



# Managing your Psychological & Emotional Wellbeing during the COVID-19 Pandemic: A GUIDE FOR PEOPLE AFFECTED BY CANCER

Being diagnosed with cancer, undergoing treatment, adjusting to life when treatment ends and/or living with cancer can bring a lot of physical and emotional challenges. We know that during the coronavirus (Covid-19) pandemic, many aspects of your care and lives will have been affected, which may in turn make facing these challenges even harder.

Overall, the last few months have brought a great deal of uncertainty and required us to find ways to live with this, which is something we can all find very difficult. Some patients will have been diagnosed during the pandemic, for others treatment may have been postponed, interrupted, or may have continued, bringing different feelings. Many patients have had to adjust to contact with their cancer team by phone or video call. There can be anxiety related either to coming into hospital for essential care, or because of being advised to avoid the hospital to reduce the risk of Covid-19.

You may have been advised to shield, which can contribute to feelings of isolation or make life at home with others more challenging. Shielding may also present real practical issues such as how to get the things you need, as well as the experience of anxiety and low mood.

Here at St George's Hospital we want to support all our cancer patients and their loved ones as much as possible through this difficult time. We have therefore gathered information and resources in this booklet to help you manage your emotional wellbeing, including signposting you to resources available from cancer charities such as Macmillan as well as from St George's.

# Living with Uncertainty

Disruptions to your usual care since the Covid-19 outbreak may have left you worried or uncertain about what might be coming next. These worries are entirely normal and understandable in the current situation.

You may also be missing the reassurance of going into the hospital clinic where you see familiar faces and feel more looked after by your clinical team. Alongside this there are also many changes to other aspects of your life, such as seeing friends/family, being able to go out, shop for yourself and doing other activities outside your home that you used to enjoy, all of which may have been coping strategies for difficult times and which are now less available to you.

General information and advice on managing uncertainty in this context can be found on the following websites:

- Dealing with uncertainty, Macmillan Cancer Support www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/uncertainty
- Managing anxiety, Macmillan Cancer Support www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/anxiety
- ➤ A guide to managing anxiety and Covid-19, St George's Hospital www.shorturl.at/lqr06
- How to respond to Covid-19 effectively, Russ Harris, Psychologist www.shorturl.at/izAHZ

In general, when you find yourself focusing on questions with uncertain answers, thinking over every possible outcome, or getting caught up in fears of the future, **try to shift your focus to things you can control.** The following section contains more resources to help you do this.

## What can I do?

The following section will help you develop ways of coping with anxiety and living alongside uncertainty. The common theme with all these ideas is the importance of focusing on doing things that are within your control, and we hope these strategies can help.

## Know your plan and who to contact

Where possible, ensure you have the contact details of your cancer care team should you have any concerns or questions. It will also help to know when your reviews or appointments will be and whether these will be in person or over the phone/by video call.

If you are unsure, contact your team to discuss the plan for your care. If you are unable to take someone with you to a face-to-face appointment, you may want to have them on the phone or video call with you during the appointment; do discuss this with your team so they can help with this if needed. If you have a phone appointment from home you may wish to have this on loudspeaker if you have someone with you who you would like to also be part of the conversation, or have a pen and paper with you so you can make any notes. If you are on your own, writing down any questions in advance and/or taking some notes can help.

## **Develop** a routine

Regular routines are valuable for our identity, self-confidence and purpose. They can help us maintain some sense of 'normality' in this ever-changing situation.

Try to start your day at roughly the same time as usual, and plan time each day for activities that are important to you, such as exercise, connecting with others, creativity and relaxation, as well as the basics of physical self-care and more routine activities around the home.

Cancer and treatment can cause fatigue, which may be heightened if you are isolating at home with less stimulation. If you don't have enough energy to do everything you used to do, you can plan around this, to focus on the things that are most important to you.

### You might find it helpful to follow the '5 Ps':

PACE	Try to get a balance of things you need to do and things you want to do, as well as a balance of activity and rest. If managing fatigue and/or pain it is better to take a little extra time to complete one task and be able to continue than to finish one too quickly and feel too tired to continue.
PLAN	Organise your day and week ahead of time where you can, trying to space activities out during the week rather than concentrating them all into one day.
PRIORITISE	Decide upon which activities are of most value to you each day and put them to the top of your to do list. If you're managing fatigue and/or pain, try to cut out unnecessary tasks.
PERMISSION	Give yourself permission not to do something that you feel you "should" and delegate to others when needed.
POSITION	Make the task easier. Could you sit down instead of stand? Can you change your position regularly? Try to avoid too much bending and twisting as this can be tiring.

# **Keep active**

Think of fun ways to keep active. That might involve adjustments, and thinking about what you can do at home - it's okay to need do things a bit differently, or to try something new. Pace yourself and set small realistic targets so you can see your progress, being gentle and encouraging with yourself.



If possible, build physical activity into your daily routine. Most of us don't have exercise equipment at home, but there are lots of activities you can do to keep your body moving, such as:

- Cleaning your home
- Going up and down stairs
- Seated exercises
- Online workouts
- Sitting less get up or change position after an hour

To hear more about the **benefits of being physically active** before and during cancer treatment visit <a href="https://www.youtu.be/ZRP">www.youtu.be/ZRP</a> <a href="https://hiwVflc">hiwVflc</a>. Below are a number of resources to help get you moving:

Useful websites for different types of exercises	Physical activity resources from Macmillan Cancer Support
Joe Wicks (British fitness coach) at-home workouts available on YouTube	Macmillan's information booklet offers advice about being more physically active following cancer treatment. You can download it or order it online to be sent to your home via <a href="https://www.tiny.cc/2gf9qz">www.tiny.cc/2gf9qz</a>
NHS Fitness Studio exercise videos (aerobic, dance, strength and resistance exercises, Pilates, yoga, chair-based Pilates and other fitness plans available):  www.nhs.uk/conditions/nhs-fitness-studio/	SafeFit Service is a free remote service for anyone in the UK with suspicion of or confirmed diagnosis of cancer. Cancer exercise specialists offer you advice, support and resources to maintain and improve physical and mental well-being. For more information visit <a href="https://www.tiny.cc/okf9qz">www.tiny.cc/okf9qz</a>
NHS One You online workouts: www.nhs.uk/oneyou/for-your-body/	Move More Service is a free (currently remote) service for cancer patients in Wandsworth, Merton and Sutton. To find out more contact Beth Brown on 0203 9590031 or <a href="mailto:waccg.movemorewandsworth@nhs.net">waccg.movemorewandsworth@nhs.net</a>
	Phone Apps: 12-week exercise plan available from the NHS Apps Library: <a href="https://www.nhs.uk/apps-library/iprescribe-exercise">www.nhs.uk/apps-library/iprescribe-exercise</a>

# Do things you enjoy

Schedule things to look forward to; cancer doesn't have to be all that you are. Although you may need to be more creative in coming up with activities during this pandemic, it's still important to explore what you can do for fun. What things can you get back to, and what new things might you like to try? What makes you laugh and feel good?



Try things such as listening to music, reading a book, watching TV, cooking or enjoying nature/gardening. Doing something creative can also bring satisfaction and joy, such as craft activities, adult colouring books or painting and puzzles. You might also want to learn about something, through reading or doing an online course. There are lots of free online videos to help you learn some new skills or crafts. Consider trying something new - such as online singing (e.g. <a href="https://www.tinyurl.com/ya69ajes">www.tinyurl.com/ya69ajes</a>) or learning a language (e.g. the free App Duolingo).

## Try mindfulness and relaxation

Approaches to relaxation such as deep breathing, imagining somewhere peaceful and letting go of muscle tension can all calm the mind and body. Make time to engage in whatever **you** find relaxing.

However, feeling positive and relaxed all the time is unrealistic. Difficult emotions will crop up and whilst it can feel uncomfortable, they don't always require you to respond or make them go away. Try to ride them out like a wave, passing through without taking over. Mindfulness can help keep you grounded in this process.

## Perhaps try a simple hand massage to ease some stress and tension:

https://www.royalmarsden.nhs.uk/your-care/living-and-beyond-cancer/complementary-therapy

## Meditation/relaxation apps which are completely, or partly free:









## These are some websites with free relaxation and mindfulness:

- Macmillan: www.soundcloud.com/macmillancancer/guided-imagery-a-walk-on-the-beach
- Mood café: www.moodcafe.co.uk
- Stress Control: <u>www.stresscontrolaudio.com</u>
- ➤ Maggie's Centres: www.shorturl.at/ersMN

## Manage your thinking

It can be helpful to check in with your thinking if you're noticing you're feeling anxious or down. Ask yourself the following questions:

- 'Is what I am thinking accurate, is there proof?'
- 'What would I say to a friend who had these thoughts?'
- 'Am I getting things out of proportion or jumping to conclusions?'
- 'Am I seeing the negatives and forgetting the positives?'

Practice balancing your thoughts, so they are more realistic and helpful.

For example, instead of "this lockdown is never going to end and I won't get the treatment I need", try "there will be a time when lockdown will ease and I know my team will make sensible decisions about what treatment I need and how to get it in the safest way".

# Try self-compassion

It's also important to try and avoid comparing yourself to others or being self-critical. Find ways to encourage and be kind to yourself. See what works for you from these suggestions:

- What's the most kind and helpful thing you would want to hear right now? Write it down, say it in your head or say it out loud.
- > Do something nice for yourself, such as ordering your favourite food or other treat, cook something, make something, watching or listening to your favourite films/podcasts/series, having a soak in the bath etc.
- ➤ If you get stuck thinking of kind things to do for yourself, think about what you would do for someone else that you could do for you to cheer you up or be of comfort? These caring ways of thinking help you feel more supported and motivated.
- Mindfulness can also help you step out of these thinking loops and focus on what you can do in the here and now. Be ready to listen, even if the content is difficult, to difficult emotions. Make space and try to understand why they're there. Remind yourself this is understandable.

# **Practice gratitude**

Though it's only human for difficulties and negative events and thoughts to have a greater impact on us than anything positive, especially when there are so many tough experiences to deal with.

Purposefully focusing on the pleasant or valued experiences of life can give some balance to the difficulties that exist, and help improve your overall mood. *Keeping a gratitude diary is one way to do this. Write down three new good things about your day, every day, however small.* 

Try these free Apps to help you practice







Gratitude

**Gratitude 365** 

Support your sleep

There are a few things you can do to improve your sleep:

- Aim to go to bed and get up at the same time each day, even at the weekend.
- Try to get some natural sunlight during the day by opening your curtains and windows where possible. This helps to regulate your body clock which can help you sleep better.
- Keep physically active at home.
- Avoid tea, coffee and alcohol in the evening.
- Establish a regular, relaxing bedtime routine that lets you unwind and sends a signal to your brain that it's time to sleep.
- If you can't sleep, don't worry about it. Get up and do something relaxing like listening to music or reading until you feel sleepy.

## Explore what's helped before

Cancer is unlikely to be the first significant challenge you have experienced.

What has worked for you in the past when facing difficulties before this pandemic? Build a 'first aid kit' of things that soothe you, including things you value, books, films, ideas and maybe even some notes to your future self with your soundest advice.



# Support at St George's Hospital



We all may need some extra support through this challenging time, so don't feel worried about asking for this if you need it. Talk to your Clinical Nurse Specialist, Oncologist, Surgeon or any member of your cancer team at St George's Hospital if you feel you would benefit from additional emotional support.

## Below are the services available to you at St George's Hospital

# Macmillan Cancer Information and Support Centre, St George's Hospital

The Centre is currently open Monday to Thursday 8:30am-4:30pm and Fridays 9:30am-4:30pm. You can also call on **020 8725 2677** or send an email to <u>cancer.information@stgeorges.nhs.uk</u>. The Centre's **YouTube channel** also offers wellbeing support and advice by video, including exercise, relaxation, mindfulness and other **complementary therapies**: <u>www.tinyurl.com/ya69ajes</u>. To learn more about support from the Macmillan Centre visit <u>www.stgeorges.nhs.uk/patients-and-visitors/help/macmillan/</u>.

## **Clinical Nurse Specialists**

Your Clinical Nurse Specialist is there to talk with you about any difficulties you are experiencing as a result of your cancer. They can support you in both practical and emotional aspects of your care and can help navigate services to ensure you get the right support from the right place. Your Clinical Nurse Specialist can help you think about small changes you can make that may help you manage how you're feeling, but can also provide information and refer you on to additional psychological and emotional support if needed.

# **Cancer Psychological Support (CaPS) Team**

The CaPS team is here to help you cope with the emotional and psychological challenges which can come with cancer, offering information, support, practical help and the chance to discuss your concerns. Patients and carers can access a range of talking therapies with a counsellor or clinical psychologist over the phone or by video call. The CaPS team can also support you in managing cancer alongside existing mental health issues, and support from a liaison psychiatrist is available for more complex mental health needs. The service is available to outpatients and also patients on the wards.

Any healthcare professional in your cancer team, your GP or the staff at the Macmillan Support and Information Service, can make a referral for you. Please request this if you think our service could help. You can also refer yourself by calling 020 8725 0461 or emailing cancer.psychologicalsupport@stgeorges.nhs.uk

For more information about the CaPS service please visit <a href="www.stgeorges.nhs.uk/service/cancer-services/cancer-psychological-support/">www.stgeorges.nhs.uk/service/cancer-services/cancer-psychological-support/</a>

# **Wider Sources of Support**



# Sources of outside support

## **Connecting with others**

Although we don't always feel like it, it can be really helpful to connect with those close to you when you can, especially during this pandemic. It can help to share concerns, and knowing you are not alone can help you cope. Explore ways of connecting that work for you, whether that's by post, over the phone, social media or video call. This could be anything from sharing a cup of tea over video, playing an online game together, or simply sending a supportive text message.

# Local psychological support

Your GP practice will be able to direct you to your options for local psychological support. You can also find out more information about for your local primary care psychology service by searching for an IAPT service (Increased Access for Psychological Therapies) in your area. You can often refer yourself to IAPT online, by email or over the phone, otherwise your GP can refer you.

## **Support from Cancer Charities**

There are lots of cancer charities offering support to those affected by cancer. This ranges from online communities, virtual support groups and workshops/courses, through to phone and telephone emotional and practical support. Macmillan has a free national phone line, as well as email and website, offering advice and support; see below. For a full list of cancer charities please see the back of this booklet.

Macmillan

Phone: 0808 808 00 00

Email: Can email via website

Website: www.macmillan.org.uk

Contact hours: Daily, 8am-8pm

Paul's Cancer Centre, Battersea

**Phone:** 020 7924 3924 or 07545485874 **Email:** support@paulscancersupport.org.uk

Website: www.pauls.org.uk

**Contact hours:** Monday to Friday, 10am–1pm

and 2-5pm

Maggie's Centres, various locations

**Phone:** 0300 123 1801

**Email:** enquiries@maggies.org **Web:** www.maggies.org

Contact hours: Monday to Friday, 9am-5pm

**South East Cancer Help Centre, Purley** 

Phone: 020 8668 0974

**Email:** <u>lizzie.hewitt@sechc.org.uk</u> **Website:** www.sechc.org.uk

**Contact hours:** Monday to Friday, 9am-5pm (Tuesdays until 8 pm) and Saturdays 9am-1pm

The Haven (Breast Cancer), Hammersmith

Phone: 020 7384 0099

**Email:** london@breastcancerhaven.org.uk **Website:** www.breastcancerhaven.org.uk **Contact hours:** Monday to Friday, 9.30am-5pm

The Mulberry Centre, Isleworth

Phone: 020 8321 6300

Website: www.themulberrycentre.co.uk
Contact hours: Monday to Friday, 10am-4pm

#### **Trekstock**

Trekstock gets young adults in their 20s and 30s moving again physically, socially and psychologically after cancer has stopped them in their tracks. For more information visit www.trekstock.com

#### Shine

Shine offers a variety of activities and support for anyone in their 20s, 30s and 40s who have been diagnosed with any type of cancer, at any stage. For more information visit <a href="https://shinecancersupport.org">https://shinecancersupport.org</a>

# **Mental Wellbeing and Covid-19**

#### NHS

Coronavirus and your mental wellbeing www.nhs.uk/oneyou/every-mind-matters

# MIND Charity Coronavirus and your mental wellbeing www.mind.org.uk/informationsupport/coronavirus

### **Anxiety UK**

**Coronavirus anxiety support and resources** 

www.anxietyuk.org.uk/coronanxiety-support-resources

# Where to get Immediate Mental Health Support

If you are in crisis out of hours you can contact the following services for advice and support:

If you just need to talk, any time of day or night you can contact free Listening Services, which offer confidential advice from trained volunteers. You can talk about anything that's troubling you, no matter how difficult:

#### **Samaritans**

They can be reached via <a href="www.samaritans.org">www.samaritans.org</a> or via their helpline on 116 123/email: <a href="jo@samaritans.org">jo@samaritans.org</a> Open 24 hours, 7 days a week.

#### Shout

They can be reached via <a href="www.giveusashout.org">www.giveusashout.org</a> or via their crisis text helpline. Text 'shout' to 85258 Open 24 hours, 7 days a week.

## Ways to Cope in a Crisis:

The Charity Mind has a website with useful resources, including: *Ways to cope in a crisis:* 

www.mind.org.uk/need-urgent-help/what-can-i-do-to-help-myself-cope

How to manage suicidal feelings:

www.mind.org.uk/media-a/2960/suicidal-feelings-2016.pdf

## **NHS Urgent Mental Health Support:**

# **GP & Local Crisis Support**

If you are concerned about your mental health, but do not feel immediately at risk you can request an urgent GP consultation. Your GP will be able to provide you with your local NHS urgent mental health details if required.

You can also look up your local NHS mental health crisis line here: <a href="www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline">www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline</a>

NHS 111: Open 24 hours, 7 days a week.

## **Emergency Services**

If you feel at immediate risk to yourself call 999, 24 hours, 7 days a week.