

Managing uncertainty



**A guide for
individuals and families
affected by rare, complex conditions**

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 as we emerge from lockdown.

Coping with Uncertainty

Do we ever reflect on a challenging situation and think how we coped?

Do we ever give ourselves a pat on the back when we have coped well?

No, we don't, we just get on and do it!

Having a rare condition, or supporting someone you love with a rare condition, puts you in a unique position.

A unique position of knowing and feeling what uncertainty is daily.

The unpredictability of symptoms, how much energy or pain you experience day-to-day, or how you might respond to treatment, are your everyday experiences when living with a rare condition. You may also have longer term worries such as, what happens if you or your loved ones' health declines further. Worries about the future, finances and family relationships are common. You may be anxious about whether your healthcare provider is familiar with your rare condition, or whether your employer will be understanding if you need to take time off work.

COVID-19 has brought another dimension of uncertainty to our lives. Familiar routines and everyday life have changed, and continue to change, almost daily.

Although it might feel overwhelming, remember this is not the first challenge you have faced. You already have a lot of the strengths and skills to get through the current situation.

With the impact of COVID-19, it is important to acknowledge the additional burden of uncertainty and change and the added worries about catching the virus. The impact and unpredictability of shielding or self-isolating, and the disruption to ordinary healthcare routines and treatments can be distressing. This can be emotionally and physically demanding, so we have brought together some top tips and exercises, which we hope will support you through these difficult times.

Managing anxiety

All in the same storm, but not all in the same boat

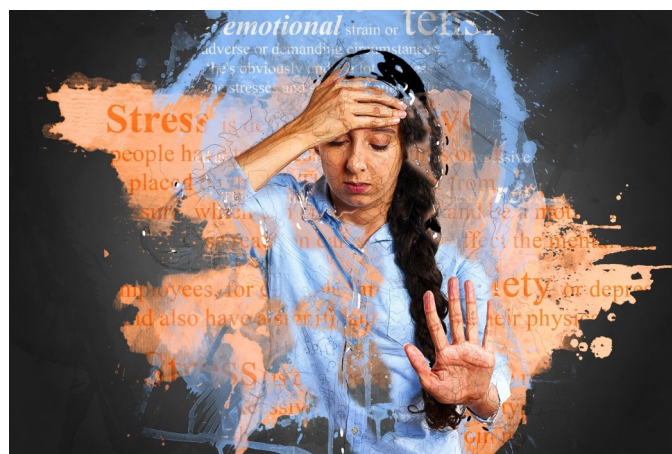
Although we have all experienced the pandemic in our own unique way, we have all shared an experience of enormous change and uncertainty because of COVID-19. This is on top of the uncertainty and challenge of living day-to-day with a rare condition. We know that some groups have been particularly impacted by COVID-19 such as children, the elderly and those within diverse communities.

The phrase '**all in the same storm, but not all in the same boat**' sums up the experience of the pandemic overall.

There has not been 'one' experience of lockdown. You might have felt overwhelmed by all you had to juggle practically and lost support structures or you might have enjoyed a different, gentler pace of life.

You may have lost people you care about without the opportunity to say good-bye; you may have lost supportive family or workplace relationships and routines, or access to your usual social, cultural, or religious community. Financially, you may have been hard hit or not impacted at all.

Whatever your circumstances, we have all had to manage a lot of sudden changes and find ways to adapt very quickly, both practically and emotionally. Even though the easing of restrictions seems like a big step forward, the virus looks likely to be with us for some time. We are all learning ways to cope that work for us, in our own unique way.



Top Tips for Coping with uncertainty

1. Accept that you can't control everything

Acceptance - Coming to terms with this can be one of the most helpful ways of coping with uncertainty. An example might be that you cannot control if certain symptoms flare up, but you might have some control over what might trigger them.

For example having control over your diet, sleep and exercise and being aware of what you need to do to recover more quickly. Having a clear Action Plan (that's made in advance) for when symptoms are more severe can also help you feel more in control. This could involve what you need to do practically, who to call on for support, or how to best manage your day to allow you to recover.

Likewise, you cannot completely eliminate the risk of getting COVID-19 but you can control your conscious choices on how you behave. For example, deciding on the number or type of activities you or your family attend, maintaining social distancing, washing your hands, ventilating your home and other safety measures.

2. Accepting uncertainty

Accepting 'how things are' allows you to become clearer about what you **can** influence and be more in control of, and what you can't.

This often means **acknowledging loss**. This might be about what life used to be like, or how you hoped and imagined it would be in the future. Talking this through with someone can often be an important part of **grieving** for what has been lost.

3. Coping with the worst

We often **overestimate** the likelihood or extent of worst-case scenarios, and **under-estimate** our own ability to cope. This is part of trying to prepare for situations that we feel frightened about.

Talking through anxieties or concerns with people you know and trust can help find a new perspective. Sometimes, talking to a professional might feel easier or more helpful. Depending on the situation, this might be a financial/welfare advisor, a healthcare professional, or a counsellor.

There are some suggestions of organisations that may help at the end of this guide.

4. Identify 'what if' triggers

Ask yourself if there is any **practical** action you can take to address your worry? If not, try talking about how you feel, with someone you trust. You could also try one of the 'worry exercises' in this guide.

If you find that worrying is triggered by a particular activity, for example engaging in social media, newsfeeds, or around other people who are themselves very anxious, consider taking a break until you feel less anxious.

5. Stick to routines

If possible, stick to routines, this can help us feel more safe and secure. Having different routines for different experiences can be helpful. For example, routines for days spent at home working/schooling, at bedtime, mealtimes, for hospital visits etc.

6. Stay in the present

Much of our anxiety is about what the future holds and involves worrying about things that have not yet happened or might never happen. Even when they do, we often cope better than we first feared.

Learning a technique like Mindfulness can help. This works by helping you focus more on the **here and now**, so you can bring your full attention to what matters now and then you can deal with the next thing in due course.

7. Be kind to yourself

When we are worried or anxious, we often behave in ways we don't feel good about. This might be snapping at a loved one, or not doing something in the way we would hope. We can then be very self-critical.

If you catch yourself being self-critical, counter every negative thought with a positive one. Sometimes, being kind to yourself simply means acknowledging all you have had to manage, but that you have kept going despite everything.

8. Talk about it

Most difficult experiences are made much more bearable by sharing them, or by talking them through. Difficult situations often feel 'lighter' and easier to manage when we feel listened to and understood.

Talking with friends, family members, your religious community or your rare condition support group may be all the help you need.

If you are still struggling, reach out to a health or social care professional.

Remember: you are not alone!

You and your relationships

If you were living alone during lockdown, there may have been times when you felt lonely or isolated. If you were in lockdown with relatives, friends, or partners it's possible you might have become closer during that time, or found tensions deepen. You might have been separated from family or friends for a long time, or be worried about those living in other countries also badly affected by COVID-19.

Given the additional pressures of living with a health condition, and especially if you also have additional money worries, it's likely that there will have been times when your relationship with a partner or in your household may have been under considerable strain. As lockdown eases, tensions may ease too. If not, it can help to talk things through together with a professional counsellor, or a trusted member of your religious/cultural community.

Different attitudes to lockdown easing, COVID-19 or about vaccinations can cause tensions in families and communities. There are suggestions about how to cope with this in the 'Managing Differences' section.

You and your medical care

Many clinical appointments have been postponed, cancelled, or delayed. You may have been feeling worried, anxious, or frustrated about this. Do let your healthcare professional know if you or your family member feel more unwell or have new symptoms. The NHS is beginning to catch up, but it will inevitably take time for backlogs to be dealt with. It's important not to underestimate how emotionally tiring 'waiting to hear' might feel.

Some appointments will have continued, but this may have been through virtual or telephone consultations instead of face to face. It looks likely that a mix of face to face and virtual appointments will be used in the future.

This might feel a positive change, allowing your care to continue without the need to travel. However, seeing your doctor or nurse in person, and travelling to the hospital itself, might also be important to you in feeling reassured and well looked after. Remember that you can always talk to your healthcare professional about what sort of appointment you would prefer and see what is possible and appropriate for you.

You and your emotional health

One of the aspects of the pandemic that has been challenging for our mental wellbeing is the degree of uncertainty over how long it would go on for, and what the implications might be for our health, jobs, finances, homes, families, and way of life. Although the degree of uncertainty we are living with may reduce, it is likely that it will continue for some time. This will be in addition to living with the more familiar, but no fewer frustrating uncertainties, of rare conditions. So, what might help?

Focus on what you can control, not what you can't.

Practice looking after yourself - such as eating healthily, exercising, not drinking alcohol, drinking enough water, and getting enough sleep.

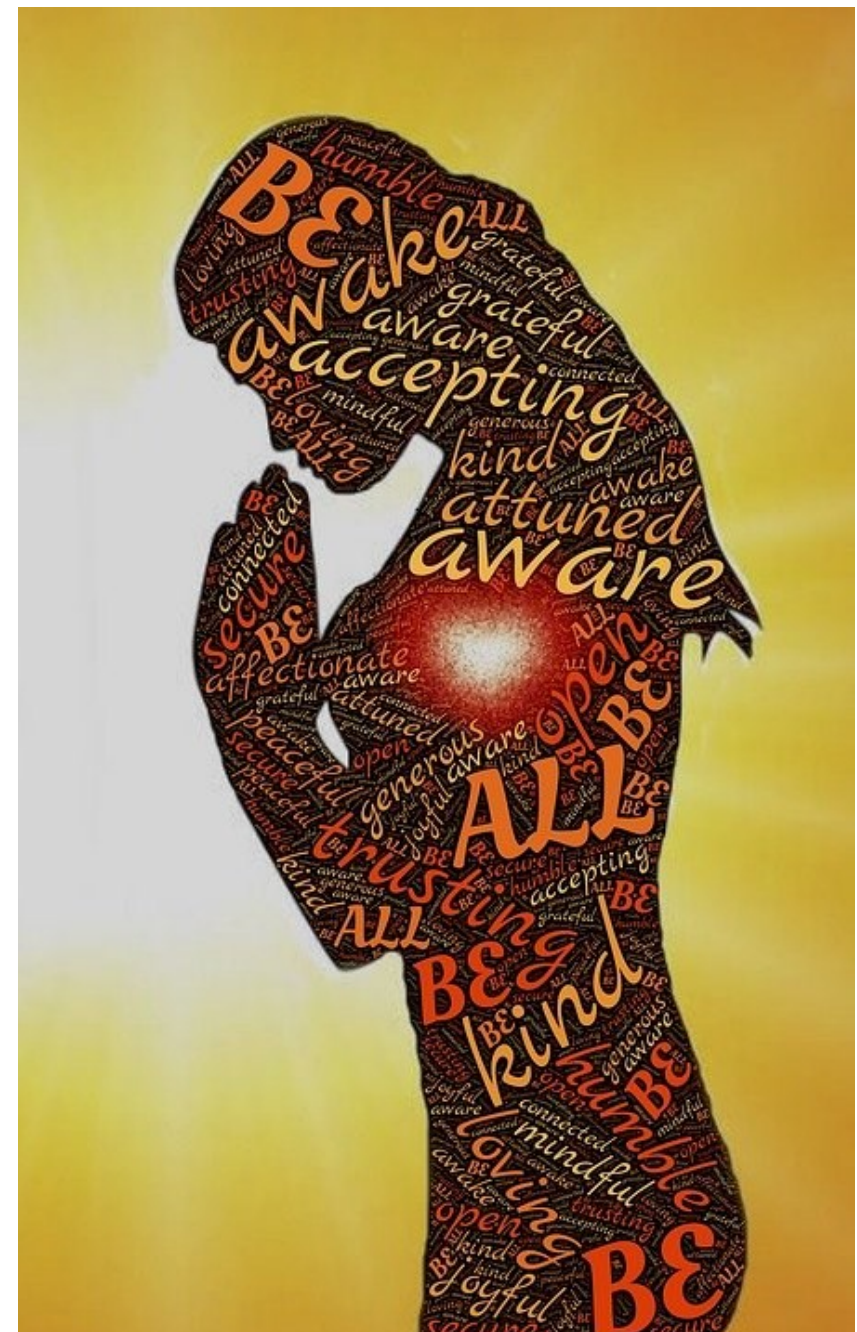
Make deliberate choices day-to-day. Some days you may only have enough energy to get through the day, so make a choice to 'let go' of some things. For example, cook an easy meal or get a take-away; have a rest rather than tidy up.

Learn a technique like Mindfulness using free App's like Insight Timer <https://insighttimer.com/>



Top Tips as lockdown eases

- 1. Take your time** – If you are nervous or worried about meeting with others again, take things slowly and build up your confidence gradually. It can be helpful, to plan ahead. For example, you might not feel comfortable meeting a large group of friends, but it might feel more doable to meet outside with one or two.
- 2. Don't avoid things completely** - Although you may feel worried about engaging with people or taking part in some activities, it is also important not to avoid taking part completely. If certain activities feel too hard, try breaking them down into smaller more manageable steps, for example, meeting for a short period of time. You could also let someone you trust know, so that they can support you through this.
- 3. Stay connected** - Many patient organisations host online forums or groups. These can be very helpful and supportive, by talking and sharing with others going through similar experiences. Connecting with nature, green spaces, and the natural world can also be important for wellbeing. This might be as simple as enjoying a breeze from an open window, caring for a small plant, or taking a trip outside to a nearby park or garden.
- 4. Managing difficult thoughts and feelings** - Talking to someone you trust often helps difficult thoughts and feelings feel easier to manage. If you don't feel comfortable talking to someone you know, consider other support, such as your rare condition community, local community, religious group, or a professional counsellor. It's important to know you are not alone. There are some suggestions for support services at the end of this article.
- 5. Coping with loss or bereavement** – As it becomes possible to meet up with wider family and friends, you may feel upset about those who you have lost during this time. Talk to your local religious or community leaders about alternative ways of remembering them or undertaking certain rituals that may not have been possible at the time. If you did not have an opportunity to say goodbye, it may be that you could think of other ways to do so now. 'At a Loss' provide details of bereavement services in your local area and 'Cruse' provide lots of advice in coping with grief.
- 6. Talk to your employer** if you need to, as many employers are now offering more flexible working. If you would like to go into your workplace less (or more) or change your role, let them know what might help you and see what might be possible. Even if you haven't disclosed before about either your own health or caring responsibilities, this could be a good time to explore a working pattern that would better suit you or your family.
- 7. Look after yourself** – Practicing self-care is not selfish, it is an important part of looking after yourself. Going through lockdown was emotionally demanding in different ways for everyone and you may have been in 'survival mode' for some time. Start trying to build back in activities and time for your own emotional wellbeing. If your healthcare needs have slipped down the agenda because you have been caring for someone else, take some time to think what might be important for your emotional and physical health at this point.
- 8. Moderate your time on news and social media** as there is a lot of evidence that too much exposure to both can impact negatively on your emotional health. Social media can be an important source of support and connection, but if it starts to leave you feeling anxious or angry it might be time to take a break.
- 9. Congratulate yourself for coping well**, or making positive changes as we are often quick to notice what we are not doing, or 'could do better.' Try to counteract every self-critical comment or thought with one (or two!) positive comments about what you have/ or are managing.
- 10. Be kind to yourself** - Coping with the pandemic and adapting to so much change so quickly has been emotionally exhausting. If you were a key worker, parent/carer or juggling different responsibilities and demands at home, there will have been additional pressures on you. Try to be kind to yourself, and others, as we enter this new phase.



Shielding, or self – isolating?

If you or a family member have decided to continue shielding it might feel hard to see things opening-up again for other people. It can feel difficult and worrying to know what the best thing to do is, particularly if government advice changes.

Moving back into self-isolation again after things have opened can also feel very frustrating and disappointing. Remind yourself that self-isolating will pass and try to re-engage with comforting activities or routines that have helped before.

You might be wondering whether to allow support workers back into your home or allow your child to attend extra external activities or care. If you live with someone self-isolating or shielding, or who is vulnerable, but needs to go out to work or for other reasons, you might feel worried about this too.

Tips for difficult decisions:

- ◆ Talk through your particular circumstances with your healthcare professional
- ◆ Talk things through with someone you trust and who knows you
- ◆ Explore with employers or support services possible options, for example flexible working
- ◆ Use trusted sources for advice and information for example your rare condition charity/support group, NHS etc.
- ◆ Try not to make difficult decisions when you are tired or stressed
- ◆ Take into account both your physical and emotional wellbeing
- ◆ Make a list of the 'pros and cons' of different actions, and reflect
- ◆ Regularly review decisions to see how they are working, or how you feel, for example in a week or months time.



Managing differences

Within families and communities there can be different, and strong, opinions about the pandemic. This might include views on vaccinations, or lockdowns. It can be frustrating and upsetting when people you care about think differently in a way that might impact you or your family's health.

Keep communication open. Sometimes explaining your worries can be enough for someone to behave differently or bear your concerns in mind - even if they don't agree with you, agree to disagree.

Remind yourself that it's ok for people to think or feel differently (including you).

Try to anticipate social situations that you might find challenging. Can you negotiate with others in advance what you are comfortable with? Decide whether to go, and how or when you might leave if you feel too uneasy.

If you don't feel safe in a situation, decide how you will address that. You might quietly leave or move away, at other times you might ask for some help, or for what you need. Try to think ahead.

If things get worse, who might be able to help? Maybe a 'neutral' or respected family member, a community/religious leader, a health or social care professional, a counsellor or mediator?

If arguments keep happening, agreeing to disagree may be an option.

Talking it through with someone you trust, can also help you find a new way of thinking about, or approaching a difficult situation.

It is OK to make decisions that feel right for you and are informed by your healthcare professionals and trusted sources such as your health charity/support group.

Exercises

Exercise: The Worry Jar

This is a helpful technique (for either adults or children) in allowing worries to be put aside for a while, whilst also knowing they are kept 'safe.' It is particularly useful for worries which are about imagined situations, or that have no straightforward solutions.

1. Find a nice bottle, container or jam-jar
2. Decorate it, and label it 'Worry Jar'
3. Whenever you have a 'worry thought', write it on a small piece of paper
4. Fold the paper up, and pop carefully in the jar
5. Once a month, go through the jar and read out your worry notes aloud
6. Throw away any worries that are no longer bothering you, or didn't happen
7. Put back into the jar any worry notes still on your mind to keep it safe for later.



Exercise: Worry Time

1. Choose a day, time and place for 'worrying'. (try not to use your bed, or a favourite chair.)
2. Designate a notebook as a 'Worry Book'
3. When a worry surfaces in the day, write it down. Tell yourself you do not have time to worry properly right now and will do so more effectively when you can give it your full attention later. Close book.
4. Get up and move about, make a cup of tea, take 5 minutes out.
5. Return your focus to the task at hand that was interrupted by worry.
6. At the allocated time, look at your worries one at a time. Decide which to worry about. (if you no longer feel worried you don't need to do this step!) Worry hard.
7. At the end of the overall allotted time, stop. Cross off any worries you no longer feel so concerned about, or feel able to let go. Leave others on as necessary.
8. Close Worry Book.
9. Repeat as needed.

Managing Anxiety - Square breathing

This is a good exercise you can do anywhere to help stay calm .

Imagine a square (close your eyes if you can/want to) Gently exhale.

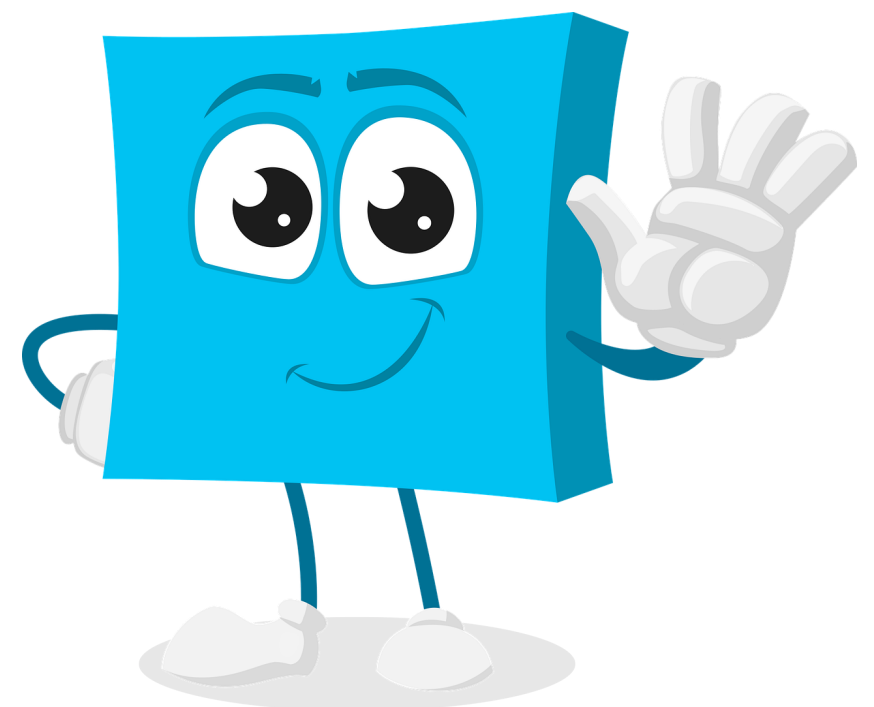
Breathe in to a count of 4 (going up the right hand side of the square)

Pause your breath for a count of 4 (going along the top of the square)

Breathe out to a count of four (coming down the left hand side of the square)

Pause your breath for a count of 4 (along the bottom of the square)

Repeat as often as needed.



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 has a range of online resources, and a helpline 03444 775 774.

MIND 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 bereavement support and advice

BACP is a website listing professionally registered counsellors and psychotherapists by local area 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

Mindfulness Resources

Oxford Mindfulness Centre offer a number of free, short introductory mindfulness exercises and podcasts, as well as longer courses 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.

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

CALM (The Campaign Against Living Miserably) 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

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

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

Gingerbread provides support, advice, and a helpline (0808 802 0925) for single parents in England and Wales 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

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

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

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.