

# Supporting your child through change



**A guide for parents whose child is affected by a rare, complex condition**

**Breaking Down Barriers** is a network of organisations working together to bridge the gap between families from diverse communities and healthcare providers. Developing inclusive and accessible services for people affected by genetic conditions and striving for equitable access to healthcare.

This guide has been written alongside the non-profit, Rareminds, Community Interest Company, utilising their knowledge and expertise around mental health and our own experience and knowledge of supporting people with rare complex conditions. It is intended to provide suggestions and tips for managing uncertainty and supporting your child as we emerge from lockdown. We have also provided details of additional resources and links to further support services at the end of this leaflet.

### Supporting your child through change

The COVID-19 pandemic has been a challenging time full of uncertainty and change, which we have all experienced in our own unique way. As the parent of a child or children living with a rare condition, you will likely be familiar with feelings of uncertainty. You may have also faced additional challenges brought on by the pandemic.

You may have been managing changes to routines, loss of support, and balancing work and family life at home. You may have needed to shield, move in and out of self-isolation, and adapt to changing circumstances very quickly. Some of you may have enjoyed the slower pace of lockdown, and become closer as a family, and some of you will have found it very stressful.

For parents who do not live together, COVID-19 may have complicated existing co-parenting arrangements or placed a strain on your relationships. If you live in a multi-generational household, there may also be different expectations about how things 'should be' or what is best.

Over this next period, you may be making difficult decisions. There may be times when you must make sudden and disappointing changes as a result of self-isolating. Different family members may have different needs and demands during this time. Not all decisions will be yours to make, such as those by your employer or children's school. It is important to remember that you can only do the best you can.

Whatever your experience as a parent during lockdown, this information aims to provide some support and ideas as restrictions change. Although the advice in this leaflet is focussed on supporting your child, it is important that you look after yourself and your own wellbeing too.



### The Impact of COVID-19 on children

Children have had to process a huge amount of change during COVID-19. They have had the loss of familiar routines, friends, school or respite care, and time with important people in their lives. Family relationships have inevitably intensified during this time. Some relationships will have become stronger, and others may feel more fragile, or turbulent.

We are all having to make adjustments as a result of COVID-19. Holidays and visits may be cancelled, and school friendships and routines disrupted as a result of self-isolating or the need to be careful around vulnerable family members. If you have a child who needs to shield, this will be hard for everyone.



It is important to remember that you know your child best, and what is helpful for one child may be different for another.

## Helping children manage changes and feelings

Children have different emotional needs at different ages. If your child has a learning difficulty, a learning disability, autism, a developmental delay or a physical disability then use these guidelines according to their needs, you know your child best.

Remember too that children will move about between developmental ages, regardless of their actual age as a normal part of growing up.



### Children aged up to 3 years old

#### What's going on?

At this age, children do not have much understanding of time. They focus on the 'here and now' and like things to be familiar and predictable. They feel secure by being in close contact with people and environments they know well.

Babies and very young children tend to 'show' when they are upset by how they behave. They may cry more often, be easily upset, develop sleep problems, or become fussier about eating. They will find it hard to understand why adults are worried or sad, or upset. They may even continue to play or seem unaffected if someone is unwell or upset around them, but most children will be picking up on what is going on around them.

#### What helps?

Familiar routines around mealtimes, bath times and bedtimes should help.

Enjoying time together at the end of the day. Children can often feel more anxious or vulnerable as night-time approaches, especially when they sleep alone.

Talk about what will happen next, even for children without speech, saying things like 'after your apple it's time for a bath' is reassuring, so they know what to expect.

Just enjoying each other's company is hugely rewarding. This can be simple things such as playing a game, dancing to music, or cuddling up to watch TV. Young children are comforted through close physical contact, finding hugs and cuddles reassuring.

### Children aged between 4 and 7 years old

Children this age are also focused on the present, and their immediate environment. They will struggle to understand things that cannot be seen or 'pictured in their mind', like illness. A child this age may know that a cough is a sign of being unwell but will not understand that some coughs are more – or less - serious than others. They are developing their own understanding of situations but may come to conclusions that aren't true. For example, they might believe that washing your hands means you will never get sick from anything.

They may be more able to tell you when something is upsetting or worrying them, but they will often express these feelings by how they behave. They might return to behaviours they had outgrown, such as not wanting to leave you or bed-wetting. Because they are working hard to understand the world around them, they may also ask a lot of questions to try to make sense of what they've heard or ask you to repeat yourself a lot.

#### What helps?

Books and stories that deal with common life experiences, including difficulties like being alone, people dying, or being different can help.

Giving names to feelings will help them manage the feeling better. Saying 'I can see you feel upset/ worried/ sad / disappointed about this' will help your child feel understood and help them to feel acknowledged. The feeling is then less likely to be expressed through difficult behaviours.

Try to answer questions simply and straightforwardly. If you don't know the answer, that's ok. Let your child know it's a good question but either it's not something anyone can answer right now, or that you can try and find something out together.

Routines and structure will also be reassuring for your child.

Children of this age find comfort through close physical contact and being with people they know and trust.



**Keeping to a routine and not forgetting those moments to cuddle, this will help your child to feel reassured.**

## Children aged between 7 and 12 years old

By now, children are coming to terms with the fact that people have different needs and perspectives. They will still tend to see the world very much from their own point of view. They are starting to understand more complex ideas and experiences such as time, illness, and death.

Your child may still have difficulty working out what they are thinking or feeling. They are becoming more aware of other people's feelings too and may worry about making you sad or angry. Physical symptoms such as tummy aches and headaches may be a way that anxious or difficult feelings are expressed.

Encourage your child to express their feelings through drawings, role play, and asking questions. It is important to normalise different feelings and share with your child ways of coping that are helpful. If they can, you can also encourage your child to be active and exercise. This helps release 'happy hormones' and reduce stress hormones. If your child wants to help (perhaps with a family member who needs physical care) be positive and encouraging, but also do not let your child take on too much of an adult role.

Finally, give your child accurate and factual explanations about COVID-19 and risks. At this age they can understand more details but may also hear things that are not true.

### What helps?

Being allowed to behave sometimes as though they are much younger through fun games and activities and being able to 'let off' steam.  
Being allowed to still 'be little' sometimes by cuddling up and needing reassurance.

## Young people aged 13 and upwards

Lockdown has been very hard for teenagers. This age group need to practise becoming more independent of their family, and lockdown has disrupted this. They may have missed out on important life events such as exams, prom, parties, and other life events. Transitioning to adult medical services may have been postponed. Just as we have, each young person will experience things differently. Some may feel relieved, and others annoyed and angry by the delay.

Teenagers are also able to understand more complex information about illness (including COVID-19) and may also be thinking more about their own (or family members) rare condition. They may also ask less questions as they are starting to work out more for themselves. They may turn more to the internet or friends for opinions or advice. Helping them to access accurate up-to date information about their condition is important, for example through your rare condition charity. Let them know you are there to help with anything they read or find out, that worries them.

Parenting a teenager can feel very challenging at times. In trying to become more independent emotionally and practically, they may both push you away and be very demanding. You too may be wanting to support their independence, but also be worried about their capacity to look after themselves.

This is also a time when you will be starting to 'let go' of closely looking after their health issues too. If your teenager has difficulties in making friendships or starting relationships there may be a lot of strong feelings around for everyone, particularly if it is related to their rare condition.

### What helps?

Acknowledge frustrations at what they cannot do right now,

Accept 'screen time' is an important way of staying connected to friends, but encourage switch off times (especially at night)

Support online studies by suggesting a realistic study time, followed by a 'reward break' doing something enjoyable

Teenagers can feel 'invincible' and may take risks with their health. This may be COVID-19 related, or with their rare condition. Try not to over-react, but explain calmly why it is important to stay healthy and well.

Create healthy routines, around their health, keeping active, getting enough sleep and getting a healthy balanced diet

Support your child in becoming independent in whatever ways are possible for them - talk to their school or social worker if you need more help and advice. Many colleges and universities also have support services for young adults with long-term conditions and can offer advice too

Take their thoughts, feelings and ideas seriously. Use phrases such as 'I'm listening.' Understanding the problem is usually more helpful for your teen than trying to fix the problem.

Support them in knowing about good online resources (there is a resource section at the end of this leaflet).



**Make time to talk. By listening carefully and calmly, you make a big difference.**

## Useful tips for all ages

Be flexible and create new routines when old ones are no longer possible, especially as a result of COVID-19 disruptions. Talk through with your child when and how any changes will be happening.

Answer questions honestly, bearing in mind what is appropriate to your child's age. If you do not know the answer, say so and suggest you could try and find out more together.

Focus on encouraging positive behaviour such as 'I really like it when you tidy your clothes away' rather than 'you never clear up, I'm sick of this mess'.

Be the safe place for your child to talk to you about strong or upsetting thoughts and feelings. It's not always possible to 'make something different' but your kind, calm care will help it feel easier for them to cope with.

Parenting tip: difficult behaviour is often about strong feelings that your child is still learning to manage. Naming the feeling can help the behaviour reduce. For example 'I know you are angry about not going out today. I can see you are upset. That doesn't mean it's ok to hurt your sibling. Would you like a hug, and then we can talk about what we can do today instead?'



## Top Tips for parenting through COVID-19 related changes

Start gradually – children may need time to feel comfortable around others again as lockdown eases. Take things slowly where you can, and explain new routines or what will be happening. Ask your child how they are feeling about changes both before, and afterwards. If they are non-verbal, notice how their behaviour demonstrates how they are coping.

Engage your child in decision making when possible – even small choices help children feel more in control of their lives.

Keep talking! Asking your child about their experiences, thoughts and feelings helps build their own self-awareness and self-esteem. It also brings you closer. If your child has communication difficulties, describing experiences to them and 'chatting' will both support your relationship and help their development.

Normalise setbacks and negative experiences– let your child know that it is upsetting but ok when things do not go as planned.

Then focus on what they can do instead, not what they can't.

Practice kind but firm 'positive parenting' - focus on good behaviours, actions and what your child does well (rather than what they don't do, or find difficult.) This will build self-esteem and lead to more of the behaviour that you want to encourage.

Try to see and understand the feelings behind 'bad' behaviour.

Build routines and structures that help everyone feel more secure. Knowing that some things are predictable is very reassuring. These can also be fun family traditions such as 'Friday night is Film night'.

Be a good role model – your own behaviour and coping strategies will have much more influence on your child than what you 'say.' Looking after yourself, and managing your own feelings positively will have a big impact. See our 'Positive Parenting: Self-care tips'

Be kind to yourself - Take time when you can to have a break and do the things that help you look after yourself during challenging times. These will be different for everyone – it could be exercise, reading a book, watching a film, having a bath or speaking with friends or family.

Talk to someone you trust if you are worried about how either you or your child is coping. Help is out there. This might be family and friends, healthcare professionals, community leaders, or your child's school. We have also listed some organisations to contact for advice and support at the end of this leaflet.

Spending quality time as a family is important, but so is 'alone time' especially for older children.

If space is hard to find in a small or crowded home, try to build 'zones', for example a den made of a blanket between two chairs, or sole use of a room for an agreed period.

## Positive Parenting: Looking After Yourself

We all know that parenting can be rewarding and an amazing journey, watching your child grow, but it can also have its challenges and bumpy times along the way.

It's very easy for your own needs to get lost when you are a parent.

Be kind to yourself – we can be much harder on ourselves than we would on other people. If you are struggling, imagine yourself as a friend.

### What would you say to a friend to be encouraging or supportive?

Accept not everything will get done – some days are about just getting through. If you feel over-whelmed, try just doing one thing that day that feels important. Tackle other tasks at another time.

Make time for your own health – such as exercising and eating healthily and don't forget some time for yourself. If this is difficult for you, start with small goals, for example 10 mins a day, or one healthy meal. Build up gradually. Ask for support if you can.

Keep connected – with friends, family members, and other parents in your cultural, religious, or rare condition community. Try scheduling catch up calls as something to look forward to, and let people know they – and the conversations - are important to you. They might not realise this unless you say. If it is hard to talk in private, try texting or using online chat.

Ask for support – and be specific about what it is that would help. Some people you know may be able to help in practical ways, and others are better for emotional support (knowing which people are best for each is very helpful!)

Create time for what you enjoy – whether it is watching your favourite TV programme, reading that book you have always wanted to, or getting creative with art, music, dancing or just a soak in the bath.

### REMEMBER!

Look after yourself too – everyone needs time to relax and recharge. Making time for yourself means you will have more energy for when any tricky moments arise.



Don't be so hard on yourself, what would you say to a friend to support or encourage them?

## Useful Resources

The **NHS Volunteer Responders** programme is still available to help support those who need it. Volunteers can collect and deliver shopping, medication, and other essential supplies. Call 0808 196 3646 between 8am and 8pm, 7 days a week to self-refer or visit <https://nhsvolunteerresponders.org.uk/services>

**Every Mind Matters** is the NHS website for mental health with a section on coronavirus and wellbeing - <https://www.nhs.uk/every-mind-matters/>

**The Mental Health Foundation** has provided guidance in several languages to look after your mental health during the coronavirus outbreak <https://www.mentalhealth.org.uk/coronavirus>

**Anxiety UK** [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk) has a range of online resources, and a helpline 03444 775 774.

**MIND** [www.mind.org.uk](http://www.mind.org.uk) have lots of useful leaflets on everything from sleep problems, to money worries, to mental health.

**Hub of Hope** provides a searchable directory of mental health services in your local area- <https://hubofhope.co.uk/>

**Carers UK** has lots of useful advice for Carers - <https://www.carersuk.org/help-and-advice/coronavirus-covid-19>

**Relate** is an organisation that offers support , advice and counselling for relationships, including on the impact of the pandemic <https://www.relate.org.uk/relationship-help/covid-19-advice-and-information>

**At a loss** has details of local bereavement services across the UK – <https://www.ataloss.org/>

**Cruse** [www.cruse.org.uk](http://www.cruse.org.uk) bereavement support and advice

**BACP** is a website listing professionally registered counsellors and psychotherapists by local area [www.bacp.co.uk](http://www.bacp.co.uk)

**Rareminds CIC** works with patient and professional organisations to provide counselling and emotional wellbeing resources for all those impacted by rare diseases [www.rareminds.org](http://www.rareminds.org)

## Mindfulness Resources

**Oxford Mindfulness Centre** offer a number of free, short introductory mindfulness exercises and podcasts, as well as longer courses [www.oxfordmindfulness.org](http://www.oxfordmindfulness.org)

## Crisis support

If you are really **struggling, or in a mental health crisis:**

Contact your **GP** or **NHS 111**. You can also go straight to **A & E**.

**The Samaritans** provide an excellent 24 hour listening/crisis support on 116 123 or [jo@samaritans.org](mailto:jo@samaritans.org).

Text **SHOUT** to **85258**

CALM (The Campaign Against Living Miserably) [www.thecalmzone.net](http://www.thecalmzone.net) 0800 585858 5pm – midnight

## Resources for Parents

**Family Lives** offers a confidential and free helpline 0808 800 2222 ( England and Wales) on all aspects of parenting and family life [www.familylives.org.uk](http://www.familylives.org.uk)

**Young Minds** has lot of resources for both parents and young people, and a helpline (0808 802 5544) for parents/carers worried about their child's mental health [www.youngminds.org](http://www.youngminds.org)

The **Association of Child Psychotherapists** have lots of resources on understanding and managing children from dealing with temper tantrums, to coping with bereavement [www.childpsychotherapy.org.uk](http://www.childpsychotherapy.org.uk)

**Gingerbread** provides support, advice, and a helpline (0808 802 0925) for single parents in England and Wales [www.gingerbread.org.uk](http://www.gingerbread.org.uk)

## Resources for Children and Young People

**Rare Youth Revolution** is an online magazine and community for young people with rare conditions [www.rareyouthrevolution.com](http://www.rareyouthrevolution.com)

Children and Adult Mental Health Services (**CAMHS**) provide signposting and downloadable resources for children and teens <https://www.camhs-resources.co.uk/>

**The Proud Trust** supports LGBT+ young people, or those questioning their identity [www.proudtrust.org](http://www.proudtrust.org)

**The black , Asian and minority ethnic family helpline (Boloh)** (0800 151 2605) for children from 11+, young people and parents/carers impacted by the pandemic in any way e.g. bereavement, physical or mental health, financial issues , unemployment, bullying or racism. You can speak to someone in English, Gujarati, Urdu, Bengali, French, Spanish, Arabic, Punjabi, Mirpuri, Pothwari, Hinko, Hindi and Sundhi (Interpreters are available for other languages) [www.helpline.barnardos.org.uk](http://www.helpline.barnardos.org.uk)

**Papyrus** the prevention of suicide helpline 0800 068 4141 for under 25's, including advice for if you are worried about someone or **text SHOUT to 85258** for anyone struggling to cope [www.papyrus-uk.org](http://www.papyrus-uk.org).

[www.breaking-down-barriers.org.uk](http://www.breaking-down-barriers.org.uk)

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