



**University Hospitals  
Bristol and Weston**  
NHS Foundation Trust

Patient information service  
**Bristol Royal Hospital for Children**

# Changes to my child's treatment: What now? Advice for parents



During the Coronavirus (COVID-19) pandemic our hospitals have been working in new and different ways to keep your child safe and to help them access treatments and care. This means they may be offered new types of appointments (for example, telephone or video calls).

In some cases, this may also mean being offered different treatment options and/or treatments at different times (for example, some operations are happening later than planned).

You may have questions about your child's treatment and the impact this could have upon them and their health.

Living with this level of uncertainty can be really difficult, so the psychology team at University Hospitals Bristol and Weston have written this guide to things to try that might help with how you and your child feel. It also tells you where you can get more information or support.

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# **Common reactions to treatment changes during Coronavirus (COVID-19)**

Living through a pandemic is hard. When it has affected or changed your child's medical care, it can feel harder still. You and your child might feel upset or angry about changes to their treatment and disappointed that they may have to miss events they were looking forward to.

It might feel more difficult if they have missed out on stuff already because of being unwell and now Coronavirus is making things trickier. You might be worried about how any changes will affect them, or the impact of any delays on their health.

You may feel concerned about what things might be like when you take your child to hospital for treatments, or if you have to talk to their medical teams in new ways, via virtual appointments, which may feel a bit strange.

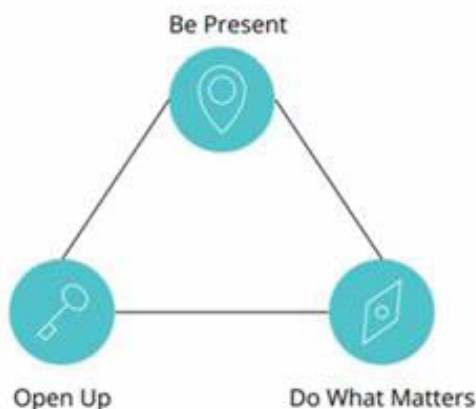
This leaflet has lots of ideas and information that might help you to deal with whatever feelings you and your child may be experiencing.

## **Looking after yourself whilst waiting for treatment**

Coronavirus (COVID-19) has been stressful for lots of people, even more so for young people living with a health condition, or who having or are waiting for medical treatment.

A lot of people, whether they have been shielding or not, have not been able to do the things they usually enjoy or that help them to relax in the same way they are used to (for example, seeing friends). However, it is still important to find ways to take care of yourself and your child, even if these are a little different to normal.

The ideas and skills outlined in this leaflet draw upon evidence-based psychological approaches, using the three principles of **Open Up**, **Be Present** and **Do What Matters**.



Remember that when trying something new it can take a bit of practice before feeling the benefit. Try to be kind to yourself and make any changes one step at a time.

# 1. Open up

## Notice your own thoughts and feelings before speaking to your child

Before you talk to your child about any changes to their treatment that might be happening because of the Coronavirus (Covid-19) pandemic, it is important to get in touch with how you are feeling first. This will help you to hold your child's emotions.

One way of doing this is to use the acronym **A.N.D** as described below. It can feel quite tricky at first, but try to focus on what you are thinking and feeling without getting caught up in the emotion of it:

### Attend

Focus your attention on your breath as you breathe in and out.

### Notice

Notice all of the thoughts, feelings and physical sensations that come with the breath.

Try not to judge whatever comes up, but observe it, as if you were a scientist, curious about the process.

If you get caught up in the thought (which is normal), gently **bring your attention back to the breath.**

### Describe

Write down what you notice, describing what is happening, without judgement.

Remember there is no such thing as a bad emotion. Any feeling is valid and real in the context of what you are experiencing.

Here are some common thoughts you might have about your child's treatment:

**"If only coronavirus hadn't happened."**

**"I feel worried about what is going to happen to my child."**

**"Why is this happening to my child?"**

**"I don't want anything to slow down my child's treatment, I just want it done. It is making me feel anxious."**

You may have similar thoughts, or ones that are completely different, but that is ok. What is important is learning to notice the type of thoughts that are popping up.

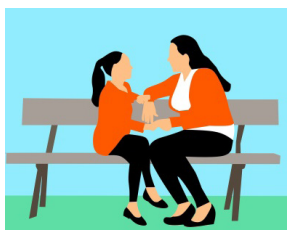
What we are trying to do is practice observing thoughts rather than being in the thoughts. When we are in our thoughts it can feel like we are swimming in a stormy sea, being overwhelmed by wave after wave of uncomfortable thoughts, feelings and sensations.

But when we are able to stand back and observe our thoughts, it is as if we are in a boat, sitting above the waves and we are able to ride them out.

We can unhook from them and view them more objectively.

## **Talking to your child about treatment changes**

Once you have identified how you are feeling about the changes, it may be useful to talk to your child about it too, dependent on their age, and whether they already knew about the treatment.



How we talk to our children will impact on how they feel about things and how they make sense of this difficult time.

## **Children's understanding will depend on their age**

**4 to 7 years:** Children of this age have limited understanding of illness, so they may fill in the blanks with inaccurate information.

Keep language simple and avoid complex explanations. Using play, teddies or stories can support understanding. Check what they have understood and give opportunity to ask questions.

**8 to 12 years:** Middle aged children will have better understanding of illness and can consider consequences. They may have more questions about what might happen.

Using stories, play, drawing or other activities can support conversations about feelings, and open up opportunities for asking questions.

**13+:** Adolescents may worry more about the impact of these changes on themselves and others, for example they may be worried about worrying you.

Offering a space for support and discussion will allow them to share these feelings, but try to let them take the lead.

Do not force them to talk about it if they do not want to, but let them know you are always available if they would like to.

## **Supporting children to open up**

### **Be creative**

Children often find it easier to open up when doing an activity side by side rather than through face to face direct eye contact as it can make them feel safer to express themselves. Think about the setting when you are planning to talk to your child about treatment.



Try talking to them whilst doing craft, games, drawing, bath time, story time or when out for a walk or a drive.

### **Stick to the facts**

Explain in simple language what has happened, and why. Then explain what the new plan is (if you know it).

For example:

**“Do you remember you were going to have an operation next month? Well, the operation is not going to happen then because of Coronavirus. We are not sure when it will happen, but the doctors at the hospital will let us know.”**

### **Name the feelings**

Help your child to name what they are feeling. Emojis (such as the ones in the picture) or books about feelings may help younger children to help identify their emotions.

For example:

**“Some children may feel happy the operation isn’t happening, whilst others may be worried. How do you feel about it?”**



## **Normalise the feelings**

Reassure your child that whatever they are feeling it is ok to feel that way, whether it be scared, angry, relieved, confused or any other emotion.

Sometimes children may think that things have changed because they have done something wrong. Reassure your child that this is not the case, and Coronavirus has impacted on all aspects of life.

## **Be honest with your child**

It is ok to let your child know how you are feeling too. For example, if you are disappointed, tell your child, as this will enable them to express their own feelings.

For example:

**“I also feel sad that the operation isn’t going to happen as planned. It is ok to feel sad.”**

## **Check understanding**

Allow your child to take in the information and then check their understanding about what you have told them. This is especially important with younger children.

Be curious about how your child is making sense of the situation and add information or correct misunderstandings if necessary.

# How your child might react



Children as young as infants can be affected by changes in their routine or to their treatment.

Children often show stress through changes in behaviour or through going back to earlier patterns. For example,

younger children may become clingier, more irritable, angry, tearful, or restless.

Older children may go quiet and withdraw. Some children may experience stress as physical symptoms (for example, headache, stomach-ache, nausea).

You know your child best so note any changes that occur and help your child to express their feelings in a safe way.

You may also find that your child can be upset one minute and perfectly fine the next. Although this can be hard to understand as adults, this is completely normal for children and is typical of how they process information.

## Helping your child to manage and express their feelings

Once you and your child have become aware of your thoughts and feelings, it is important to give them space and allow them to surface, rather than bottle them up or ignore them.

Keeping feelings in is like trying to constantly hold an enormous inflatable beach ball under the water. It keeps popping up in front of our faces however hard we try.

However, we can allow the ball to float around us, just letting it be. So rather than suppressing difficult feelings or thoughts, we can stop fighting them, and let them be, without reacting to them.

## **Create space**

Allowing your child opportunities to open up about their feelings by giving them time to play and engaging with them on their level will make them feel safe and reassured.

Allow your child to ask questions and don't be surprised if these pop up at unusual times, like in the car or during bath time.

Remember, you don't have to have all the answers. If you don't know, be honest with your child about what is happening and say you don't know but will find out by speaking to the healthcare team.

## **Be creative**

There are various ways to help you and your child express their emotions, which are as individual as they are!

Some people like to talk to about their feelings, whilst older children may prefer to keep a journal or diary or write poems.

Encourage release of feelings through creative outlets such as role play with dolls/action figures, art and craft, dancing or listening to music.

If you or your child are feeling frustrated, irritable or angry, physical expression is a good way to release tension. Try ripping up or scrunching some paper and throwing it at a wall. Kick or throw a ball with feeling.

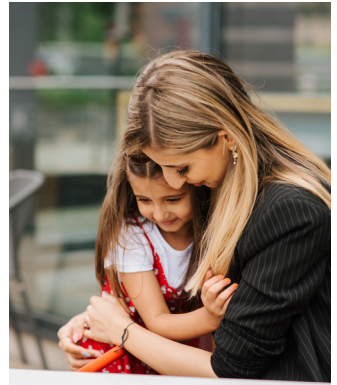
If you or your child are able to, go for a jog, bike ride, or do any other type of sport. Singing and shouting can also help to release pent up feelings.

## **Model ways to cope**

Children look to others, especially parents to learn how to deal with difficult feelings, so it can be helpful to model effective ways of coping.

Let them know it is ok to cry about changes to treatment, and it is also ok to feel angry, but then show them how to express these feelings in safe ways.

For instance, "Sometimes crying and a cuddle helps me feel a little better. I also find talking helps. Do you want to sit together and talk for a while? I am here for you whenever you need me."



## **Help your child to use their imagination**

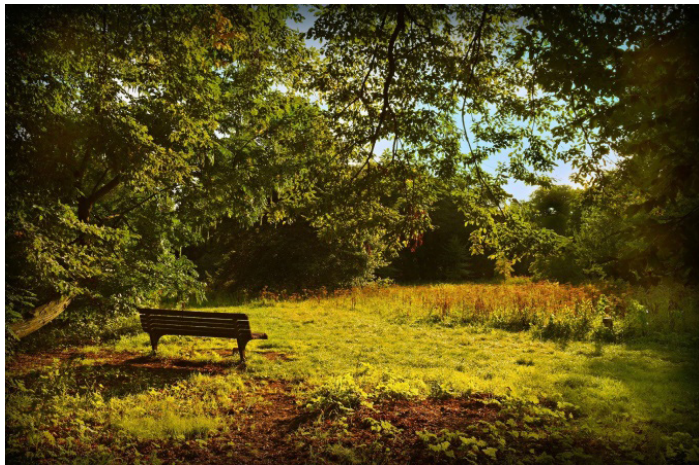
Children often have very vivid imaginations so it can be helpful to harness this to help them feel more relaxed and create a sense of calm in the face of uncertainty about treatment.

Sit or lie somewhere comfortable. Close your eyes. Imagine somewhere you feel calm, peaceful and safe.

It may be somewhere you have been before, or somewhere you would like to visit. You may have seen it in a film or a picture, or it may be something from your imagination.

- Focus on what you can see all around you. Any colours, shapes, light, movement or texture.
- Notice any sounds you can hear.
- Think about any smells you notice.
- What can you feel? For instance the breeze, the sun, the ground beneath you.
- What word or phrase reminds you of this place?
- You can visit this place any time you want to by saying the cue word.

For younger children, it can be helpful to get them to draw their peaceful place out on a piece of paper. They can then put it by their bed and think about their safe place before they go to sleep.



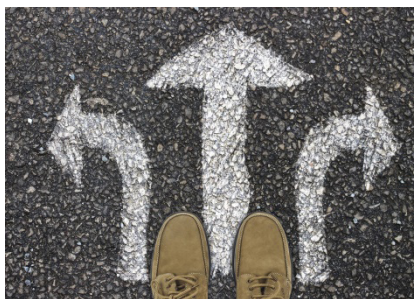
## 2. Be present

Finding ways to stay connected to the present moment, rather than worrying about what might happen in the future, can help us to manage uncertain situations over which we feel we have little or no control, like when your child's medical treatment changes.

### Helping you and your child manage uncertainty

Living with uncertainty can be tricky!

When faced with situations which seem uncertain, such as changes to your child's treatment, we often use worry as a way to cope to try to predict what is going to happen in the future.



However, worry about things we cannot solve does not change or stop things happening in the future and worry might actually make you feel worse and unable to cope.

We know it is difficult not to worry, but here are some suggestions of alternative, and hopefully, more helpful ways to help you and your child to manage the difficult thoughts and feelings.

### Look at the most probable scenario

Our brain finds it hard to differentiate possible danger from probable danger. It would rather warn us of all possible dangers to keep us safe, rather than the ones that are most likely.

For example, you might have the thought:

**“What if my child’s treatment gets worse and they can’t get the treatment they need?”**

When you notice yourself focussing on all possible dangers (known as catastrophising), make a mental note in your mind:

**“I am thinking of the worst case but I do not know it will happen, what is the best case?”**

Then, try thinking through what would be **most likely to happen**. Or, try to notice all the other possibilities your mind is not thinking of.

For example:

**“My child’s medical team will make sure they get treatment.”**

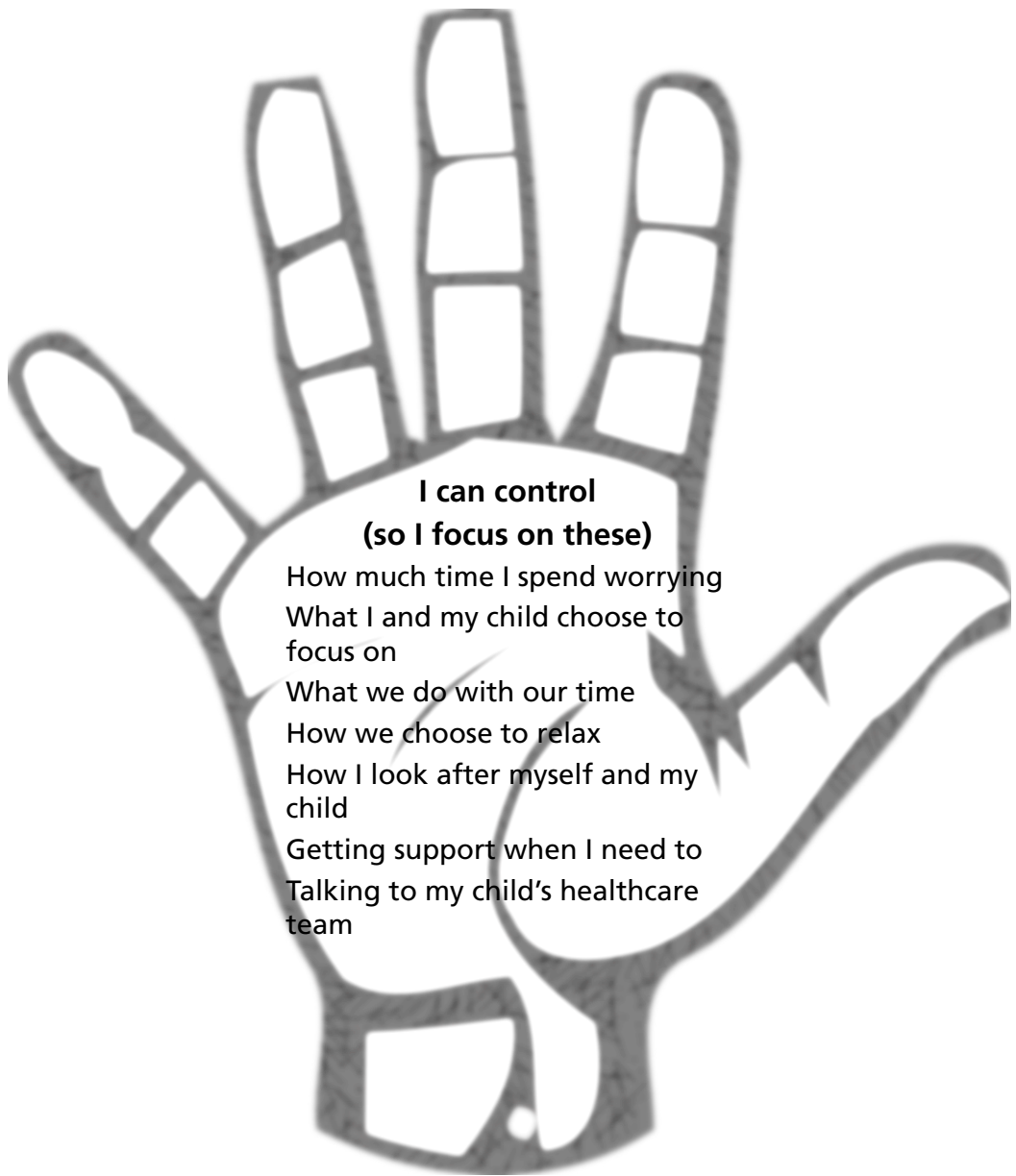
By focussing on the most likely possibilities, rather than the catastrophic ones, we can avoid getting drawn into an unhelpful spiral of worry and “what if” thinking.

## **Focus on what you can control**

Understanding what we can and cannot control is important. When we focus on things we cannot control, such as your child’s treatment, we may feel worried and overwhelmed. If we focus on what we can control, this can help us feel calmer and less anxious.

Think about what you can and cannot control in relation to your child’s treatment. The diagram overleaf has some suggestions but feel free to add your own.





**I can control  
(so I focus on these)**

How much time I spend worrying  
What I and my child choose to  
focus on  
What we do with our time  
How we choose to relax  
How I look after myself and my  
child  
Getting support when I need to  
Talking to my child's healthcare  
team

**I cannot control (so I let go of these)**

My child's treatment  
Other people & their actions  
COVID-19 restrictions  
How long COVID-19 will last  
What is going to happen in the future

## **Living alongside worry using mindfulness**

Mindfulness is a technique that teaches us to sit alongside our worries rather than trying to fix them.

It teaches us to notice what is happening in the present moment, rather than worrying about the past ('if only Coronavirus hadn't happened...') or future ('what if my child's treatment keeps getting delayed?').

Mindfulness can help us to feel more self-aware and in control of thoughts and feelings and it is something you can do yourself as well as with your child.

Mindfulness is essentially training our mind to pay attention, without judging.

We like to think of it like training a puppy to sit, our brain is an untrained puppy, jumping all over the place. But with practice, the puppy can learn to sit and rest, until it becomes second nature (although the puppy will still run off from time to time!).

### **How can I try mindfulness?**

There are lots of apps that can help you to give mindfulness a try, such as Headspace or Calm.

Smiling Mind is a brilliant app that has lots of short mindfulness exercises for children of all ages, including ones narrated by LEGO Movie characters! There are also lots of mindfulness exercises on YouTube.

You and your child can also be mindful whilst doing any activity, like walking, cleaning your teeth or cooking by engaging all your senses fully in what you are doing. This can help take your mind off any worries about treatment and bring you back to the present moment.

## Mindful breathing exercise

Below is a mindfulness exercise you can try with your child.

Take a snow globe and shake it up.

Tell your child, "The snow is like your thoughts when you are stressed or worried. See how it whirls around and makes it really hard to see clearly?"

"Now watch what happens when we leave the jar still for a couple of moments. See how the snow starts to settle and the water clears."



"Your mind works the same way. When you are calm for a little while, your thoughts start to settle and you see things much clearer."

Sit or lie somewhere comfortable and peaceful. Ask your child to place a hand on their tummy and imagine they can smell something nice (like hot chocolate or flowers).

Ask them to breathe it in through their nose, then to breathe out slowly as if they were slowly blowing a big bubble.

Repeat this several times.

Encourage your child to focus on their tummy rising and falling with each breath. You can also say "relax" with each out breath to imagine the tension draining from your body.

## 5-4-3-2-1 technique

One tip to help you and your child be more mindful and bring you back to the present moment is to use your senses (sight, touch, sound, smell, taste) with the 5-4-3-2-1 technique.

It might feel a little unusual at first but stick at it, as it should feel easier the more you try.

**5**

Take a few moments to look around and notice five things that you can see.



**4**

Notice four things that you can feel with your body. For example, the ground, the chair, clothes, air.



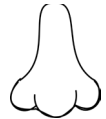
**3**

Become aware of three things that you can hear. (You may want to label these in your head).



**4**

Notice two things that you can smell. Do not worry if you find this difficult, the attempt to do this is helpful in itself.



**1**

Finally, focus on one thing that you can taste. For example, whatever taste is currently in your mouth (which might be subtle) or maybe take a sip of water or have a mint.



### 3. Do what matters

When facing stress, such as that caused by delays or uncertainty about your child's treatment, we may stop doing things that are important to us as we get caught up in the worry.

The restrictions imposed due to Coronavirus (COVID-19) can limit us further and prevent us from connecting to people and things that help us in the here and now.

However, in the face of such uncertainty and changes to our routine, it is more important than ever that we and our children make time to do the things that matter to us and that give us a sense of purpose and fulfilment.

#### Try to stick to a routine

Daily routines have changed for many families because of steps taken to prevent the spread of Coronavirus (COVID-19).

It can be easy and understandable to feel overwhelmed and disorientated when our usual routine has been disrupted. Try to take things one day at a time.

Children and grown-ups thrive on predictable routines, even if they're just 'for now.' Together with your child, write a daily schedule (giving children choices when possible) and post it where everyone can see.

Remind children that they are an important part of the family team, and include some age-appropriate responsibilities such as picking up toys, feeding pets, or helping you sort laundry.



## Connect to what you care about

Spend some time with your child thinking about what matters to you both, for instance, what you enjoy and what gives you meaning.

Think about how you can connect with and engage in those things each day. Invite your child to join in things that interest them, even if it's just for a few minutes. This might take some creativity with Coronavirus (Covid-19) restrictions, but if you can figure out what it is that you really value in an activity, it becomes easier to think of other possibilities.

Perhaps you are already doing things, such as video calling family and friends, or having virtual playdates. Think about why this is meaningful to you; for instance, connection with others by talking to them, caring for others by checking in with them, having fun by laughing together.

Listening to music or an audiobook together can have different meanings. For example, it can provide pleasure by doing something that you enjoy, curiosity to explore new artists or authors, and mindfulness by being present with the here and now.



Going outside to have a scavenger hunt can help you and your child to connect to nature. You can try to find different leaves, flowers or 'mini beasts'. Being outdoors in nature, walking and focusing on small details gets you and them engaged in the present moment and this in turn invites calm.

It may feel hard but try to bring joy to your and your child's day through humour, fun and silliness. Now is a great time to escape through making up silly stories, dancing around the kitchen and playing fun games to counteract worry about treatment.

With your child, try to think of one thing each day that you are thankful for, despite the challenges. If this feels too hard, then that is ok, you can only do what you can do. Recognise that things are difficult right now and give yourself some kindness.

## **Be kind to yourself**

### **Self-care**

Being kind to yourself means ensuring you are looking after yourself and your child physically. Eating well, sleeping well and staying as active as you can.

#### **Eat well**

It can be hard to stick to usual eating patterns when you are stressed, but what you and your child eat can affect how you both feel.

Eating regular meals and making sure they are mostly healthy (with the occasional treat!) will help your body to feel as strong and well as it can.

Try to avoid alcohol, caffeine and sugary drinks.

#### **Sleep well**

Feeling worried can affect how well you sleep; but lack of sleep in turn can also make you feel low.

Try to keep bedtime for your child the same if at all possible, maybe choosing one lullaby or story they can look forward to every night, which can give children a sense of control and help them to feel safe.

Ensure the bedroom is dark and cool, and free from phones, tv's and tablets.

Parents should avoid caffeine and alcohol before bed as it can affect quality of sleep.

Apps like Sleepio can be helpful, as can doing mindfulness and breathing exercises.

## **Stay active**

Being active is as important for your and your child's mental wellbeing as it is for your physical health. Physical activity releases hormones that lift mood, provide energy and release pent-up stress and anger.

If you're able to, go for a walk, jog or bike ride, or do an online workout at home with your child (e.g. PE with Joe Wicks). Try to both move about regularly to avoid long periods of sitting.

## **Self-compassion**

It is important whilst going through difficult times, to be kind to yourself and give yourself some compassion. Self-compassion is about recognising and opening up to our own and others distress and then making a commitment to do something to help ease it.

We can often be our own worst critics, especially in times of stress or when trying something new. Try giving yourself kindness and understanding – what you are going through is hard. Imagine what you would say to a friend who was going through a similar situation with their child.



Think about tone of voice, the words you would use or the encouragement you might give. Then, gently lay a hand on your heart and send into your body a sense of warmth, kindness and caring.



The ideas mentioned in this leaflet all take practice. It is about trying things out, finding what works for you and then making a commitment to put these things into practice in small steps. Be gentle with yourself.

The principles outlined in this leaflet are drawn from an evidence-based psychological approach called Acceptance and Commitment Therapy (ACT). If you would like to find out more about ACT, go to this link or scan the QR code:  
<https://contextualscience.org/act>



## **If you need further support**

If you, or someone you support, are a patient of University Hospitals Bristol and Weston NHS Foundation Trust, you can enquire about additional psychological support by contacting your clinical team.

You can also access our wellbeing toolkits with advice about how to navigate wellbeing alongside a health condition:

<http://www.uhbristol.nhs.uk/patients-and-visitors/support-for-patients/psychological-health-services/resources/>



You may also want to access general mental health or emotional support if you are struggling to cope:

- Samaritans free 24/7 helpline on: 116 123 or email: [jo@samaritans.org](mailto:jo@samaritans.org)
- Mind Bristol – free helpline, open 7 nights per week, 7-11pm on: 0808 808 0330; or during office hours on 0117 980 0370 or email: [info@bristolmind.org.uk](mailto:info@bristolmind.org.uk)
- Shout: access a 24/7 text service by texting 'SHOUT' to 85258

## **If you feel in crisis or at risk of immediate harm:**

- Call 999 or attend A&E
- Bristol Crisis number: 0300 555 0334
- Weston Coronavirus (COVID-19) support line – 0300 3031320 (8am to 10pm) for people with psychological distress in the context of Coronavirus (COVID-19).
- Weston Intensive Support Team: 01934 836497
- Contact your local GP, if appropriate

## Notes

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research.  
To find out more please visit: **[www.uhbw.nhs.uk](http://www.uhbw.nhs.uk)**

Help us prevent the spread of infection in hospital. Please make sure your hands are clean. Wash and dry them thoroughly/use the gel provided. If you have been unwell in the last 48 hours please consider whether your visit is essential.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact  
**NHS Smokefree on 0300 123 1044.**

Drinkline is the national alcohol helpline. If you're worried about your own or someone else's drinking, you can call this free helpline in complete confidence.  
**Drinkline on 0300 123 1110.**

For access all patient leaflets and information please go to the following address:  
**<http://foi.avon.nhs.uk/>**

**Bristol switchboard: 0117 923 0000**  
**Weston switchboard: 01934 636 363**  
**[www.uhbw.nhs.uk](http://www.uhbw.nhs.uk)**



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print or PDF format, please email [patientleaflets@uhbw.nhs.uk](mailto:patientleaflets@uhbw.nhs.uk).

