



Understanding Chromosome & Gene Disorders

Self-isolation



rarechromo.org

SELF-ISOLATION

We are living in unprecedented times. Many parents and children will be feeling worried and scared about this new virus that is finding its way around the world. Our children with rare chromosome or gene disorders might have little understanding of what is going on; why their routine has been disrupted and why they are not going out to childminder, nursery, school, day care, respite care, etc. We have put together this guide to help provide resources and positivity to our parents and their children, whilst we are all self-isolating at home. We are not going to focus too much on Covid-19 throughout the guide, links to that information can be found quite easily. However, because there is lots of fake information doing the rounds, we have included links to official Covid-19 guidance, because they are necessary.

General advice regarding Coronavirus (#COVID19) for patients with rare genetic disorders is now available on the Unique website at <https://www.rarechromo.org/covid19update> This Includes patients with developmental disorders and undiagnosed developmental delay, rare single-gene disorders and chromosomal disorders. This document will be updated as further information becomes available. With thanks to British Society of Genetic Medicine, Clinical Genetics Society and The Royal College of Physicians.

◆ **NHS guidelines:**

<https://www.nhs.uk/conditions/coronavirus-covid-19/#>

◆ **WellChild** <https://www.wellchild.org.uk/2020/03/18/ten-ways-to-keepmy-child-with-complex-health-needs-safe/>

A 10-point plan & information specifically for parents/carers of medically complex children: This includes a link to a poster to put on your front door to advise visitors to your home of the precautions they need to take.

◆ **UK government** – latest information on Covid-19

<https://tinyurl.com/tfurwg9>

Easy read stay at home guides and charts <https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>

⇒ **England**

The Department for Education and Public Health England

<https://tinyurl.com/wzg252j>

Guidance for vulnerable children and young people including those who have a social worker and those up to the age of 25 with education, health and care (EHC) plans.

◆ **Get coronavirus support as an extremely vulnerable person**

<https://www.gov.uk/coronavirus-extremely-vulnerable>

Register if you have a medical condition that makes you extremely vulnerable to coronavirus. For example, you'll be able to ask for help getting deliveries of essential supplies like food. You can also register with your local council in the same way.

- ⇒ **Scotland** <https://www.gov.scot/coronavirus-covid-19/>
- ⇒ **NHS** <https://www.nhs24.scot/>
- ⇒ **Wales** <https://gov.wales/coronavirus>
- ⇒ **NHS** <https://tinyurl.com/uev9xwa>
- ⇒ **Northern Ireland** <https://www.health-ni.gov.uk/coronavirus>
- ⇒ **Republic of Ireland** <https://www.gov.ie/en/>

◆ **USA government**

<https://www.usa.gov/coronavirus>

◆ **USA health advice**

<https://www.cdc.gov/coronavirus/2019-ncov/>

◆ **Australian government**

<https://tinyurl.com/qnfrj79>

◆ **Social distancing - guidance**

<https://tinyurl.com/ql6ak74>

◆ **Free E book from Books beyond words, explaining the virus to children and adults (pictures only)**

<https://tinyurl.com/ugh76qo>

◆ **The World Health Organisation**

Has produced factsheets on helping children to cope with stress (PDF) during the COVID-19 outbreak. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>

◆ **The Royal College of Obstetricians and Gynaecologists (RCOG)**

<https://tinyurl.com/t5swnho>

has published information for pregnant women and their families on COVID-19 and pregnancy.

◆ **Social Story** <https://tinyurl.com/ukmx4rn>

To help children understand about the virus.

◆ **Meet the helpers**

<https://www.meetthehelpers.org/meet-the-helpers-coronavirus/>

An American PBS project aimed at talking to children about the coronavirus.

◆ **Young Minds**

<https://youngminds.org.uk/blog/what-to-do-if-you-re-anxious-about-coronavirus/>

Information for young people feeling anxious during this time.

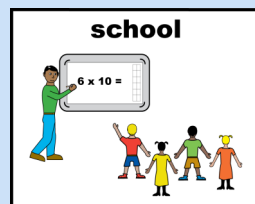


Please note:

Information on the current situation is evolving and changing all the time, you may find you have to revisit some of the links mentioned in this guide, for up-to-date current information as it changes. Please keep checking our website homepage for further news.

Education at home

Many of you will have been sent work or links to access work online by your children's school, it is best to continue with their work so that we will all be working from the 'same page' when they return to school. Keep to a strict routine, start at the same time school would normally start. With a morning break, lunch and an afternoon break, or maybe a short working afternoon and then play. Because home and school are usually separate it might be a bit of a struggle for some, so try the little and often approach if a full daily routine doesn't work for you. If you have the ability to turn a room of your house into a classroom that would also help, your dining room might be ideal. It might help if your child(ren) want to wear their school uniform, or part of it. If you like a structured day for your children, this timetable might help to plan over different days.



- ◆ **9.00am - PE with Joe Wicks** <https://tinyurl.com/vjhxmqb>
- ◆ **9.30am - Wildlife with Steve Backshall**
<https://www.facebook.com/stevebackshallofficial/>
- ◆ **10.00am - Maths with Carol Vorderman**
www.themathsfactor.com
- ◆ **11.00am - English with David Walliams**
<https://www.worldofdavidwalliams.com/elevenses/>
- ◆ **Or science with Maddie Moate**
<https://www.youtube.com/user/maddiemoate>
- ◆ **11.30am - Dance with Oti Mabuse**
<https://www.facebook.com/OtiMabuse/>
- ◆ **12.00pm - Lunch (cooking with Jamie Oliver)**
<https://www.jamieoliver.com/features/category/get-kids-cooking/>
- ◆ **1.00pm - Music with Myleene Klass** (twice a week)
<https://www.youtube.com/channel/UCQh2wgJ5tOrixYBn6jFXsXQ>
- ◆ **1.30pm - DDMIX/DDMIX for Schools and Darcey Bussell**
<https://twitter.com/diversedancemix/status/1241098264373592065>
- ◆ **2.00pm - History with Dan Snow** (free for 30-days)
<https://tv.historyhit.com/signup/package>
- ◆ **4.00pm - Home Economics with Theo Michaels** (Mon/Wed/Fri)
<https://www.instagram.com/theocooks>

Non-daily events include:

Science with Professor Brian Cox, Robin Ince & Guests
<https://cosmicshambles.com/stayathome/upcoming-schedule>

For older kids, 50 free revision resources for 11+, GCSEs and A-Levels:
<https://tinyurl.com/wo3ccjo>

School closure toolkit (USA) <https://tinyurl.com/yxxb3kyq>

Phonics and Early Reading

- ◆ **Cbeebies Alphablocks**

<https://www.bbc.co.uk/cbeebies/shows/alphablocks>

- ◆ **Cbeebies Numberblocks**

<https://www.bbc.co.uk/cbeebies/shows/numberblocks>

- ◆ **Explorify** <https://explorify.wellcome.ac.uk/>

Science app

- ◆ **ICT games (literacy and Maths)** <https://www.ictgames.com/>

- ◆ **Letters and Sounds** <http://www.letters-and-sounds.com/>

- ◆ **Oxford Owl** <https://home.oxfordowl.co.uk/>

- ◆ **Phonics Bloom** <https://www.phonicsbloom.com/>

- ◆ **Phonics Play** <https://new.phonicsplay.co.uk/>

- ◆ **Scholastic learn at home**

<https://classroommagazines.scholastic.com/support/learnathome.html>

- ◆ **Spelling shed** <https://www.spellingshed.com/>

- ◆ **Teach handwriting** <https://www.teachhandwriting.co.uk/>

- ◆ **Teach your monster to read**

<https://www.teachyourmonstertoread.com/>

Primary/Secondary aged children

- ◆ **Acorn to Oak Education**

<https://acorntooakeducation.org/our-services-advice-and-support/>

SEN experts, know a lot about home-schooling for SEN and about the educational programmes and resources that can help. They have an offer at the moment for a free 45-minute telephone appointment and then you can pay what you can afford for any future sessions. Available for calls booked by 30 April.

- ◆ **Classroom secrets**

<https://classroomsecrets.co.uk/>

During this difficult time, they're providing fun, interactive and practical home learning resources that are designed to be used by children. These include interactive games, video tutorials and downloadable home learning packs.

- ◆ **Education otherwise**

<https://educationotherwise.org/index.php/links>

This website has lots of resources for home educating families.



- ◆ **From ABC's to ACT's** <https://fromabcstoacts.com/>
Lots of educational and play resources on this website, for all age groups.
- ◆ **Handwriting worksheets (USA)** <https://www.handwritingworksheets.com/flash/cursive/>
personalised manuscript or handwriting worksheets to print out at home.
- ◆ **Master the Curriculum** <https://masterthecurriculum.co.uk/>
Maths resources.
- ◆ **Mrs Mactivity** <https://www.mrsmactivity.co.uk/free-art-activity-sheets/>
Fun to learn free activity sheets.
- ◆ **News** <https://www.bbc.co.uk/newsround>
Up-to-date news for children.
- ◆ **Premier League Stars** <https://plprimarystars.com/>
Videos and activities to support Maths, Literacy, PSHE and PE.
- ◆ **Primary Stars Education** <https://primarystarseducation.co.uk/>
Free service during the school closure.
- ◆ **Science** <https://www.youtube.com/watch?v=I5-dl74zxPg>
Mark Rober makes great easy to understand videos, this one explains how germs spread.
- ◆ **The pepper experiment and why you should wash your hands** <https://www.youtube.com/watch?v=WVxMKpLLRoM>
- ◆ **Super Movers** <https://www.bbc.co.uk/teach/supermovers>
Interactive videos for KS1 and KS2 Maths, literacy, PSHE and PE learning. Lots of fun.
- ◆ **Top Marks** <https://www.topmarks.co.uk/>
- ◆ **Twinkl** <https://www.twinkl.co.uk/resources/covid19-school-closures>
Subscription based but offering free service during the school closures, enter code **UKTwinklhelps** . Worksheets, powerpoints, and interactive games to support learning.
- ◆ **White Rose Maths** <https://whiterosemaths.com/homelearning/>
Home learning resources.



Social stories

♦ **ASD Bright Ideas - Autism - Autistic - Special Needs visual resources** <https://www.asdbrightideas.co.uk/asd/>

♦ **How to write a social story or comic strip conversation** <https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>

♦ **Off We Go** <https://www.otb.ie/offwego>

♦ **Books beyond words** <https://booksbeyondwords.co.uk/>

They have a free one on offer at the moment entitled 'Beating the Virus'

♦ **The Isabella Trust**

[https://www.theisabellatrust.org/visuals-and-communication-support/](https://www.theisabellatrust.org/visuals-and-communication-support/Visuals and choice boards.)
Visuals and choice boards.

For children with a rare chromosome or gene disorder, temporary home-schooling might be very difficult. Children may not understand because school is a separate place that they normally go to and often therapies are done at school, not necessarily in the home. Personally I wouldn't stress too much about structured learning. Little and often might be better, they can learn so much more just from everyday life, if you can keep them occupied and find things that they like to do and incorporate into family living. Try not to stress too much over academic learning.

“ There are so many ‘resources’ out there – (we are bombarded with them)– that this might all feel overwhelming, with lots of parents trying to do it all and be the perfect parent, substituting for teacher, carer, grandparent, auntie and colleague all at once. We need to pace ourselves. This could go on for some time and as parents we need to be here for the long haul, so we must make sure we have time for ourselves, avoiding burnout, doing what you can, not perfection or what somebody else manages to do. Social media shows best examples but they are not typical. This is so much more important for single parents and those who don't have a family around them. We'll all need to dig deep. As parents of Unique children we know this – we've been doing it for years – with varying degrees of support. Support especially at a time like this comes from all sorts of unexpected places. Routine, fresh air, reasonable nutrition, taking it one day at a time and doing what you can in your own circumstances is the best most of us can achieve. ”

Ideas for keeping the kids entertained.

Crafting, sewing, painting, drawing, messy play, jigsaw puzzles, cooking, board games, garden games. Leapfrog, crab walks, stretches, jumping, rolling, gardening, etc.

♦ **Audible at Amazon**

<https://stories.audible.com/start-listen>

Amazon have cancelled the subscription of books and audio stories for children of all ages as long as schools are closed. Stream stories, including titles across six different languages, that will help them continue dreaming, learning, and just being kids. All stories are free to stream on your desktop, laptop, phone or tablet.

“ We race each other like animals. So for example: crab walking. I also do wall push ups next to my son. It’s fun, gives them movement and input, and has nothing to do with a computer or screen, as most of our kids are having to do computer based learning. ”



♦ **Balloon Volleyball**

Blow up a balloon and use a piece of masking tape to mark a centre line on the ground. For older children/adults: If you have more than one person playing, you can add more balloons to make the game more challenging.

♦ **Chester Zoo**

Live animal videos at 10am every day via its Facebook page
<https://www.facebook.com/chesterzoo1/>

♦ **David Walliams @davidwalliams**

will be releasing an audio story every day for the next 30 days for free. First up is The Terrible Triplets! To listen:
<https://bit.ly/AudioElevenses>

♦ **Google 3D animals**

Google an animal, E.G: ‘giant panda’. Just underneath the image search results, there will be a Wikipedia description of the panda, you’ll be able to see a little box that says, “Meet a life-sized giant panda up close”.

♦ **Indoor treasure hunt**

<https://www.facebook.com/thetutoringterminal/>

The Tutoring terminal has lists of ideas for indoor and outdoor scavenger hunts. For older children: Use riddles as clues. For example: Find something that gets wetter the more it dries. E.g. (a towel)

♦ **Minecraft** <https://www.minecraft.net/en-us/>

Minecraft is making its educational worlds available free, to help pupils no longer able to attend school because of the self-isolation period.

◇ **Spread the Happiness – 101 things for kids to do**

<https://www.spreadthehappiness.co.uk/>

◇ **The Imagination Tree** <https://theimaginationtree.com/>

Lots of ideas for kids sensory play including homemade natural fruit or gluten free playdough, etc.

◇ **Twister**

This classic game is a great way to keep kids moving, help them work on gross motor skills, and give them practice telling left from right. If you don't have the game, you can use coloured paper or magazine pictures to create your own twister mat.

◇ **Rainbow pictures**

What is the meaning behind the pictures of rainbows?

Children up and down the country have been drawing/painting rainbows to put in their windows. They are to cheer people up, rainbows are used as a symbol of peace and hope. Parents out with their children go spotting pictures of rainbows in other children's houses, whilst out on their daily walk, there is a Twitter hashtag #ChaseTheRainbow



◇ **Over the rainbow** sung by our very own Unique Rosie, who is happy to share her cover version of this beautiful song with you all
<https://tinyurl.com/uzzxzph>



◇ **Singing hands** <https://singinghands.co.uk/>
Online classes and videos using Makaton.

◇ **House Party** <https://houseparty.com/>
An app. to keep in touch with friends and family, you can also play games with each other via the app.

◇ **Widgit symbols** <https://tinyurl.com/wh4lhdm>

email: info@widgit.com

Free and unrestricted access to Widgit Online and it's ready-made materials for 30 days. Use code **WIDGIT30**. If you already have an individual subscription or trial you can use the same codes to unlock all of the ready-made materials available in Widgit Online.

“ Send regular emails and little film clips to adult children living in shared lives or independent living (if they can access them) . ”

You could get your children to help with the chores, but make it fun, with a reward for doing so. This could just be as simple as sticking stars on a sticker chart or piece of paper with their name on.

Therapy at home

As with all therapies, if you are practising at home, it is best to seek the advice of your regular physiotherapist, to see if they have any exercises that you can do with your child safely whilst self-isolating.

◆ **Bumble Bee physio**

<https://www.facebook.com/bumblebeephysio/>

Live Physiotherapy videos.

SENSORY INTEGRATION THERAPY

◆ **Fox Wood Sensory Activity Challenge** <https://tinyurl.com/vqcjb8j>

Every day a different sensory activity is posted that you can try at home. **NB:** this activity will not be suitable for all children/families/homes - parents/carers are asked to watch the clips first and then only use the ideas and/or share the clip with children, if you think it is safe to do so. All children should be supervised whilst carrying out the activities to ensure their safety. All activities are carried out at your own risk.

◆ **Sensory stuck at home**

<https://www.facebook.com/groups/sensorystuckathome/>

◆ **ASIWISE** <https://www.facebook.com/ASIWISEORG/>

◆ **Pathways** <https://pathways.org/topics-of-development/sensory/>

◆ **Pathways videos**

[https://pathways.org/video-search?](https://pathways.org/video-search?age=19&query=)

[age=&topic=19&query=](https://pathways.org/video-search?age=19&query=)

◆ **checklists and brochures**

<https://pathways.org/all-ages/brochures/>

Exercise for everyone

◆ **CBeebies Andy's wild workouts**

<https://www.bbc.co.uk/programmes/p06tmmvz>

7 minutes of exercise in each workout.

◆ **Joe Wicks** <https://tinyurl.com/vjhxmqb>

Videos of 30 minutes of exercise every day.

◆ **Dance**

Music is good for the soul and can help your child burn off some extra energy. Put together a playlist of music your whole family can enjoy. Just dance!

◆ **Go Noodle** <https://www.gonoodle.com/>

Movement and mindfulness

◆ **NHS stretch and Flex podcasts**

<https://www.nhs.uk/live-well/exercise/strength-and-flex-exercise-plan/>



♦ **Walking**

If you live near woods, your once a day walk could be a nature walk, get your kids listening to the birds and try to identify them, or leaves on the trees, etc. If you are walking just around the houses, make it more interesting by not only looking for any rainbows in windows, but spot a particular colour front door, or car. Children can get very bored, so it helps to make it more interesting and fun. Play i-spy. Remember you aren't supposed to be out for longer than one hour and you mustn't meet up with anyone.

YOGA

♦ **Cosmic kids yoga**

<https://www.youtube.com/user/>

Fun Yoga for children.

♦ **Down Dog** <https://www.downdogapp.com/>

All apps - Down Dog, Yoga for Beginners, HIIT, Barre, and 7 Minute Workout - completely free until May 1st



PARENTS

Find the courage and strength to have a little 'me' time. You may say that you don't have time to think about yourself. Find time to read quietly if you can, soak in the bath tub, knit or crochet, phone friends or 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.

Mindfulness links.....

♦ **NHS**

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

♦ **Be Mindful** <https://bemindful.co.uk/>

♦ **Be Mindful online** <https://www.bemindfulonline.com/>

♦ **Mindful** <https://www.mindful.org/>

♦ **Smiling Mind**

<https://www.smilingmind.com.au/>

♦ **Headspace** <https://www.headspace.com/>

Offering FREE GLOBAL support during the outbreak. Focused mindfulness and stress-relief within your day.

♦ **10 tips to help if you are worried about coronavirus**

<https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips/>

♦ **Your Self Help Survival Guide** <http://bit.ly/corona-anxiety>

Created by Dr Jenn Cooper, a Chartered Counselling Psychologist. Find practical strategies to help to manage any anxiety or distress that Covid-19 is causing.

◆ **Libraries are closed but you can still borrow books**

Although all libraries are now temporarily closed, that doesn't mean that you can't enjoy a good book! The Devon Libraries Digital Library <https://www.devonlibraries.org.uk/web/arena/ebooks> lets you stream loads of free eBooks, eAudioBooks, eMagazines and much more.

◆ **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.

◆ **Theatres are closed but many have chosen to livestream**

[Live streamed theatre and opera](#)

◆ **National Theatre (from April):**

Starting with One Man, Two Guvnors, Jane Eyre, Treasure Island and Twelfth Night <https://www.nationaltheatre.org.uk/at-home>

◆ **Met Opera:**

Each day, a different encore presentation from the company's Live in HD series is being made available for free streaming on the Met website, with each performance available for a period of 23 hours, from 7:30 p.m. EDT until 6:30 p.m. the following day.

<https://www.metopera.org/user-information/nightly-met-opera-streams/>

◆ **Royal Opera House (FB and YouTube)** have created a schedule of free broadcasts and live content that audiences can access for free anywhere, anytime across the globe, bringing both ballet and opera to every home and every device. This will include the following productions offered on demand and for free via the ROH's Facebook and YouTube channels:

- ⇒ Acis and Galatea, The Royal Opera, 2009 – 3 April 2020, 7pm BST
- ⇒ Così fan tutte, The Royal Opera, 2010 – 10 April 2020, 7pm BST
- ⇒ The Metamorphosis, The Royal Ballet, 2013 – 17 April 2020, 7pm BST

FOOD

If you are struggling to get out to find fresh produce, many of the wholesalers that previously sold to market traders, shops, pubs and restaurants have a lot of stock that needs to be sold, so they are now selling/delivering to the general public. **The new Covent Garden market** is 75% down in sales. Sign up for home delivery of veg and fruit boxes. They can deliver milk, bread etc. too.

<https://www.newcoventgardenmarket.com/fruit-veg>

Many of these suppliers are in the London/Surrey postcode area, but if you do some research, you will find other suppliers local to you that will be offering the same service.

COPING IN AN EMERGENCY

It is important to keep a list of contacts, in case of an emergency. It is advisable to have one inside your front door and may be a separate copy to give to all of the people on the list. The one in your house would be best laminated.

♦ Carers UK

<https://tinyurl.com/vbm6rgd>

Has published guidance for carers during this time and will be regularly updating the page as new information becomes available. It includes advice on emergency planning and advice for working carers.

♦ Together Matters

<https://www.togethertomatters.org.uk/resources-and-information/>

Has lots of information and resources on emergency planning on its website.

There is an organisation that is currently pulling together a double-sided hospital passport template for this particular situation. The passport can be laminated, so that if your child has to go into hospital, this document can go with them and can be wiped clean. As this becomes available, we will update our website/Facebook page. These are mainly used for adults with communication difficulties. It is important to realise that should your adult child be admitted to hospital you might not be allowed to stay with them, so it is important to have this type of document at the ready, to go with them.

Talk to your friends and family by phone (I'm sure you are already doing that) but if you have what's app on your phone/tablet set up a what's app group, so that you can chat at any time via text. You can also download apps like:

⇒ **Zoom** <https://zoom.us/>

where you can arrange meetings and can see and hear each other. You can sign up and get 40 minutes of talk time for free.

⇒ **Houseparty**
<https://houseparty.com/>



♦ Working families

<https://workingfamilies.org.uk/article-categories/covid19/>

Working Families is the UK's work-life balance charity. They help working parents and carers and their employers, find a better balance between responsibilities at home and in the workplace. They provide free legal advice to parents and carers on their rights at work.

♦ **Special Needs Jungle** <https://tinyurl.com/r6hqu5f>

Using direct payments during the virus outbreak.

Unique family diary.....

One of our parents kindly shared this text from her family diary, I think this will help a lot of families, so I have included all of the text because it is so helpful.

“ We have a blackboard in the kitchen that has our usual weekly schedule on it. We've amended it and made it a bit more fun and also used the liquid chalk markers on the patio doors to let the kids get creative. We've been making little video diaries and putting them in a private album on FB just for a select audience so they can't be freely shared. Even their grandparents have sent a video message back. So yesterday I was interviewed by my 9 yr old and today she interviewed her sister about her favourite things. I love that we are creating a little bit of history and sharing some happiness with the world. We have been using YouTube a lot, live streaming of songs and stories by artists. I ordered a projector off amazon to link up with my iPad, so that I can use it to share with everyone. We've done pantomimes with dens under the table, we've done interactive PE sessions, we've accessed live web feeds of aquariums, because water is really soothing and fish are relaxing to look at. We've been spending time in the garden. Playing with balls and making up games. Most importantly we haven't been schooling. We have let the kids do the learning they want. M. at times has wanted to do some schoolwork, but we are doing fun word-searches and creative things mostly. She is missing her classmates and her teachers and it's important to acknowledge that. We have taken the time to be together as a family and to support the girls through such a difficult transition. We have explained the situation and reminded them that everyone is doing the same thing. Using online live links, they are still feeling connected with the world. We have prioritised fun and space, had lots of little activities that are easy to do and that we can dip in and out of. We've spent a long time with the TV on, watching iPlayer and Netflix and the most important thing in all this, is that I am not allowing myself to feel guilty about any of it. We are a unique family and we must do things differently. We don't compare ourselves to other families at other times, so we aren't comparing ourselves now. It doesn't matter if little Jonny has done 4 hours of schoolwork and that Jane's mum and dad can work full time from home because they've got home-schooling nailed. The truth is that I've been home-schooling our little monkey for 11 weeks now because of issues at her school not related to Coronavirus and what we are experiencing now is not Home Education or Home Schooling. We are all in a period of confinement and when you normally home educate can't do that. It's just not possible.



For families who have two parents working from home, you have to recognise that something has to give. It is best to see if you can both work part time and see if you can schedule your day so that you can both get work done separately. Alternatively, you can do what we do sometimes and stick on their favourite film and both get an hours work done before it descends into chaos. No-one is expecting you to be wonder-woman and superman, it's just not possible. Accept that you will have to work reduced hours and make up a timetable for each day. Start with times that you have meetings and calls that cannot be avoided, things that must be done on sensitive or urgent timescales. Then prioritise what else you need to get done and what can wait.

Use the three baskets or boxes traffic light method.

The smallest one is red, that's the one urgent thing that you need to do that can't wait, no matter what. Then the middle sized one is amber/orange, that's the stuff that you want to get done, but isn't as urgent as the ONE RED THING (okay if it's a conference call or something urgent then you can add two or three, but prioritise them) then once you have half a dozen things in the amber one, everything else goes into the green. If it's not urgent it can wait. Make sure that you put one thing with your child in the amber box, you need to prioritise a bit of time or an activity with them and I don't mean lunch or dinner. Something fun that you will both enjoy. It's important to your mental health that you do this, feeling guilty about not spending time with your kids is a real thing and it eats away at you. It also means that at the end of all this when you look back you will have some happy and fun memories to draw on. Make sure if there are two of you, that you schedule a bit of time for each other and that you keep the lines of communication open, if something is bugging you, or you need a bit of help, then have a phrase where you know instantly that the other person isn't okay and just needs to step out for 5 minutes. In our house I will say to my hubby "I just need to step away" and he knows instantly that I need him to take over the kids and give me a few minutes to process my feelings, work through my thoughts and ground myself. I leave the room and do some

deep breathing and empty my mind, then slowly let back in what's happened and how I am going to move forward. Likewise, he will say to me "I need you now" and I know he needs the same. We don't use these phrases at any other time, which is why it works. We have a home office because of my degree (and sofa bed for family to come and provide respite overnight for us; as well as to spend time as a family) as we don't have visitors and L has to work from home, we have set up a three-person office, where we all have our own space and this includes a little workstation for our mainstream daughter to give her a space to do work if she wants. She likes feeling like a grown up. This also gives her space from her sister, they are not used to being around each



other all the time. We have a baby gate in the hall to allow T safe space in her room to play and be away from M. It has become apparent over the last two weeks that what people are struggling with, is time to themselves and space to be apart. It is hard having everyone at home and for us creating spaces for them to be together and apart has been ideal. We are forever evolving in this situation and trying to make the most of it. We are sorting out our adult bikes this weekend as mine has a puncture, so that we can go cycling as it's a great way to get some fresh air and practice social distancing safely. We have a Weehoo turbo trailer for T and she loves it. We are making window decorations and painting lots of things. We've



printed out colouring pages to paint so that the girls can have more inspiration and variety. There is a lovely artist called Flossie Hunt who is creating a special range of sketches to colour, the series is called Crayonavirus and they are beautiful. If you email her she will add you the mailing list and send you out each set of illustrations as they're ready. Her Facebook page is Flossie Hunt Illustrations and her website is:

<https://www.flossiehuntillustration.com/crayonavirus>

Often T doesn't want to colour as she finds it difficult, but she will sit and pick the colours for me and tell me which bits to colour. It's a great way to share an activity. We've been enjoying Kai & kids Sing-along show on Facebook which is live at 10am every weekday, they are professional entertainers and he is a brilliant ventriloquist. Our girls are enjoying it so much, they sat yesterday and played their ukuleles (badly) as they sang along. We have also made sure there are batteries in their kids VTech cameras so they can have fun and explore. We have had them in the



kitchen taking it in turns to help with cooking and baking. It doesn't matter how the food turns out, it's the time together and the experience that is important. If my kids come out of this with extra skills, then that's a bonus. We have had to accept that we can't do things like other families do. That our needs are very different and that we need to be realistic in our expectations. So L and I sat down whilst the kids were asleep a few days ago and talked about what we hoped to achieve from this

self-isolation period and what we will do going forwards, as the reality is, that we are likely to be in this situation for many weeks. We agreed that an academic education isn't a priority at all. That our aim for M ending mainstream is to simply retain all the knowledge she has learnt thus far, and that the greatest thing we can educate her in is life skills:

- ◆ conflict resolution - we all need to be able to have this skill
- ◆ caring for animals and other people - we have two cats and she has a tropical fish tank
- ◆ confidence and projection - through video diary and FaceTime with family and friends
- ◆ tolerance for others - again, something we all want to work on
- ◆ understanding the situation - to teach them that this isn't normal, but it is part of history.
- ◆ reinforcing the importance of good hygiene and why we are spending time inside (I know a lot of families have children who can't understand this, but that's where visuals come in)
- ◆ flexibility and taking turns - we have got games from peaceable Kingdom which are cooperative games, it's about achieving an objective instead of having one-person win. We especially love Bedtime Bunny, one which is aimed at age 2+ and can be played by the kids on their own.

To help M feel better, we have also made some fabric face masks as they love playing doctors. We have a proper doctors set up with a stethoscope, sats finger monitor and eye pen torch so that when the girls are in hospital they're familiar with the equipment and don't get anxious. When we have been out before, they've noticed people wearing face masks and they've seen them on TV. So we got out the sewing machine and made some that are fully working and washable. They like pretending to be doctors and now if we had to go out, or someone had to come round, it's easy, because they're safe and it's reassuring for them in a positive way. It generates so much interest on their video diary, that we've been asked to make some for a friend who is a community midwife. We've sent some to elderly family members and M really feels like she's helping and making a difference. It all bolsters her mental health, as she is so fragile and we worried how she would cope with such a drastic change in circumstances. We have worked on a lot of sensory integration across the house. We have sheets and blankets (and pegs) for den building and we are also using pegs and ribbon to display our artwork around the house and have somewhere for all the pictures to dry. It's also visually stimulating. We've made dough using hair conditioner and cornflour, we've made bubble baths and water play, a fun activity. We've got chalk sticks out for the garden, lots of balls and bubbles too. We've got a light projector in T's room with dark curtains that allows us to have a quite space to relax. I have a kids meditation audiobook with relaxing music through audible, who have actually released a lot of kids audiobooks for free lately. Great if your child has visual problems and it is also quite relaxing. We have ordered glass painting window decorations and are currently in the process of making a hanging mobile from them. As

they are plastic and you just put paint on, its perfect for kids with little or poor motor skills and looks great when it's dry. We've got an old clothes rail and put all the dressing up stuff on it, so it's easier to see what they have and for them to play with. We are spending more time playing with the children. We tried the Lego challenge, but that didn't work for us, instead we made a Lego city mixing normal Lego with Duplo. Most importantly we recognise that this is hard for everyone. The kids are struggling but the more we get anxious about it the more they seem to pick up on it. So, we have taken a step back. L's work are aware of our situation and are grateful for him being able to do work from home. But he steps away when I need him to help and we have found a way to make it work. Communication for us has been key. If the kids don't understand, we find a way of showing them, we mirror the behaviour we want them to have and we concentrate on keeping calm and reminding everyone to have realistic goals and expectations of each other. I remind the children that I am only one person and that sometimes they may have to wait, or I may have to say no and reassure them that we are doing the best we can. I remind them that the prime minister and government have told us we have to stay at home and that it's not our fault and that we don't want them to get sick and poorly. We have family speaking to them telling them stories of what they have been up to and reassuring them that they are okay and stuck inside too, it helps the kids to know it's not a punishment and that we are following instructions and that we as adults have to do as we are told sometimes too. Mostly, we do what we can, we do what works for us and we forgive ourselves when it all goes wrong. We can't change what has been, we can't change the situation we find ourselves in, but we can change what we do about it and for us, that's doing things our way. ”

Remember you are not alone and we are all in this together. Do use our Unique network café group on Facebook to chat with other parents. Stay safe, stay strong and remember to stay 2 metres apart from anyone when going outside. Keep washing your hands. We will get through this.





Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
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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
Please help us to help you!

Our thanks to all of our parents that contributed towards this guide. It was compiled by Unique and reviewed by Lisa Bryson, Paediatric registrar, Royal Hospital for Children, Glasgow.

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Version 1 (MM)

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