



Back-to-Work Guide for Head and Neck Cancer Patients

A practical guide to support people living with
Head and Neck Cancer in returning to work

This is an interactive guide to ensure that you can get the
most out of the information and support provided.

-  *Navigate your way through the guide by clicking on the
tabs throughout.*
-  *Make the forms and templates your own by filling in the
information to assess your working circumstances.*
-  *Don't forget to click on the links for further support!*

Start



This Back-to-Work Guide has been created and funded by Bristol Myers Squibb in partnership
with The Swallows and the Mouth Cancer Foundation and supported by Working With Cancer,
Salivary Gland Cancer UK and members of the Head and Neck Cancer patient community.

ONC-GB-2100022 | March 2021

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Why we have written this guide

Good advice can be hard to find (and to give)

Meet the Back-to-Work Guide Steering Group

A recent UK survey showed that following treatment for Head and Neck Cancer, 23% of patients had not returned to full-time work.¹

While there may be many reasons why people don't go back to work after treatment, including personal choice, these figures could suggest something far more serious is going on - possibly even something specifically related to Head and Neck Cancer treatment.

Returning to work after treatment is not always easy – something that individuals living with or supporting people with Head and Neck Cancer in the UK have known for a long time.

So what might be standing in the way of someone who *does* want to return to the workforce?

A working group of Head and Neck Cancer survivors and supporters came together to write this guide with the aim of answering exactly that question and providing some solutions.

So if you want to get back to work, whether for an existing employer or for a new one, we hope this booklet will help you achieve your goal as easily and smoothly as possible.

Following this guide will not guarantee that you will feel 100% ready to return to work or that you will get the opportunities you desire. However, we hope it will help you to assess your options, have positive conversations with employers, avoid some possible pitfalls and overcome some potential barriers.

We wish you every success in the next stages of your work life!

The Back-to-Work Guide Steering Group

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Good advice can be hard to find (and to give)

You may already know that more than 30 areas of the head and neck can be affected by different cancers.² Each cancer, and its treatment, affects an individual in different ways. Indeed, even people with the same type of cancer can experience very different symptoms and challenges.

Given that Head and Neck Cancer as a group is relatively rare, as a survivor of such a diverse category, it can be difficult to find guidance that is specific for your situation.

This guide has been written based on the personal experience of the steering group as well as the stories they have heard from other people with Head and Neck Cancer through their networks and organisations.

The fact that you are reading this guide suggests that going back to work is on your mind. There may be many reasons for this.



“While we cannot hope to cover every individual’s circumstances and situation, we have tried to provide practical guidance and advice for people who are getting their lives back on track after treatment for Head and Neck Cancer.”

*Chris Curtis,
Chairman, The Swallows, and cancer survivor*

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Going back to work is a big decision, which is why this guide has been written to support you. Before we get into the detailed guidance, here are our top tips:



There is legislation to protect your right to work and all employers should be familiar with their legal obligations towards you



People need time and space to recover before returning to work, so don't rush into it before you are ready



When you are ready to go back to work, make sure that your health and recovery is still your priority because this is essential for success in and out of work. For example, continue with the good habits regarding exercises and lifestyle that you have been doing as part of your recovery



In our experience, a phased return to work is probably the best approach and is more likely to set you up for a successful comeback



Not all disabilities are visible and you may need to explain things about your condition to employers and colleagues so that they can support you properly



There are bound to be some challenges to overcome, and these may vary depending on the work setting, but most of these can be overcome with planning and flexibility from you and your employer

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Ambassador and cancer
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Ambassador and cancer survivor,
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Barbara Wilson

Founder and Director,
Working With Cancer

“Returning to work after Head and Neck Cancer treatment is very difficult for many. I want to do something to change that.”

Emma Kinloch, Chair, Salivary Gland Cancer UK, and cancer patient advocate

“This guide will really help Head and Neck Cancer survivors navigate the sometimes challenging journey back into the workplace. The Mouth Cancer Foundation is pleased to do anything it can to make life easier for patients and carers at every stage of recovery.”

Elizabeth Laverack, Media and Public Relations, Mouth Cancer Foundation

Considerations about going back to work

Getting back to work after an enforced break due to Head and Neck Cancer and its treatment can have huge benefits. Apart from the financial gains, working (or not) can affect your sense of personal identity, self-esteem and social recognition.³ It can also give you a sense of structure, purpose and normality as well as valuable social interaction.

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You may be interested to know that a Macmillan Cancer Support survey revealed that⁴

87%



of people employed when diagnosed with cancer said it was important to continue working after their diagnosis. Of those:



62%

said it gives them a sense of normality



55%

said it helps keep them positive



54%

needed the money

In fact, most mental health professionals agree that the workplace environment can have a significant impact on an individual's mental well-being.³

And, of course, you want that impact to be a positive one!

Returning to work is usually a gradual process that takes time. It may be difficult to assess whether you feel ready to return to work. The questions in this guide suggest some things to think about.

Some people find that volunteering is a good opportunity to get a flavour of what returning to work would be like and whether you are truly ready. It can give you a sense of purpose and help you get into a routine of working life, but without the added pressure of bosses and deadlines.



TOP TIP

“Look at volunteer roles to get you back in to the mind of working again. This gives you the flexibility to stop and start depending how you feel, plus an opportunity to show future employers you are ready for work.”

*Chris Curtis, Chairman,
The Swallows, and cancer survivor*

Your work rights

There are two main pieces of legislation in the UK that protect your rights at work and support you in making a successful return as a cancer survivor.

1. The Equality Act (2010) covers England, Scotland and Wales

Before the Act came into force, there were several pieces of legislation to cover discrimination, including the Sex Discrimination Act (1975), the Race Relations Act (1976) and the Disability Discrimination Act (1995).⁵

2. In Northern Ireland, your rights are covered by the Disability Discrimination Act (1995)

Knowing about the legislation and how it relates to people with cancer can help you to feel more confident asking for the support or adjustments to your working practices that you need in order to do a good job. The fact that there is a legal framework that supports you requesting certain adjustments to the way you work is a reminder to you that you are not being difficult or demanding; you simply want to create an environment that supports your productivity – and that's good for you and for the business you work for.

All employers should be familiar with the relevant laws, and any good employer will want to support you as much as they can regardless of their legal obligations to do so.

Sadly, a survey by Macmillan showed that one in five people with cancer who returned to work after their diagnosis faced discrimination at work.⁴ In the rare event that an employer does not support you sufficiently, knowing about the legislation yourself may help you to recognise if you

are being treated unfairly and take steps to rectify the situation.

Here are the main points of the legislation that relate to working post-cancer treatment.

- ✓ **You cannot be treated less favourably than anyone else** because you have cancer, or for reasons connected to the cancer⁶
- ✓ **The protection is lifelong** from the moment of diagnosis, even if you are in remission
- ✓ **Everyone with a cancer diagnosis** is classed as having a disability
- ✓ **The legislation covers all areas of employment**, including when you are applying for a job, during your employment or getting references for a new job
- ✓ **You are entitled to ask for adjustments to the way you work**, and your employer must make these adjustments providing they are reasonable and practical

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What are reasonable adjustments?

While there is no legal definition of 'reasonable adjustments', it basically means anything that is needed in order for you to do your job. It could be any or a combination of the following and they can be:

- ✓ Working from home some/all of the time; this has become much more common and easier to do in recent years
- ✓ Changes in what you actually do - for example, in a highly physical job you might take on more of an advisory role for other colleagues rather than being as 'hands on' as before
- ✓ Changes to where your desk is placed, e.g. if you need to be moved away from the window due to radiotherapy making your skin sensitive
- ✓ Changes in your working hours, e.g. longer breaks and/or shorter overall hours
- ✓ Access to a clean, private space for making up enteral feeds and cleaning tubes
- ✓ Time off for medical appointments



Your employer should be aware that some adjustments might be short-term and some may be permanently needed. In either case, your rights are the same.



TOP TIP

"I would explain to my employer what workarounds I need to use in order to maintain my performance and what they need to do in order to facilitate that. Simple things such as a supply of tissues for those who drool as a result of their treatment; a good supply of wholesome water at room temperature for those with dry mouth syndrome; not to be a 'hand wringer' and continually ask how I'm feeling. No two cancer survivors will have the same needs.

Head and Neck Cancer hasn't taken away my drive or abilities. Simply because I may have difficulty pronouncing certain letters or words doesn't mean that I've lost my intellect."

Stuart Caplan, Mouth Cancer Foundation Ambassador

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How to check your rights

Your first point of call regarding your rights is likely to be your company's HR department. They can also advise you on any company policies that give you more than the minimum legal requirement, e.g. for sick pay or leave.

There is also useful guidance and a list of places to go for advice on the Working With Cancer website:

Working With Cancer

When to go back to work?

Only you can answer this question. And your decision is not just about *whether* to return to work, it may also be about *how* you return to work. The decision to go back to work, and how your work life may be different from before, is likely to depend on multiple factors, such as the treatment you had and its side effects, your financial position and the level of practical support you have from family, friends and work colleagues or managers.

To help you make your decision, here are some questions you might find useful to ask yourself and/or discuss with a trusted friend or family member. Try to take the time to think through these questions and write down your responses in the sections below:

How ready do I feel emotionally, psychologically and physically to go back to work?

Do I feel under pressure to return to work quickly? If so, where is this pressure coming from?

Do I want to return to work gradually to ease myself into a different routine?

Do I have a good support network outside of work to help me transition back to 'normality'?

How understanding and supportive do I feel my previous employer will be about my needs and recovery?

Do I want to change how I work, e.g. going part time, working from home more or even going freelance?

Would it be helpful to do some volunteer work first, which might ease me back into the working mindset and help me test whether I'm ready?

If returning to a previous employer, how well do I feel I will be supported by my colleagues and managers to do a good job?

Do I want to go back to the same job that I did before?

Try to answer these questions for yourself, with real honesty. If you don't feel ready to go back to work right now, that's OK. You're more likely to have a successful transition back to work if you are as ready as possible and take things at your own pace.

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Managing your mental health at work

There's no doubt that you have been through an incredibly tough time from diagnosis through the months of treatment. Once your treatment plan is finished, you and those close to you might expect you to breathe a sigh of relief and move on with your life.

Unfortunately, our psychological processes often take longer to recover than our physical and biological ones. And each of us is different. Even those who seem to bounce back from the toughest of ordeals can find that the full psychological impact only becomes apparent some time later.

That's why it is important to ask yourself the questions outlined in the previous section and answer them honestly. The only person who can decide when you are psychologically ready to go back work **is you!**

What is normal?

The impact of cancer makes it unlikely that life will go back to exactly how it was before. However, you will build a new normal for yourself. Cancer changes people. It can reveal immense courage and inner strength. It can also throw light on aspects of our character, or that of others, that we don't like so much. It can refocus or completely change our priorities in all aspects of our lives, including work.

What's more, your life since diagnosis has been anything but normal. So what does normal really mean? Or, more importantly, what do you want it to mean now?

In terms of work, these questions might make you keener than ever to return to a job that you found fulfilling. Alternatively, you may be thinking about changes to your priorities and aspirations that lead you to another conclusion – a different role within your company, a new job entirely or shorter or more flexible hours, for example.

Planning for the future

Part of the process of deciding what your new normal looks like involves planning. However, planning can be particularly difficult after the end of your treatment. During treatment, it's likely that most of your plans were relatively short-term. You may have been living day-to-day or week-to-week, with timeframes probably linked to your treatment intervals, and your forward-planning not extending far beyond your next clinic appointment. So making longer-term plans can take some time to get used to again.



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Going back to work confidently – In my experience

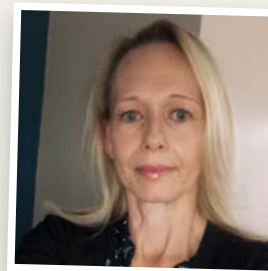
Name: Karen

Type of cancer: Diagnosed with Tongue Cancer in 2016

Treatment: Surgery and radiotherapy

Job: Full-time Nursery Assistant

Hobbies: Running (part of a running club)



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The Challenge



My confidence took a hit because of a number of factors. Primarily, my surgery and radiotherapy severely impacted my speech and communication. My diet had to change because I was unable to eat certain foods and I would take a long time to eat, and because of the physical scars from surgery and radiotherapy. Working in a school, all of these factors are a big part of my daily life, so I needed to overcome them in order to fulfil the job I love.

The Solution



I found someone at work who I could confide in. This person became my confidante and I kept her up to date with everything. I had someone close, who understood me and the challenges I faced, and she was able to advise and help me. I had someone to lean on rather than feel isolated and alone. Being open with my colleagues gave me confidence as I was reassured they understood more about why I may be having difficulties.

The Outcome



I feel confident in supporting the children I teach every day with the development of their own speech and communication skills.

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Another perspective

“On the way to work, I would give myself pep talks to put my situation into perspective – I would tell myself things like, ‘You’ve got this. After everything you have been through, what’s the challenge? What’s the worst that’s going to happen?’”
Ben, Head and Neck Cancer survivor



Going back to work confidently

There's also an element of self-confidence that is needed in order to go back to work. For a start, the natural belief in our own indestructibility that most of us once took for granted has been dented and eroded. Secondly, we've been relying on others more than usual during our treatment – the expertise of our doctors, the understanding of our friends, the physical and emotional support from our families.

So it's natural to wonder, *"have I still got what it takes to do this job?"*

Trusting yourself, building your confidence and taking control of your future is something you have to re-learn to a certain extent. And that takes time.

Remember, you have just as much to offer an employer now as you did before cancer, if not more!

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Tips for rebuilding your self-confidence and finding your new normal

You might consider trying some of these tips to help retrain your psyche.

To build self-confidence:

Start with small goals and gradually build up as you achieve each one – these could be really small goals at first; it's the number of goals you achieve that adds to your self-confidence

To tackle negative thoughts:

It might be helpful to remind yourself of any things your doctors and nurses have said in the past that helped put your fears into perspective – it doesn't make the fear go away, or claim that your worries aren't real, but it can make the concern or negative feeling more manageable in the moment

To look at the future:

Members of your family and well-meaning friends might want you to put cancer behind you and 'move on'. Although you might feel the same, sometimes people close to you aren't the most objective people to discuss your future plans – or lack of plans - with. Do ask your GP or local cancer support group what help might be out there for you to tap into. Some counselling, coaching or support groups at this stage can be really helpful to guide you to your own best future. Also, your employer might be able to arrange counselling or coaching support.



Managing your physical health at work

The physical effects of Head and Neck Cancer cover a wide range. Here are some of the common aspects and some ideas on how to minimise their impact on your life inside and outside of work.

Explaining these physical effects to your line manager and colleagues can help them to understand any adjustments that might need to be made and help you work together to plan a realistic phased approach to your return.

By managing your own, and your manager's, expectations from the outset, you may be able to avoid any disappointment as you transition back to work.

Some larger employers have occupational health advisors who can provide guidance about adjustments and a phased return to work. However, the advice they give may be quite general and their knowledge of Head and Neck Cancers may be limited. You are most likely to be the expert when it comes to determining how best your employer can make your return to work as easy as possible.



TOP TIP

"Some employers wait for the employee to make the request for adjustments, which is wrong, but they assume the employee will take the lead, or they don't know about adjustments and don't offer them, or they don't offer them in the hope that the employee won't need or want them (and therefore make their life difficult)!"

*Barbara Wilson, Working With Cancer,
Founder and Director*



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Changes to physical appearances – In my experience

Name: Lisa

Type of cancer: Diagnosed with Oral and Thyroid Cancer in 2019, after surgery, the Oral Cancer returned, and I was diagnosed again in 2020

Treatment: Surgery and radiotherapy

Job: Administrative Assistant, Bereavement Services

Hobbies: Spending time with my family at our caravan in Anglesey, having days out locally, plus girly shopping trips with my daughter



Section 1

The Challenge



Having my thyroid removed left me with a big scar across my neck. You wouldn't be able to see it now as it's right in the crease of my neck, but at first it was clear as day. When I first saw a picture of myself from my sister-in-law's wedding (just five days after the operation!) with the scar I was mortified and didn't want anyone else to see it.

The Solution



I got around it initially by wearing scarves. It sounds simple but I would always wear a scarf to cover up the scar across my neck, which really helped when it was at its most obvious.

The Outcome



After a while, I became confident in approaching the matter with people and explaining what had happened. For those first few months however, scarves really helped my confidence, and allowed me to avoid having to talk to people about it if I didn't want to. I've also now got a lovely scarf collection!

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Another perspective

"I made sure that I was always dressed appropriately. I found that wearing a vest was a good way to conceal the PEG – making sure that the focus was my job, rather than any physical side-effects from my treatment."

- Ben, Head and Neck Cancer survivor



Changes in physical appearance

Changes in your physical appearance may be the most visible sign of your Head and Neck Cancer. The physical signs of surgery as a result of Head and Neck Cancer can lead to profound psychological trauma and distress. The face plays a huge role in an individual's sense of self-esteem.⁷

We are all affected by how others respond to us in personal interactions. Compliments or criticisms are internalised and can

influence our self-esteem. And it is a sad fact of human existence that people are judged by appearance.⁷

We hope that by the time you are considering going back to work you have had some psychological support, which may include helping you 'mourn' and confront the loss of your previous image and reframe your new appearance in terms that are acceptable, realistic and positive.⁷

Potential solutions

- ✓ **Increasing your interaction with people gradually** before you go back to work, starting with people who know you and moving on to strangers, can help you to understand the reactions that you may get from other people and develop coping strategies
- ✓ **Preparing your colleagues before your return to work** can help to avoid embarrassment or awkwardness when they first see you – this could be described in an email (from you or your manager) or even a photograph
- ✓ **For further support** on the psychological implications for you, individual or group psychotherapy may be useful

(A psychotherapist will examine your perceptions, areas of struggle, and coping strategies to help them understand the impact on you of the physical changes and help you strengthen your coping strategies or develop new ones)⁷

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Video calls – In my experience

Name: Ben

Type of cancer: Diagnosed with stage 4 cancer of the throat, tongue, tonsil, roof of mouth and lymph nodes in September 2017

Treatment: Chemotherapy, radiotherapy and surgery

Job: Information Security Consultant / Personal Trainer

Hobbies: Fitness and adventure



Section 1

The Challenge



I had physical side-effects from my treatment: stage 3 burns from the radiation, infections on my neck and my teeth have been badly damaged. These could be visible when I am on video calls with current or potential new clients.

The Solution



I always consider the position of the camera and the lighting. By positioning my camera a little higher and making sure that lighting is correct, it minimises the view of my physical side-effects. It's important not to shy away from it, but I can be clever with it.

The Outcome



When I have video calls with people, they can't really see or tell that I had lymphoedema on my neck or notice the other physical side effects.

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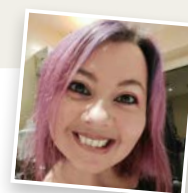
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Another perspective

"In preparation for scheduled calls at work, I make sure that I have a glass of water, tissues, and saliva spray nearby in case my mouth starts to get sore or if I over-salivate"

Laura, Oral Cancer survivor



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Video calls

The way people work has fundamentally changed over recent years, with more and more people deciding to work from home. This is a positive as it makes working from home, if you wish to, a much more acceptable option than before for many office-based jobs. On the downside, you may not be entirely comfortable with video conferencing, particularly with people you don't yet know.

Potential solutions

- ✓ **Even on a video call**, you don't **have** to use video if you don't wish to
- ✓ **If you are talking to someone for the first time**, you might consider beginning the call with your video feed off and explaining that your appearance might be somewhat different from what they expect before you turn the video on

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Fatigue – In my experience

Name: Ben

Type of cancer: Diagnosed with stage 4 cancer of the; throat, tongue, tonsil, roof of mouth and lymph nodes in September 2017

Treatment: Chemotherapy, radiotherapy, and surgery

Job: Information Security Consultant / Personal Trainer

Hobbies: Fitness and adventure



The Challenge



Early January 2018, two months after my treatment, I decided it was time to go back to work, but it was probably too early, I was still feeling really tired, and had a total lack of energy, but I needed to for many reasons, including finance and self-worth.

The Solution



I let my direct team know that I had been through cancer and quite brutal treatment, and this then meant I tended to get quite tired throughout the day. I worked closely with my client and set clear, achievable deliverables.

When I was at work, I scheduled my day, planning for peaks and troughs in my energy levels. For example, by mid-morning, my energy would dip so I would take a break to make a cup of tea. At lunchtime, I would go and sit in the car and some days I would have a nap. If I needed to, I would also leave work early. When I returned home, I'd sleep for 30 minutes, maybe up to an hour, then I would spend time with my family.

The Outcome



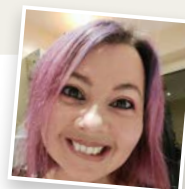
I was able to meet my deliverables, ensure that my client saw the value I brought and, therefore, cancer wasn't a barrier.

Another perspective



"I've noticed that some survivors swing from night owls to early birds and sometimes early birds like me have turned into night owls. So when looking at employment opportunities the ability to work on 'flexitime' may be attractive not only to the candidate but also to the employer. Flexi-time would also enable the cancer survivor to accommodate the 'fatigue curtain' when it descends."
Stuart, Mouth Cancer Foundation Ambassador

Another perspective



"Being open and honest with my employer was helpful as they understood when I needed to take a break. The office that I worked in had private quiet rooms for meditation where I could take a nap if needed."
Laura, Oral Cancer survivor

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Fatigue

After chemotherapy and radiotherapy, fatigue can be a real problem. Fatigue is often misunderstood by those who have not experienced it themselves, so you might need to explain it to your bosses and colleagues. Fatigue is not just tiredness. It is an overwhelming exhaustion that doesn't go away, even after you rest and sleep.⁸

Potential solutions

- ✓ Asking your employer for adjustments to your working hours, such as job share or flexible working, can be good ways to work around fatigue or changes to your body clock
- ✓ It may be helpful to keep a fatigue diary and discuss it with your doctor or nurse who can suggest solutions or workarounds⁸
- ✓ Try to plan ahead and be realistic about what you can do; if you can identify times when you tend feel more or less fatigued (maybe by using a fatigue diary as above), you can use this information to help you plan your day⁸
- ✓ Eating well and drinking lots of fluids can help increase your energy levels,⁸ although we know eating and drinking come with their own problems, which we cover in the following pages
- ✓ Being physically active can also improve your energy levels and increase your appetite⁸
- ✓ The NHS-endorsed Untire self-help app provides a step-by-step guide to help with cancer-related fatigue. Download: [App Store](#) | [Google Play](#)

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Eating and Drinking – In my experience

Name: Karen

Type of cancer: Diagnosed with Tongue Cancer in 2016

Treatment: Surgery and radiotherapy

Job: Full-time Nursery Assistant

Hobbies: Running (part of a running club)



Section 1

The Challenge



Due to my treatment, I do not have any sensation in my mouth and it also gets a very dry. As such, eating certain foods can be very difficult and I also do not know when I have finished all the of the food in my mouth. This can be embarrassing if you go to speak and food comes out. I also take a long time to eat. When I was started on a percutaneous endoscopic gastrostomy (PEG) for a few months, this came with lots of challenges too, including catching the tube on clothing, unable to feed via the tube in a public place, etc.

The Solution



I carefully plan what I am going to have for lunch and bring in lunches which have a lot of sauce and are easily chewed. Soups, lasagne, shepherd's pie, etc, are perfect for me. Working in a school can mean I don't always get the full lunch allocation I need, so I ensure I prioritise the foods I know I need. I also always give myself five minutes after eating to go to the bathroom and wash my mouth out, to ensure all the food is gone. Important things to remember with a feeding PEG is that it can be quite messy. I would wait until I had a quiet, private space, where I could sit down and make sure the area was relatively clean. I carried a bag with me everywhere which had a special towel, wipes, medication and food, along with spare clothes, if needed. Again, being prepared for every eventuality is key with a PEG, to avoid an embarrassing situation.

The Outcome



I feel confident going into work knowing I have the food I need to get through the day. The key message with returning to work is that you can't forget self-care, and that includes diet. If you look after yourself whilst at work, you can ensure your return to work is long lasting and continuous.

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Another perspective

"I developed a love for soups, as I didn't have to spend hours chewing them. They became a staple part of my diet when I first went back to work after surgery and was struggling with solid food."

Lisa, Oral Cancer survivor



Eating and drinking

While eating and drinking is not specifically work-related, it can be an important part of team building, whether that is having lunch together or attending work-related functions.

Difficulty swallowing is a common after effect of Head and Neck Cancer and its treatment. Some people experience a dry mouth, which can also affect swallowing. Difficulties with eating and drinking can have a profound effect on your self-confidence, possibly even leading you to avoid such social situations.

Problems with eating and drinking can also include loss of your sense of taste.

When eating is not an enjoyable experience, that can lead to weight loss, lack of energy and low mood.

If you use a percutaneous endoscopic gastrostomy (PEG) feeding tube, you will need access to a fridge to store opened containers. You might also prefer a private space to set up, use and clean the tube and the stoma site.

When eating and drinking around colleagues, it may be easier if they understand some of the challenges you experience. This could potentially be covered before your return to work in an email from you or your manager. However, it is always your choice as to what you feel comfortable saying and to whom.

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Potential solutions

- ✓ Extra time for meal breaks
- ✓ Time and a clean, private place to clean your mouth after eating
- ✓ If you use a PEG feeding tube, ask for a clean area (private if you wish) where you can make up and use the mixture and then clean the tube
- ✓ You may find it helpful to keep the lines of communication open with your speech and language therapist for ongoing support on coping techniques, such as mindful eating, to help you regain pleasure in food
- ✓ Your speech and language therapist can also see whether any further interventions might help you with eating difficulties

Speech and communication – In my experience

Name: Stuart

Type of cancer: Tongue Cancer

Treatment: Chemotherapy, radiotherapy and surgery

Job: Business consultant

Hobbies: Enjoying the performing arts; ballet, theatre, opera and music



Section 1

The Challenge



I had two thirds of my tongue removed and had a new tongue flap built from my own thigh tissue by a maxillofacial surgeon! This essentially meant I had to learn to talk again and work out new ways to pronounce words. I also had excess saliva as a result, which made it difficult to speak for long periods of time.

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The Solution



I have a three-stage approach. I start by speaking. If the person I'm talking to doesn't understand, I simply write what I'm going to say and give them the note; if my writing is illegible to them then I revert to the app. However, over time my speech has improved so I haven't really used it since I left hospital 7 years ago.

To get my speech back, I downloaded tongue-twisters and using a hand mirror my wife gave me, I recited them continually for 12 hours. I sat up all night doing that. My mouth then became accustomed to working with the tongue flap so it was job done! I discovered many workarounds – for instance, I can't pronounce the letter 'k' so I use a hard 'g' instead.

The Outcome



I regularly communicate with clients as part of my day-to-day role, and whilst there may be some challenges, overall people understand what I'm saying first time.

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Another perspective

"Through joining a local Head and Neck Cancer support group, I was put in touch with a speech and language therapist. This person really changed my life around. I was given mouth and tongue strengthening exercises which I still do five times a day, each time lasting about five minutes. If I stop doing them, there's a noticeable difference in speech and communication, I will have to keep them up for the rest of my life."

Karen, Tongue Cancer survivor



Section 5

Speech/communication

Dry mouth and hoarseness can affect your ability to speak clearly, while surgery can make certain sounds or words difficult to pronounce. Practice can certainly help improve your speech and communication, and you may be able to find workarounds for certain sounds or words.

Talking to strangers can be particularly stressful as they are unlikely to know that you have had treatment for Head and Neck Cancer. Sadly, there can be a perception that people with speech difficulties may have intellectual difficulties. Correcting these misconceptions as kindly as possible may become part of your daily norm.

Potential solutions

- ✓ If you have a dry mouth, ensure there is plenty of water available near your place of work; some workplaces have restrictions on having drinks in certain work areas, in which case a compromise or workaround may need to be found
- ✓ If you have excess saliva, you will want to keep kitchen roll or tissues to hand and have somewhere to dispose of the used ones
- ✓ Devise workarounds for letters or sounds that you can't pronounce
- ✓ Text-to-speech apps or iPhone settings

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Environmental considerations

Depending on the treatment you have had and any personal needs, there may be certain considerations about the environment you work in. These probably don't require huge adjustments, but it is worth discussing them with your manager or human resources (HR) team as early as possible so that everything is ready from day one of your return.

The environmental considerations very much depend on what your place of work is. For example, an office environment might be easier to adapt than a warehouse or outdoor space.



If you have had radiotherapy, the skin there may be very sensitive to sunlight



If you work in an office, your desk will need to be in a shaded area not right next to a window



For outside jobs, it may be necessary to wear a bandana to keep your neck covered, so any dress code would need to allow for that



You may wish to be near to a water fountain or kitchen, particularly if you are not allowed to have food or drink at your workstation



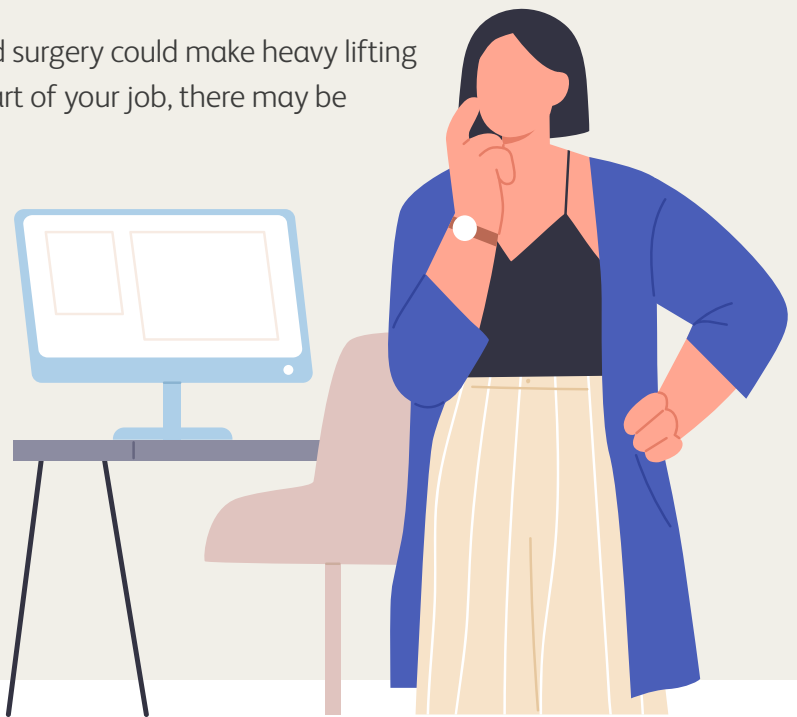
In larger office buildings or outside jobs, you might need to ensure that a toilet is nearby



Working from home might be an option if there are environmental considerations that can't be accommodated in your normal place of work; however, you can lose the benefits of the social side of work with home working

Heavy lifting

Neck and arm ache due to radiotherapy and surgery could make heavy lifting difficult or not an option. If this was a key part of your job, there may be other ways you can contribute to the team.



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Returning to your existing workplace

Everyone is familiar with how it feels to go back to work after a couple of weeks', holiday. It takes time to get up to speed with what has happened at work while you were away and to re-establish your routine.

The day before going back to work after a holiday can be associated with a very big 'Sunday feeling' of anxiety. Multiply a couple of weeks doing something nice to potentially months doing something challenging like cancer treatment, and it's clear that returning to the world of work is a pretty big step.

If you're returning to your existing workplace, the chances are you have had some contact with the company during your treatment. You will also have had some conversations with your line manager and/or HR department when you were diagnosed or when treatment meant you couldn't work for a while. It's important to have these conversations because things might have changed at the company while you've been away.

Having an onboarding or induction meeting prior to starting will ensure you are aware of what you are going back to.

Returning to work is rarely as easy as it might seem from the comfort of your own home. By discussing and planning your return to work, the transition can be as smooth as possible.

It's a good idea to start these conversations around a month before you return to work so that there is time to make a realistic plan and agree any adjustments that might need to be made.

While you are under no obligation to tell your employer all the details about your cancer or treatment, the more you share with them, the better they will be able to support you.

Being as open as possible will also head off any problems later on if your ability to do your job is temporarily affected in any way, e.g. needing to take time off for appointments or having some 'down time' if you are feeling overwhelmed or are suffering from fatigue.

Because cancer affects each person differently, conversations with your line manager and/or HR team will be very individual to your circumstances. There is no blueprint for cancer. It may be that you only need very minor adjustments to how you worked before, such as a longer lunch break. Or you might be most effective at work with larger changes such as text-to-speech software or a different level of responsibility.

On the next few pages are some ideas about how you might have these conversations with your line manager and/or HR team.



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The 'what I can do' template

You can use this template before you have a conversation with your employer, or fill it in together. By focusing on what you can do, rather than what you can't, both you and your employer can make a plan to help you be as productive as possible.

There may be some things that you only realise you have difficulty with once you've gone back to work. Your employer should be prepared for the fact that your needs and abilities may change over time or fluctuate during your recovery and reintegration into the workplace. Some adjustments to how you work may be needed in the short term and some may be needed for longer or permanently. However, having a think about this now will be a good start.

We have put some examples in the rows, but you can add as many things as needed to reflect your own work situation. A blank template is on the next page for your use.

What I can do	...as before	...with modification	...with difficulty
Use a keyboard	✓		
Make telephone calls		I will be speaking more slowly	
Travel for work		I might need to do this less frequently and have an 'understudy' in case I am feeling unwell on that day	



TOP TIP

"I think that employers need to be made aware of two important points. Firstly, Head and Neck Cancer hasn't taken away our drive and abilities and secondly, just because I may now have difficulty pronouncing certain letters or words doesn't mean that I've lost my intellect. Radiotherapy, chemotherapy or surgery doesn't turn a person into the village idiot."

*Stuart Caplan,
Mouth Cancer Foundation patient ambassador*

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The 'Back-to-Work' form

Another way to approach the conversations with your employer is to use a form or checklist. Your HR department might already have a template available, or you can use the one below as a starting point.

This can be used as an agenda for a meeting with your line manager or HR department or for you to prepare for what you want to discuss before you actually start work. There may be some information that is worth thinking about and jotting down in preparation for this meeting, such as ideas for practical support or adjustments you think you'll need. Other aspects might not be possible to answer until you have the meeting, and things might have changed at work while you've been away.

Remember, you don't have to have all the answers now, but thinking about the potential questions will help you to be prepared.. Make sure you include anything that you want to ask about. There is a blank template on the next page that you can use if you wish.

Clear description of the expected workload and who is doing what now and in the next weeks/months

e.g. At first, I will be working along with Sharon on the Company X account – Sharon will have responsibility for the day-to-day activities, and I will oversee the strategic direction and give operational input where needed. After two months, if all is going well, I will also work with Derek on the Company Y account and take on more of the day-to-day operational work on both accounts

Steps in a phased approach to your return with realistic expectations (from you and your employer); don't put too much pressure on yourself straight away, even if you feel well

e.g. First two weeks: induction and refresher training (two half days per week); From week two to four: working the equivalent of two days per week (flexible); etc

Details of any practical support or adjustments needed

e.g. Flexible working hours, change to office layout

Agree who needs to know about your health status and how this will be communicated

e.g. Email from your line manager (that you see and approve beforehand), or an educational team meeting on Head and Neck Cancer

Sharing medical information

e.g. Some employers might ask to see a medical report from your doctor to be sure you are able to return to work – you are entitled to see any report before it is shared with your employer; you might also be asked to provide a list of medications that you will be bringing into work

Is there any support you will need from family, friends or work colleagues?

e.g. Transport to/from work, flexible or fixed start/finish times

How will your transition back to work be monitored?

e.g. Will you have regular meetings with your line manager or HR?

What support services does your company offer?

e.g. Some offer career coaching or counselling packages

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Clear description of the expected workload and who is doing what now and in the next weeks/months

Steps in a phased approach to your return with realistic expectations (from you and your employer); don't put too much pressure on yourself straight away, even if you feel well

Details of any practical support or adjustments needed

Agree who needs to know about your health status and how this will be communicated

Sharing medical information

Is there any support you will need from family, friends or work colleagues?

How will your transition back to work be monitored?

What support services does your company offer?

Other points to ask/discuss

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The first days, weeks and months



Although it is different for everyone, it is highly likely that your progress in returning to work will not be linear – there will be ups and downs. By expecting these from the outset and being realistic, hopefully you and your employer can avoid any disappointment.

In the run up to restarting work

As mentioned earlier in this guide, activities like volunteering can help you to ease you back into the working mindset. In fact, anything that gives you a regular commitment outside your normal routine and gets your mind engaged can be a good ‘warm up’ for the workplace.

In the first few days:

These are almost certainly going to be pretty tiring – try to keep the workload light while you settle in and reconnect with your colleagues.

Memories of how you used to work may come flooding back and it’s likely that you’ll be working a bit differently now – be kind to yourself and don’t expect too much too soon.

In the first few weeks:

As you start to get settled back in, the workload and expectations may increase – make sure you (and your colleagues) are following your back-to-work plan and that you keep the flexibility to balance your personal and work needs.

If you have a ‘bad day’ and start to have doubts about your decision to return to work, discuss your concerns with your family and friends – try to remember the reasons you had for going back to work.



TOP TIP

“You are not alone, there are people out there to help and that’s what this guide is for.”

Laura. Oral Cancer patient

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In the first few months:

Scheduling a regular meeting with your line manager every couple of weeks is a good way of keeping tabs on how things are going for you and for the business – these meetings can help to fix any problems and recognise your achievements.

Remember to tell your manager when you are ready to take on more responsibility as well as flagging if the workload is too much.

Ongoing

Remember to keep the lines of communication open with your manager.

If your health status changes or you need to have further treatment, this open communication may help you to consider and discuss your work options more easily.

Some of the effects of Head and Neck Cancer and its treatment, such as fatigue, can last for a long time, even years. So keeping a regular eye on how you are feeling, and letting your employer know if you need more support, will be helpful on an ongoing basis.

Don't forget your recovery

While going back to work might be an important milestone for you in your recovery plan, your health is still a top priority. When you get back to work, it can be easy to forget the good habits of exercise or rehabilitation that you have been doing at home. Be mindful of this and make sure you are still taking good care of yourself.

**TOP TIP**

“Differences in function/challenges can be permanent – sometimes employers/team members may forget! In some ways, we all want them to forget as it means we are ‘normal’ but many patients will not be ‘normal’ ever again and allowances/adaptations need to be long-term/permanent.”

“Try keeping your mind engaged while you are re-learning how to speak through a course, or volunteering, or other type of activity that ‘gets you going’. This can be used as a great ‘warm up’ to the workplace. I learned to play bridge when I was recovering – I didn’t have to speak to anyone, it was new and fun, forced me to leave the house and mix with people, and it kept my mind active.”

Emma Kinloch, Chair, Salivary Gland Cancer UK, and cancer patient advocate

Reconnecting with your colleagues

People are generally well-meaning and will be glad to have you back at work. However, they might feel awkward at first and not know what to say. Should they ask about your cancer or not? Is it OK for them to comment on any physical signs from your treatment? Is it right to ask you how you are feeling?

Although it is different for everyone, it is highly likely that your progress in returning to work will not be linear – there will be ups and downs. By expecting these from the outset and being realistic, hopefully you and your employer and colleagues can avoid any disappointment.

One way of helping your colleagues might be to send out an email in advance of your return to work. Discuss with your manager whether this comes from you or from them. The email might include the following:

New message

To

Subject

Why you want to return to work and what you are looking forward to, e.g. seeing your colleagues again or contributing to the important work of the business

How you are feeling right now, e.g. ready for work, excited, a little nervous

What your colleagues can expect from you, e.g. working at 75% of your usual capacity, your determination to do a good job

How your treatment went, e.g. any side effects that they might notice and how they can help you with them, any differences in how you speak

Any 'hidden' side effects they need to know about, e.g. fatigue or a need to avoid the sun due to radiotherapy treatment

You might even consider attaching a photo of yourself if there are noticeable signs from surgical treatment – this can avoid embarrassing moments when people see you for the first time and you look different from how you did before

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Be kind to any colleagues who 'get it wrong' when they interact with you. The chances are they have never met someone who has gone through Head and Neck Cancer before. By gently correcting misconceptions or directing the conversation to topics that are more comfortable to talk about, you will soon re-establish connections with your colleagues. Of course, there may always be people who just don't understand, or don't want to understand your perspective. You can only do so much.

Here are some phrases that you might find helpful to use with colleagues:



"I'm not ready to go into detail about that right now, but thank you for asking"



"Cancer affects everyone differently"



"I think we all find that difficult, I just find it difficult in a different way"

After cancer treatment, your life has changed. The lives of your colleagues may have stayed largely the same. Sometimes it can be a shock to see that the world has continued without you just as before. Although it can be difficult, helping people to see what it's like to walk in your shoes, and also trying to see the world from their perspective, are good places to start.



Looking for a new job

The whole experience of having Head and Neck Cancer can have a surprising up side. Going through something traumatic can help you to focus on what you want out of life and how you want to spend your time. And sometimes your priorities change as a result of this renewed focus on what matters to you.

Perhaps your old job was unsatisfying, but you stuck with it because it was secure. Maybe you've always dreamt of working for a different company or in a different role, but parked that as something for the future. Maybe you feel that your old job is not feasible, even with modifications.

Now could be a good time to make a change and apply for a new job with a new company. Or it could be that a change in your career path within the same company you worked for before would help fulfil your work ambitions. A note of caution though: looking for a new job puts quite a lot of pressure on you to be at your best. While you focus on your recovery, think carefully about whether this pressure will be manageable for you.

An alternative that you might want to consider is self-employment. While this comes with its own challenges and pressures, some people find self-employment very empowering.

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The decision to become self-employed involves a large range of considerations. Here are some:⁹

- ✓ Do you know what you want to do and are you qualified?
- ✓ The income is likely to be irregular and you might need to invest in the business to start with, so can you afford to be self-employed?
- ✓ What financial options are available, e.g. grants, bank loans, investors, crowd funding?
- ✓ Do you have a business plan? This can really help you focus your efforts and work out if your business idea will be profitable
- ✓ How will it affect your personal life or commitments? Although being self-employed usually gives you flexibility, many self-employed people find they work harder and longer than they did before
- ✓ Have you spoken with your family about their concerns? If your decision might affect them, it's a good idea to chat it through with them
- ✓ Are you aware of the legalities? Depending on what type of business you intend to run, there may be legal requirements and you'll also need to familiarise yourself with your tax and national insurance contribution commitments

It's a good idea to seek professional advice before embarking on self-employment.

The ‘what I want to do’ template

This template may help you to decide if now is the right time to look for a new job. We have put some examples in the rows, but you can add as many things as needed to reflect your own work goals and aspirations.

What I want to do	Could my current job fulfil this goal (possibly with changes)?	What new job would enable this to happen?
<i>I want to apply my design skills to a creative job</i>	<i>No, my company does not have creative roles</i>	<i>Designer at a creative agency</i>
<i>I want to work term-times only to spend holidays with my kids</i>	<i>I could go part time, but it's unlikely I would get the holidays off</i>	<i>Teaching assistant</i>
<i>I want to work with people who make a difference to the world</i>	<i>Yes, but not in my current department</i>	<i>Working for a charity</i>
<i>I would like more variety in my job</i>	<i>Yes, I could discuss a change of role with my boss</i>	<i>I might consider becoming a freelance consultant</i>



See page 38 to read more about Laura’s approach to finding a new job



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Looking for a new job – In my experience



Name: Laura

Type of cancer: Diagnosed with stage 4 Oral Cancer in May 2019

Treatment: Surgery to remove the tumour

Job: Support at a media company

Hobbies: Keen cook and baker

The Challenge



Being made redundant due to the pandemic exacerbated my fear of not being able to speak properly and I put off the job hunt for a few months. I was worried that people may laugh at my speech impediment.

The Solution



After my surgery, I made sure to practice taking control of my pitch by singing and using tricks like speaking slower or over articulating to improve my speech. I watched and listened to a lot of Freddie Mercury to see how he articulated words which helped. I spoke to my sister for the first time after my surgery and she mentioned how much my speech had improved – this gave me the boost in confidence I needed to start looking for a job.

The Outcome



My confidence has increased, and I now work for a media company.

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Applying for a new job

Applying for a new job can be daunting at any time, but if you are looking for a change or a new challenge it might be the right thing for you to do.

When looking at available jobs turns to actually applying for them, it's worth taking a moment to think about your reasons for leaving your current employer. It's easy to make hasty decisions, particularly if you are still coping with the emotional and physical rollercoaster of treatment and side effects.

On the other hand, if you are currently unemployed, applying for a new job may be your only option in terms of restarting work. In this case, the guidance earlier in this booklet about ensuring you really are ready is good to revisit before you actually submit your job application.

While your cancer experience does not need to define you, it may have given you exactly the skills or insights or perspective that an employer is seeking.

Just as if you were returning to an existing company, you are under no obligation to tell a potential employer all the details about your cancer or treatment. However, the more you share with them the better they will be able to support you if and when they offer you a job. Look at the guidance earlier in this book about communicating with employers and colleagues.

Remember, The Equality Act states that your chances of getting a job or promotion cannot be affected just because of cancer.

There are four main stages in getting a new job:



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The search

There are lots of ways of looking for a new job, and covering a number of different angles will throw your net as wide as possible to help you identify the ideal job for you. The main ways are:¹⁰



Networking



Speculative approaches



Recruitment agencies



Internet job adverts



Networking:

This means reaching out to everyone you know (and people they know too) to identify potential opportunities.

Think about how best to approach them: e.g. if you have speech difficulties, you might prefer to start by using LinkedIn or social media to 'test the water' before arranging a conversation. Have one clear objective, e.g. to gain an introduction from your contact to someone who has a job up for grabs or to find out information that might help your search.



Speculative approaches:

There may be particular companies that you would like to work with – contacting them regardless of whether there is a job being advertised is a speculative approach; most companies will keep your CV on file until something suitable comes up, or your approach might prompt them into telling you about a position they haven't advertised yet.

Written approaches should be professional and concise and give all your contact information. Find out as much as you can about the company before you approach them.

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Recruitment agencies

Temping agencies can be a great way of getting back into work and expanding your network and experience.

Recruitment agencies will have access to a large number of companies, and it is in their interests to match you with the right company because they only get their commission from the company if the company offers you a job.

The more information you can give the agency about your expertise, experience and work preferences, the more likely they are to find the right match for you.

There are some recruitment organisations listed at the back of this booklet that are particularly sympathetic to individuals looking for work who are either undergoing cancer treatment or returning to work post-treatment.

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Internet job boards/adverts

It is always worth doing some research beyond the advert; if you can tailor your application not just to the job but also to the culture or values of the company, your chances of success will be higher. See if the company has a LinkedIn or other social media page, for example, to get a flavour of the company culture.

The application

The CV is the backbone of any job application. Even if the company asks you to fill in a form, the chances are the information will be largely the same as a CV. You can also send out your CV when you make speculative approaches to companies.

Top tips for making your CV stand out:

Ensure it covers all the information that would be expected:

- ✓ Career/employment history (this can include volunteer work if applicable to the job you are applying for)
- ✓ If you were self-employed, list your main clients and the sort of work you did for them
- ✓ Professional qualifications
- ✓ Educational qualifications
- ✓ Personal interests



Download CV templates from Working With Cancer

You may worry that an employer will be put off if there is a gap in your employment history due to your cancer treatment. Don't! Remember this is your CV and as long as you are truthful and include the key information above, you can put whatever you want in it.

You might consider putting a section in the CV that explains (briefly) your cancer experience and any positives that have come out of this that would benefit the employer.

While the facts on your CV are set in stone, it is a good idea to tailor your CV for different companies or roles if possible, e.g. highlighting the key strengths (amongst the many that you have), which are of most relevance.

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The interview

The interview is undoubtedly the most nerve-wracking part of going for a new job. There are three keys to success: preparation, preparation and preparation!

STEP 1



Find out what type of interview it is going to be (ask if they don't tell you):

Job history: this is where the interviewer uses your CV as a guide to talk through your qualifications and job history, asking you about your achievements along the way and the reasons for your career choices¹⁰

Competency-based: certain questions are asked to give you an opportunity to describe an actual situation you have been in and the behaviour you displayed at that time to make a difference, along with evidence for this; the competencies you will be expected to demonstrate will relate to the role you are applying for, e.g. leadership, technical knowledge, problem solving, teamwork, strategic planning¹⁰

STEP 2



Once you know what type of interview it is going to be, prepare yourself accordingly. For the job history format, try talking through your CV with a friend or family member to practise how you will make sure your achievements are understood by the other person. If it's going to be a competency-based interview, think really carefully about all the things in your career that you are proud of. Don't hold back! Remember, you are selling your skills and strengths.

One word of caution: it might not be possible to find out what type of interview it is going to be and the interviewer might use a mix of both of the formats described above. The best thing is to be prepared for both eventualities.



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STEP 3

If it's a face-to-face interview, don't forget the basics: the time, location and who to ask for when you arrive. Be early, but not too early. If there is a café nearby where you can compose yourself for 20 minutes before you enter the office, that is a better option than waiting in reception for ages.

If it's a phone or, more likely nowadays, a video call, there are several things you can do to make it go as smoothly as possible:

- ✓ **Give the interviewer the heads up:** if you have speech difficulties or visible effects from surgery, you might consider giving the interviewer a short explanation beforehand; doing this shows the interviewer that you have care and empathy for others (an essential skill in pretty much any job)
- ✓ **Choose your lighting:** in an ideal world, make sure you are lit from the front – if you have a window behind you they won't be able to see you (try to avoid any temptation to purposely make it difficult for the interviewer to see you)
- ✓ **Use a headset if possible:** headsets are great for ensuring your voice comes through loud and clear and that you can hear the interviewer's questions
- ✓ **Try to avoid interruptions:** now that working from home is so common, people are more understanding about children or dogs interrupting calls, **but** it's not going to give a good impression in an interview



TOP TIP

"I feel that patients/survivors should never dwell on – 'why me' – cancer doesn't pick and choose. That mindset will come across to an employer often with negative consequences."

Stuart Caplan, Mouth Cancer Foundation Ambassador



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Starting your new job

Just as if you were returning to an existing company, you are under no obligation to tell your new employer all the details about your cancer or treatment. However, the more you share with them, the better they will be able to support you.

At a minimum, before you start working for them, you'll want to have discussed any adjustments you'll need, such as time off for medical appointments.

Look at the guidance earlier in this book about communicating with employers and colleagues.

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"Going back to work is a nerve-wracking experience. Cancer has a huge impact on your both physically, mentally and emotionally. Going back to work helps bring you back to some normality – that was really important for me"

"I found someone at work who I could confide in. This person became my confidante and I kept her up to date with everything. By having someone close, who understood me and the challenges I faced, she was able to advise and help me."

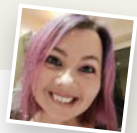
- Karen, Tongue Cancer survivor



"Look at everything you have gone through, you have gone through so much, and because of that, there is nothing that you can't achieve."

"Reframing – you're looking at a scenario and you have a number of ways to look at it. You take it, and you reframe it. People didn't think I was going to make it, but I did. When walking into an office, ask yourself how bad can it be?"

- Ben, Head and Neck Cancer survivor



"Asking for help is empowering. The first time you ask for help, you realise it's not a hard thing to do."

- Laura, Oral Cancer survivor

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Talking about Head and Neck Cancer

Facts you might want to share with colleagues and/or bosses

Types of Head and Neck Cancer

Treatments

Talking about Head and Neck Cancer

The consequences of Head and Neck Cancers can last well beyond the end of treatment. There is a huge range of things that can continue to affect a person's life, including pain and difficulty with eating, speaking and drinking. These effects are not just physical; there are psychological implications that are just as important to consider.¹

Some of the effects of Head and Neck Cancer are visible and some are hidden.¹ This can be difficult to deal with if you feel self-conscious about the visible symptoms and/or find it difficult to explain the hidden ones to other people.

Sometimes it can be helpful to explain to others what Head and Neck Cancer is. The following pages have some top-line information that you might find useful to share with people you work with.

By giving out factual information, you may feel more comfortable starting a conversation about cancer with your colleagues or bosses, rather than jumping straight into the personal impact it has on you. The chances are, they don't know much about Head and Neck Cancer. And even if they do have some awareness, they certainly don't know as much about it as you do!



Facts you might want to share with colleagues and/or bosses

What is Head and Neck Cancer?

As the name suggests, Head and Neck Cancer is any cancer affecting the head and neck. While that might seem like quite a small part of the body, it is a highly visible part and is made up of lots of different areas – each of which has a cancer named after it.

Types

Head and Neck Cancers are also described based on the type of cell the cancer started in.

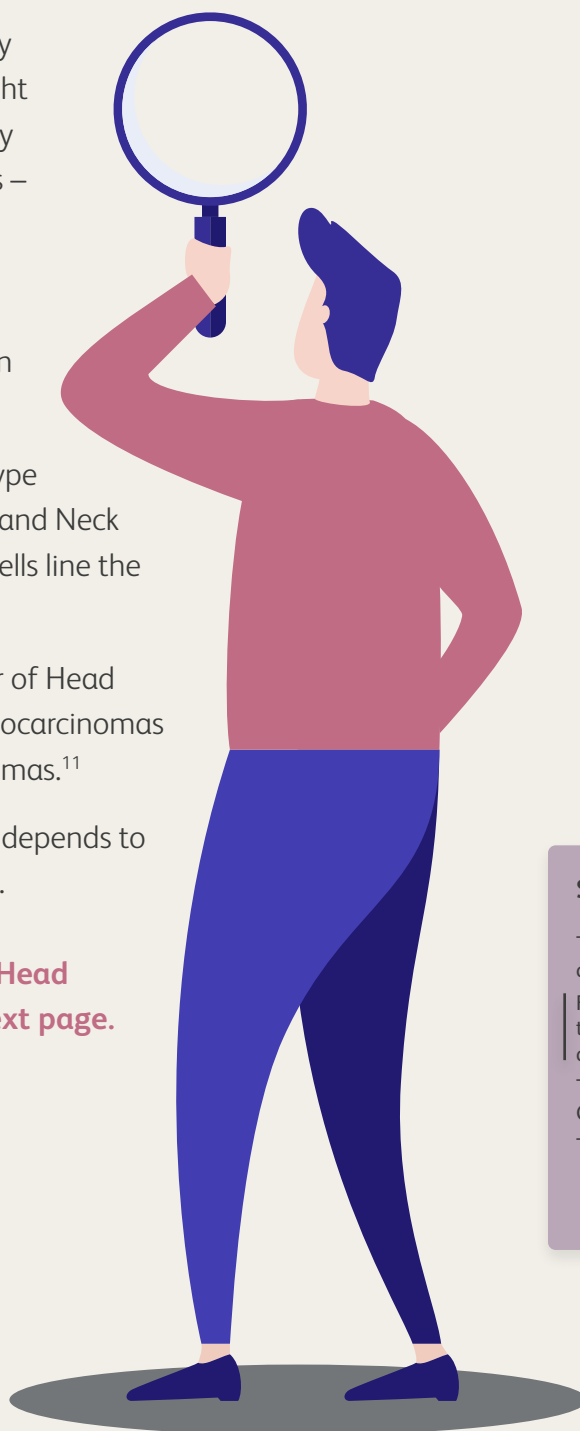
Squamous Cell Cancer is the most common cell type of Head and Neck Cancer. About 9 out of 10 Head and Neck Cancers (90%) start in squamous cells. Squamous cells line the mouth, nose and throat.¹¹

Other cell types can be involved in a small number of Head and Neck Cancers. These include lymphomas, adenocarcinomas (cancers that start in the mucous glands) and sarcomas.¹¹

Your treatment and ongoing impact of the disease depends to some extent on which type of cancer you have had.



There is more information on the types of Head and Neck Cancer on the diagram on the next page.



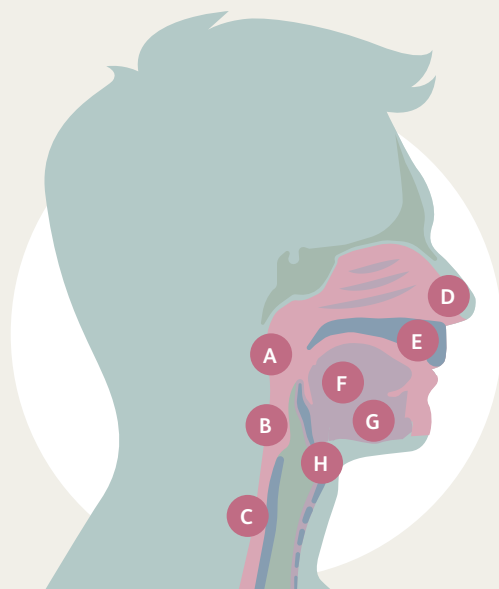
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Types of Head and Neck Cancer



A. Nasopharyngeal Cancer

This affects the part of the throat that connects the back of the nose to the back of the mouth.¹²

B. Oropharyngeal Cancer

This forms in the oropharynx, which is the part of the throat just behind the mouth. The oropharynx includes the base of the tongue, the back of the roof of the mouth, the tonsils, and the side and back walls of the throat. Human Papillomavirus (HPV), may increase a person's risk of Oropharyngeal Cancer.¹³

C. Hypopharyngeal Cancer

The hypopharynx is the lower part of the throat and is the hollow tube which starts behind the nose, goes down the neck and ends at the top of the windpipe and the oesophagus.¹⁴

D. Nasal Cavity and Paranasal Sinus Cancer

This is when cancer forms in the space just behind the nose (nasal cavity) or the nearby air cavities (paranasal sinuses) and sometimes spread to lymph nodes. Nasal Cavity and Paranasal Sinus Cancer are rare.¹⁵

E. Oral Cancer

The oral cavity includes the lips, the inside lining of the lips and cheeks, the teeth, the gums, the front of the tongue, the floor of the mouth, and the roof of the mouth.¹³

F. Tonsil Cancer

The tonsils are the two glands at the back of your throat. Tobacco use and regular consumption of large amounts of alcohol are leading risk factors of tonsil cancer. HPV is also thought to be a risk factor.¹⁶

G. Salivary Gland Cancer

This is found in the glands that produce the saliva responsible for breaking down food. There are two main types of salivary glands; major and minor salivary glands. Of the major salivary glands, there are three main pairs; the parotid glands (under the ear lobe), sublingual glands (under the tongue) and submandibular gland (under the jawbone). There are over 600 smaller, minor salivary glands throughout the lining of the mouth and throat. Salivary Gland Cancer is rare.¹⁷

H. Laryngeal Cancer

The larynx is commonly called the voice box and is located at the top of the windpipe (trachea) and in front of the food pipe in the upper part of the neck (pharynx). This tube-shaped organ is involved in breathing, talking and swallowing. The larynx also contains the epiglottis, a small piece of tissue that moves to cover the larynx and prevent food from entering the windpipe.¹⁸

Treatments

Most Head and Neck Cancers are treated with surgery, radiotherapy or a combination of both. Chemotherapy alone is rarely appropriate for these forms of cancer, but chemotherapeutic agents are sometimes used to enhance the effects of radiotherapy; this is known as chemoradiation.¹⁹ Plastic or reconstructive surgery and specialised dentistry are often needed.¹⁹

Ongoing physical effects of treatment

Radiotherapy can be debilitating, with many persistent side effects.¹⁹ These may include fatigue, which can last for weeks or months after treatment finishes, and sore or red skin. Skin problems usually settle within a month of treatment, but during this time you may need to protect your skin from the sun with a high factor sunscreen or wear loose-fitting clothing.²⁰

Unlike other cancers, the physical effects of Head and Neck Cancer can be particularly noticeable.

Those who have undergone laryngectomy (surgical removal of the larynx) must permanently cope with breathing through

an opening in the neck (stoma) and with dealing with any secretions coughed out through the stoma, as the airway is completely separated from the gullet (pharynx and oesophagus). It is also necessary to learn to communicate in a new way.¹⁹

Those who undergo oral and facial surgery may face difficulties with eating, drinking and talking, and may have to learn to live with facial disfigurement.¹⁹

Symptoms people continue to experience after completion of their treatment for Head and Neck Cancer may include the following:¹



Dry mouth
68%



Trouble swallowing
56%



Jaw stiffness
53%



Changes to voice/speech
66%



Pain or numbness
50%



Loss of taste
53%

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Psychological effects of treatment and Head and Neck Cancer

The psychological effects of your journey to date with cancer might actually ramp up around the same time as you are considering going to work.

In the Bristol Myers Squibb Head and Neck Cancer patient survey, 52% of patients reported feeling anxious before treatment and this dropped to 47% after their most recent treatment.¹ The relatively minor change is consistent with other data and suggests that the higher levels of psychological distress among people with Head and Neck Cancer is linked to lower quality of life.²¹

In the period after diagnosis and while you were going through treatment, you may have been putting all of your focus and emotional strength into getting through each day and each step of your cancer therapy. Now that you are looking to the future and considering reintroducing more normal aspects of your life such as work, you might find you are experiencing unpleasant feelings such as anxiety, loss of confidence or even physical manifestations, such as panic attacks.

If negative feelings come up after you've 'beaten' the cancer, this can take you by surprise. This is perfectly normal. Nobody can 'hold it together' forever, and your fears and uncertainties need to come out at some point.

Having a good support network of family and friends around you can be really helpful to get you through these feelings. Supportive work colleagues can also help when you go back to work, or even when you are preparing to do so.

Nobody can 'hold it together' forever, and your fears and uncertainties need to come out at some point.



More sources of information and support

ORGANISATIONS REPRESENTED IN OUR STEERING GROUP

Mouth Cancer Foundation:

www.mouthcancerfoundation.org

The Mouth Cancer Foundation is a charity dedicated to raising awareness and support for those suffering from or at risk of Mouth Cancer, Throat Cancer, and other Head and Neck Cancers, as well as providing assistance and information on living with Mouth Cancer for families, friends and carers.

Salivary Gland Cancer UK

www.salivaryglandcancer.uk

This charity is for people with rare Salivary Gland Cancers such as Adenoid Cystic Carcinoma. Their aim is to build a UK-wide information and support network for people affected by, or treating, these conditions.

The Swallows:

www.theswallows.org.uk

This nationwide Head and Neck Cancer Charity holds regional meetings and has a 24/7 telephone support line

Working With Cancer:

www.workingwithcancer.co.uk

Working With Cancer has a wide range of information and downloadable resources (some free, some priced at £9.99); the organisation also offers personal career coaching and advice services

APPS AND TOOLS: Eating

Mouth Cancer Foundation publication

'Brenda's Easy-To-Swallow Cookbook':

<https://www.mouthcancerfoundation.org/merchandise/>

APPS AND TOOLS: Fatigue

The Untire self-help app:

www.nhs.uk/apps-library/untire-beating-cancer-fatigue/

The Untire app is NHS-endorsed and provides a step-by-step guide to help you and your family and friends beat cancer-related fatigue

APPS AND TOOLS: Text-to-speech

Text-to-speech facility on iPhone or iPad

- Launch 'Settings' and tap on 'Accessibility'
- Tap 'Spoken content'
- Slide the Speak Selection toggle to 'ON'
- Optionally, adjust the 'Speaking Rate' slider to an appropriate setting

Text-to-speech on Android devices

- Open your device's Settings app
- Select 'Accessibility', then 'Text-to-speech' output
- Choose your preferred engine, language, speech rate, and pitch

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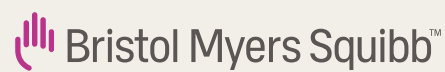
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More sources of information and support
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This Back-to-Work Guide has been created and funded by Bristol Myers Squibb in partnership with The Swallows Head and Neck Cancer Charity and the Mouth Cancer Foundation and supported by Working With Cancer, Salivary Gland Cancer UK and members of the Head and Neck Cancer patient community.

