

Journey to wellbeing

A practical guide to life after cancer



Every cancer journey is different

How you might feel, what you need and the type of treatment you receive won't be the same as someone else's experience.

The same can be said for life after cancer, when your treatment has ended, and you've received the all-clear. While in many cases it can be a relief, having worries and questions about what comes next is completely normal and can differ from person to person.

It's not a straightforward journey – there's no map to follow, no timeline to stick to, no survival pack given.

There's no right or wrong way to navigate things.

We hope the information and resources covered in this guide provide reassurance that support is available – for you and your loved ones – throughout your cancer journey.

92%

of Life after Cancer's community told them that they find life after cancer harder than cancer treatment ¹. Knowing what support is available after you've had cancer is just as important.

¹ Post Cancer Support: Life After Cancer. A charity that brings people together who have finished cancer treatment to form support groups, with an aim to increase their physical, mental, emotional and social wellbeing.

Mental health and emotional wellbeing

Receiving the all-clear after cancer treatment is undoubtedly a relief and marks the end of an incredibly challenging chapter.

But it's important to recognise the mental and emotional impact your experience can have. As you shift from active treatment to post-treatment, you may find that you have more mental and emotional space to process things, leading to a deeper understanding of your journey and its effects on your life.

How can cancer affect your mental health?

It affects people in different ways, but some common feelings during and after treatment can be:

- shock
- sadness
- anger
- anxiety
- frustration
- hopelessness

- isolation
- fatigue
- lack of confidence
- loss or lack of identity and direction in life
- mistrusting your body

Sometimes, these emotions can develop into mental health conditions.

These can include:

- depression
- anxiety
- · suicidal thoughts
- post-traumatic stress disorder (PTSD)
- feeling like you're disconnecting from reality.

Read more about how having cancer can make you feel and the support that's available to you.

VISIT THE CANCER RESEARCH UK WEBSITE

Mental health charity, Mind, has more information on these conditions, including treatment and selfcare information.

VISIT THE MIND WEBSITE

Why it's normal to fear the 'what next?'

Receiving the all-clear can be a lot for your brain to process, especially after your focus has previously been on navigating diagnosis and treatment. Now you're in the post-treatment stage, the regular support you had from your medical team might now be lessening or stopped altogether, which can result in shock or fear setting in.

"Scanxiety" or scan anxiety is also common after the all-clear.

Although appointments might have ended, feeling fearful is completely normal. Seeking external support groups to talk to, and being with others in a similar position, can help alleviate any worries.

The pressure to be "ok" after the all-clear

There can be a common misconception that now someone is cancerfree, they should be happy and "back to their old selves".

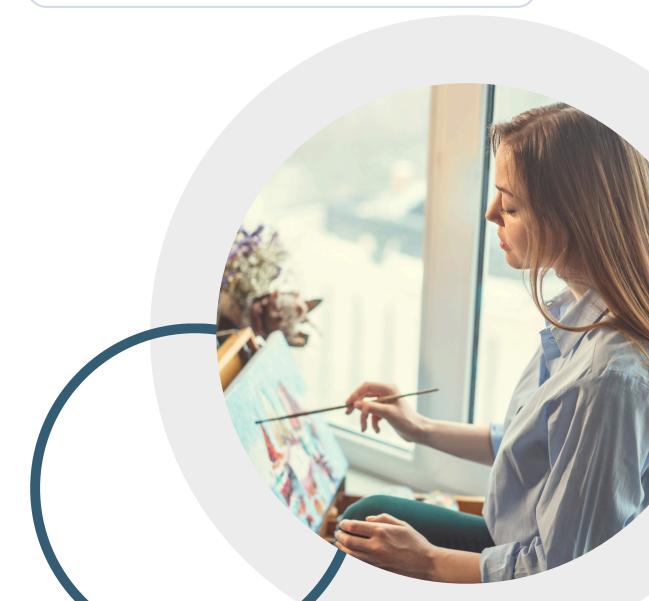
Everyone deals with cancer differently and at their own pace. It's perfectly ok to not put on a façade and instead be honest with your feelings. Equally there shouldn't be any pressure, internally or externally, to go back to how things were. You might want to just forget about it all and resume life, or you might need time to heal physically and emotionally.

There's no right or wrong way of navigating this journey of being 'you' after cancer. It's common to experience a mix of emotions and experiences. Try not to expect too much of yourself too soon, or to 'bounce back'. You might find it helpful to take the time and think about what you need in the here and now to meet your needs.

Rediscovering your identity

Facing and overcoming cancer can impact how you see yourself and the world around you - from your perspective and priorities to your sense of self. Embracing these changes and allowing your identity to shift and grow in response to the challenges you've faced is a normal part of the healing and recovery process.

Engaging in activities that bring fulfilment, reconnecting with hobbies or passions, and seeking new experiences can all contribute to rediscovering your sense of self.



Discovering positive coping mechanisms for cancer



Adjustment and acceptance: Acknowledge what your body's been through. Give yourself permission to grieve the changes and loss involved in your journey.



Take time to recover: Slow down and allow yourself time and space to heal emotionally and physically.



Professional support from a qualified counsellor, therapist or psychologist can provide a safe space to process emotions and develop coping strategies.



Joining a support group to connect with others who have gone through similar experiences can be incredibly validating and comforting. A sense of community and understanding can help process emotions.



Practising mindfulness and meditation can help reduce stress, increase self-awareness, and provide a sense of calm.



Creative expression such as writing, music and art can provide an outlet for processing and making sense of your cancer experience.



Reflection through journalling can be a powerful way to express and reflect on your thoughts.



Learning more about cancer survivorship can help in understanding the psychological and emotional aspects that can be involved, which can help in navigating your own feelings.



Staying active and maintaining a healthy lifestyle: Regular physical activity, a balanced diet, and adequate sleep can contribute to your overall wellbeing and help manage anxiety. Staying active doesn't have to be about hitting the gym – it's about movement, whether it's a walk at lunch time, going swimming, or a kitchen disco.



Finding moments of joy: Participating in activities you enjoy can help shift focus away from your worries and promote emotional wellbeing. Whether that's enjoying a hot chocolate with a magazine or cooking a favourite meal - feed your soul with regular moments of joy during your day.



Creating a plan: Developing a plan with your healthcare team for monitoring your health and addressing any concerns about processing your cancer journey or worries around reoccurrence can provide a sense of control and reassurance.



Limiting exposure to triggers: Identify situations, conversations, or media that trigger anxiety about cancer reoccurrence, and limit your exposure to these triggers as much as possible.



Celebrating the small wins: Anything that gives you a sense of achievement can be a small win. Making your bed, mindful breathing, reaching out to a friend, engaging in a hobby - all can have a cumulative effect that can lead to positive changes in your overall wellbeing.

Maintaining a healthy lifestyle

Fitness and nutrition can support your body's recovery, boost your energy levels and contribute to your long-term wellbeing.

Fitness

It's important to keep active at all stages of life - including during and after a cancer diagnosis and treatment. Not only being active, but also reducing inactivity and time being still. Government guidelines for exercise are for adults to achieve 150 minutes of moderate intensity exercise per week² and this should include some resistance and strength-based exercises.

Outside of this, we can implement small changes to our routine to increase activity and reduce sedentary time by doing things like parking a little further away from where we usually park, taking the stairs instead of lifts/escalators, spending time in the garden and going for a short walk during work breaks.

Nutrition

Avoid high calorie and ultra processed foods, eat more fibre, limit red and processed meat consumption to two portions per week, limit sugar sweetened drinks, avoid alcohol or stick to the government guidelines of no more than 14 units per week³. Ensuring UV protection and avoiding sun burn is also recommended.

This information relates to globally recognised guidance to the primary prevention of cancer. However, it's also broadly applicable to those with, or who are recovering from, cancer. Professional guidance can help you decide what is best and advise you on how to tailor this guidance to your personal circumstances.



2 <u>Physical activity guidelines - GOV.UK</u> 3 <u>Alcohol and health - GOV.UK</u>

Self-care

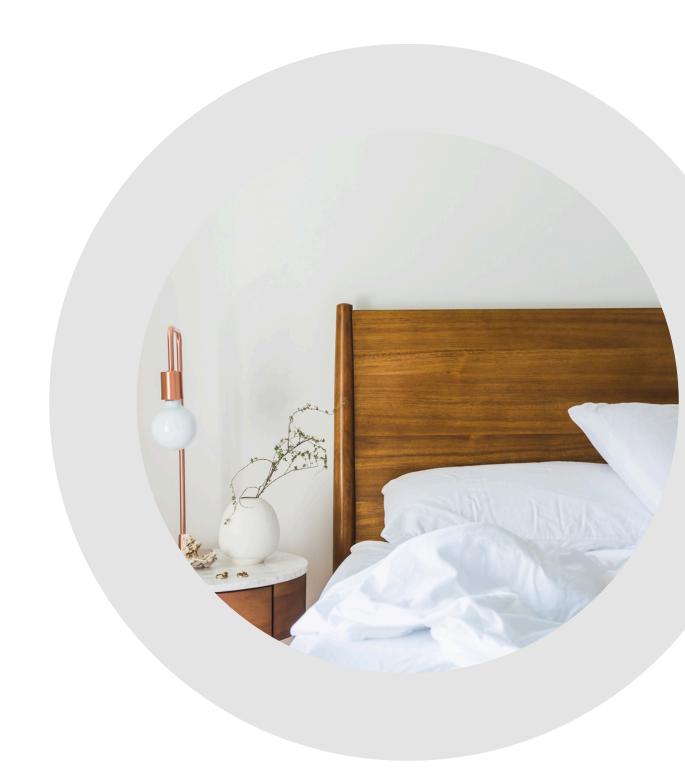
There are other areas outside of fitness and nutrition that can improve your wellbeing.

70%

of people with cancer experience problems with sleep 4 ...

...while reported insomnia prevalence amongst newly diagnosed or recently treated cancer patients varies from 30.9% - 54.3%.5

Living with the physical and emotional demands of cancer can often result in feeling like you need more sleep than usual. Effects of medication can also range from insomnia to feeling energised. Some medications can also reduce the production of melatonin - a sleep hormone.



4 <u>Cancer Survivorship: Insomnia and Sleep Disturbance - CancerConnect</u> 5 <u>Prevalence of Insomnia in an Oncology Patient Population - National Library of Medicine</u>

Things that you can do to catch more zzz's

While there's over-the-counter medication you can take to help with sleep, you must consult your healthcare provider before taking anything to ensure it's safe for you to do so.



Reducing screen time before sleep: Blue light from screens can interfere with your natural sleep-wake cycle, making it harder to fall asleep. It can also reduce the overall quality of your sleep.



Light: Exposure to natural light during the day can help regulate your body's internal clock and improve sleep quality.



Getting up and doing a calm activity until you feel sleepy.



Comfort: Sleeping in a comfortable environment, such as a supportive mattress, cosy bedding, and a quiet, soothing atmosphere, can help.



A consistent bedtime routine: A great way to signal to your body that it's time to step away from the screen and wind down and relax before the land of nod. This will help establish a regular sleep-wake cycle.



Noise: Earplugs, white noise machines, or soothing background sounds, such as nature sounds or calming music, can mask disruptive noises and create a more peaceful sleeping environment. Soundproofing your bedroom or using heavy curtains can also help reduce external noise disturbances.



Temperature can influence your body's ability to regulate its internal temperature during the night. A cooler room temperature, typically between 15-19°C, is generally considered optimal for promoting better sleep, as it helps your body enter into a state of relaxation to fall – and stay – asleep. A room that is too warm may lead to restlessness and disruptions in your sleep cycle.



Breathing and relaxation techniques can promote a state of calm and reduce stress and anxiety, which are common factors that can interfere with falling asleep. They can also help slow down your heart rate, relax your muscles, and quieten your mind, making it easier to transition into a restful state for sleep.



'Nodcasts': Pop your headphones on and listen to calming voices, soothing sounds, and gentle storytelling to aid sleep.

Sky before screen

This refers to the practice of spending time outdoors and experiencing the sky, rather than immediately turning to electronic screens. It can have mental benefits by allowing you to disconnect from the digital world, reduce stress, and promote mindfulness through the observation of nature and the sky. A break from constant digital stimulation can foster a sense of calm and mental clarity.

Hobbies and clubs

From sewing to rowing, cooking to scrapbooking - there's a hobby and club for every interest. They can offer a sense of community, encourage new interests, provide the opportunity to learn something new and can become a welcome distraction from anything that's taking up too much headspace.

Getting out into nature

As well as the physical benefits, taking a walk in a natural environment can help reduce stress, anxiety, and depression.

The fresh air and greenery can also have a calming and rejuvenating effect on your mind and body. It's also a great opportunity to engage in something that brings you joy - whether it's a walk, feeding the birds or gardening.

Charity work

Making a positive impact in the world through charity work is a great way to give back to your community, connect with others, gain new skills, and find a sense of purpose and fulfilment.

Making connections with those going through a similar journey

Connecting with other cancer survivors can provide valuable emotional support and understanding during your recovery journey. Sharing experiences and insights can help build a sense of community and resilience among those who are facing similar challenges.

Your healthcare provider, cancer charities, hospital support groups and community centres can work with you in making these connections.

Maggie's:

CANCER SUPPORT GROUPS

Macmillan Cancer Support:

SELF-HELP AND SUPPORT GROUPS



Did you know?

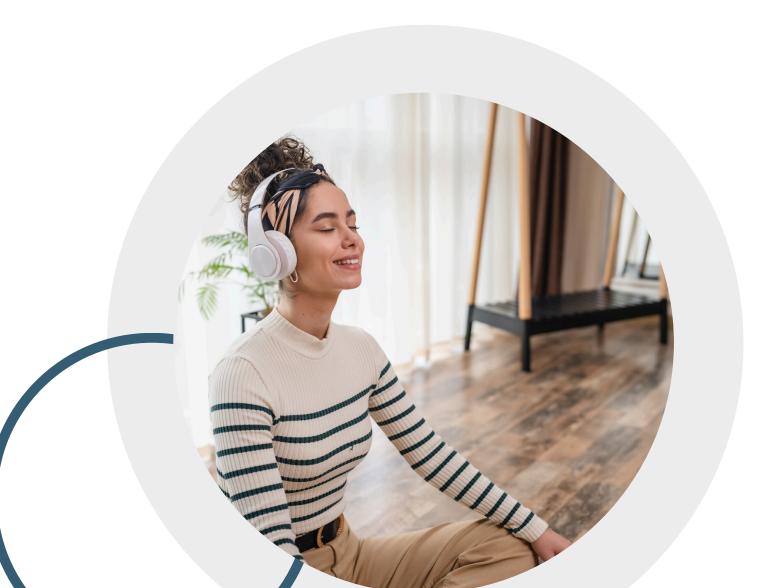
Maggie's provides sleep support should you need it. You can talk things over with a cancer support specialist and find out more about ways to manage your sleep issues. The charity also runs relaxation sessions and some of its centres run sleep workshops. Benefits advisors are also available to talk through any money worries should this be adding to your sleeplessness.

Setting boundaries to protect what's most important to you

Your cancer journey can spark a new perspective on things, and what you value most in life.

Setting boundaries in this context is less about blocking things out, but more a way of protecting the things in your life that you value most. Time is precious – it's a way to spend it wisely.

Setting boundaries ensures your time is spent in the places that matter most to you.



This can include:

- prioritising self-care
- staying connected to the people and activities that are most meaningful to you
- managing stress
- communicating your needs with friends, family, employers, healthcare providers
- setting limits on activities or commitments to prioritise rest and recovery
- seeking support when you need it.

Managing the side effects of treatment

It's a common misconception that side effects stop once treatment is finished. But for some cancers, the side effects can continue after the all-clear is given. For example:

Cancer of the womb, ovaries, or cervix

In the case of the ovaries being removed (called a total or radical hysterectomy) then surgical menopause will be experienced, regardless of age⁶. If a hysterectomy leaves one or both ovaries intact, then menopause might be brought on earlier compared to someone who hasn't had the procedure. The decline in oestrogen means menopause symptoms will occur such as hot flushes, fatigue, and night sweats.

Chemotherapy

Cancer Research UK highlights how chemotherapy for some people can cause long-term changes in the body months or years after treatment 7. For example, problems with certain organs such as your heart, lungs or liver, or cognitive changes where you experience changes in memory or concentration.

Cancer-related fatigue (CRF)

Up to 90% of people with cancer experience fatigue⁸, making it one of the most common side effects of cancer treatment⁹. It can occur at any time, not just during but after treatment, too. The severity and duration of the fatigue can depend on the type of cancer and treatment undertaken but it can also be caused by the emotional impact of cancer.

Asking for support from a GP, cancer team, or employer (if returning to work) is important in helping manage fatigue symptoms.

CRF affects everyone differently

Physical symptoms can include:

- exhaustion
- weakness
- · unusually worn out after doing simple things - such as getting dressed or cooking
- breathless after gentle activity
- lightheaded or dizzy
- less interested in sex.

Emotional changes - you may find you're feeling:

- low in mood
- more emotional generally.

Mentally, you may find it harder to:

- think, speak or make decisions
- concentrate and remember things
- sleep
- wake up and feel alert.

^{6 &}lt;u>Hysterectomy - Considerations - NHS</u>
7 <u>Late side effects of chemotherapy - Cancer Research UK</u>
8 <u>Cancer-related fatigue - Macmillan Cancer Support</u>
9 <u>Cancer fatigue - National Cancer Institute</u>

Cancer-related fatigue can continue months, or years after treatment

How do I manage cancer-related fatigue (CRF)?

It might take time to understand what works best for you. Before making any big changes, speak with your healthcare provider to ensure anything you're planning is suitable for you.





Physical activity such as walking quickly is one of the best ways to help reduce symptoms of fatigue. Being active can also increase appetite, boost energy, improve sleep and lift spirits.



Eating well and keeping to a healthy weight can help maintain or regain your strength, and give you more energy. A food diary will help you play detective to see how your energy levels react after certain foods/meals.



Keep your fluids up. Dehydration can exacerbate feelings of tiredness and lethargy. Opting for water, herbal teas, and fresh juices can contribute to proper hydration and may help alleviate some of the symptoms of fatigue.



Keep a fatigue diary. Recording your energy levels at different times of the day can help you understand any patterns, discover things that make your fatigue better or worse, and help you to plan important activities for when you have more energy. It's a good idea to share your diary with your healthcare team. They can talk to you about how you can plan your day depending on how you feel.



Try to keep a normal sleep routine if possible. Good quality sleep can help your fatigue and reduce your need to sleep during the day.



Complementary therapies such as relaxation, mindfulness-based stress reduction (MBSR) and yoga can help with fatigue. Some therapies may be available on the NHS or you may be able to get them through a <u>cancer</u> <u>support group in your local area</u>. If you find a complementary therapist, make sure they are qualified and registered. Macmillan provides useful <u>information and guidance</u> on this.

Fatigue affects up to 90% of cancer patients in the first year after diagnosis 10, and one in three patients continue to experience fatigue up to 10 years post-diagnosis impacting millions of people worldwide. 11

Recognising and managing this persistent symptom is crucial for improving quality of life.

Energy tracking can be a game-changer in planning daily activities and regaining energy.

Mindfulness-based stress reduction exercises help to reduce cortisol levels.

Physical activity prevents deconditioning and helps build strength, while nutrition and sleep hygiene are vital for overall recovery.

This combined approach works best with the support of family, friends, support groups or a therapist - but you can also start on your own and take small steps towards feeling better.

How to build up your reserves and maintain your energy

Pacing can help you manage your activities and energy levels to prevent overexertion. By balancing periods of activity with periods of rest, you avoid pushing yourself too hard and experiencing fatigue or setbacks. This approach helps in conserving energy and maintaining a sustainable level of activity without causing excessive strain on your body.

Ask yourself:

- What do I want to do vs what do I need to do?
- Are my expectations realistic? Can it be 'good enough' for now?
- What can I ask someone else to do for me?

How to rest and switch off

Relaxation is personal to you. What one person might find relaxing might not work for you. Try to find something, or a few things, that you enjoy and that allow your mind to relax and quiet. This could include going for walks or other forms of exercise, taking a bath, reading, listening to music/podcasts.

The key is to be proactive as opposed to reactive. Don't wait until you are feeling extremely fatigued to do what relaxes you - do it regularly and prioritise it to keep your energy levels from depleting.

^{10 &}lt;u>Cancer-Related Fatigue in Patients with Oncological Diseases – National Library of Medicine</u> 11 <u>Nonpharmacological Interventions for Cancer-Related fatigue: A Literature Review – National Library of Medicine</u>

Returning to work

For many, work can be important to their psychological wellbeing and recovery by providing a focus outside of cancer. While some people carry on working during treatment, others need to stop.

The Equality Act 2010¹² considers a diagnosis of cancer as a disability, which gives you important rights. These rights mean you can negotiate for reasonable changes in your workplace. 'Reasonable' refers to any changes or adaptations that must be practical for your employer, in regards to cost and effects on other workers. For example, it might be reasonable to have more flexible working hours so you can carry on working.

The Act also gives you legal protection if you feel your employer has treated you unfairly.

Employers can provide support by offering flexible work schedules, accommodations for medical appointments, and a gradual return to work.

Additionally, they can provide access to employee assistance programmes, counselling services, and resources to help manage your transition back to work.

It's also important for employers to communicate openly with you, show understanding, and provide a supportive work environment to facilitate a smooth transition back to work.

Your company should be putting reasonable adjustments in place in the workplace to help you transition.

Cancer Research UK provides additional information on returning to work.



Survivorship support

Many of these organisations¹³ also support your family during your cancer journey.

Maggie's - a charity that provides free expert care and support in centres across the UK and online.

https://www.maggies.org/

Future Dreams - in-person and online services providing practical, emotional and psychological support for those diagnosed with breast cancer.

https://futuredreams.org.uk/

Macmillan - provides specialist health care, information and financial support to people affected by cancer.

https://www.macmillan.org.uk/

Life After Cancer - brings people together who have finished cancer treatment to form support groups, with an aim to increase their physical, mental, emotional and social wellbeing.

https://www.life-aftercancer.co.uk/

The NHS website provides helpful information and resources.

https://www.nhs.uk/conditions/cancer/

Speaking to other people who are going through the same thing as you can be a great support. It can help you remember you're not alone.

Cancer Care Map - an online resource that aims to help you find cancer support services in your local area, wherever you are in the UK.

https://www.cancercaremap.org/

Hub of Hope - a national mental health database, bringing help and support together in one place. Use your postcode to search for support groups in your area.

https://hubofhope.co.uk/

If you do receive a cancer diagnosis, the news can feel overwhelming and you'll have a lot of questions. Explore our <u>cancer care articles</u> for more information. If you're a member with PHC, here's more information on our <u>dedicated cancer support service</u> you may have access to.

¹³ PHC doesn't endorse any particular website, isn't responsible for third-party content and the use of such resources is at a member's own risk. PHC isn't liable for any losses other than those arising from any liability that cannot be excluded by law. On signing up to any such website, you'll be agreeing to the terms of that website. Please make your own checks before using a site and always follow the advice of your medical professionals.

Support guidance

There are many ways partners, family, friends and employers can support someone throughout their cancer journey, even after the all-clear.

Don't neglect your own needs as a carer

Cancer is an individual journey, and once diagnosed, friends and family play a huge part in support. Partners of individuals with cancer quickly become a carer for that person. Allow your loved one time to talk and recognise all the varied emotions they will go through from diagnosis to acceptance.

From both a practical and emotional sense, carers often neglect their own needs. Attending appointments, expected to recall medical information and then interpreting what was being said can be overwhelming. Most information given during a consultation is forgotten if not written down. Advising the partner/friend to start a notebook with information is essential.

Cancer initially can bring people together however, over time, it can be very isolating as support from family and friends falls away. Partners can become disengaged as they slip into a carer role, and friends only ever ask after how the person with cancer is. This can lead to resentment over time from the principal carer. Carers need support too.

Keep supporting

Once a person has been given the 'all-clear' following cancer treatment, the support may seem to diminish somewhat. What many people don't realise is that the monitoring scans and follow-ups are really difficult for the cancer survivor as there is always the chance that the cancer could return at any point.

If the support could continue during follow up, even if it is just a quick message or a call following the consultation, it could make all the difference. Just knowing that there is still the ongoing support and care is important.

Provide practical support

Doing the food shop, running errands and offering lifts can be really helpful. Make sure to offer help in a way that's sensitive to how they're feeling - it's important to be respectful of their independence and autonomy when offering support.

Cook meals, offer to help around the house and in the garden. Try to behave normally around your friend or family members, being sensitive and allowing them to talk if they want to, but not putting pressure on them to do so. Allow them to talk about their fears, family and understandable worries about children.

For more information on how to support a family member or friend with cancer, visit the **Macmillan website**.



16

Supporting our members

Every cancer journey is different, which is why we offer our members a number of services to support you and your family after the all-clear.

Cancer Care Team

Our Cancer Care Team is here to support you during every step of your cancer journey. If your membership covers your cancer treatment and you're diagnosed with cancer, we'll connect you to your very own cancer case manager.

You'll be given a direct phone number for them and they'll ensure your notes are always up to date, so you won't have to explain your situation if your case manager happens to be away.

24/7 health support line

As a PHC member, you can also speak to our specialist cancer nurses. Call our claims line on **0800 068 7111** (9am to 8pm Monday to Friday and 9am to 5pm Saturday) and a member of the team will put you in touch with a nurse on diagnosis.

Outside of these hours our experienced nurses provide round the clock support by phone on **0800 027 1393**.

We want to make sure you feel supported after being given the allclear. Our members can access our health coaching service for up to two years after treatment ends.

FIND OUT MORE

Health coaching

Supporting our members to make informed and conscious choices about their health.

We know that helping you recover from cancer is about more than just beating the disease.

That's why we've worked with clinical experts to create a dedicated health coaching service. It's designed to look at every aspect of our members' health and help them feel more like themselves, both during and after treatment.

This service is available to members with cancer cover on selected plans. Please refer to your Membership Handbook to see whether this is something available to you.

This six-month coaching programme provides regular online sessions with a dedicated health coach. They'll provide support in setting goals, and give personalised expert guidance, such as:

- eating better and exercising more
- getting better sleep
- · managing side effects
- · dealing with low mood or lack of energy.

It's important you feel seen and heard.

Feel understood.

Have a safe space.

Know the next steps.

Feel as best as you can.

We hope this guide reassures you - and your loved ones - that information and support is available during the all-clear stage of your cancer journey.

To find out more about the support available, including what is and isn't covered, call the PHC claims team on **0800 068 7111** or email us at **claims@thephc.co.uk**.

