <https://www.mindful.org/>

- **The Mindful Life**

website: <https://www.themindfullife.co.uk/>  
Offers free courses to carers worldwide.



## Mindfulness retreats

There are mindfulness retreats that you can go to. The cost of these will vary, but some will include classes and workshops, as well as food and board. There are several of these in lots of different countries. Here are just a selection that are based in the UK:

■ **Plum Village** website: <https://www.plumvillage.uk/>  
Email: [hello@plumvillage.uk](mailto:hello@plumvillage.uk)

■ **The Mindfulness Network**  
website: <https://www.mindfulness-network.org/>

■ **The Sharpham Trust in Devon**  
website:  
<https://www.sharphamtrust.org/mindfulness-retreats/sharpham-house-retreats>

■ **Mindfulness retreats in Surrey and Sussex**  
website: <https://mindfulnessretreats.co.uk/>  
Telephone: 07989 965994

■ **Bosham, West Sussex**  
website: <https://www.boshamretreats.co.uk/lodges.html>  
Telephone: 01243 572109

■ **Breathing space, Norfolk**  
website: [www.breathingspacenorfolk.com](http://www.breathingspacenorfolk.com)  
Telephone: 01692 597198

■ **The Tree Earth in North Yorkshire**  
Website: <https://www.thetree.earth/>  
Telephone: 01751 417219  
Email: [relax@thetree.earth](mailto:relax@thetree.earth)

■ **Embrace, Northern Ireland**  
website: [www.embraceholistic.co.uk/carers/](http://www.embraceholistic.co.uk/carers/)

■ **Neals Yard retreats** website:  
<https://www.nealsyardholidays.com/Destination/view/all-uk-retreats>

**Disclaimer:** Unique cannot vouch personally for any of the retreats mentioned above, so please do your own research.

“ *Sometimes we have to take time for ourselves. It took me 10 years to realise it, do it and not feel guilty about it.* ”



■ **Memory improvement - Brain games** Website: <https://www.memory-improvement-tips.com/brain-games.html>

## Talking Therapies:

### **Cognitive Behaviour Therapy (CBT)**

Talking therapies are a free NHS service offered by most NHS trusts. They are open to anyone and give support to those struggling through a difficult time. Talking therapies can help with anxiety, depression, stress, phobias, addictions, adjusting to difficult life events and more. Each NHS trust offers a slightly different service, but the options may include one-to-one counselling, guided self-help or therapeutic groups. You can ask your GP what is available in your area or you could look online. You can self-refer to many of the services (there can be a bit of a wait). You can do an online search for 'NHS talking therapy' along with your location or follow this link for more information:

■ **NHS** Website: <https://www.nhs.uk/conditions/stress-anxiety-depression/>

This website also has links to a wide range of different resources including practical information, tools and videos that you may find helpful.

■ **Therapy directory** website: <https://www.therapy-directory.org.uk/>

This website helps you to find a class near you, acupuncture, aromatherapy, massage, reflexology, etc.

## **Physical Exercise**

Physical exercise of any kind can be good for your mind as well as your body. These days you don't need to join a gym, as many local parks contain free to use gym equipment. Alternatively, take a dance class. These days you can learn just about any type of dancing from Ballet to Zumba.

## **Tai-Chi and Yoga can help with developing awareness of your breathing.**

### **Tai Chi**

Tai Chi is a very good way to relax your mind and body. It is an ancient Chinese tradition that, today, is practiced as a graceful form of exercise. It involves a series of movements performed in a slow, focused manner and accompanied by deep breathing. It's a good idea to watch a class or attend a free taster session before signing up for a course. If you have a medical condition, any health concerns or haven't exercised for a long time, speak to your GP before you start tai chi.

For more information and to find a local instructor visit

■ **Tai Chi union** website: [www.taichiunion.com/instructors/](http://www.taichiunion.com/instructors/)

### **Yoga and Pilates**

Yoga and Pilates are often thrown into the same category. They are similar practices, but they have some major differences. The practice of yoga originated in India more than 5,000 years ago. It has evolved over the centuries and cultures into many different types of yoga.

**Pilates** is a much younger practice, beginning in the mid-20th century by an athlete named Joseph Pilates. He created the exercises as a form of rehabilitation and strengthening. Both yoga and Pilates bring an understanding that the mind and body are connected. However, yoga adds an additional element to the mix—the spirit. Exploring spirituality is a huge part of yoga practice, especially through meditation. While Pilates focuses on creating an understanding that the mind and body are connected and how this can help in everyday life, yoga focuses on the mind/body/spirit connection. You don't have to be fit and flexible to join a class, as there are many different types of class and they can be geared towards each individual. For more information on classes near you visit:

■ **Yoga** website: [www.localyogaclasses.co.uk/](http://www.localyogaclasses.co.uk/)

■ **Fitness studio exercises**

Website: <https://www.nhs.uk/conditions/nhs-fitness-studio/>

■ **Walking for Health**

website: <https://www.walkingforhealth.org.uk/>

Many local councils are now running guided walks for people with health conditions, or those that just want to keep fit. Walking is good for the soul and the mind and you get to meet with lots of different people and of course it can help to prevent illness. To find a scheme near you please visit the website or contact your local council to see if they run one close to you.

■ **Walks with wheelchairs**

Website: [www.walkswithwheelchairs.com/](http://www.walkswithwheelchairs.com/)

Walking routes that are suitable for those with access challenges.

**Books**

The 'Dummies' range of books includes guides on Anxiety, Mindfulness and Cognitive behavioural therapy (CBT), available to buy from most bookshops and Amazon. There are many other books available on the subject of mindfulness, meditation, etc, just type mindfulness into a search engine and you will see many different titles.

*“ I need to step back and take time for me. ”*



## Keeping healthy

Often carers don't think about their own health. They are too busy caring for their family, or working and caring. It is difficult to take time to think of our own selves. This can also lead to depression and worry. About 40% of carers are thought to be at risk of depression or stress because of their caring role. As carers, we need to remain in good health to be able to continue our caring role. If your body is telling you that something is wrong, or you have a pain that won't go away, don't ignore it, go and see your doctor or nurse and get checked out.

### ■ NHS Choices <https://www.nhs.uk/>



Call 111 for non-emergency medical advice

Carers Direct helpline: **0300 123 1053** if you need help with your caring role and want to talk to someone about what options are available to you.

The website provides access to information and advice about healthy living, healthcare, illness including conditions and treatment, local health services with an A-Z guide to the NHS and information for carers.

**Back problems are common amongst carers.** Lifting the person you care for and helping them dress or move around can place great strain on your back. Knowing how to protect your back can help to keep it in good shape.

### ■ The NHS website has a guide on back pain

<https://www.nhs.uk/conditions/back-pain/>

You could also check with your local carers health team if they offer **manual handling** courses to parents.

## Flu Jabs

Those of us who have experienced influenza (flu) know how debilitating it can be. The seasonal flu vaccine is the best way to protect yourself and the person you care for from flu, and will prevent you being stopped from being able to care. As a carer, you should be eligible for a free flu jab. Ask at your GP surgery. They are usually offered around September/October time each year.



## Caring and working

If you are working when your child is diagnosed, it may be helpful to tell your employer about your situation. Many parents don't want to do this and it's not obligatory, but it might help them to understand - should you need to take time off for appointments for your child.

There are several things that you and your employer can do to help you combine your caring role with employment. Caring for a child with a chromosome disorder is often unpredictable and finding the right care for them is not always easy. Think about how your employer could best help you and talk to them about your needs. If you want to work, it is in your employer's best interest to help you work and continue caring. Many larger employers offer help to carers in-house, so it might be worth asking your employer if they can offer you any support. Ask them about flexible working arrangements. There are many different ways of working flexibly. You could work from home or have flexible starting or finishing times. Other working arrangements might be:

- Compressed working hours (where you work your normal number of Hours in a shorter time)
- Or shortening your hours to accommodate your needs)
- Working during school terms
- Job-sharing
- Part-time working
- Flexible holidays to fit in with alternative care arrangements. The right to request flexible working regulations gives working parents of disabled children under 18 the right to request flexible working arrangements from their employer. You also have the legal right to ask your employer for flexible working if you're caring for an adult who:
  - ⇒ Is a relative
  - ⇒ Lives at the same address as you

### ■ Working families

Website: <https://www.workingfamilies.org.uk/>

Facebook <https://www.facebook.com/WorkingFamiliesUK/>

Helpline for parents & carers: 0300 012 0312

Email: [advice@workingfamilies.org.uk](mailto:advice@workingfamilies.org.uk)

Helping working parents and carers and their employers find a better balance between responsibilities at home and work. Any employee (other than an employee shareholder) with 26 weeks of service with the same employer has the right to make a request to work flexibly; you don't have to be a parent and carer.

*“ Go with your gut instinct and do what's right for you. ”*



## Emergency planning

Sometimes we are so busy caring we don't always think about what might happen in an emergency situation. If you are a working parent and have worked for your employer for at least a year, you are entitled to take time off if it is a care related emergency. Most carers know they can get emergency leave, but there are other leave arrangements that your employer might be able to offer. They include:

- Compassionate leave
- Borrowing or buying leave
- Career breaks
- Parental leave (If you've legal parental responsibility for a disabled child under 18, you may take up to 18 weeks **unpaid** parental leave).

If you are working, it may be helpful to talk to your employer and tell them that you are a carer. Caring for a disabled relative is often unpredictable and care arrangements can be complex. You could talk to your employer about your concerns and commitments. It is easier to deal with emergencies if you have planned for them beforehand. If you access Social Services, talk to a social worker to ask them about what would happen to the person you care for, in an emergency.



Be sure to add **ICE** (In Case of Emergency) in front of the person you would want contacted in an emergency, in your mobile phone. For example: ICE: Auntie Laura 01234 123456 making sure you put ICE before their name, as workers in the emergency services very often look at phones for this information.

Some councils or other local organisations offer an **Emergency card scheme** for carers. Contact yours to see if they offer this. You carrying a credit card sized card with a number to contact in an emergency. The emergency services on finding the card will ring the number of the organisation holding your details and they will be able to tell them all about you and the person your care for. Make a list of emergency numbers; you could put them on your fridge under a magnet, so you have them to hand if you need them in a hurry. Make sure they include phone numbers for:

- Your GP, including out of hours numbers
- Local council (social services), including out of hours numbers
- Emergency card scheme (if you are registered)
- Other people (friends and family) who might be able to help.

Tell others in the family, or close friends about what you would want to happen to the person you care for, if you should be involved in an emergency situation. Many people don't do this and then family and friends are left wondering what to do. If you want an emergency card for your child or yourself to carry, that is a bit more fun, have a look at:

- **Ice card** website: <https://www.icecard.co.uk/>

■ **Lions Club International** do a 'Message in a bottle' scheme

Website: <http://lionsclubs.co/MemberArea/message-in-a-bottle/>

Telephone: 0121 441 4544 Email: [mdhq@lions.org.uk](mailto:mdhq@lions.org.uk)

Message in a Bottle enables people to keep their personal and medical details on a standard form and in a common location - the fridge! You also get a sticker to put on your front door, so that emergency services know you have one and will know where to look for it.



## Carers support services and advice services

Most counties in the UK will have a carer's support service and/or a parent's forum. They can help you by being a listening ear, and providing practical information and emotional support. Many carer's support services hold meetings and events, where groups of carers can meet others similar to them. Very often they have parent carer meetings and meetings for parents of adult children with a learning disability or Autism. Some services offer access to low cost complementary therapies (aromatherapy, Reiki, Indian head massage, etc.) and some also offer free counselling services. To find out about your local carer's support service, please visit your local council website, or phone your local council or library for their details. Alternatively you can just type in Carer's support service, followed by your town or county, into a search engine on the internet.

■ **Princess Royal trust for carers**

Website: [www.carers.org](http://www.carers.org)

→ England office 0300 772 9600

→ Wales office 0292 009 0087

→ Scotland office 0300 123 2008

General email enquiries: [info@carers.org](mailto:info@carers.org)

Carer support Email: [support@carers.org](mailto:support@carers.org)

Help, advice and information for all carers.



■ **Carers UK** Website: [www.carersuk.org](http://www.carersuk.org)

Advice line: 0808 808 7777

Help, advice and information for carer's.

■ **HFT family carer support service** Website:

<https://www.hft.org.uk/our-services/family-carer-support-service/>

Freephone: 0808 801 0448 Email: [familycarersupport@hft.org.uk](mailto:familycarersupport@hft.org.uk)

HFT's Family Carer Support Service (FCSS) is a free national service for family carers who have a relative with a learning disability. They offer support to family carers in a variety of ways:

- One-to-one support by telephone, letter or email
- Family carer workshops about issues affecting family carers
- Updating family carers about issues and legislation that affect them.

## ■ Citizens Advice Bureau (CAB)

To find an advice service in your area, contact your local council or library. website: [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

Advice line, their national phone service, is fully operational in Wales for people who live or work there. . If it is not yet available in your area, you will hear options for recorded information:

Telephone:

⇒ England: 03444 111 444

⇒ Wales: 03444 77 2020

⇒ Scotland: 0808 800 9060

## ■ Disability Information and Advice Line (DIAL)

Website: <https://www.dialuk.info/>

Telephone: 01302 310123

DIAL is a network of disability information and advice services. It is made up of a team of experienced experts with a common interest on disability and catering to all aspects of living with a disability.

## Carers legislation

The Care Act 2014 sets out carers' legal rights to assessment and support. It came into force in April 2015 and significantly increased the rights of carers to get the support they need at the time they need it. More information is available at:

■ **The Care Act** website:

<https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

The Care Act relates to adult carers (aged 18 and over) who are caring for another adult. This is because young carers (aged under 18) are assessed and supported under a separate children's legal framework.

### What does the Care Act do?

It means being treated equally to the person you care for. The Care Act gives Local Authorities a responsibility to assess a carer's need for support, where the carer appears to have such needs.

## Carers wellbeing fund

A grant from the carer's wellbeing fund is usually a payment of up to £300 (although this might vary slightly in different parts of England). You can apply for this grant via your carer's support service or nominated organisation. The grant must be something that benefits yourself (the carer) to help promote **your** health and wellbeing. You might like to apply for a mini breakaway, or a gym membership, or a therapy, or other item or service that benefits **you**. The grant is not means tested and each application will be considered by a panel of people. You can apply for the grant every year.

## Carer's assessment

If you are a parent of a disabled child aged under 18, your child can be assessed by the local authority under the Children and Families Act 2014, the current law relating to the needs of children. You will also be included in the assessment because social services will look at the needs of the family as a whole. This is often referred to as a "holistic" assessment. The assessment should take into account detailed information about your family, including:

- The family's background and culture
- Your own views and preferences
- The needs of any other children you have.

The assessment looks at whether you are able and willing to provide care now and in the future. The assessment also considers the impact on activities outside of the care you provide such as your work, education, training and enjoying yourself, as well as your mental and physical health. The assessment is not a test of your parenting skills, but should be a sensitive look at any difficulties the family has as a whole, with a view to considering what support or services are needed.

## Carer's assessments and NHS continuing care

As well as any care and support organised by the council, some children are also eligible to receive help from the NHS. This help may be a nursing service for children who are ill or recovering at home after leaving hospital. It could include things like changing the dressings on wounds, or giving medication. If your child is eligible for this kind of help, a health professional such as your GP or community nurse should be able to tell you. In exceptional circumstances, where an adult has a complex medical condition and substantial ongoing care needs, the NHS provides a service called NHS continuing healthcare. NHS continuing healthcare provides care and support in a person's home, care home or hospice. If you look after someone who qualifies, you may want to find out more about NHS continuing care.

- **NHS continuing healthcare** website:

<https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/>

## Carer's assessment for those caring for an adult over 18

The carer's assessment for those caring for an adult with a disability is different to the assessment for looking after a child. A carer's assessment is an opportunity to discuss with the local council what support or services you need. The assessment will look at how caring affects your life, including for example, physical, mental and emotional needs, and whether you are able, or willing, to carry on caring.

### **Who can have a carer's assessment?**

Any carer who has a need for support should be offered an assessment. You will be entitled to an assessment regardless of the amount or type of care you provide, your financial means or your level of need for support.

You don't necessarily have to live with the person you are looking after or be caring full-time to have an assessment. You may be juggling work and care and this is having a big impact on your life. You can have an assessment whether or not the person you are looking after has had a needs assessment, or if the local council have decided they are not eligible for support. For more information please visit:

- **Carers UK** website: <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

## Carer's allowance

If you spend at least 35 hours a week caring for someone you may be able to claim Carer's Allowance. The person you care for must get either

- Disability Living Allowance (DLA) care component at the middle or higher rate, or
- Personal Independence Payment (PIP) daily living component at any rate, or
- Attendance Allowance (AA).

Carer's Allowance is paid directly to you (the carer) but the amount you get may be affected by your other benefits or the amount you earn.

Claiming Carer's Allowance can also help you get extra money if you claim other benefits or Pension Credit. You can claim Carer's Allowance anywhere in the UK, but some of the rules are different if you claim Carer's Allowance in Northern Ireland.

## Pension planning

### ■ **UK Government caring and your pension**

Website: <https://www.gov.uk/carers-credit>

Information on caring and pensions, and how to claim Carer's Credit.

### **Carer's credit**

Carer's credit is a National Insurance credit that helps with gaps in your National Insurance record. Your State Pension is based on your National Insurance record. Your income, savings or investments won't affect eligibility for Carer's Credit. To get Carer's Credit you must be:

- Aged 16 or over
- Under State Pension age
- Looking after one or more people for at least 20 hours a week

The person you're looking after must get one of the following:

- Disability living allowance care component at the middle or highest rate
- Attendance allowance
- Constant attendance allowance
- Personal Independence Payment - daily living component, at the standard or enhanced rate
- Armed forces independence payment

If the person you're caring for doesn't get one of these benefits, you may still be able to get Carer's Credit. When you apply, fill in the 'Care Certificate'

part of the application form and get a health or social care professional to sign it. Carers who don't qualify for Carer's Allowance may qualify for Carer's Credit, even if you have breaks from caring (up to 12 weeks in a row). For example, you'll still get Carer's Credit for 12 weeks if:

- You take a short holiday
- Someone you look after goes into hospital
- You go into hospital

Keep the Carer's Allowance Unit updated if you have a break in caring of more than 12 weeks in a row.

■ **Carer's Allowance Unit:** 0800 731 0297

You don't need to apply for Carer's Credit if you:

- Get Carer's Allowance - you'll automatically get credits
- Get Child Benefit for a child under the age of 12 - you'll automatically get credits
- Are a foster carer - you can apply for National Insurance credits instead.

*“ As a carer, I was entitled to claim carer's allowance, and not be so out of pocket, having had to give up my paid employment for my caring role (I was entitled when my daughter was between the ages of 7 and 18, but didn't realise and never received a penny). ”*

## Legal advice; Carers rights



### ■ Luke Clements

Website: [www.lukeclements.co.uk/carers-and-their-rights/](http://www.lukeclements.co.uk/carers-and-their-rights/)

Luke Clements is the Cerebra Professor of Law at Leeds University where he has a Chair in Law and Social Justice. Luke is also a solicitor with Scott-Moncrieff & Associates Ltd. He has helped draft and promote a number of Parliamentary Bills aimed at improving the rights of people experiencing social exclusion - including Bills that became the Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004. In 2013 he was the Special Adviser to the Parliamentary Committee that scrutinised the draft Bill that resulted in the Care Act 2014. He has written widely; his books (jointly written) include: Disabled Children: A Legal Handbook 2020; Carers and their Rights (Carers UK) 2015; Clustered injustice and the level green (2020); Community Care and the Law (2019).

### ■ CASCAIDr

Website: <https://www.cascaidr.org.uk/>

Email: [belindaschwehr@cascaidr.org.uk](mailto:belindaschwehr@cascaidr.org.uk)

CASCAIDr is a specialist advice charity, with a mission to try to help put right some of the not-so-good things going on in Adults' Social Care and NHS health service allocation in this country.

■ **Civil legal service direct** Website: [www.clsdirect.org.uk](http://www.clsdirect.org.uk)

Telephone: 0845 345 4345

Directory of Civil Legal Service advice centres and solicitors in England and Wales.

■ **Law centres Federation** website: [www.lawcentres.org.uk](http://www.lawcentres.org.uk)

Telephone: 020 7428 4400

Email: [info@lawcentres.org.uk](mailto:info@lawcentres.org.uk)

Details of law centres in England, Wales and Northern Ireland.

■ **Scottish law centres**

website: [www.govanlc.com](http://www.govanlc.com)

“ When I was younger I never thought about what would happen to my daughter when I was gone. If I had known, I would have started years ago. ”

## Wills and Trusts

Often the last thing on our minds is thinking about making a will. However, it is really important to do this as soon as possible; to set out our wishes should the inevitable happen, but also as the parents of a child with a chromosome or gene disorder, it is important to plan ahead and make sure that you have a plan for them.

■ **MENCAP** Website: [www.mencap.org.uk/willsandtrusts](http://www.mencap.org.uk/willsandtrusts)

Telephone: 0207 696 6925 email: [willsandtrusts@mencap.org.uk](mailto:willsandtrusts@mencap.org.uk)

Mencap run free Planning for the Future seminars for carers all over England. They also have some helpful guides on their website.

## Dads

■ **Dad at home**

Website: [www.dadathome.co.uk/](http://www.dadathome.co.uk/)

DadAtHome provides a wealth of information and advice for fathers bringing up children. It looks at the financial implications and how to plan a budget, apply for Child Benefit and Child Tax Credit, and set up a Child Trust Fund. There is practical advice on how best to child-proof the home, change nappies and bath babies.

■ **Dads matter UK**

Website: <https://www.dadsmatteruk.org/>

Provides support for dads worried about or suffering from Depression, Anxiety and Post-Traumatic Stress Disorder (PTSD).

■ **Contact** have a guide for Fathers

Website: <https://contact.org.uk/media/782590/fathers.pdf>



## Single parents

### ■ GINGERBREAD

Website:

<https://www.gingerbread.org.uk/>

→ **England:** free helpline 0808 802 0925

Email: [info@gingerbread.org.uk](mailto:info@gingerbread.org.uk)

→ **Wales:** 02920 471900

email: [wales@gingerbread.org.uk](mailto:wales@gingerbread.org.uk)

A leading charity working with single parent families. Supporting, advising and campaigning with single mums and dads to help them meet their family's needs. There is lots of information on their website including a forum for parents.



### ■ Single Parents Support

Website: <https://do-it.org/organisations/single-parents-support>

Facebook: <https://www.facebook.com/groups/spsguk/>

An online community for single parents with support from experienced parenting facilitators that brings together essential information. The online groups also act as a support group, where people can gain information and support from others who have been through similar experiences.

*“ As it's a role for life not just childhood, to preserve my health and wellbeing - help from other sources from the beginning to share the task is not a sign of weakness, but the key to enabling you to not just care and cope, but to enjoy your child for who they are. That can be hard as a single parent. ”*

*“ Search out carer's support groups within your area earlier where possible, I left it until my daughter was 12 and wish I had done it much earlier. I joined a wonderful group who made me feel so welcome and made me realise I don't have to do this by myself. I have made some amazing friends from the group, gained so much information and to make things even better, our children & young adults have also become friends with each other, which is brilliant. 10 years on we are still all together, we laugh, we cry, we help each other out and we socialise, in fact we have just booked a panto trip for 33 people, the theatre is not going to know what hit it! ”*



## Grandparents

Grandparents groups have been established with the recognition that grandparents also feel isolated and in need of support. Some of the parent support networks may not always be accessible for grandparents. It is also useful to make use of your own support networks, your friends and relatives. If the child has other grandparents it may be useful to pool ideas and work together in offering support and sharing the burden. You should also be realistic about the kind of help you can offer and remember that you have needs too including considerations about your own health.

■ **CONTACT** have a page on their website for grandparents

Website: <https://contact.org.uk/grandparents>

And also a Grandparents guide:

<https://contact.org.uk/media/770883/grandparents.pdf>

■ **Kinship carers**

Website: <https://kinship.org.uk/>

Advice line: 0300 123 7015

Email: [info@kinship.org.uk](mailto:info@kinship.org.uk)

Offer support to grandparents in England and Wales who are caring for their grandchildren full time (kinship carers) or have childcare responsibilities for their grandchildren.

## Siblings as carers

Many of Unique's children are sometimes cared for by their brothers or sisters to help their parents, but in some cases siblings can be their main carer. Unique have produced a comic book aimed at primary aged siblings, it can be downloaded from the

■ **Unique** website:

<https://www.rarechromo.org/cms/wp-content/uploads/2017/07/UniqueTales.pdf>

■ **Sibs**

Website: <https://www.sibs.org.uk/>

Facebook: [www.facebook.com/SibsCharity](https://www.facebook.com/SibsCharity)

Advice line: 01535 645453

Sibs is the only UK charity specifically representing the needs of siblings of disabled children and adults. Sibs has a number of fact sheets on issues for siblings, parents and professionals, runs a support network and workshops for parents and siblings.

Unique has a guide for **Young Carers** and a separate guide for **Siblings** on the website:

<https://www.rarechromo.org/practical-guides-for-families>

## Parents say.....

Some quotes are included throughout this guide, but here are a few more...

“ If I had to say one thing, it would be to say that it's ok not to be ok, sometimes.”

“ I would like to have known what little disregard the professionals involved in my sons health, education and care would have for my position as his carer. I would have kept records of every appointment and every aspect of his care. I would have liked to have known how important it is to keep copies of all documentation in connection with his health, education and care. To keep a diary is extremely important. ”

“ You won't get a medal at the end of the day for doing absolutely everything and actually taking a break and letting someone else take over now and again is fine, for both Mum & child. I also think you need to toughen up and realise that most of the rest of the world judges you based on their own experiences, e.g. raising normal, healthy children, and they really shouldn't pass comment on any decisions you make as a family, and you have to let a LOT of things go. ”

“ You don't have to feel guilty for taking anytime out for yourself. I found after 15 years that if I am not in a good emotional/mental health state, then my child with 1p36 mirrors my emotions with often awful outcomes in behaviour- so take a break before the responsibility of caring breaks you. ”

“ As a carer don't take support that you are offered just because it's been offered, if it is not right for you as a family you are only going to worry more. ”

“ It is a very lonely place to be and you will require strength of mind as you would have never thought possible.”

“ Trust your own judgement, if you think something is not right for either you or your child, then question it.”

*“ It took me 12 years and getting right to the edge of a nervous breakdown, to learn to ask for help. Things would have been so much easier if I had learned earlier not to keep putting a brave face on things. ”*

*“ Support from others is great. But we all find different ways of getting support, so if one way doesn't work, another way might. ”*

*“ The fact that I didn't see myself as a carer, but a mum and it was up to me to cope .I think if someone had got through to me earlier - that as a mum I could still access the carers centre etc. and not feel guilty, or that I had failed. ”*

*“ The one thing I did for my own self-care and me time was start a diploma in counselling. I seem to remember I got my level 2 paid for as I was receiving income support. The lessons were during school hours, so I could do them while my son was at school. It gave me a real sense of purpose and helped get my identity back from being his mam to being me. I am now almost finishing my degree and doing an assignment on counselling parents of chromosome cuties. I believe Self-care is really important. If we don't look after ourselves, how can we look after our children. ”*

*“ As a carer, never look too far into the future as the road ahead will likely bring you to your knees, instead focus on the here and now, live in the moment and try not to worry about things you can't change. I would also say to all carers, choose your battles with the system wisely, fight those you know you are going to win and walk away from those you can't. It isn't a sign of failure to do that, as you have so little reserves left after your caring role to fight for anything and you will always have to fight for your child. Also it can appear that the very people who are meant to be there to help you are the people who are finding the most barriers to the solution and it can be frustrating. Have it clear in your mind of what you need to achieve for your child and as long as it is reasonable and you truly believe in it, don't let them bully you. Always research everything so that you can talk to professionals with knowledge as knowledge is power. ”*

# Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group  
The Stables, Station Road West, Oxted, Surrey RH8 9EE,  
United Kingdom  
Telephone: +44(0)1883 723356  
Email: [info@rarechromo.org](mailto:info@rarechromo.org) | website: [www.rarechromo.org](http://www.rarechromo.org)

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at [www.rarechromo.org](http://www.rarechromo.org)  
Please help us to help you!



Hazelwood School

The publication of this guide was made possible through the generous support of the Hazelwood School Community Fund.

Our thanks to all of the parents that contributed towards this guide.  
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Version 3 (MM)

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