



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

Patient information service  
**Psychological Health Services**

# Changes to my treatment: What now?



During the Coronavirus (COVID-19) pandemic our hospitals and services have been working in new and different ways to keep you safe and to support you to access treatments and care.

This means you may be offered new types of appointments or ways to access care (for example, video consultations). 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 treatment and the impact this could have upon you and your health. Living with this level of uncertainty can be really difficult, so Psychological Health Services at University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) have written this guide to things to try that might help with how you feel. It also tells you where you can get more information or support.

# Contents

Common reactions	4
Looking after yourself whilst waiting for treatment	4
<b>1. Open up</b>	<b>6</b>
Notice thoughts and feelings	6
Become an observer	7
Unhook from our thoughts	8
Allow thoughts and feelings	9
Expand the mind	10
<b>2. Be present</b>	<b>11</b>
Managing uncertainty	11
Look at probable scenarios	11
Focus on what you can control	12
Use a worry tree	14
Living alongside worry using mindfulness	16
<b>3. Do what matters</b>	<b>18</b>
Connect to what you care about	18
Be kind to yourself	19
Self-compassion	

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

Living through a pandemic is hard. When it has affected or changed your medical care or treatment, it can feel harder still.

Common reactions may include feeling upset or angry about changes to your treatment and disappointed that you may have to miss events you were looking forward to. You might be worried about how these changes will affect you, or the impact of any delays on you and your health.

You may feel concerned about what things might be like when you come into the hospital for treatments, or if you have to talk to your medical teams in new ways, via virtual appointments, which can take time to get used to.

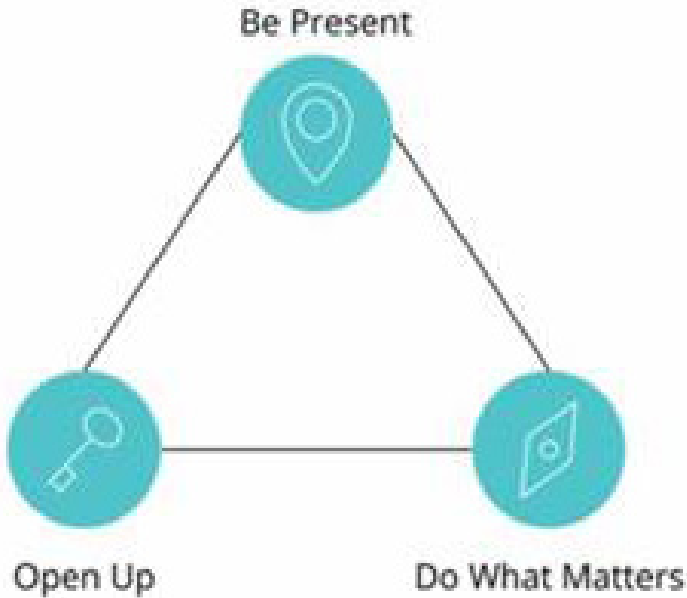
This leaflet has lots of ideas and information that might help you to deal with whatever feelings you may be experiencing.

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

Coronavirus (COVID-19) has been stressful for lots of people, even more so for people living with a health condition, or who are going through, 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, eating at a restaurant, seeing friends). However, it is still important to find ways to take care of yourself, 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 thoughts and feelings

One of the first and most important things you can do is to become aware of what your mind is thinking and feeling (this can be words or pictures) without letting emotions take over. If you are not used to doing this, it can feel quite tricky at first, but the acronym **A.N.D** can help.

### 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 examples of common thoughts and feelings around changes to treatment:

**“I feel worried about what is going to happen ”**

**“I would like answers from my healthcare team”**

**“I don’t want anything to slow down my treatment, I just want to get it done. It is making me feel restless”**

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.

## **Become an observer**

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.

All of us have this observer-part of our mind, but it can be tricky to engage, and our mind will almost certainly try to hook us back into the swirling sea of difficult thoughts and feelings.

However, there are several techniques we can try to help us get unhooked.

## Unhook from our thoughts

When we get hooked by thoughts they seem completely true, important, scary and taking all of our attention, which can have an enormous influence over how we feel and what we do.

It can be helpful to recognise that our thoughts are **not** facts. They are nothing more than a stream of words, sounds and pictures that come and go, a bit like radio chatter. We do not have to buy into this chatter, or believe what it tells us. We can choose to step back from it and lessen the power it has over us.

Unhooking strategy	Example
Let your thoughts come and go.	Imagine your thought on a cloud passing across the sky or on a leaf bobbing down a stream.
Become aware of the thought.	"I am aware I am having the thought that..."
Notice what your mind is doing right now.	"There goes my my mind, worrying again! Always thinking the worst!"
Feign interest.	"There's an interesting thought."
Thank the mind.	"Thanks mind, but I am actually spending time with my friends now."
Imagine the thought in a different voice.	Say the thought in a silly voice, or in the voice of a TV, film or cartoon character. You could even sing the thought out loud!
Alter the speed of the thought.	Slow it down. Speed it up. Repeat it over and over.



Unhooking strategy	Example
Imagine the thought on a computer screen, like email in an inbox. The words are there but we do not have to read them.	Change the font colour and format. Animate the words. Add in a bouncing ball.
Recognise the fleeting nature of thoughts.	This will pass.

## Allow thoughts and feelings

Once you 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 try to ignore them.

It's like trying to constantly hold an enormous inflatable beach ball under the water, but it keeps popping up in front of our faces. However, we can allow the ball to float around us, just letting it be. So rather than stop the thoughts, we can stop fighting them, and let them be, without reacting to them.

There are various ways to do this, which are as individual as you! Some people like to talk about their feelings whilst others prefer to keep a journal or diary.

Others may release emotions in creative ways through doodling, drawing, painting, writing poetry, songs, or music.

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

With everything going on right now, it is completely normal to feel overwhelmed, sad and tearful. Do try to be kind to yourself, this is a very difficult situation, and, if you feel like crying, that's ok. Releasing sadness in this way can actually feel nice too, and a bit of relief if we have been holding our feelings in.

## **Expand the mind**

Using our imagination can help us to feel more relaxed and create a sense of calm in the face of uncertainty about treatment.

## **Peaceful place imagery**

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.

Spend time immersing yourself in this peaceful place.

- 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.
- Bring your mind to any skin sensations you can feel in your peaceful place. The earth beneath you, the movement of air, the temperature.
- Think of a word or phrase you can call this place to help you bring the image back any time you need to.



## **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 our medical treatment changes.

### **Managing uncertainty**

Living with uncertainty can be tricky! When faced with situations which seem uncertain, we often use worry as a coping strategy to try to predict what is going to happen in the future.

However, worry about things we cannot solve, such as changes to treatment, does not alter or prevent future outcomes and may lead you to 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 manage the difficult thoughts and feelings.

## Look at probable scenarios

Our brain finds it hard to tell the difference between **possible** danger and **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 condition gets worse and I cannot access the treatment I need?”**

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

**“I am thinking of worst case scenarios, but I do not know that 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 medical team will ensure I get the treatment I need.”**

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

There are many factors during the Coronavirus (COVID-19) pandemic which we cannot control, such as when we will be in lockdown, how long it will last or whether our medical treatment will be affected because of it.

When we focus on things that we cannot control, we may feel worried, overwhelmed and powerless. If we focus on what we **can** control in the day to day, here and now, this can help us to feel calmer, less anxious and empowered.

The diagram overleaf gives examples of things which might feel out of your control, and some things which might be more helpful to focus on, which may be within your control.

These things will be individual to you, so it may be useful to write a list of all the things that you can control in your school, work, home and wider life, however small, and let go of the things that you cannot.

Ultimately, you can control **what you do** and **how you respond** in the day to day. Both of which will make a real difference to you and the people close to you.

## **THINGS I CANNOT CONTROL**

(so I let go of these)

Changes to  
my treatment

Decisions and  
actions of others

## **THINGS I CAN CONTROL**

(so I focus on these)

How much time I spend worrying

How I choose to relax

Who I spend time with

How I look after myself

What is going  
to happen in  
the future

How long  
Covid-19 will  
last

## Use a worry tree

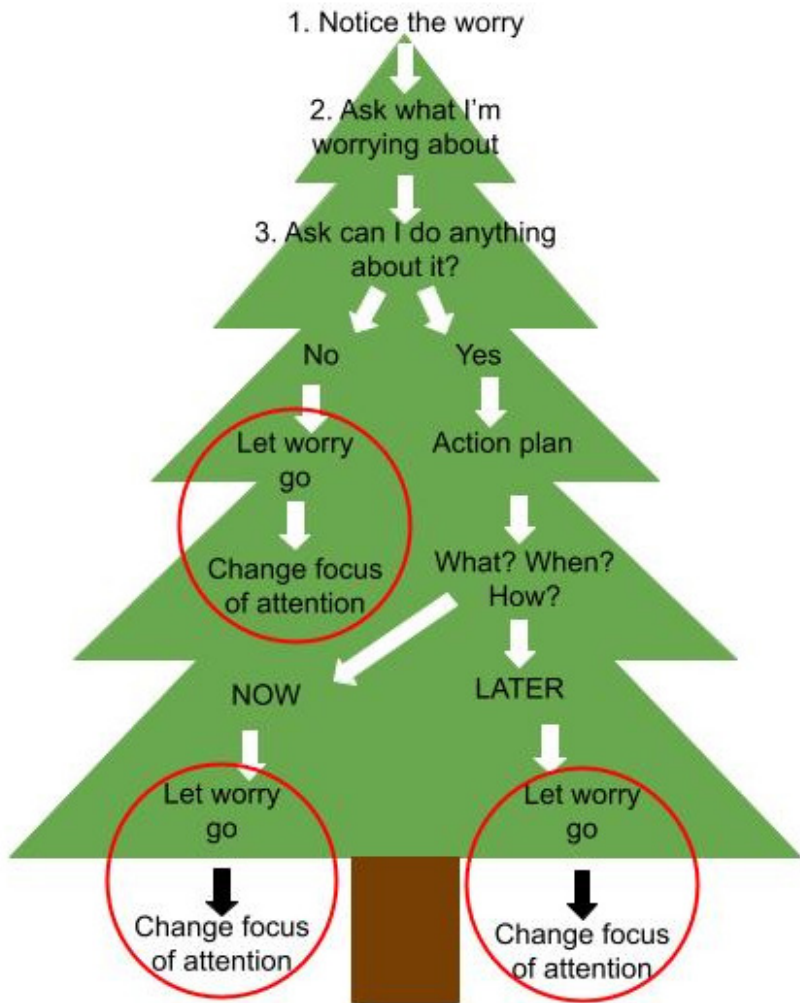
A good way of helping to notice what is in our control is to use a 'worry tree', like the one pictured. We can use the worry tree to help us to work out if our minds are using **helpful or unhelpful** worry.

**Helpful** worry is when there is something we can do to solve the worry. We can work through the possible solutions and put an action plan in to place. This works for worries which are probable, within our control, and not too far in the future.

**Unhelpful** worry is worry for situations that are outside of our control and cannot fix the problem. These sorts of worries often end up swirling around our heads, going nowhere.

This is when we should try to let the worry go, and focus our attention on something else, like engaging in a hobby or a task. The unhooking techniques are also helpful in letting us see thoughts as just a stream of words, rather than accurate predictions based on fact.





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

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

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

**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.



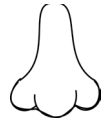
**3**

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



**2**

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.



This technique will not make your feelings 'go away' and it is not about trying to avoid them but it may help you to slow down and create a space around the feelings.

# 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...') or future ('what if?'). It can help us to feel more self-aware and in control of thoughts and feelings.

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, Calm or Smiling Mind.

You 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.

### 3. Do what matters

When facing stress, such as that caused by delays or uncertainty about 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 make time to do the things that matter to us and that give us a sense of purpose and fulfilment.

#### **Connect to what you care about**

Spend some time thinking about what matters to you, what you enjoy, what gives you meaning.

Think about how you can connect with and engage in those things each day. This might take some creativity with the current 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 phone or video calling family and friends. Think about why this is important to you; for instance, connection with others by talking to them, caring for others by checking in with them, having fun by laughing together.



Growing plants, whether indoors or outdoors could be an example of engaging with what matters, through

connection with nature, self-development from learning new skills, and fitness by engaging in physical activity.

Listening to music or an audiobook 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 in the here and now.

## **Be kind to yourself**

### **Self-care**

Being kind to yourself means ensuring you are looking after yourself 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 eat can affect your mood. 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 getting into a good sleep routine by ensuring your room is dark and cool, turning your phone off and avoiding caffeine. Apps like Sleepio are also helpful.



## Stay active

Being active is as important for your 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 cycle, or do an online workout at home (like PE with Joe Wicks). 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 improve it.

We can often be our own worst critics, especially in times of stress or when trying something new. Try to be kind to yourself. Imagine what you would say to a friend going through a similar situation. Think about your tone of voice, the words you use or the encouragement you might give.



Gently lay one hand upon 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 finding out what works for you and then making a promise to put these things into practice in small steps.

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, scan the QR code or go to this link:  
<https://contextualscience.org/act>.



## If you need further support

If you, or someone you support, are a patient of UHBW, you can enquire about additional psychological support by contacting your/their 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 to 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: call 0300 555 0334
- Weston Coronavirus (COVID-19) support line: 0300 3031320 (8am-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

## 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).

