

# My illness has come back, WHAT CAN I DO?



## Why is it important to talk about what I can do when I have received a diagnosis that my illness has come back?

There are times when people who have been treated for a health condition in the past receive a diagnosis that it has come back. There are steps that you can take to help you cope if your illness has come back. It can be helpful to identify the difference between concern about a diagnosed condition, e.g. “the doctor has told me my cancer has come back”, and concern about whether your illness may come back in the future, e.g. “I am worried that the doctor will tell me that my illness has come back”. There are different ways of responding to each of these concerns, so we have made a separate toolkit for how to manage worries about illness coming back in the future. If you are worried about the possibility of your illness returning in the future, please refer to the toolkit titled ‘What can I do if I am worried about my illness coming back?’.



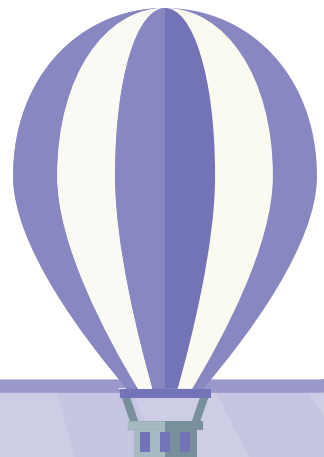
### **What is the impact of knowing what I can do when I have received a diagnosed that my illness has come back?**

It is very common to be concerned when diagnosed that your illness has come back; at such a time it is natural to feel a range of emotions, such as worry, fear and anger. We know that when feeling such emotions we may think or do things differently, which may have a negative impact on ourselves and our relationships with other people. There are a number of different things that you and other important people in your life can do to help at a time when you are likely to be feeling a range of emotions.

### **How can you use this toolkit?**

This toolkit is designed to provide you with information about some of the things that you can do when you receive a diagnosis that your illness has come back. At the end of the toolkit there are also links to further information if you wish to explore this area in more detail and gain more support to do so.

It is normal to be feeling a range of different emotions when you find out that your condition has come back. These may be a mix of sadness, worry, anger or frustration, to name a few. People may find that their moods change very quickly and with no clear trigger. Everyone is different in how they think about and make sense of information given to them about their condition. Often strong feelings become more manageable as you adjust to the information you have received, ensure that you ask for advice or support if you feel that you would benefit from it – this can be available from a variety of sources (see strategies and links below).



# Top tips and strategies

What can I do if my illness comes back?

**1** **People may try to not tempt fate** by not booking plans for the future, e.g. trips away or family visits. However, by not having things booked in to look forward to, we can quickly lose motivation and feel depressed or hopeless. So try to have things to look forward to and achieve as this adds value to our lives.

**2** **Stay involved in activities** which give you a sense of achievement or pleasure e.g. arts and crafts, gardening, listening to music etc.

**3** **Set yourself manageable goals** and pace yourself by balancing out activities with periods of rest.

**4** **Make sure goals are SMART:** Specific (you know what it is you want to do); Measurable (you can tell how much you've done and record it to track your progress); Achievable (it's something you're likely to succeed in completing); Realistic for where you're at now; and Timely (you know when you're going to do your activity and for how long).

**5** **Focus on what is important to you and engage in activities you enjoy** and spend time with people you care about. By identifying what's important to you, i.e. what you

value, it will help you to stay connected with meaningful people and activities. Identifying your values can help you adapt your activities and goals for times when you may not feel able to do what you have previously. E.g. imagine one of your values is self-care, your goal at certain time may be playing football, at other times a more manageable goal may be taking a walk and relaxing in a scenic spot – the goals look different, but are still guided by the same value.

**6** **Try to identify unhelpful thoughts and develop more balanced perspectives.** When people feel low or worried, they tend to filter out neutral or positive information and focus on negative e.g. a catastrophic thought could be "I have been told that my illness has returned, my life is over"; this is likely to make existing low mood and worries worse and stop you from engaging in meaningful activities; developing a more balanced perspective e.g. "my illness has returned, there are many things I can still do which bring value and meaning to my life, I'm going to focus on the here and now".

# Top tips and strategies

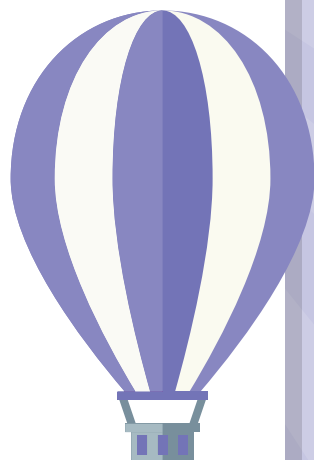
What can I do if my illness comes back?

**7** **Develop mindfulness skills to help you focus on the here and now, rather than 'predict' what may or may not happen in the future.** Mindfulness is defined as 'developing non-judgemental present moment awareness' and is based on Buddhist meditation practices. It has been used extensively with people with physical health conditions and shown to have both mental and physical benefits, such as reducing the experience of pain and low mood.

**8** **Write down questions which you would like answering,** often when feeling worried it's easy to forget some of the things people want to discuss.

**9** **Some people may want to think about and plan for the future** – your healthcare team will be able to advise you on your own situation and care plan and what kind of advanced decisions may be helpful to think about – discuss the information at a pace which feels most manageable for you. You may want to have a family member, friend or advocate with you in your consultations to help take in the information – it is likely that you'll be feeling a range of emotions, which can make it harder to take in information and remember it afterwards.

**10** **You may find it helpful to discuss with your family and friends what amounts of information you find manageable** – they may find it helpful to know more that you at certain times, if so, discuss this with your medical team so they are aware which relevant people to share what amounts of information with.



# WHAT SUPPORT IS AVAILABLE?

- 1 Speak to your healthcare team if you feel concerned about your condition or other things that may be going on in your life – they may be able to direct you to services where you can access guidance and support.
- 2 Some teams in the hospital have a psychologist and/or counsellor as a member of their team, who can speak to patients and their families if they feel low or depressed – ask a member of your healthcare team who knows you well, such as your clinical nurse specialist, if they can make a referral on your behalf.
- 3 If you are a patient or family member of a patient of the Bristol Haematology and Oncology Centre (BHOC), there is an information and support centre in the main entrance, which has lots of leaflets which can help you if you need some more information and advice. There are also counsellors who can speak to you individually to offer further support.
- 4 There are additional resources on the UH Bristol website for managing common concerns, such as overcoming low mood and worry, and how to tell your child that you have a serious illness - please refer to these guides for more information and support.



# WHAT SUPPORT IS AVAILABLE?

## Links to appropriate resources

1. Condition specific websites contain information and support which may be helpful to you, such as: Macmillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk) ; or the British Heart Foundation [www.bhf.org.uk/heart-health](http://www.bhf.org.uk/heart-health).

2. There are commonly face to face, or internet based support groups available to help you and other people who are in a similar situation to you. Ask your healthcare team if they know of anything in your area and/or look at the website of a charity or organisation related to your condition (see bullet one).

3. King's College Hospital NHS Foundation trust has developed a range of self-help materials

designed for people who have been affected by health conditions. These include: Living with health problems <http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/Self-Help-Materials/Living-with-Health-Problems.pdf>; the mind-body link <http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/Self-Help-Materials/Mind-Body-Link.pdf>; and making the most of your life <http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/Self-Help-Materials/Making-the-most-of-your-life.pdf>.

4. The NHS Choices website has more information and practical techniques for you to try, with links to more information if desired <http://www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx>.



These toolkits have been written by NHS clinical psychologists and neuropsychologists working for University Hospitals Bristol. They have been co-designed with service users and healthcare staff. These toolkits are only intended to provide general advice and information. Please discuss your individual needs with your doctor or specialist nurse. If you would like more information about psychology services please go to:

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

We would like to thank patients and other healthcare staff for their contributions to this toolkit.

For access to other patient toolkits please go to the following address:

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

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

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